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Research Involvement
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REVIEW **Open Access**

How are patient partners involved in health service research? A scoping review of reviews

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Abstract

Background Including patients and next of kin as partners in research can help promote the development and dissemination of results that are inclusive, usable and relevant to health service settings. However, the impact of such involvement remains largely anecdotal, necessitating research to identify methods for achieving meaningful involvement.

Objectives The aim was to examine how patient partners are involved in research across health service settings by addressing three objectives: (1) How are patient partners involved in the research process? (2) What is the impact of involving patient partners in research? (3) What defines effective patient partner involvement in research?

Methods We conducted a scoping review by searching five databases (Embase, Scopus, MEDLINE, CINAHL, PsycINFO) and grey literature. Published reviews within health service settings examining patient partner involvement were included. Protocol papers and reviews on patient involvement in treatment and care were excluded. The review adhered to Arksey and O'Malley's methodological framework and followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Checklist.

Results A total of 124 reviews were included. Most reviews have been published after 2014, primarily from the United Kingdom, Canada and the United States of America. Patient partners were involved with consultation and collaboration approaches in different stages of the research process, including identifying and prioritising ($n=49$), designing ($n=57$), managing ($n=40$), undertaking ($n=53$) and disseminating ($n=51$) and less in commissioning ($n=11$), implementing ($n=6$) and evaluating impact ($n=17$). Impact reporting varied, with few reviews ($n=11$) explicitly defining 'impact' and its related concepts. Sixteen key enablers for effective patient partner involvement were identified. The most reported enablers included partnerships built on trust and inclusive communication ($n=56$), training and support for patient partners ($n=53$), flexibility ($n=48$) and adequate resources ($n=45$).

Conclusion A significant gap exists in defining and measuring patient partner involvement. Adequate resources and training are essential for furthering trust-based, inclusive partnerships between researchers and patient partners. Future research should prioritise improving impact assessment, addressing power imbalances and refining best practices to enhance effective involvement.

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Patient and public contribution Two authors contributed with lived experience as patients and next of kin. Four patient partners were consulted about the results, one of whom coauthored this scoping review.

Plain English Summary

Patients and next of kin are encouraged to participate in planning, conducting and evaluating research studies. This involvement can generate more diverse, usable and valid research results. However, what constitutes 'good enough' involvement has not been thoroughly investigated. We aim to describe how patients and next of kin can be involved in research by answering three main objectives: (1) How are patient partners and next of kin involved in research? (2) How does involvement change the research? (3) What makes patient involvement in research work well? We carried out a scoping review, a type of research that maps out what has been studied so far, to summarise how researchers report involving patient partners in their studies and how this involvement affects the quality of the studies. We looked at 124 reviews. Most of the reviews were published in the United Kingdom, Canada, and the United States of America. Patients and next of kin take part in different research, mostly by giving advice or working closely with researchers. However, most reviews did not define what impact or related terms mean. Most also pointed out that researchers do not report clearly how patient involvement makes a difference. Sixteen enablers were found to foster the effective involvement of patient partners. In short, good teamwork based on trust, clear communication, and enough funding, training, and support is key to making patient involvement work well. We suggest that future research should create better guidelines to support effective involvement and find ways to measure its impact.

Keywords Patient and public involvement, Patient involvement, Patient engagement, Patient participation, Patient partner, Health services research, Scoping review

Background

The involvement of patient partners in health services research is now integral to designing and delivering effective health services research that benefits patients and health service outcomes [1–3]. The role of patients in research has evolved from being only participants to being active decision-makers within research teams. This is commonly referred to as *patient and public involvement* (PPI), which entails conducting research 'with' or 'by' patient partners, including next of kin, rather than 'to', 'about' and 'for' them [1, 4–6]. Several compelling arguments justify this shift. Greenhalgh et al. [7] justify this shift with several key arguments: researchers have a moral obligation to mitigate existing power imbalances between patients and researchers; patient partners increase research effectiveness and value by offering grounded, real-world insights based on lived experience; and collaboration with patient partners strengthens research accountability and transparency [2]. Evidence suggests that PPI benefits patients, researchers and the health service system by yielding more inclusive, valid and usable results in health service practice [8, 9].

Despite acknowledging the benefits of PPI, many reviews highlight that significant challenges exist in effectively involving patient partners: Domecq et al. [10] suggest the need for more research to identify optimal methods for achieving meaningful involvement; Harris et al. [11] stress the importance of defining 'good enough' involvement; Brett et al. [12] argue that assessing the impact of patient partner involvement is essential for understanding how it works, for whom, why and under what circumstances, and; Staley [13] argues that much of the evidence on the impact of PPI is anecdotal, highlighting the need for more robust evidence measures. These issues underscore the need for more robust evidence on the effectiveness of patient partner involvement across various health domains and research settings [2, 10–13].

Several countries have national guidelines to support researchers in integrating PPI into their research [14], including the National Institute for Health and Care Research in the United Kingdom (UK) [15], the Patient-Centered Outcomes Research Institute in the United States of America (USA) [16] and the Strategy for Patient-Oriented Research by the Canadian Institutes for Health Research [17]. However, limited evidence exists regarding the diverse needs of patient partners in research involvement and the measures used to assess their impact. Without robust evidence, how can researchers ensure effective patient partner involvement?

A scoping review methodology was chosen to systematically 'map' existing reviews within the field of PPI, summarise key results and identify research gaps [18]. This scoping review aims to synthesise current evidence on involving patient partners in research across various health service settings. The objectives are to explore: (1) How are patient partners involved in the research process? (2) What is the impact of involving patient partners in research? (3) What defines effective patient partner involvement in research?

Table 1 Defining the key concepts within our aim

Concept	Definition
Patient and Public Involvement (PPI)	Research conducted 'with' or 'by' members of the public rather than 'for' or 'to' them [6].
Health service research	A multidisciplinary field that investigates access to, and the use, costs, quality, delivery, organisation, financing and outcomes of health services to generate new knowledge about the structure, processes, and effects of health services for individuals and populations [23]. In a health service setting, the primary role of health professionals is to perform health-related duties in places such as hospitals, care homes, and dental clinics.
Patient partner	A member of the public with lived experience within the health service systems, including next of kin, who actively contributes to any health services research process through approaches such as consultation, collaboration, or co-production [6].
Impact	The "difference" that involving a patient partner makes across areas such as the research process, agenda, design, involved patient partners, researchers, participants, the broader community and its organisations, and implementation [13].
Effective	Patient and public involvement is deemed 'effective' when an association between 'how' patient partners are involved and a positive impact of this involvement is observed.
Research process	Patient partners can be involved in one or more stages of the research cycle, including involvement in [6]: 1. Identifying and prioritising research (for example, collaboration between researchers and patient partners to establish a shared agenda. 2. Commissioning (for example, reviewing research proposals or being in a commissioning panel). 3. Designing (for example, designing the research or ensuring that recruitment is practical and feasible) and managing (e.g., a member of a study steering group). 4. Undertaking (for example, carrying out interviews and analysing and interpreting results) 5. Disseminating research (for example, providing feedback on results or co-authoring journal articles) 6. Implementing research (for example, establishing relationships with policymakers). 7. Evaluating impact (for example, monitoring and evaluating involvement and its impact throughout the project) [6].

Methods

Design

A scoping review of existing reviews was conducted to: (1) answer the objectives based on a comprehensive evidence base, (2) capture broader patterns within an evolving field, and (3) identify gaps across the literature. A previously published study protocol outlined the rationale for the scoping review and its planned course of action [19]. As the review progressed, we expanded from two to three objectives to enhance clarity. We adhered to the methodological framework of Arksey and O'Malley [20], which was further refined by Levac et al. [18]. This framework comprises a six-stage iterative guide: (1) identifying the research question; (2) identifying relevant studies; (3) study selection; (4) charting the data; (5) collating, summarising, and reporting the results; and (6) consultation [18]. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA-ScR) Checklist was employed to report this scoping review, as it offers a standardised and evidence-based approach to guide the review process (Additional file 1) [21].

Table 2 Sample search string for medline

Search terms connected with 'OR':
("Patient Participation").mp, [ti.ab.]
("Stakeholder Participation").mp, [ti.ab.]
("Community Participation").mp, [ti.ab.]
"Patient and Public Involvement" [ti.ab.]
"Public Involvement" [ti.ab.]
"Patient Engagement" [ti.ab.]
"Patient Partner" [ti.ab.]

Stage 1: identifying the research question

The aim of this scoping review remains unchanged from the scoping review protocol [19]. Still, we moved the term 'effective' from the aim to a third objective to explicitly address how to involve patient partners effectively. This distinction helped us structure the result and discussion section and guided the analysis of the included reviews. Key terms related to the aim and objectives of this scoping review are defined in Table 1.

Stage 2: identifying the relevant studies

Following the recommendations of Levac et al. [18], we adopted a comprehensive yet practical and feasible strategy. An extensive literature search was conducted in April 2022 and updated in April 2024. The electronic databases Medline, CINAHL, Scopus, PsycINFO and Embase were searched in 2022 and 2024 from the databases' inception. The search strategy was developed based on the research question and key concepts (Table 1) with support from two health services research specialists at Aarhus University. A broad search approach was used because of the many synonyms for involving patient partners in research. The final search string for Medline is shown in Table 2. Search terms were tailored for each database and the same search strategies were used in 2022 and 2024 (Additional file 4). We included reviews published in English, Danish, Swedish and Norwegian. To maximise the number of eligible reviews, we did not restrict inclusion by country of origin or year of publication.

We conducted a grey literature search to identify records beyond academic databases and ensure that no eligible papers were missed. Given its high relevance to our aim, we first screened all published papers in the journal 'Research Involvement and Engagement' using the search term 'review'. Next, we searched Google Scholar with our search terms connected by 'or' (see Table 2). Finally, we sought expert input from the co-authors of this review, leveraging their expertise in the field. The abbreviation '.mp' refers to MeSH terms used in Medline (Ovid or PubMed), while 'ti.ab.' indicates the search terms have been searched in titles and abstracts. Additionally, we conducted a citation search of the 13 (10% of the total) most recently published reviews included in this scoping review.

Stage 3: study selection

The inclusion and exclusion criteria were developed through team discussions during the protocol development, the scoping process and refinement throughout the screening process (Table 3). By 'review', we refer to all reviews with an explicit methods section describing the literature search. We included reviews that examined 'empirical papers' referring to collecting and analysing primary data based on direct observation or experiences in the field. Health service settings refer to health services and include, for example, research on care homes and dental research, but it excludes research on schools and prisons. We use the term 'investigate' to emphasise our interest in how patient partners could be involved and the impact of that involvement. Accordingly, we excluded reviews that focused on involving patient partners in the review process itself or those addressing methodological issues. Additionally, we refer to the definition of 'research process' provided in Table 1.

The review selection process comprised two steps. First, the titles and abstracts of all records were screened. Second, the full text of the studies that met the inclusion criteria was reviewed to determine their eligibility, and the main reason for exclusion was recorded. In both rounds, two independent reviewers screened the studies. In both rounds, two independent reviewers screened the studies. SCT acted as the primary reviewer, while ALJ, JF, GR, TWV and LØR shared the task as the alternate reviewer. Disagreements were resolved by discussion; if unresolved, HLB adjudicated the remaining discrepancies. All reviewers documented the process using the Covidence online platform [20]. During the full-text screening, four reasons for exclusion were recorded: (a) not a published review of empirical work, (b) lack of investigation into patient partner involvement in the research project, (c) not conducted in a health service setting, and (d) multiple reasons for exclusion. No more studies were included after April 2024. After two reviewers had screened all records in two rounds to ensure eligibility, SCT rechecked all records according to the inclusion and exclusion criteria; if SCT had doubts about a record's eligibility, ALJ and LØR re-examined the records. This process continued throughout the data coding phase. All three authors (SCT, ALJ, LØR) reached a consensus on which studies to include.

Table 3 Inclusion criteria and exclusion criteria

Inclusion criteria	Exclusion criteria
Published reviews of empirical work in health service settings examining the involvement of patient partners in research.	Protocol papers and published reviews of empirical work assessing involvement in treatment and care.

Stage 4: charting the data

First, a data-charting form was developed to systematically extract relevant details from each review (Additional file 2). Next, two authors (SCT, ALJ) piloted the form using a purposive sample of 10% of the included reviews, selected to represent diverse review types and health service settings. The test was conducted in NVivo using the 'coding comparison query' function to assess inter-rater reliability [21]. Cohen's kappa coefficient was less than 93% on all codes. The results were discussed (SCT, ALJ, LØR), and a consensus was reached, resulting in more detailed descriptions of certain variables. Finally, SCT coded data from all reviews using NVivo 15 [22]. Only data reported within the reviews were coded; supplemental material was excluded.

Stage 5: collating, summarising and reporting results

After data coding, we initiated a process of collating and summarising to address the review's aim and objectives. The analysis was conducted using NVivo [22], guided by the review's overarching aim and objectives. First, we aimed to provide an overview of the sources of evidence, including the reviews and their embedded empirical papers. Next, we identified the most relevant variables from the data-charting form to address the three objectives. Results related to objectives one and two were derived from a descriptive analysis, while those for objective three emerged through thematic analysis [23]. Figures 3 and 4 were drafted by SCT and qualified by the author team during the analysis process to visualise key results.

Stage 6: consultation

Patient partners and researchers were involved throughout the scoping review to enhance its quality and relevance to stakeholder needs. This involvement resulted in several modifications during the literature search: (1) Two authors (SCT, JF) with lived experience discussed the review methods at the outset and added two additional variables to the data-charting form, including

'Identified barriers to the effective involvement of patient partners' and 'Identified facilitators to the effective involvement of patient partners'. (2) A workshop was held to incorporate the author team's diverse professional perspectives relevant to the review's primary audience. (3) Four patient partners were consulted about the preliminary results, leading to clearer language in tables and figures. All four patient partners were invited to contribute to the final manuscript. (4) One patient partner (FOJ) agreed to coauthor this scoping review and collaborated with the author group throughout the writing process. All consultations were documented using the Guidance for Reporting Involvement of Patients and the Public (GRIPP2) Short Form, which is appropriate for reporting the use of PPI (Additional file 3) [24].

Results

Search results

The PRISMA Flow Diagram illustrates the selection process, resulting in 124 eligible reviews (Fig. 1) [25]. All reviews were identified through database searches, except one retrieved via chain searching and one through Google Scholar [26, 27].

Objective #1: how are patient partners involved in the research process?

Characteristics of included reviews

Origin and publication year of the reviews

Table 4 summarises the key characteristics of the 124 included reviews. The reviews were published from 2005 to 2024, with most published after 2014. Based on the first author's primary affiliation, the reviews were conducted across 20 countries. The majority were undertaken in the UK (46/124), Canada (29/124) and the USA (10/124). Each of the following countries is represented by a single review: Sweden [28], Belgium [29], South Africa [30], New Zealand [31], Austria [32], Luxembourg [33], Finland [34] and Singapore [35]. The origin of one review is not stated [36].

Review types

Sutton et al. [38] categorise review types into seven 'review families'. Table 4 illustrates the distribution of the included reviews across six of these families, which are: 'traditional review family' (12/124) [34, 35, 38–47], 'systematic review family' (41/124) [5, 10, 12, 32, 37, 48–82], 'rapid review family' (8/124) [83–90], 'qualitative review family' (4/124) [91–94], 'mixed method review family' (4/124) [11, 95, 96], and 'purpose-specific reviews' (46/124) [2, 8, 14, 28, 29, 31, 33, 36, 38, 79, 97–131]. Two

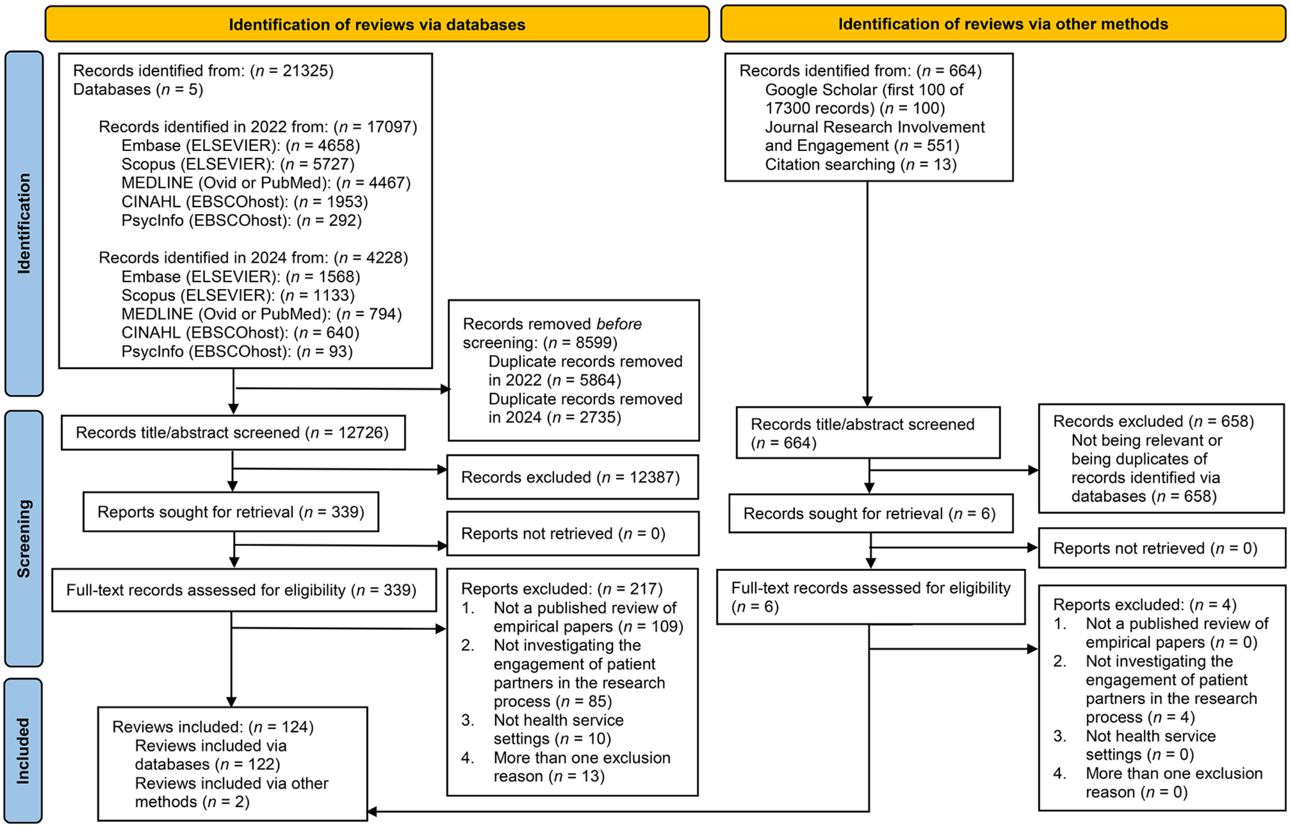

Fig. 1 PRISMA flow diagram [25]

Table 4 Characteristics of included reviews

Category	References	*n* (*n*%)
Country, according to the first authors' primary affiliation		
United Kingdom (UK)	[2, 4, 5, 11, 12, 27, 41–78]	44 (36%)
Canada	[9, 38, 40, 79–105]	29 (23%)
United States of America (USA)	[10, 39, 106–113]	10 (8%)
Australia	[114–122]	9 (7%)
Denmark	[14, 123–126]	5 (4%)
Germany	[127–131]	5 (4%)
The Netherlands	[132–135]	4 (3%)
Norway	[136–139]	4 (3%)
Ireland	[1, 140, 141]	3 (2%)
Switzerland	[8, 142]	2 (2%)
France	[143, 144]	2 (2%)
Other countries	[28–36]	9 (7%)
Publication year		
≤ 2004		0 (0%)
2005–2009	[41, 49, 71]	3 (2%)
2010–2014	[10, 12, 42, 50, 65, 68, 69, 76, 106, 107]	10 (8%)
2015–2019	[1, 4, 5, 11, 28, 31, 34, 36, 39, 40, 44, 47, 48, 52, 53, 55–60, 67, 72–75, 80, 84, 86, 90, 92, 102, 108–114, 120, 123, 126, 128, 132, 134, 140, 143, 145]	47 (38%)
2020–2024	[2, 8, 9, 14, 29, 30, 32, 33, 35, 38, 43, 45, 46, 51, 54, 61–64, 66, 70, 78, 79, 81, 82, 85, 87–89, 91, 93–101, 103–105, 115, 116, 118, 119, 121, 122, 124, 125, 127, 129, 130, 133, 135–137, 139, 141–144, 146–148]	65 (52%)
Health service setting		
Across different diseases/health service settings	[1, 2, 5, 14, 27, 28, 31, 34–36, 40, 42, 43, 47, 48, 52–61, 70, 71, 73, 75, 77–80, 82, 84, 86–90, 98, 102–104, 106–110, 113–116, 123, 125, 132–134, 136, 137, 139–141, 144, 148, 149]	66 (53%)
Medicine with only one specific disease	[8, 9, 11, 29, 38, 39, 41, 62, 63, 81, 92, 101, 105, 111, 117, 122, 127, 131, 135, 143, 147]	21 (17%)
Psychiatry	[30, 44, 97, 100, 121, 126, 129]	7 (6%)
Surgery	[118, 124]	2 (2%)
Review type		
Traditional review family	Narrative reviews [33, 50, 60, 109, 112, 115, 133], narrative reviews of case examples [68, 69], integrative narrative review [55], a critical literature review [44], integrative literature review [34]	12 (10%)
Systematic reviews family	Systematic reviews [5, 10, 12, 31, 36, 39, 42, 48, 52, 59, 63, 64, 70, 71, 74, 88, 100, 101, 104, 107, 108, 119–123, 127, 129, 134, 138, 143, 150, 151], systematic reviews and narrative syntheses [46, 54, 76], systematic review and meta-analysis [47], systematic review and modified Delphi methodology [53], systematic review and synthesised framework [110]	41 (33%)
Rapid review family	Rapid reviews [45, 77, 102, 105, 125], rapid realist review [79, 152], patient-oriented rapid review [93]	8 (6%)
Qualitative review family	Qualitative systematic reviews [73, 98], Qualitative review [111], review and synthesis of the framework [80]	4 (3%)
Mixed methods review family	Realist review [11], critical interpretive synthesis [87], methodological review [144]	3 (2%)
Purpose-specific reviews	Scoping review [2, 8, 14, 27, 28, 30, 32, 35, 38, 40, 43, 46, 56, 57, 61, 62, 66, 67, 72, 78, 81, 82, 84–86, 89–91, 94–96, 99, 103, 113, 114, 116, 118, 124, 126, 130, 135–137, 141], mapping review [58]	46 (37%)
Other review types	Exploratory literature review [4], lexical review [153]	2 (2%)
Review type not specified	[1, 41, 49, 51, 65, 106, 128, 147]	8 (6%)
Measurement		
Using measurement	[2, 9, 11, 14, 30, 54, 61, 64, 74, 82, 95, 97, 99, 100, 105, 116, 118, 119, 122, 143, 144, 147]	22 (18%)
Terminology for involving patient partners		
Patient and Public Involvement (PPI)	[4, 5, 8, 33, 44, 53, 56, 57, 60, 61, 63, 67, 116, 118, 128, 129, 137, 141, 144, 147, 148]	21 (17%)
Public involvement	[35, 46, 55, 68, 75, 119, 120]	7 (6%)
Patient engagement	[84, 85, 92, 98, 104, 139, 149]	7 (6%)
Community-Based Participatory Research	[106, 108, 109]	3 (2%)
Public involvement in research	[50, 69, 76]	3 (2%)
Patient-Oriented Research	[9, 66, 93]	3 (2%)

Table 4 (continued)

Category	References	*n* (*n*%)
Participatory research	[31, 73, 131]	2 (2%)
Public Involvement and Engagement	[2, 125]	2 (2%)
Co-research	[36, 77]	2 (2%)
Co-production	[43, 45]	2 (2%)
Other terminologies	[1, 34, 38–40, 47, 72, 78, 80, 82, 86, 90, 94, 102, 110, 115, 132, 134, 135]	19 (15%)
Number of empirical papers included in the reviews		
Less or equal to 20	[9, 31, 36, 40, 43, 44, 50, 52, 56–58, 60, 63, 64, 67–69, 73, 75–77, 81, 84, 86, 93, 95, 97, 100, 103, 104, 111, 113, 121, 124, 128, 129, 131, 135–138, 140]	42 (34%)
21–40	[1, 2, 11, 27, 29, 30, 38, 45–48, 61, 62, 87–89, 91, 99, 105–107, 109, 114, 116, 120, 123, 126, 132–134]	30 (24%)
41–60	[5, 14, 28, 35, 49, 54, 80, 90, 92, 96, 98, 108, 112, 118, 122, 141]	16 (13%)
61–80	[4, 12, 42, 51, 59, 85, 94, 102, 125, 142]	10 (8%)
81–100	[33, 34, 53, 55, 74, 127, 143, 148]	8 (6%)
100 or more	[8, 10, 32, 39, 41, 65, 66, 70–72, 78, 82, 101, 110, 115, 117, 119, 144]	18 (15%)

reviews could not be categorised into a review family [4, 133], and eight review types were impossible to specify [1, 134–140]. No review from the sixth family, called ‘review of review family’, was included in this scoping review, which may be explained by the fact that only reviews of empirical papers are included.

Measurements

Twenty-two reviews use quantitative data-collecting tools to report on the involvement or assess its quality (Table 4). GRIPP2 [76] is used twice as an evaluation tool. The rest of the tools are used once, for instance: Quality of Reporting Involvement of Patients and the Public Appraisal Tool (QRIPPAT), Shier’s Pathways to Participation Model and Participatory Research Impact Framework [2, 28, 37].

Terminology

Forty-six reviews explicitly define the involvement of patient partners in research (Table 4). The most frequently used terms are ‘patient and public involvement’ (21/124), ‘public involvement’ (7/124) and ‘patient engagement’ (7/124). The last fourteen other reviews use terms such as ‘service user involvement’, ‘knowledge translation’, ‘health research partnership’ and ‘stakeholder engagement‘ [1, 38–40].

Number of empirical papers

The number of empirical papers included in review papers varies, with most reviews (72/124) including a maximum of 40 empirical papers (Table 4).

Characteristics of empirical papers

Origin and publication year of the empirical papers

To understand how patient partners are involved in the research process, the characteristics of empirical papers are presented according to the reviews’ descriptions. Generally, there was little consistency in how PPI was reported, collated and evaluated. However, 65 of the 124 reviews reported the publication year of the included empirical papers. Although PPI has been documented in empirical papers since 1994 [126], most empirical papers were published between 2000 and 2022 [2, 28, 33, 35, 37, 43, 62, 66, 80–82, 85, 88, 90, 91, 96, 98, 100, 103, 106, 116, 118, 127, 129, 137, 139, 141, 144, 150, 154, 155], with more published in later years. The geographical origin of the empirical papers could be coded in 70 reviews [1–3, 5, 8, 9, 12, 14, 28, 31–33, 36, 37, 40–43, 46, 47, 49, 50, 52, 57, 58, 64, 66, 68, 70, 73, 74, 79, 80, 82–86, 88, 90, 91, 93, 94, 96–98, 100, 103–105, 114, 116, 118, 125, 126, 128, 129, 131, 132, 138, 141, 142, 148, 151, 152, 154–158]. These studies originated from 48 countries. As illustrated in Fig. 2, most studies stem from the UK and Ireland (1,220 empirical papers), the USA (787), Canada (486) and Australia (232). Most empirical papers seem to originate from Europe, North America, Oceania (Australia) and South America (Brazil), with fewer from Asia and Africa. Countries shown in grey on the map indicate no reported empirical papers. For 32 reviews, the distribution of empirical papers could not be determined. However, many of these reviews still reference studies primarily conducted in the UK, the USA and Canada, supporting the pattern shown in Fig. 2.

Patient partner roles

The majority (92/124) of reviews describe the various roles that patient partners play in empirical work [1–5, 8–10, 14, 27–31, 33–35, 40–44, 46, 47, 50–54, 56–58, 60, 64, 67, 69, 74, 75, 77, 78, 81–83, 88–92, 94, 96, 99–102, 104, 106, 108, 111, 114, 116, 117, 119–122, 129, 131, 132, 135, 139–145, 147, 149–153, 156–163]. Overall, patient partners are involved in a range of roles across various stages of the research process, either as individuals or in groups of differing sizes [1–3, 8–10, 33–35, 40–44,

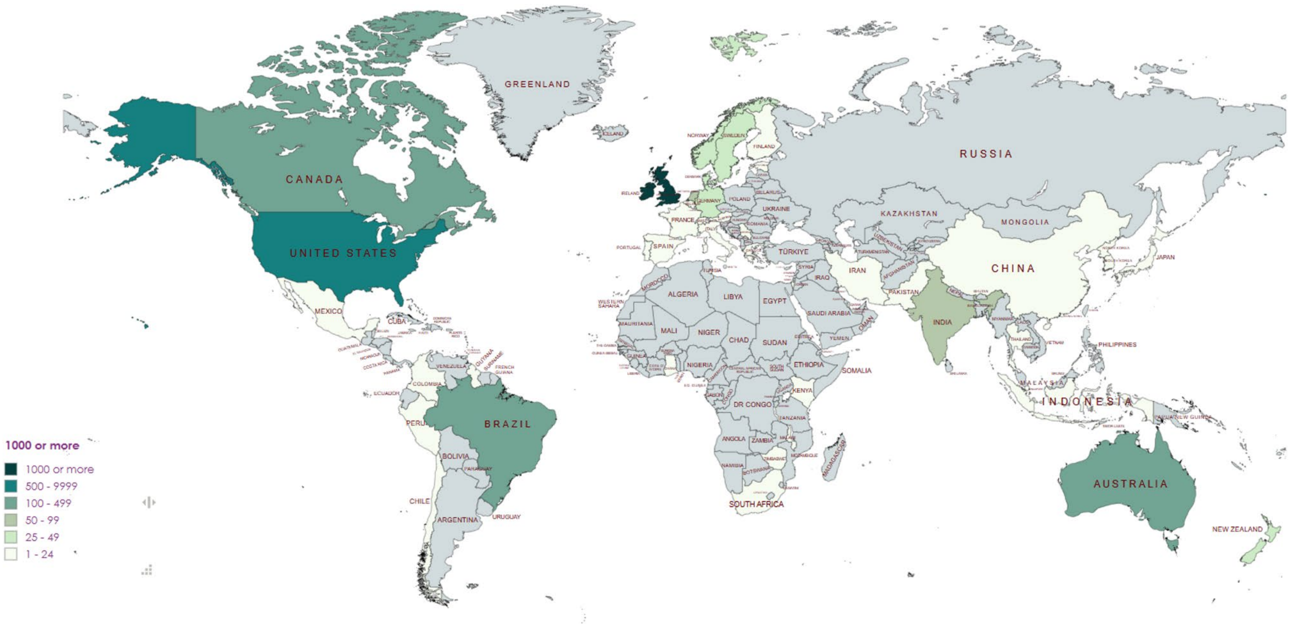

Fig. 2 The geographical origin of the empirical papers [159]

46, 47, 52–54, 57, 58, 60, 67, 69, 77, 78, 81, 82, 90, 92, 94, 99, 100, 108, 111, 116, 129, 131, 132, 140, 141, 145, 156, 162]. Involvement mainly occurs through face-to-face meetings, focus group interviews, individual interviews, workshops, advisory boards, stakeholder groups, meetings, and feedback sessions [1, 5, 8–10, 14, 29, 33, 40, 43, 46, 50, 51, 53, 60, 67, 69, 78, 81, 83, 90, 95, 100, 102, 106, 109, 110, 117, 120, 121, 135, 139–145, 147, 151, 152, 154, 156, 162]. Involving patient partners as interviewees is reported by 30 reviews, typically as one among other roles [1, 8–10, 14, 29, 33, 34, 40, 50, 54, 60, 67, 69, 77, 83, 100, 102, 106, 117, 121, 139–142, 147, 151, 152, 154, 156]. However, this is rarely justified in terms of how it constitutes research 'with' patient partners, as per the National Institute for Health and Care Research's definition [6]. Nevertheless, Hallam-Bowles stands out by describing how residents of care homes were interviewed to contribute to the research process [40].

At the outset of the research, patient partners typically contribute to prioritisation and agenda setting, for example, by identifying topics [2, 4, 34, 52, 83, 139, 147, 151, 161]. They are also frequently involved in conducting research, particularly in data collection and analysis, often as part of the research team [2, 34, 40, 42, 46, 52, 53, 74, 75, 108, 147]. In the dissemination and evaluation phases, they most commonly contribute to disseminating results, for example, by assisting in producing research papers [2, 4, 40, 46, 52, 74, 75, 92, 96, 109, 116, 147, 149].

When in the research process are patient partners involved

Descriptions of when patient partners are involved in the research process seem generally brief, inconsistent and with limited details. Additionally, the use of varying terminology complicates interpretation across studies. Figure 3 provides an overview of when patient partners are involved in the research process, based on the review data and inspired by the research cycle presented by the National Institute for Health and Care Research and summarised in Table 1 [6]. Figure 3 divides the research cycle stages into three categories: Plan, conduct and evaluate. In addition, it was beneficial to split up designing and managing research, as it is also described differently by the National Institute for Health and Care Research [6]. The totals in Fig. 3 represent the number of reviews reporting involvement at each phase; individual reviews may be counted in more than one phase. In total, 76 reviews describe the involvement of patient partners in one or more phases of the research process. In the planning phase, 67 reviews report involvement, distributed as follows: 'Identify and Prioritise' ($n = 49$) [5, 8, 10, 11, 14, 26–29, 32, 33, 36, 37, 39, 40, 43, 46, 57, 58, 69, 72, 73, 80, 84, 86, 88, 91, 99, 100, 102, 106, 107, 110, 114, 116, 122, 125, 128, 132, 135, 136, 139, 142, 143, 148, 151, 154, 155, 157, 160–162], 'Commissioning' ($n = 11$) [3–5, 10, 29, 32, 46, 110, 116, 125, 139] and 'Designing' ($n = 57$) [2, 5, 8, 10–12, 14, 26–29, 33, 36, 37, 43, 45–47, 57, 58, 62, 68, 73, 81, 82, 84, 86, 91, 100, 102, 105, 106, 109, 110, 114, 116, 118, 122, 125, 128, 132, 135–137, 139, 142, 144, 148, 150, 151, 154, 155, 157, 160, 161, 163]. In the 'Conduct' phase, 58 reviews describe involvement: 'Manage' ($n = 40$) [2, 5, 8, 11, 12, 14, 26, 33, 43, 46, 47, 57, 62, 68, 71, 73, 80, 82, 84, 88, 91, 99, 100, 102, 106, 107, 110, 114, 122, 128, 132, 135–137, 139, 144, 148, 151, 155, 163], and 'Undertake' ($n = 53$) [2, 5, 8, 10–12, 27, 29, 33, 36, 37, 40, 43, 46, 47,

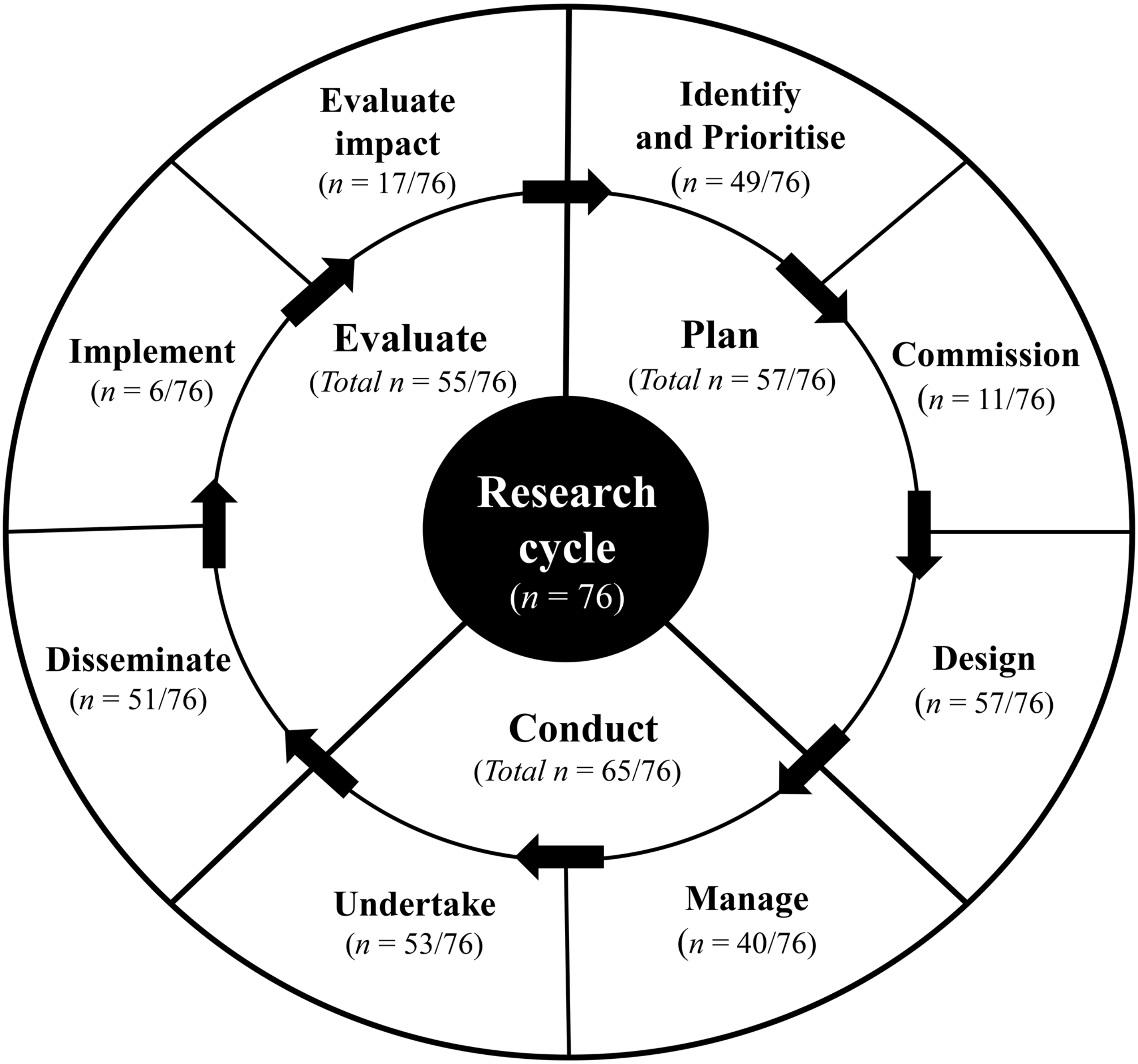

Fig. 3 When patient partners are involved in the research process

57, 68, 69, 71, 73, 80–82, 84, 86, 88, 91, 99, 100, 102, 103, 105–107, 110, 114, 116, 118, 122, 125, 128, 132, 135, 136, 139, 144, 148, 151, 154, 155, 157, 162, 163]. In the category 'Evaluate', 55 reviews describe involvement: 'Disseminate' ($n = 51$) [2, 5, 8, 10–12, 27, 29, 33, 39, 40, 46, 57, 58, 62, 69, 71–73, 80, 82, 86, 88, 99, 100, 105–107, 110, 114, 116, 118, 122, 125, 128, 132, 136, 137, 139, 144, 148, 151, 154, 155, 163], 'Implement' ($n = 6$) [12, 40, 110, 116, 122, 148] and 'Evaluate impact' ($n = 17$) (17/76) [43, 58, 71, 73, 80, 99, 100, 106, 107, 109, 110, 116, 118, 122, 132, 142]. Some reviews indicate that patient partners were involved throughout the entire research process. However, descriptions and evaluations from the patient partners' own perspectives seem to be absent [67].

Approaches to involving patient partners

Fifty (50/124) reviews report on the approach or level of patient partner involvement [3, 4, 8, 9, 27, 28, 32, 36, 43, 46, 49, 50, 52, 59–62, 66, 68–71, 74, 82, 84, 87, 88, 91, 93, 100, 102, 105–107, 110, 116, 118, 122, 128, 129, 131, 132, 134, 135, 138, 143, 157, 162, 164, 165]. The level of detail and terminology used varies considerably. For instance, Crockett et al. [82] and Parry et al. [105] refer to involvement such as 'consult', 'involve', 'collaborate' and 'empower'. Manafo et al. [102] distinguish between 'consultative' and 'deliberative' involvement, while Flynn et al. [84] use the terms 'learn/inform', 'participate', 'consult', 'involve', 'collaborate' and 'lead/support'. Many reviews only provide superficial information about approaches for involvement, making it difficult to compare approaches across studies and make overall conclusions [9, 93, 110]. Most reviews report involvement at the 'consultation' level or similar terms, typically indicating that researchers lead the process and retain decision-making authority, while patient partners contribute during in one or more stages [6, 8, 46, 50, 60, 61, 68, 69, 107, 118, 135, 143, 162]. Also, involvement as a collaborative approach is often reported, indicating that decisions are more shared and patients can influence the research process [9, 27, 59, 66, 100]. Several reviews reflect on the strengths and limitations of different approaches. For example, Menzies et al. [60] argue that consultative methods are relatively easy to organise and enable researchers to learn more about people's views and perspectives. Still, these methods are limited by the lack of two-way dialogue, which can result in participants feeling unheard. Forsythe et al. [107] note that most of the studies they reviewed used consultative methods, but they suggest that collaborative methods may be more effective.

Objective #2: what is the impact of involving patient partners in research?

Terminology concerning impact

In total, eleven reviews explicitly defined the terms 'impact' [9, 27, 35, 57, 90, 127, 137], 'outcome' [38, 47, 88] and 'evaluation' [113], although these terms were defined differently. For example, Røsvoll et al. [54] outline nine different kinds of impact of PPI, including 'research agenda, research design and delivery, research ethics, public advisors, researchers, research participants, the wider community, and the implementation or change resulting from the research in which people were involved'. Sellars et al. [29] note that impact can be positive and negative, stating, 'Impacts may be observed on the research, the researchers, the service users, the community, on policy and funders.' In contrast, Luna Puerta et al. [35] refer to impact as it is understood and reported by empirical papers [35]. The term 'outcomes' is defined as: 'enrolment and/or retention rate' [47]; 'a result of the changes made from PPI input' [57]; 'eligibility criteria or strategy' [155]. The term 'evaluation' is described as any approach used by researchers to capture the perspectives of collaborators regarding their participation in scientific inquiry by Martinez et al. [106].

Lack of consistent impact reporting

In total, 88 of the 124 reviews draw conclusions related to impact and related terms [1, 3–5, 8–12, 14, 27, 28, 31, 32, 35, 36, 40–43, 45–50, 52, 54–57, 59–64, 67, 68, 70, 72, 73, 75–77, 80–82, 84–86, 88, 90, 91, 94, 96–101, 103, 105–107, 109, 113, 114, 116, 119, 120, 122, 125, 129, 132, 134, 135, 137–139, 141, 144, 148, 150, 151, 153–156, 164]. A common criticism across reviews is that the reporting of impact in empirical papers is inconsistent, limited, poor and anecdotal. This issue is reported across all health service settings and populations in this review. Some reviews problematise that this lack of reporting makes it difficult to understand what works, for whom, under what circumstances and why [5, 62]. Some reviews advocate for enhanced impact reporting through qualitative and quantitative measures, alongside more standardised methodologies [2, 12, 85, 106]. Three reviews note that challenges in reporting impact may be exacerbated by journal word limits and emphasise the need for more space in academic publishing to provide fuller accounts of processes and outcomes [8, 87, 94]. Evidence of best practice in involving patient partners is limited. Most reviews suggest strengthening the evidence base on the impact of involving patient partners as a priority for future research. Some reviews note that empirical papers tend to report more positive than negative outcomes [62, 82, 154] and that impacts are often presented from the perspective of researchers and authors rather than derived directly from the data [3, 48, 62].

Impacts on patient partners

In addition, reviews report that empirical papers more frequently highlight positive rather than negative impacts [62, 82, 154]. Some reviews also note that the effects on the patient partners remain underexplored [148]. Reported impacts for the patient partners and next of kin include enhanced research-related knowledge and skills, opportunities to network with other patient partners, feelings of empowerment and positive experiences – all of which may strengthen willingness to participate in future research. Conversely, reviews also document negative impacts, such as high workload demands, insufficient funding and resources, strained relationships, dissatisfaction with involvement levels and inadequate training [31, 62, 100]. For instance, when patient partners experience their involvement as tokenistic or sense a lack of commitment from researchers, they may feel undervalued and unimportant. Such experiences can discourage further participation in research [42].

Impacts on researchers

Regarding the impact on researchers, reviews highlight that patient partners offer a 'real-world connection' [1, 2, 81], help share the workload [31], contribute a unique, experience-based perspective [1, 81, 107, 114], reduce interpretive bias, offer new insights to the researchers and often shift researchers' mindsets [12, 81, 114, 164]. In addition, patient partners can play a role in safeguarding ethical standards [132], and many reviews report that their involvement supports the recruitment of under-represented communities [49, 52]. Although less frequently reported, some challenges for researchers include increased workload and strained relationships [31].

Impact on the research process and outputs

In terms of impacts on the research process and outputs, patient partners can enhance the relevance and quality of research questions, methodologies and results; contribute to cultural appropriateness; and support better participant retention [12, 45, 47, 49, 84, 107, 109, 122, 125, 156]. Many reviews emphasise that for PPI to be beneficial, it must be implemented effectively, as it can yield positive outcomes for all stakeholders and enhance the relevance and quality of research [55]. Generally, most reviews conclude that the potential benefits of involving patient partners in research generally outweigh the potential drawbacks [64, 100, 139]. However, two reviews question the value of patient partners' involvement. For instance, Erwin et al. [45] acknowledge the positive impacts of involving vulnerable children and young people but cite an empirical study that '(…) after weighing up the cost, time and resources required to co-produce research, expressed doubts about the quality of the research produced by the vulnerable children and young people co-researchers'. Similarly, Malterud et al. [138] report that involving patient partners does not necessarily lead to more advanced knowledge production or ensure the anticipated outcomes. Summing up, the various reporting of involvement practices can cause difficulty in determining what constitutes effective involvement. Considering this, we find it essential to present what the reviews define as enabling effective involvement, which will be discussed in the next section.

Objective #3: what defines effective patient partner involvement in research?

Enablers for effective involvement

Most reviews (117/124) identify factors that facilitate effective involvement in practice. Figure 4 illustrates the most frequently reported enablers to consider when involving patient partners. The enablers are depicted in a circular format to reflect how effective involvement often results from multiple interrelated factors. For instance, Goedhart et al. [114] argue that 'Recruiting a diverse group of patient partners' calls for 'Flexibility', 'Investing adequate time' and 'Inclusive methods' to address the needs of those living in vulnerable circumstances. The sixteen enablers, categorised into the four domains - 'Relational', 'Training and support', 'Processes', and 'Context' - will now be discussed in detail.

Partnerships built on trust and inclusive communication

The relational domain comprises six enablers. The first enabler, 'Partnerships build on trust and inclusive communication', refers to using communication as a tool to create a welcoming and safe environment where patient partners can share their views and lived experiences [5, 26, 33, 36, 37, 52, 53, 61, 71, 78, 84, 85, 88, 90, 91, 93, 96, 100, 102–104, 125, 128, 134, 150, 151–153, 154, 155, 156, 157, 158, 159, 160, 161, 162, 163, 4, 41, 43, 44, 46, 47, 72, 75, 76, 89, 160, 162, 167, 168, 169, 5]. Trust is explicitly highlighted in 24 reviews, emphasising the importance of building a trusting relationship between the researcher and the patient partner [5, 26, 31, 33, 36, 37, 42, 52, 53, 67, 84, 85, 88, 90, 100, 103, 114, 125, 126, 132, 152, 157, 164, 166]. Inclusive language implies using accessible and plain language and ensuring that all communication is tailored to the needs of patient partners. For example, when involving vulnerable children and young people, researchers may offer debriefing at the end of meetings or ensure that a known and trusted support worker is available throughout to help safeguard their wellbeing [45]. A commonly mentioned impact of inclusive communication and relationships is creating a safe and supportive space [52, 57, 62]. Some reviews stress that inclusive communication and relationships are the most critical enablers of effective partnerships [45, 168]. For example, Brett et al. [42] argue that the success of PPI in research often relies on the quality of interpersonal interactions, which should not be underestimated when aiming to generate positive impacts. Additionally, a trusting partnership can help address power imbalances [84], resulting in increased openness, mutual growth and broader community involvement in research [157]. Reviews largely attribute this enabler to the researcher's skills and initiative. Still, the patient partner can also contribute to a trustful partnership and must feel genuinely included in the process [42, 164].

Flexibility

Another frequently reported enabler within the relational domain, observed across various health service settings, is 'Flexibility'. This enabler captures different ways in which involvement can be adapted to demonstrate consideration for patient partners (48/117) [3, 9, 28, 31, 33, 36, 37, 40–43, 45, 46, 48, 52, 53, 55, 57, 61, 62, 64, 67, 73, 78, 82, 84–86, 88, 98, 100, 103, 104, 115, 128, 129, 132–134, 142, 143, 151, 152, 154–157, 166]. Examples include extending research timelines to accommodate patient partners [157], being open to adjusting communication styles [37], considering cultural contexts [115, 142, 166], preparing for unpredictability [86] and respecting individual preferences by enabling diverse forms of participation [36, 86]. The reported benefits of flexibility include promoting inclusivity [53], facilitating ethically justifiable involvement [135], supporting patient partners with limited resources [44] and helping address power imbalances [84]. Both the researcher and the organisation must

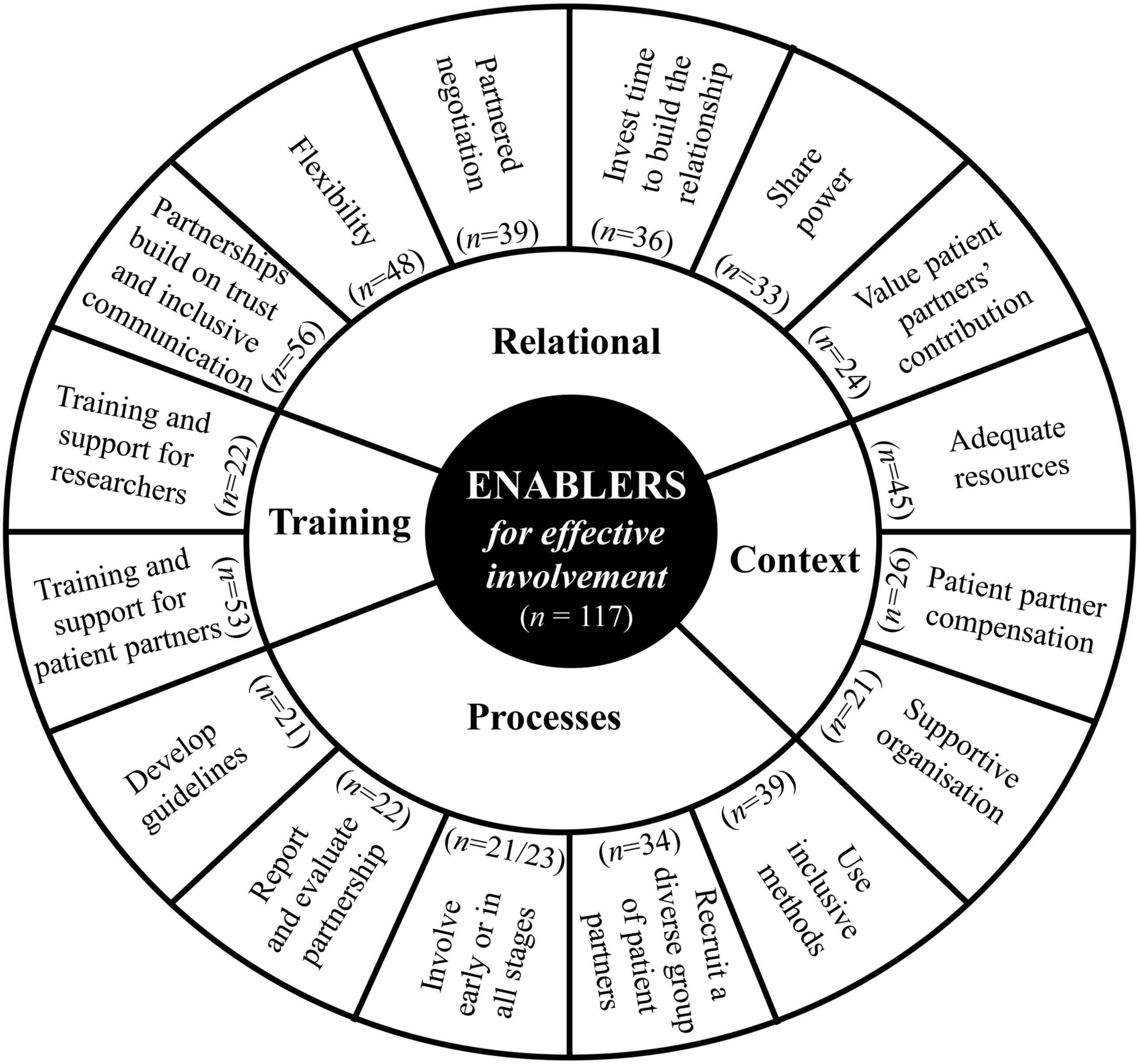

Fig. 4 Most reported enablers for effective involvement

demonstrate flexibility to support effective patient partner involvement [36, 156].

Partnered negotiation

Also within the relational domain, 'Partnered negotiation' (identified in 39 of 117 reviews) refers to patient partners and researchers jointly negotiating key aspects of the partnership, such as the research agenda, mutual expectations and the definition of different roles [3, 9, 12, 28, 29, 31, 33, 36, 40, 43, 45, 55, 64, 66, 75, 78, 80, 82, 84, 86, 90, 93, 97, 98, 100, 102, 103, 105, 114, 118, 126, 135, 137, 152, 154–157, 164]. While the researcher typically initiates this enabler, the success of partnered negotiation also depends heavily on the active contribution of the patient partner [29, 40]. Even though partnered negotiation can be valuable throughout the research process, reviews generally stress that it should begin at the outset of the collaboration. Shared negotiation can also involve establishing a consensus on a shared language [9] or jointly determining the level and approach of involvement [126]. The outcomes of partnered negotiation include fostering a more effective partnership [3], strengthening team motivation and identifying the training needs of patient partners [80] and reducing unnecessary research [80].

Sharing power

The enabler 'Sharing power' (33/117) is also a part of the relational domain. Sharing power imply working as equal partners, addressing power dynamics, sharing decisions and a two-way learning process [3, 4, 12, 26, 28, 29, 35, 36, 40, 45, 49, 53, 55, 60, 62, 73, 78, 82, 84, 88, 98, 100, 103, 107, 114, 118, 121, 128, 129, 152, 157, 164, 166]. The impacts of sharing power are preventing a tokenistic partnership [36], empowering all members of the research team [43], and helping ensure patient partners are meaningfully involved [73]. To this, Brett et al. [71] add that patient partners' roles are 'equal but different' to researchers due to the researchers' role to ensure high-quality science while the patient partners have a unique perspective by having lived experience. Sharing power can relate to the initiation and skills of the researcher, the organisation's readiness to share decisions, and the assurance that researchers can share power with patient partners. Still, the patient partner also has a central role in accepting power [36, 84].

Invest time to build relationships

The enabler 'Invest time to build relationships' is also part of the relational domain. This enabler refers to the additional time researchers may need to invest in building relationships with patient partners through regular communication and ongoing updates [3, 5, 9, 10, 12, 27, 31, 33, 36, 40, 45, 46, 50, 53, 55, 60, 62, 64, 78, 82, 84, 85, 88, 93, 98, 100, 102, 104, 114, 115, 125, 128, 131, 134, 148, 154, 155, 157, 166]. According to Boden et al. [93], one outcome of investing time in relationship-building is that patient partners are more likely to realise their full potential as team members, fulfilling an important role rather than just holding a symbolic title. Communication can take many forms; however, 19 reviews highlight that holding meetings in inclusive and accessible locations is particularly beneficial [11, 27, 31, 36, 45, 46, 49, 60, 62, 78, 86, 88, 103, 128, 132, 133, 152, 154, 155].

Value patient partners' contribution

The last enabler within the relational domain is 'Value patient partners' contribution'. This enabler refers to researchers actively recognising and appreciating patient partners for their contributions and experiential knowledge (24/117) [3, 12, 43, 46, 52, 53, 55, 56, 61, 62, 67, 73, 78, 82, 85, 88, 90, 98, 100, 102, 103, 114, 128, 157]. Patient partners are more likely to feel motivated when they believe their opinions are valued as legitimate evidence and that their involvement has a meaningful impact [56, 88]. If the knowledge contributed by patient partners is recognised as a valid source of evidence, it can support successful implementation into practice [56].

Adequate resources

The following domain, 'Context', comprises three enablers. The most frequently reported contextual factor for effective involvement is 'Adequate resources' (identified in 45 of 117 reviews) [12, 26, 29, 31, 36, 37, 40–43, 45, 48, 50, 53, 55, 56, 62, 64, 68, 69, 78, 82, 85, 87, 88, 93, 96, 97, 99, 100, 102, 103, 114, 115, 128, 133, 142, 148, 151, 152, 154–158, 164, 167]. Resources are typically referred to as funding and financial support, but they may also include time, staff and other organisational assets [37, 53, 97, 115]. The rationale for addressing this issue is that research involving patient partners tends to require more time and resources than traditional research approaches [156]. According to Anderst et al. [115], organisations prioritising PPI by allocating sufficient resources signal to researchers that involving patient partners is valued. The positive impacts of providing adequate resources include fostering effective partnerships [53], greater success in recruiting frail patient partners [88] and enhancing the effectiveness of PPI [46].

Patient partner compensation

The second enabler within the contextual domain is 'Patient partner compensation', identified in 26 of 117 reviews) [3, 5, 9, 26, 27, 36, 40, 46, 49, 82, 85, 86, 88, 98, 100, 103, 104, 114, 120, 124, 125, 152, 154, 155, 157, 169]. Compensation is mainly described as financial reimbursement for patient partners' work and is typically considered a shared responsibility between the researcher and the organisation [5, 86, 114]. However, compensation can also take non-financial forms, like meals and refreshments during meetings, offering childcare, providing acceptable workloads or being paid for in gift cards [26, 86, 114]. Providing compensation for patient partners is described as a key facilitator of involvement [5], an essential step in achieving high-quality involvement [36], and a means of enabling the involvement of people for whom financial constraints might otherwise pose a barrier [98].

A supportive organisation

The final enabler within the contextual domain is 'A supportive organisation', which is essential for effective involvement according to 21 of 117 reviews [4, 32, 33, 49, 52, 55, 56, 78, 85, 88, 91, 96, 103, 104, 114, 115, 128, 148, 154, 157, 160]. A supportive organisation is often characterised by a positive learning culture. A shift in organisational culture and support mechanisms can be required to ensure meaningful patient partner integration into the workplace [52, 56, 96, 114]. According to Dews et al. [78], practical and social support provided by organisations is fundamental to achieving long-term, effective and emotionally meaningful patient involvement.

Involve early or in all stages

The processes domain includes enablers described by the reviews that can support the researcher in making effective decisions when planning to involve patient partners. First, the reviews do not identify a single effective approach for involving patient partners in the research process. Twenty-one reviews advocate for ‘Involve early’ (21/117) [4, 12, 32, 36, 47, 61, 81, 82, 85, 86, 103, 106, 115, 124, 135, 152, 154, 157, 164] and 23 reviews advocate for ‘Involve in all stages’ (23/117) [27, 29, 33, 41, 43, 46, 56, 58, 71, 81, 82, 87, 90, 105, 114, 115, 120, 122, 132, 133, 148, 151, 160, 164]. In Fig. 4, ‘Involve early’ and ‘Involve in all stages’ are combined into one enabler called ‘Involve early or in all stages’, as they are related and referenced by similar numbers of reviews. Based on evidence from this scoping review, both approaches can be advantageous, considering the specific patient partners and context. Early involvement enables patient partners to contribute to setting research priorities and to influence the research from the beginning [32]. The proposed benefits of early involvement include aligning research with the needs and preferences of patient partners, thereby increasing its relevance [135], fostering the democratisation of research, enhancing the applicability of research results and improving practical implementation [32]. Conversely, involving patient partners from the outset and throughout the entire research process is described in several reviews as the best way to enhance the relevance of research and the most effective way of involving patient partners [33, 58, 164]. In addition, eight reviews recommend involving patient partners on a more ‘ad-hoc’ basis, depending on the nature and needs of the specific project [74, 80, 82, 98, 127, 133, 143, 164]. In summary, no agreement exists on the optimal timing for involving patient partners in the research process. Still, involving patient partners either early or throughout the research process is generally recommended as a priority.

Recruit a diverse group of patient partners

‘Recruit a diverse group of patient partners’ refers to the importance of involving patient partners from varied backgrounds, as highlighted in 34 of 117 reviews [9, 27, 29, 41, 43, 46, 55, 62, 73, 78, 81, 82, 91, 93, 96, 98, 100, 102, 105, 113–115, 120, 121, 126, 128, 132, 133, 139, 151, 157, 164, 169]. Diversity may entail variations in gender, age, socioeconomic status and other sociodemographic factors. Additionally, some reviews also highlight the benefits of recruiting multiple patient partners to reduce feelings of intimidation and isolation and to maximise the breadth of input [115, 157]. Arguments for enhancing diversity include increasing the credibility of research results [55] and improving the quality of the research [62].

Inclusive methods

Applying ‘Inclusive methods’ is mentioned by 39 of the included reviews [4, 7, 9, 10, 27, 29, 33, 36, 37, 40, 46, 48, 53, 55, 57, 60, 62, 67, 68, 70, 74, 78, 84, 88, 100, 104, 126, 128, 129, 133, 134, 152, 155, 157, 162, 164, 165, 167]. This enabler refers to methods of facilitation, communication and interaction with patient partners tailored to the needs of individual patient partners and the specific context. Inclusive methods are appropriate for all patient partners, especially those with lower literary skills. For these groups, using, for example, flipcharts and photos can build on patient partners’ strengths and can improve communication [40]. For example, using tangible objects and materials encouraged the participation of people with dementia [41]. For children and adolescents, various communication tools – such as social media, smartphone apps, texting, etc. – can be combined with interactive methods that allow non-verbal expression [28, 60, 134]. For some patient partner groups, culturally sensitive tools may be helpful [102] and offering remote access can help facilitate their involvement [33]. Applying inclusive methods can help researchers better understand patient partners’ needs [24], overcome challenges with involvement [50] and improve overall research quality [33]. According to Muir et al. [68], placing greater emphasis on reporting and evaluating involvement may improve the quality, consistency and transparency of research.

Report and evaluate involvement

To support effective involvement, 22 reviews explicitly mention ‘Report and evaluate involvement’ as an enabler for researchers to consider [2, 4, 29, 31, 41, 53, 59, 64, 80, 90, 96, 102, 103, 105, 118, 120, 122, 137, 151, 157, 160, 169]. Some reviews stress the need for well-designed and transparent methods for reporting and evaluating involvement [26, 80], while others emphasise that evaluation should take place throughout the involvement with patient partners [157]. Several reviews recommend that researchers use GRIPP2 as a reporting guideline [58, 118, 122]. Additionally, 21 reviews advocate for developing and using guidelines to facilitate effective involvement (21/117) [4, 14, 26, 29, 39, 50, 55, 57, 67, 78, 81, 96, 97, 113, 115, 118, 141, 144, 148, 152, 155]. Reviews propose a range of needs, including universal principles of involvement [53], quality standards for involvement [78] or country-specific frameworks or policies for PPI [14]. Developing and implementing such guidelines may improve the effectiveness of patient partner involvement [14] and encourage broader adoption of patient-centred practices [115].

Training and support for patient partners

The training domain includes two enablers. The first, ‘Training and support for patient partners’, is the second most reported enabler for effective involvement across reviews, cited in 53 of the 117 reviews [4, 8, 9, 11, 12, 26, 27, 29, 31, 33, 35–37, 40, 45, 46, 48–50, 53, 55, 60, 62, 64, 68, 69, 73, 78, 81, 82, 85, 86, 90, 93, 96, 98, 100, 103–105, 114, 115, 118, 120, 125, 126, 128, 129, 131, 144, 152, 154–157, 162, 164, 166, 169]. Many reviews argue that training must be tailored to the patient partners' needs and that consulting with them beforehand can help identify appropriate training requirements [9, 26, 129]. Training and support may be formal or informal and are typically delivered by researchers or initiated by research organisations [36, 46, 156]. Informal training may imply researchers supporting patient partners in conducting interviews [49], offering support before or after meetings [50] or providing practical, emotional and financial support [53]. Formal training may include basic training in research and research methods, decision making or leadership [68, 98, 118]. Informal training may also comprise mentorship, network opportunities and hiring a research assistant as a mentor to help develop patient partners' research skills [37, 40, 96]. Providing training and support may foster more effective involvement [118], empower patient partners and increase their confidence [104], help them better understand their role, reduce power imbalances [8] and enable full participation throughout all stages in the research process [78]. In contrast, five reviews adopt a more cautious stance towards training patient partners [31, 94, 132, 133, 156]. For instance, Goedhard et al. [133] stress that researchers should adapt their methods to suit the needs of citizens in vulnerable circumstances rather than expecting citizens to adapt to research practices. In summary, training and support for patient partners seem key to effective involvement. Still, researchers must be mindful of how to be inclusive and how best to use patient partners' time.

Training and support for researchers

The second enabler within the training domain is 'Training and support for researchers', identified in 22 of the 117 reviews [9, 14, 35, 62, 67, 78, 85, 90, 91, 96, 100, 103, 104, 114, 115, 120, 131, 152, 155, 161, 166, 169]. This enabler implies that organisations should provide education and network opportunities for researchers to enhance their skills in conducting inclusive involvement [67] and education and guidance on how to effectively integrate PPI in their research [14]. Dews et al. [78] go further, recommending that training for researchers be made mandatory. Training and support for researchers can offer unique opportunities to understand people's diverse and intersecting needs [166], help overcome common misconceptions, improve understanding of barriers to involvement, and equip the researcher with the skills to work in partnership [115].

Summarising results

The key results of this scoping review are: (1) Most studies originate from the UK, US, and Canada, and patient partners are predominantly involved in identifying, prioritising, designing, and disseminating research, rather than in commissioning, implementing, and evaluating impact. (2) Few reviews explicitly define 'impact' or related terms, and reporting varies widely. (3) Key enablers of effective involvement include trust-based partnerships, inclusive communication, flexibility, training and support and sufficient resources.

Discussion

Objective #1: how are patient partners involved in the research process?

The first objective of this scoping review was to examine how patient partners are involved in the research process. The descriptive overview showed that most reviews and empirical papers were published in recent years and were predominantly from the UK, Canada and the USA. This trend is consistent with other recent reviews, underscoring that PPI is most widely adopted in industrialised high-income countries [8, 81, 85, 105, 122, 125, 141]. Furthermore, the predominance of native English speakers in the UK, the USA and Canada may facilitate easier access to research literature and terminology, unlike in countries where patients may face language barriers. The concentration of reviews and empirical papers in high-income, English-speaking countries highlights a need for more inclusive international involvement, particularly in low-income countries. Another key result is that patient partners assume various roles, most commonly through consultation and collaboration [6]. They seem to be typically involved in planning, conducting and evaluating research, although their involvement is less frequent in certain stages of the research process. The reviews indicate that patient partners are most involved in the phases 'Identify and prioritise', 'Design', 'Manage', 'Undertake' and 'Disseminate research' and are less involved in 'Commission', 'Implementing' and 'Evaluate impact'. According to the National Institute for Health and Care Research [6], commissioning may entail reviewing research proposals, participation in commissioning panels or boards and involvement of user-led organisations in commissioning research [6]. One possible reason for the limited reporting of involvement in commissioning could be that few patient partners are involved in this phase or that such involvement is insufficiently documented in the reviews. Alternatively, as commissioning often occurs before the empirical study begins, it may fall outside the scope of this review and thus be underreported. The limited reporting of patient partner involvement in the implementing phase may reflect that implementation is not a current research priority, that patient partners are excluded from this stage or that such involvement is not described in the reviews or the empirical papers. Additionally, some reviews observe that PPI results often reflect researchers' perspectives rather than the patient partners' perspectives. To ensure that involvement enhances research quality in ways that align with patients' needs rather than solely the researchers' priorities, further research is needed into the extent of patient partners' influence on research outcomes and how researchers can better share power with patient partners.

Objective #2: what is the impact of involving patient partners in research?

Exploring the impact of involving patient partners in the research process showed that only eleven reviews explicitly defined the terms 'impact', 'outcome' and 'evaluation'. However, while most reviews draw conclusions about the impact of involving patient partners, a common criticism is that the impact reporting in empirical papers is inconsistent, limited and often anecdotal. In line with existing literature, Brett et al. [12] argued in 2012 that much of the evidence base was weak and required substantial development in the years ahead. Subsequent reviews have continued to highlight the paucity of evidence investigating the impact of involving patient partners [10, 11, 82]. The results of this scoping review, alongside existing literature, emphasise the need for greater transparency in defining terms such as 'impact', 'outcome' and 'evaluation' of involvement, as well the adoption of more systematic and evidence-based methods to evaluate the impact of PPI. The limited range of measurement tools identified in this scoping review further underscores the need for improved impact reporting.

Objective #3: what defines effective patient partner involvement in research?

The various and limited reporting of involvement practices and the impact of PPI made it difficult to determine what constitutes effective involvement. Nevertheless, this scoping review identified sixteen enablers that support effective PPI. The most influential enablers identified were: 'A partnership built on trust and inclusive communication', 'Training and support for patient partners', 'Flexibility' and 'Adequate resources'. Compared with other literature in the field, Harrison et al. [169] conducted a narrative review outlining foundational principles and best practice activities. They identified values such as respect, trust and equitable power – alongside training and education for both patient partners and researchers and providing financial compensation – as essential for successful involvement. These results align with our results, suggesting that building trust, offering training and ensuring adequate funding are crucial. In addition, Bird et al. emphasise the importance of addressing power dynamics, valuing patient partners' roles and developing inclusive recruitment and training strategies. These priorities correspond with several enablers from this scoping review, including 'Share power', 'Value patient partners contribution', 'Training and support for patient partners' and 'Recruit diverse patient partners'. In addition, Brett et al. [42] found that inadequate training and preparation hindered patient partners' ability to contribute meaningfully, and researchers struggled to incorporate PPI due to limited time and funding. These challenges align with the enablers' 'Training and support for patient partners', 'Invest time to build relationships' and 'Adequate resources'. The sixteen enablers identified in this scoping review align closely with the six UK Standards for Public Involvement, which provide a framework for high-quality involvement [6]. For example, the standard 'Inclusive opportunities' is similar to the enabler 'Use inclusive methods'. The standards 'Working together' and 'Communication' reflect the enablers within the relational domain. The standard 'Support and learning' is similar to the enabler 'Training and support for research partners'. The enabler 'Governance' seems similar to the context domain and the 'Share power' enabler. The standard 'Impact' unfolds the enabler 'Report and evaluate partnership' [6]. The consistency between the sixteen enablers and the UK standards for public involvement suggests their potential relevance in broader health service contexts. Considering this, further research is needed to explore the applicability of these enablers beyond the UK context, particularly given that most reviews included in this study originate from the UK. Dengsø et al. [14], for example, explore PPI in Nordic health service research and conclude that the diverse application of PPI methods suggests a lack of established international recommendations.

Summing up

An interpretation of the key results of this scoping review, along with potential next steps, includes: (1) Most studies originate from the UK, US, and Canada, raising concerns about the limited representation from non-English-speaking and low-income countries. Patients are predominantly involved in identifying, prioritising, designing and disseminating research but are less involved in commissioning, implementing and evaluating impact. Further investigation is needed to clarify when and why patient partners are involved in particular stages, especially since early or continuous involvement appears to be an effective approach. (2) Few reviews explicitly define 'impact' or related terms, and reporting varies widely, making it difficult to assess effectiveness. Developing standardised evaluation methods remains a challenge. (3) Key enablers of effective involvement include trust-based partnerships, inclusive communication, training and support, flexibility, and sufficient resources. While these align with UK public involvement standards, further research is required to assess their applicability in other health service systems. To support researchers involving patient partners in the research process, future research must focus on offering actionable advice and consistent reporting of practices.

Strengths and limitations

The strengths of this scoping review include: (1) The scoping review design, which enables us to examine the extent, range and nature of this emerging field, especially in relation to how patient partners are involved in research. (2) A published protocol. (3) An interdisciplinary research team including: a patient partner co-author (FOJ), two authors with lived experience as patient partners and next of kin (SCT, JF), and researchers from different institutions and with various educational backgrounds and different expertise in health service research and PPI. (4) Consultations with two librarians, enhancing the quality of the literature search. (5) Consultations with stakeholder groups, a patient partner co-author (FOJ) and two authors (SCT, JF) bringing lived experience to the table. This improved both the quality of this scoping review and the relevance of the review for key stakeholders. (6) An updated systematic literature search was conducted in 2024, which improved the inclusion of the most recent literature.

The limitations of this scoping review include: (1) Only publications written in English, Danish, Swedish and Norwegian were included, which may be a limitation as relevant evidence could exist in work published in other languages. In addition, the predominance of research published in English may partly explain the high number of publications derived from English-speaking countries such as the UK, the USA, Canada and Australia. Besides, including 124 reviews from 20 countries and empirical papers from 49 different countries demonstrates the breadth of this scoping review and raises the question of whether the inclusion of other languages would significantly alter the results. (2) A citation search of more than 10% of the included reviews may have identified additional eligible reviews. Though we chose not to, as we expect key reviews to be cited in the recently published literature. Additionally, screening 15461 studies also shows the breadth of the search.” (3) Including supplemental materials in the analysis may have contained information on the role and impact of patient partners. Due to time constraints, this was not possible for the author team. Still, we do not expect this matter to change the results and conclusions of this scoping review, as we expect the most important results are included in the review manuscripts. (4) This review relied on reading and coding the included reviews rather than the empirical papers. As such, results were based on the reviewers' interpretations, which may introduce misrepresentation or misunderstandings. (5) While two authors with patient partner experience (SCT, JF) contributed to the protocol, the inclusion of a patient partner co-author without an academic background might have further strengthened the integration of the patient perspective during protocol development.

Table 5 Implications for practice

Recommendation	Elaboration
Consider geographical and cultural diversity	• The concentration of PPI research in high-income, English-speaking countries highlights a need for broader international involvement, particularly in low-income countries. • Future practices should consider addressing linguistic and cultural barriers and adapting PPI strategies to diverse global contexts to improve the quality of health service research worldwide.
Prioritise involvement across all phases	• While patient partners are most involved in identifying, prioritising, designing and disseminating research, they are less involved in commissioning, implementing and evaluating research impact. • To ensure comprehensive patient-centred input throughout the research process, future PPI practice should focus on including patient partners early or in all research phases.
Improve the reporting of impact	• The inconsistent and anecdotal reporting of PPI impact suggests a need for better methods to measure and report its outcomes. • To ensure more robust evidence on the effectiveness of PPI practices: (1) future research should prioritise developing clear definitions of involving patient partners in research and impact, and (2) more robust measurements should be developed for evaluating and reporting the impact of patient partner involvement.
Support flexible and context-dependent involvement	• Effective involvement should not follow a one-size-fits-all model. • Future practice should focus on context-specific, flexible approaches that account for diverse patients, researchers and settings. • This includes providing appropriate training, support and resources for patient partners and researchers and fostering an environment of trust and flexible collaboration.
Address power dynamics and share decisions	• Addressing power imbalances is crucial for fostering effective patient partnerships. • Future practices should focus on creating an equitable balance of power, ensuring that patient partners are actively involved in decision-making processes and have a meaningful role in shaping research outcomes and evaluating involvement processes.

Implications for practice

The implications for future practice derived from this scoping review are listed in Table 5.

Conclusion

This scoping review reveals that PPI research is predominantly concentrated in high-income, English-speaking countries, raising concerns about its applicability in lower-income and non-English-speaking settings. Patient partners are most commonly involved in research design and dissemination but are less frequently involved in commissioning, implementation and impact evaluation, indicating areas for further development. This scoping review also identifies a substantial gap in how the impact of PPI is defined and measured, with existing evidence being inconsistent, anecdotal and lacking standardised evaluation frameworks. This underlines the urgent need for more robust methods to assess the effectiveness of patient partner involvement in research. Despite these limitations, the review identifies sixteen enablers for effective PPI, with key factors including trust-based partnerships, inclusive communication, adequate training and support, flexibility and sufficient resources. However, further research is needed to determine their relevance and effectiveness beyond the UK and similar high-income settings. Future research should focus on increasing patient partner involvement in the beginning and throughout all research phases, improving impact assessment, addressing power imbalances and adapting best practices to diverse health service systems worldwide.

Abbreviations

PPI	Patient and Public Involvement in Research
UK	United Kingdom
USA	United States of America
PRISMA-ScR	The Preferred Reporting Items for Systematic Reviews and Meta-Analyses
GRIPP2	Guidance for Reporting Involvement of Patients and the Public

Supplementary Information

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Supplementary Material 1

Supplementary Material 2

Supplementary Material 3

Supplementary Material 4

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Author contributions

S.C.T. drafted the scoping review and contributed as the project lead and first reviewer, screening all articles, extracting data, and drafting manuscripts for all authors to comment on and revise. A.L.J. screened articles as a second reviewer and supported all aspects of the review. H.L.B. contributed to the design of the review, served as the third reviewer in resolving conflicts, and supported all aspects of the project. T.W.V., J.F., and G.S.R. served as second reviewers in the screening process and contributed to the design and critical revision of the scoping review. J.A.Ø. contributed to the design and critically revising the scoping review. F.O.J. assisted in writing the layman summary and critically revising the scoping review. L.Ø.R. contributed to the design of the review, served as the second reviewer in screening the articles and supervised all stages of the project. All authors approved the final manuscript.

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Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

According to Danish legislation, this type of research is exempt from ethical approval.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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References

1. Tierney E, et al. A critical analysis of the implementation of service user involvement in primary care research and health service development using normalization process theory. Health Expect. 2016;19(3):501–15.
2. Rouncefield-Swales A, et al. Children and young people's contributions to public involvement and engagement activities in health-related research: A scoping review. PLoS ONE. 2021;16(6):e0252774.
3. Bird M, et al. Preparing for patient partnership: A scoping review of patient partner engagement and evaluation in research. Health Expect Int J Public Particip Health Care Health Policy. 2020;23(3):523–39.
4. Tembo D, et al. Is Co-production just a pipe dream for applied health research commissioning?? An exploratory literature review. Front Sociol. 2019;4:50.
5. Dawson S, et al. Black and minority ethnic group involvement in health and social care research: A systematic review. Health Expect. 2018;21(1):3–22.
6. National Institute for Health and Care Research. Briefing notes for researchers - public involvement in NHS, health and social care research. 2024 May 2024

[cited 2024 November 26]; 2.0:[Available from: https://www.nihr.ac.uk/briefing-notes-researchers-public-involvement-nhs-health-and-social-care-research

7. Greenhalgh T, et al. Frameworks for supporting patient and public involvement in research: systematic review and co-design pilot. Health Expect. 2019;22(4):785–801.
8. Colomer-Lahiguera S, et al. Patient and public involvement in cancer research: A scoping review. Cancer Med. 2023;12(14):15530–43.
9. Paolucci A, et al. The impacts of partnering with cancer patients in palliative care research: a systematic review and meta-synthesis. Palliat Care Soc Pract. 2022;16:26323524221131581.
10. Domecq JP, et al. Patient engagement in research: a systematic review. BMC Health Serv Res. 2014;14:89.
11. Harris J, et al. How patient and community involvement in diabetes research influences health outcomes: A realist review. Health Expect. 2019;22(5):907–20.
12. Brett J, et al. Mapping the impact of patient and public involvement on health and social care research: a systematic review. Health Expect. 2014;17(5):637–50.
13. Staley K. Is it worth doing?' measuring the impact of patient and public involvement in research. Res Involv Engagem. 2015;1:6.
14. Dengso KE, et al. Patient and public involvement in nordic healthcare research: a scoping review of contemporary practice. Res Involv Engagem. 2023;9(1):72.
15. Research N. I.f.H.a.C. Who we are. 2024 [cited 2024 December 16]; Available from: https://www.nihr.ac.uk/about-us/who-we-are
16. Institute TP-COR, About PCORI. 2024 [cited 2024 December 16]; Available from: https://www.pcori.org/about/about-pcori
17. Research C. I.o.H. Strategy for Patient-Oriented Research. 2023 November 7, 2023 [cited 2024 December 16]; Available from: https://cihr-irsc.gc.ca/e/41204.html
18. Levac D, Colquhoun H. O'Brien, scoping studies: advancing the methodology. Implement Sci. 2010;5:69.
19. Tscherning SC, et al. How to engage patient partners in health service research: a scoping review protocol. Res Involv Engagem. 2021;7(1):20.
20. Covidence, About Us. 2024 [cited 2024 November 26]; Available from: https://www.covidence.org/about-us-covidence/
21. O'Neill M, Booth S, Lamb J. Using NVivo™ for Literature Reviews: The Eight Step Pedagogy (N7 + 1). The Qualitative Report, 2018.
22. Lumivero. NVivo 15. 2024 2024 [cited 2024 November 26]; Available from: https://lumivero.com/products/nvivo/
23. Svend Brinkman LTP. Kvalitative metoder. En Grundbog. 4 ed. København: Hans Rietzels Forlag; 2025.
24. Staniszewska S, et al. GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. BMJ. 2017;358:j3453.
25. PRISMA. PRISMA flow diagram. 2020 [cited 2025 May 16]; Available from: https://www.prisma-statement.org/prisma-2020-flow-diagram
26. Crooks J et al. Opportunities and challenges in involving people with lived experience of inclusion health as co-researchers in palliative and end of life research: a rapid review and thematic synthesis. Res Involv Engagem, 2023. 9(1).
27. Sellars E, et al. Young people's advisory groups in health research: scoping review and mapping of practices. Arch Dis Child. 2021;106(7):698–704.
28. Larsson I, et al. Children and young people's participation in developing interventions in health and well-being: a scoping review. BMC Health Serv Res. 2018;18(1):507.
29. Shakhnenko I, et al. Elements of successful patient involvement in clinical cancer trials: a review of the literature. ESMO Open. 2024;9(4):102947.
30. Bastable K, et al. How are stakeholders with autism spectrum disorder included in the social validation of augmentative and alternative communication research?? A scoping review. Am J Speech Lang Pathol. 2021;30(2):817–32.
31. Baldwin JN, et al. Impacts of older people's patient and public involvement in health and social care research: a systematic review. Age Ageing. 2018;47(6):801–9.
32. Grill C. Involving stakeholders in research priority setting: a scoping review. Res Involv Engagem. 2021;7(1):75.
33. Aguayo GA, Methods to Generate Innovative Research Ideas and Improve Patient and Public Involvement in Modern Epidemiological Research, et al. Review, patient viewpoint, and guidelines for implementation of a digital cohort study. J Med Internet Res. 2021;23(12):e25743.
34. Kiili J, Moilanen J. Participation as a methodological and ethical issue in child protection research. Journal of Children's Services, 2019. ahead-of-print(ahead-of-print).
35. Luna Puerta L, et al. The reported impact of public involvement in biobanks: A scoping review. Health Expect. 2020;23(4):759–88.
36. Di Lorito C, et al. Co-research with adults with intellectual disability: A systematic review. J Appl Res Intellect Disabil. 2018;31(5):669–86.
37. Kiili J, Moilanen J. Participation as a methodological and ethical issue in child protection research. J Children's Serv. 2019;14(3):143–61.
38. Hoekstra F, et al. Systematic overviews of partnership principles and strategies identified from health research about spinal cord injury and related health conditions: A scoping review. J Spinal Cord Med. 2023;46(4):614–31.
39. Day S, et al. Stakeholder engagement to inform HIV clinical trials: a systematic review of the evidence. J Int AIDS Soc. 2018;21 Suppl 7(Suppl Suppl 7):e25174.
40. Camden C, et al. Engaging stakeholders in rehabilitation research: a scoping review of strategies used in partnerships and evaluation of impacts. Disabil Rehabil. 2015;37(15):1390–400.
41. Hubbard G, et al. A review of literature about involving people affected by cancer in research, policy and planning and practice. Patient Educ Couns. 2007;65(1):21–33.
42. Brett J, et al. A systematic review of the impact of patient and public involvement on service users, researchers and communities. Patient. 2014;7(4):387–95.
43. Hallam-Bowles FV, et al. Approaches to co-production of research in care homes: a scoping review. Res Involv Engagem. 2022;8(1):74.
44. Jennings H, et al. Best practice framework for patient and public involvement (PPI) in collaborative data analysis of qualitative mental health research: methodology development and refinement. BMC Psychiatry. 2018;18(1):213.
45. Erwin J, et al. Co-production of health and social science research with vulnerable children and young people: A rapid review. Health Expect. 2024;27(2):e13991.
46. Burgher T, Shepherd V, Nollett C. Effective approaches to public involvement in care home research: a systematic review and narrative synthesis. Res Involv Engagem. 2023;9(1):38.
47. Crocker JC, et al. Impact of patient and public involvement on enrolment and retention in clinical trials: systematic review and meta-analysis. BMJ. 2018;363:k4738.
48. Bailey S, et al. Involving disabled children and young people as partners in research: a systematic review. Child Care Health Dev. 2015;41(4):505–14.
49. Hubbard G, Kidd L, Donaghy E. Involving people affected by cancer in research: a review of literature. Eur J Cancer Care (Engl). 2008;17(3):233–44.
50. Boote J, Baird W, Sutton A. Involving the public in systematic reviews: a narrative review of organizational approaches and eight case examples. J Comp Eff Res. 2012;1(5):409–20.
51. Abrams R, et al. Lost in reviews: looking for the involvement of stakeholders, patients, public and other non-researcher contributors in realist reviews. Res Synth Methods. 2021;12(2):239–47.
52. Backhouse T, et al. Older care-home residents as collaborators or advisors in research: a systematic review. Age Ageing. 2016;45(3):337–45.
53. Baines RL, Regan de S, Bere. Optimizing patient and public involvement (PPI): identifying its essential and desirable principles using a systematic review and modified Delphi methodology. Health Expect. 2018;21(1):327–35.
54. Bowness B et al. Participatory research with carers: A systematic review and narrative synthesis. Health Expect, 2023. 27(1).
55. Chambers E, et al. Patient and carer involvement in palliative care research: an integrative qualitative evidence synthesis review. Palliat Med. 2019;33(8):969–84.
56. Gillard S, Foster R, Papoulias C. Patient and public involvement and the implementation of research into practice. J Mental Health Train Educ Pract. 2016;11(4):256–67.
57. Miah J, et al. Patient and public involvement in dementia research in the European union: a scoping review. BMC Geriatr. 2019;19(1):220.
58. Howard Wilsher S, et al. Patient and public involvement in health literacy interventions: a mapping review. Res Involv Engagem. 2017;3:31.
59. Cook N, et al. Patient and public involvement in health research in low and middle-income countries: a systematic review. BMJ Open. 2019;9(5):e026514.
60. Menzies JC, et al. Patient and public involvement in paediatric intensive care research: considerations, challenges and facilitating factors. Res Involv Engagem. 2016;2:32.
61. Williamson R, et al. Patient and public involvement in research published in the British journal of occupational therapy 2015–2021: A scoping review. Br J Occup Therapy. 2023;86(6):400–12.
62. Kirby P, et al. Patient and public involvement in Technology-Related dementia research: scoping review. JMIR Aging. 2024;7:e48292.

63. Owyang D, et al. Patient and public involvement within orthopaedic research: A systematic review. J Bone Joint Surg Am. 2021;103(13):e51.
64. Arnstein L, et al. Patient involvement in Preparing health research peer-reviewed publications or results summaries: a systematic review and evidence-based recommendations. Res Involv Engagem. 2020;6:34.
65. Stewart RJ, et al. Patients' and clinicians' research priorities. Health Expect. 2011;14(4):439–48.
66. McCarron TL, et al. Patients as partners in health research: A scoping review. Health Expect. 2021;24(4):1378–90.
67. Burton A, Ogden M, Cooper C. Planning and enabling meaningful patient and public involvement in dementia research. Curr Opin Psychiatry. 2019;32(6):557–62.
68. Boote J, Baird W, Beecroft C. Public involvement at the design stage of primary health research: a narrative review of case examples. Health Policy. 2010;95(1):10–23.
69. Boote J, Baird W, Sutton A. Public involvement in the systematic review process in health and social care: a narrative review of case examples. Health Policy. 2011;102(2–3):105–16.
70. Marshman Z, et al. Seen and heard: towards child participation in dental research. Int J Paediatr Dent. 2015;25(5):375–82.
71. Marshman Z, et al. Seen but not heard: a systematic review of the place of the child in 21st-century dental research. Int J Paediatr Dent. 2007;17(5):320–7.
72. Pollock A, et al. Stakeholder involvement in systematic reviews: a scoping review. Syst Rev. 2018;7(1):208.
73. Bradbury-Jones C, Isham L, Taylor J. The complexities and contradictions in participatory research with vulnerable children and young people: A qualitative systematic review. Soc Sci Med. 2018;215:80–91.
74. Wallace A, et al. Traumatic dental injury research: on children or with children? Dent Traumatol. 2017;33(3):153–9.
75. Gradinger F, et al. Values associated with public involvement in health and social care research: a narrative review. Health Expect. 2015;18(5):661–75.
76. Boote J, Baird W, Sutton A. Public involvement in the design and conduct of clinical trials: a narrative review of case examples. Trials. 2011;12:S1.
77. Crooks J, et al. Opportunities and challenges in involving people with lived experience of inclusion health as co-researchers in palliative and end of life research: a rapid review and thematic synthesis. Res Involv Engagem. 2023;9(1):25.
78. Dews SA, et al. The power of language: how to Bridge the gap between healthcare research and patients - a scoping review. Curr Med Res Opin. 2024;40(2):279–91.
79. Zibrowski E, et al. A rapid realist review of patient engagement in patient-oriented research and health care system impacts: part one. Res Involv Engagem. 2021;7(1):72.
80. Jull JE, et al. A review and synthesis of frameworks for engagement in health research to identify concepts of knowledge user engagement. BMC Med Res Methodol. 2019;19(1):211.
81. Farah E, et al. Beyond participation: evaluating the role of patients in designing oncology clinical trials. Curr Oncol. 2023;30(9):8310–27.
82. Crockett LK et al. Characterizing research partnerships in child health research: A scoping review. J Child Health Care, 2024: p. 13674935241231346.
83. Zych MM, Berta WB, Gagliardi AR. Conceptualising the initiation of researcher and research user partnerships: a meta-narrative review. Health Res Policy Syst. 2020;18(1):24.
84. Flynn R, Walton S, Scott SD. Engaging children and families in pediatric health research: a scoping review. Res Involv Engagem. 2019;5:32.
85. Sheikhan NY, et al. Exploring the impact of engagement in mental health and substance use research: A scoping review and thematic analysis. Health Expect. 2023;26(5):1806–19.
86. Shen S, et al. How and why should we engage parents as co-researchers in health research? A scoping review of current practices. Health Expect. 2017;20(4):543–54.
87. Corrado AM, et al. Participatory action research with older adults: A critical interpretive synthesis. Gerontologist. 2020;60(5):e413–27.
88. Ludwig C, et al. Partnering with frail or seriously ill patients in research: a systematic review. Res Involv Engagem. 2020;6:52.
89. Martineau JT, Minyaoui A, Boivin A. Partnering with patients in healthcare research: a scoping review of ethical issues, challenges, and recommendations for practice. BMC Med Ethics. 2020;21(1):34.
90. Manafo E, et al. Patient engagement in canada: a scoping review of the 'how' and 'what' of patient engagement in health research. Health Res Policy Syst. 2018;16(1):5.
91. Fox G, et al. Patient engagement in preclinical laboratory research: A scoping review. EBioMedicine. 2021;70:103484.
92. Bethell J, et al. Patient engagement in research related to dementia: A scoping review. Dement (London). 2018;17(8):944–75.
93. Boden C, et al. Patient partners' perspectives of meaningful engagement in synthesis reviews: A patient-oriented rapid review. Health Expect. 2021;24(4):1056–71.
94. Frisch N, et al. Patient-oriented research competencies in health (PORCH) for researchers, patients, healthcare providers, and decision-makers: results of a scoping review. Res Involv Engagem. 2020;6:4.
95. Bird M, et al. Preparing for patient partnership: A scoping review of patient partner engagement and evaluation in research. Health Expect. 2020;23(3):523–39.
96. Hawke LD, et al. Research evidence and implementation gaps in the engagement of people with lived experience in mental health and substance use research: a scoping review. Res Involv Engagem. 2023;9(1):32.
97. Ali AZ, et al. Patient engagement in child, adolescent, and youth mental health care research - a scoping review. Child Adolesc Ment Health. 2023;28(4):524–35.
98. Lauzon-Schnittka J, et al. The experience of patient partners in research: a qualitative systematic review and thematic synthesis. Res Involv Engagem. 2022;8(1):55.
99. Vanderhout SM, et al. The impact of patient and family engagement in child health research: A scoping review. J Pediatr. 2023;253:115–28.
100. McCabe E, et al. Youth engagement in mental health research: A systematic review. Health Expect. 2023;26(1):30–50.
101. Benizri N, et al. Patient and family representation in randomized clinical trials published in 3 medical and surgical journals: A systematic review. JAMA Netw Open. 2022;5(9):e2230858.
102. Manafò E, et al. Patient and public engagement in priority setting: A systematic rapid review of the literature. PLoS ONE. 2018;13(3):e0193579.
103. Chudyk AM, et al. Scoping review of models and frameworks of patient engagement in health services research. BMJ Open. 2022;12(8):e063507.
104. Pratte MM, et al. Researchers' experiences with patient engagement in health research: a scoping review and thematic synthesis. Res Involv Engagem. 2023;9(1):22.
105. Parry M, et al. Community- and Patient-Partner engagement in women's cardiovascular disease research: A rapid review of the evidence. CJC Open. 2024;6(2Part B):485–502.
106. Vaughn LM, Wagner E, Jacquez F. A review of community-based participatory research in child health. MCN Am J Matern Child Nurs. 2013;38(1):48–53.
107. Forsythe LP, et al. A systematic review of approaches for engaging patients for research on rare diseases. J Gen Intern Med. 2014;29(Suppl 3):S788–800.
108. Banna J, Bersamin A. Community involvement in design, implementation and evaluation of nutrition interventions to reduce chronic diseases in Indigenous populations in the U.S.: a systematic review. Int J Equity Health. 2018;17(1):116.
109. Brown Speights JS, et al. Engaging African American women in research: an approach to eliminate health disparities in the African American community. Fam Pract. 2017;34(3):322–9.
110. Shippee ND, et al. Patient and service user engagement in research: a systematic review and synthesized framework. Health Expect. 2015;18(5):1151–66.
111. Lee DJ, et al. Patient engagement in the design and execution of urologic oncology research. Urol Oncol. 2017;35(9):552–8.
112. Harrison JD, et al. Patient stakeholder engagement in research: A narrative review to describe foundational principles and best practice activities. Health Expect. 2019;22(3):307–16.
113. Martinez J, et al. Stakeholder engagement in research: a scoping review of current evaluation methods. J Comp Eff Res. 2019;8(15):1327–41.
114. Joss N, Cooklin A, Oldenburg B. A scoping review of end user involvement in disability research. Disabil Health J. 2016;9(2):189–96.
115. Anderst A, et al. Engaging consumers in health research: a narrative review. Aust Health Rev. 2020;44(5):806–13.
116. Muir R, et al. Patient and public involvement in emergency care research: a scoping review of the literature. Emerg Med J. 2023;40(8):596–605.
117. Dadich A, Wyer M. Patient involvement in Healthcare-Associated infection research: A lexical review. Infect Control Hosp Epidemiol. 2018;39(6):710–7.
118. Muir R, et al. Patient involvement in surgical wound care research: A scoping review. Int Wound J. 2020;17(5):1462–82.
119. Zirnsak TM et al. Public involvement in Australian clinical trials: A systematic review. Clin Trials, 2024: p. 17407745231224533.

120. Nunn JS, et al. Public involvement in global genomics research: A scoping review. Front Public Health. 2019;7:79.
121. Roche L, Adams D, Clark M. Research priorities of the autism community: A systematic review of key stakeholder perspectives. Autism. 2021;25(2):336–48.
122. Bergin RJ, et al. The nature and impact of patient and public involvement in cancer prevention, screening and early detection research: A systematic review. Prev Med. 2023;167:107412.
123. Pii KH, et al. Current trends in patient and public involvement in cancer research: A systematic review. Health Expect. 2019;22(1):3–20.
124. Mojadeddi ZM, Oberg S, Rosenberg J. Low degree of patient involvement in contemporary surgical research: A scoping review. J Postgrad Med. 2023;69(3):153–8.
125. Karlsson AW, et al. Roles, outcomes, and enablers within research partnerships: A rapid review of the literature on patient and public involvement and engagement in health research. Res Involv Engagem. 2023;9(1):43.
126. Sangill C, et al. Service user's actual involvement in mental health research practices: A scoping review. Int J Ment Health Nurs. 2019;28(4):798–815.
127. Rach C, et al. Involving patient groups in drug research: A systematic review of reasons. Patient Prefer Adherence. 2020;14:587–97.
128. Schilling I, Gerhardus A. Methods for involving older people in health Research-A review of the literature. Int J Environ Res Public Health, 2017. 14(12).
129. Totzeck C, et al. Systematic review: patient and public involvement of children and young people in mental health research. Clin Child Fam Psychol Rev. 2024;27(1):257–74.
130. Kowe A, et al. The impact of participatory dementia research on researchers: A systematic review. Dement (London). 2022;21(3):1012–31.
131. Kowe A et al. The impact of participatory dementia research on researchers: A systematic review. Dementia (London), 2022: p. 14713012211067020.
132. Frankena TK, et al. Active involvement of people with intellectual disabilities in health research - A structured literature review. Res Dev Disabil. 2015;45–46:271–83.
133. Goedhart NS, et al. Engaging citizens living in vulnerable circumstances in research: a narrative review using a systematic search. Res Involv Engagem. 2021;7(1):59.
134. Haijes HA, van Thiel GJ. Participatory methods in pediatric participatory research: a systematic review. Pediatr Res. 2016;79(5):676–83.
135. Tiemens DK, et al. Patient engagement in the design of clinical research in Noonan syndrome spectrum disorders: a scoping review. Orphanet J Rare Dis. 2021;16(1):449.
136. Flotten KJO, et al. Adolescent and young adult patients as co-researchers: A scoping review. Health Expect. 2021;24(4):1044–55.
137. Rossvoll TB, et al. Patient and public involvement in occupational therapy health research: A scoping review. OTJR (Thorofare N J). 2023;43(1):119–26.
138. Malterud K, Elvbakken KT. Patients participating as co-researchers in health research: A systematic review of outcomes and experiences. Scand J Public Health. 2020;48(6):617–28.
139. Velvin G, Hartman T, Bathen T. Patient involvement in rare diseases research: a scoping review of the literature and mixed method evaluation of Norwegian researchers' experiences and perceptions. Orphanet J Rare Dis. 2022;17(1):212.
140. Ni She E, et al. Clarifying the mechanisms and resources that enable the reciprocal involvement of seldom heard groups in health and social care research: A collaborative rapid realist review process. Health Expect. 2019;22(3):298–306.
141. Gilfoyle M, et al. Recruitment of patients, carers and members of the public to advisory boards, groups and panels in public and patient involved health research: a scoping review. BMJ Open. 2023;13(10):e072918.
142. Elhai M et al. Involving patients as research partners in research in rheumatology: a literature review in 2023. RMD Open, 2023. 9(4).
143. Ahouah M, Rothan-Tondeur M. End-Users and Caregivers' Involvement in Health Interventional Research Carried Out in Geriatric Facilities: A Systematic Review. Int J Environ Res Public Health, 2019. 16(16).
144. Husson M, et al. Patient and public involvement is suboptimal in randomized controlled trials addressing a chronic condition. J Clin Epidemiol. 2023;160:71–82.
145. Burns KEA, et al. Patient and family engagement in the ICU. Untapped opportunities and underrecognized challenges. Am J Respir Crit Care Med. 2018;198(3):310–9.
146. Treacy S, et al. Patient and public involvement (PPI) in prisons: the involvement of people living in prison in the research process - a systematic scoping review. Health Justice. 2021;9(1):30.
147. Preston J, et al. Developing a more tailored approach to patient and public involvement with children and families in pediatric clinical research: lessons learned. Therapeutic Innov Regul Sci. 2022;56(6):948–63.
148. Cluley V, et al. Mapping the role of patient and public involvement during the different stages of healthcare innovation: A scoping review. Health Expect. 2022;25(3):840–55.
149. Carroll P, et al. Applying patient and public involvement in preclinical research: A co-created scoping review. Health Expect. 2022;25(6):2680–99.
150. Banna J, Bersamin A. Community involvement in design, implementation and evaluation of nutrition interventions to reduce chronic diseases in Indigenous populations in the U.S.: a systematic review. Int J Equity Health. 2018;17(1):NPAG–NPAG.
151. Pii KH, et al. Current trends in patient and public involvement in cancer research: A systematic review. Health Expectations: Int J Public Participation Health Care Health Policy. 2019;22(1):3–20.
152. Ní Shé É, et al. Clarifying the mechanisms and resources that enable the reciprocal involvement of seldom heard groups in health and social care research: A collaborative rapid realist review process. Health Expect. 2019;22(3):298–306.
153. Dadich A, Wyer M, Patient Involvement in Healthcare-Associated Infection Research. Lexical Rev Infect Control Hosp Epidemiol. 2018;39(6):710–7.
154. Bethell J, et al. Patient engagement in research related to dementia: A scoping review. Dement (14713012). 2018;17(8):944–75.
155. Hoekstra F et al. Systematic overviews of partnership principles and strategies identified from health research about spinal cord injury and related health conditions: A scoping review. J Spinal Cord Med, 2022: pp. 1–18.
156. Fløtten KJØ, et al. Adolescent and young adult patients as co-researchers: A scoping review. Health Expect. 2021;24(4):1044–55.
157. Bowness B, et al. Participatory research with carers: A systematic review and narrative synthesis. Health Expect. 2024;27(1):e13940.
158. Martineau JT, Minyaoui A, Boivin A. Partnering with patients in healthcare research: A scoping review of ethical issues, challenges, and recommendations for practice. BMC Med Ethics. 2020;21:20.
159. MapChart. World map: Simple. 2025; Available from: https://www.mapchart.net/world.html
160. Dean O, et al. Patient and public involvement within orthopaedic research: A systematic review. J Bone Joint Surg Am Volume. 2021;103(13):1–6.
161. Zirnsak TM, et al. Public involvement in Australian clinical trials: A systematic review. Clin Trials. 2024;21(4):507–15.
162. Boote J, Baird W, Sutton A. Public involvement in the design and conduct of clinical trials: A review. Int J Interdisciplinary Social Sci, 2011. 5.
163. Benizri N et al. Patient and family representation in randomized clinical trials published in 3 medical and surgical journals. JAMA Netw Open, 2022. 5(9).
164. Jennings H et al. Best practice framework for patient and public involvement (PPI) in collaborative data analysis of qualitative mental health research: methodology development and refinement. BMC Psychiatry, 2018. 18(1).
165. Bastable K, et al. How are stakeholders with autism spectrum disorder included in the social validation of augmentative and alternative communication research?? A scoping review. Am J Speech-Language Pathol. 2021;30:817–32.
166. Speights JSB, et al. Engaging African American women in research: an approach to eliminate health disparities in the African American community. Fam Pract. 2017;34(3):322–9.
167. Lee DJ, et al. Patient engagement in the design and execution of urologic oncology research. Urologic Oncology: Seminars Original Investigations. 2017;35(9):552–8.
168. Brett J, et al. Impact of patient and public (PPI) involvement in the life after prostate Cancer diagnosis (LAPCD) study: a mixed-methods study. BMJ Open. 2022;12(11):e060861.
169. Harrison JD, et al. Patient stakeholder engagement in research: A narrative review to describe foundational principles and best practice activities. Health Expectations: Int J Public Participation Health Care Health Policy. 2019;22(3):307–16.

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