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SCOPING REVIEW

Evaluation Tools for Patient and Public Involvement (PPI) in Health Research: A Scoping Review

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Abstract

Background Patient and public involvement (PPI) is crucial for aligning research with public needs, reducing research waste, and enhancing the relevance and quality of evidence. Evaluating PPI is necessary to ensure its effectiveness. However, despite its recognised importance, researchers have reported a lack of robust tools for evaluating PPI systematically. To clarify which tools are used to evaluate PPI in health research, we conducted a scoping review.

Objective We aimed to identify and map evaluation tools that have been used in empirical health research studies to assess PPI, and to describe reported outcomes related to PPI.

Methods A scoping review was conducted in accordance with Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) guidelines. A comprehensive search was undertaken in MEDLINE, Embase, CINAHL and Scopus to identify studies published between 2021 and 2024 describing evaluation tools for PPI in health research contexts. Studies evaluating PPI were included, irrespectively of tool validation. Study selection and data charting were guided by principles from structured extraction frameworks and results were synthesised descriptively and narratively.

Results Thirty studies were included. Positive personal outcomes for PPI partners were reported, including increased well-being and skill development. Despite the existence of robust validated evaluation tools, many were adapted or developed de novo. An ‘us vs them’ dynamic was noted, reflecting differing engagement levels between PPI partners and researchers during evaluations. The need for additional training for both PPI partners and researchers to enhance collaboration was a recurring theme.

Conclusions Patient and public involvement evaluation tools are often developed or adapted to fit specific contexts, with multiple methods used for assessment. Challenges include low researcher response rates in evaluations and the need for better researcher preparedness for PPI.

1 Introduction

Recognition of the importance of patient and public involvement (PPI) in health research has been growing from the Alma-Ata Declaration of 1978 [1, 2] to the most recent Helsinki Declaration in 2024 [3], marking five decades of acknowledgement. Within this, a growing focus on research quality has highlighted the concept of “research waste”, which PPI can mitigate by ensuring that research addresses relevant questions and produces meaningful outcomes [4–6].

Thus, as the global interest in PPI increases, the need for improved practices intensifies. In 2017, the International Patient and Public Involvement Network (IPPIN) was established in the UK to promote Standards for Public Involvement and draw on practices previously established by the National Institute for Health and Care Research (NIHR) [7–9]. Furthermore, to enhance transparency and quality in PPI, the Guidance for Reporting Involvement of Patients and the Public (GRIPP2) framework was published in 2017, offering two checklists to guide the reporting of PPI research [10].

Alongside the increased interest in PPI within conventional health research, participatory traditions such as co-production, community-based participatory health research

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Key Points for Decision Makers

Well-established and validated evaluation tools are often modified or adapted, or new evaluation tools are developed de novo.

Evaluation of patient and public involvement in health research contributes to positive personal outcomes for patient and public involvement partners, including improved well-being and the development of new skills.

A noticeable 'us vs them' dynamic was seen, with patient and public involvement partners typically showing higher response rates than researchers during evaluations.

and participatory action research have been developed. These practices are grounded in distinct theoretical and methodological backgrounds with roots in rights-based approaches [11]. The core principles of PPI—participation, equity and recognition of experiential knowledge—often stand in tension with conventional evaluation frameworks that prioritise standardisation and measurable outcomes, complicating comparisons across these diverse traditions [12]. Foundational values in conventional health research, such as objectivity and standardisation, can present challenge evaluative practice, particularly in participatory context like PPI. As highlighted by researchers in the field, differing epistemological and managerial traditions complicate how such approaches are assessed and compared. Nevertheless, evaluating the impact of PPI on research outcomes is essential to facilitate adjustments that enhance research relevance and quality [13–15].

Various global guidelines exist for involving and evaluating patient and public input, including the work of Smits et al. and de Wit et al. [16–18], initiatives from the NIHR [9], the Patient-Centered Outcomes Research Institute (PCORI) [19] and the Canadian Institutes of Health Research (CIHR) [20]. However, some studies raise critical reflections on PPI in research, suggesting that prioritising the involvement process may potentially undermine the quality and rigour of the generated evidence; a systematic review by Malterud and Elvbakken found that co-research may not necessarily produce more relevant knowledge. Their results indicate that some projects seem to value PPI itself rather than the outcomes of research processes, raising questions about the relevance of PPI in research and the effective allocation of resources [21].

Similarly, Grindell et al.'s review indicates a lack of evidence that co-approaches actually lead to improved health outcomes [22]. The assertion of insufficient quality of PPI evaluation in studies aligns with findings by Boivin et al. and Shahid et al., emphasising the need for a rigorous assessment of PPI in research [23, 24]. Both review studies found that the evaluation of the quality of PPI was inconsistent, with various methods applied; most of these focused on the engagement process rather than outcomes. Shahid et al. also found a lack of discussion-based methods and ongoing assessment during projects. Thus, despite the growing emphasis on PPI in research, insufficient standards of evaluation appear to undermine the field, leading to participation that is often symbolic rather than substantive [21, 23–26]. Brett et al. go further, arguing that PPI is sometimes implemented merely to meet policy requirements, reducing it to a symbolic gesture and compromising the quality of the research [27]. This necessitates the development of innovative evaluation tools to address deficiencies in current practices.

The aim of this study was to identify and map available evaluation tools for PPI in health research, including the reported outcomes of PPI in research. The study was guided by an open approach to identify recurring elements in the evaluation of PPI in research. Rather than seeking predefined evaluation tools, we examined empirical studies to identify how PPI is evaluated in practice and which outcomes are reported. We were guided by the following research question: How is PPI evaluated in empirical health research in terms of the tools applied, and the outcomes reported, and what are the recurring themes across studies in relation to these evaluations?

2 Methods

Given the heterogeneity within the field of PPI evaluations in health research, a scoping review was deemed appropriate to address the research question [28, 29]. Following the UK Standards for Public Involvement in Research, we defined PPI as research carried out *'with'* or *'by'* members of the public rather than *'to'*, *'about'* or *'for'* them. This is also referred to as consumer involvement [30].

2.1 Protocol and Registration

The methodology for scoping reviews described by Levac et al. was employed to guide this research [28]. To ensure comprehensive and transparent reporting, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) guidelines were applied [31]. A protocol was developed and registered in the Open Science Framework https://osf.io/czymh/ [32].

2.2 Eligibility Criteria

We included the literature that evaluated PPI in the context of health research and explicitly described an evaluation model or tool. Inclusion was restricted to studies published in English or Nordic languages published within the years 2021–2024, with the full text available via the University Library of Southern Denmark. The original search strategy included the years 2011–2024, but the quantity of literature identified was unmanageable and the publication range was consequently narrowed to 2021–2024. The cut-off of 2021 was adopted based on Shahid et al.'s review, which concluded in that year. As the number of PPI-related publications is rapidly growing [33, 34], we decided that material building on Shahids et al.'s sample would be adequate to add to existing knowledge. These adjustments were made with the assistance of an information specialist experienced in designing search queries within the field of PPI. As a result, the initial eligibility criteria outlined in the protocol diverged slightly from those applied. We excluded studies in which patients or public representatives also participated as subjects without a clear delineation of their role as research partners.

2.3 Information Sources and Search Strategy

A systematic search was performed in the CINAHL, Scopus, MEDLINE and Embase databases (4 March, 2024 and re-run June 2025). The search strategy was inspired by Shahid et al. [24] and Boivin et al. [23] and was structured using the PCC (Population or Participants/Concept/Context) framework [35].

The search strategy included free-text terms, MeSH terms and subject headings for title, abstract and keywords. Boolean operators ("AND" and "OR") were applied to combine concepts, and truncation was used to capture several grammatical declinations. Afterwards, the search strategy was adapted to fit each database and validated by an information specialist. The generic search strategy is presented in Table 1 and the full versions of the Embase and MEDLINE searches are documented in the Electronic Supplementary Material.

2.4 Selection of Sources of Evidence

Identified literature was exported to Endnote Version 20.6 (Bld 19 1333) (https://endnote.com/), where duplicates were removed before importation to Covidence (www.covidence.org). Two reviewers (SN and BN) independently screened the titles and abstracts. Full-text screening was performed by the first author with subsequent validation by another reviewer (BN). Inconsistencies and disagreements throughout the process were resolved through discussions. The process is illustrated as a flowchart in Fig. 1.

2.5 Data Charting and Data Items

Data extraction was performed by a single reviewer (SN), guided by the Joanna Briggs Institute template [32] and validated by a second reviewer (BN). The following items were extracted: author(s), year of publication, country (based on first author affiliation), aim/purpose, name and type of evaluation model/tool (e.g. scale, interview), type of PPI activity, role of research partner (as outlined by the NIHR) and key findings that relate to the scoping review question/conclusion of included studies (see Table 2).

We evaluated PPI roles as defined by the NIHR:

Consultation: eliciting public input to inform decisions.

Collaboration: a sustained partnership with joint decision making.

Co-production: a collaborative effort with shared authority and accountability.

User-controlled research: research directed and managed by users [36].

The extracted data were managed in a customised sheet in Microsoft 365 Excel Version 16.84 (24041420) and Microsoft 365 Word Version 16.84 (24041420).

2.6 Synthesis of Results

Study characteristics are presented descriptively, with patterns across the studies identified and presented narratively. This approach, as delineated by Lucas et al., is well suited for reviews aiming to describe the existing body of literature, including the scope of what has been studied and the strength of available evidence, and to identify gaps that need to be addressed [37].

3 Results

3.1 Selection of Sources of Evidence

We identified 9536 records and after removing duplicates, 6994 records were screened by title and abstract. After screening, 6882 articles were excluded and 112 full texts selected; 110 were available for full screening. Of these, 86 were excluded because of not reporting PPI evaluations, wrong language or access issues. Backward chaining yielded five additional records, resulting in an overall inclusion of 30 records. All details are shown in Fig. 1.

Table 1 Generic search strategy

Population	Concept			Context
Patient/public	Patient and public involvement evaluation tool			Health research
Patient/public	Involvement	Evaluation	Tool	Health research
Patient*	Involv*	Evaluat*	Model	Health research
Lay person	Engag*	Assess*	Tool	Public health research
Public	Participat*	Measur*	Instrument	Biomedical research
Consumer*	Consultat*	Effectiveness	Questionnaire Scale	Health services research
Citizen	Partnersh*	Process	Grid	
Service user	Collaborat*	Quality assessment	Framework	
Community member stakeholder	Contribut*		Interview	
	Collaborative inquiry		Self-report	
	Expert by experience			
	Co-design			
	Peer research			
	Research involvement			
	Collaboration with consumer			
	Co-researcher			
	Co research			
	Co-research			
	Participatory action research			
	Community-based participatory research			
	Co-designed research			
	Co-production			
	Action research			
	Participatory research			

*Truncation is used to capture various word endings or forms, allowing for a broader search

3.2 Characteristics of Sources of Evidence

Among the included studies, five were published in 2025, eight in 2024, eight in 2023, three in 2022 and six in 2021. Of these 30 publications, 29 were journal articles [38–66] while one was a conference abstract [67]. Eight countries were represented: 12 studies originated from Canada [38, 42, 44, 49, 50, 52, 54–56, 59, 60, 65], seven from the UK [39, 40, 45, 46, 58, 63, 67], five from the USA [41, 43, 47, 57, 66], two from the Netherlands [51, 64] and one each from Australia [53], Brazil [48] Finland [62] and Germany [61]. Seventeen research areas were represented, with most studies pertaining to mental health ($n = 4$), paediatrics ($n = 4$), coronavirus disease 2019 ($n = 3$), rheumatology ($n = 2$) and dementia ($n = 2$). The remaining research areas were, rehabilitation, brain cancer, asthma and chronic obstructive pulmonary disorder, ageing, doctoral research, palliative care, primary healthcare, health services research, gastroenterology, environmental health, implementation/hospitalisation, ambulatory surgery and imaging, non-specified patient-oriented research, public health or health equity research. Patient and public involvement partners were primarily patients or individuals with lived experience ($n = 22$), family partners/caregivers and parents ($n = 12$), with other included parties being patient, community and citizen representatives ($n = 12$), and professional and organisational stakeholders ($n = 9$)

In 12 studies, PPI consisted of a combination of consultation and collaboration in their research project. A further 11 studies involved collaboration. Two studies conducted PPI as consultation alone, and three study implemented co-productive PPI. In evaluating PPI, 14 studies used mixed methods, 12 studies used quantitative methods and four studies used qualitative methods.

In 15 studies, PPI partners alone were evaluated [38, 41, 43, 44, 46–48, 50, 53–55, 57, 58, 65, 67], with researchers also evaluated in 15 studies [39, 40, 42, 45, 49, 51, 52, 55, 56, 59–64, 66]. In all included studies, the researchers were evaluators; PPI partners also acted as evaluators in eight studies [38, 46, 55, 58, 61–64].

Fourteen studies conducted ongoing evaluations [41, 42, 44, 46–48, 50, 55–58, 61, 62, 64, 65], while seven studies evaluated at the end of the project [39, 40, 45, 49, 54, 63, 65]. In eight studies, the specific timing of the evaluation was not explicitly disclosed [38, 43, 51–53, 59, 67]. All studies, except one [67], included an evaluation of the process. Fifteen studies incorporated evaluation of the process, impact and outcomes [39, 40, 42, 45–48, 50–52, 54, 56, 57, 60, 62, 64, 65]. Five studies focused solely on process evaluation [41, 43, 44, 53, 63, 66], and one on impact alone [67]. One study evaluated process and outcome [61], and five studies evaluated process and impact [38, 49, 55, 58, 59].

Seven studies reported their findings in accordance with the GRIPP2 guidelines [39, 40, 49, 55, 58, 59, 61]. Of these,

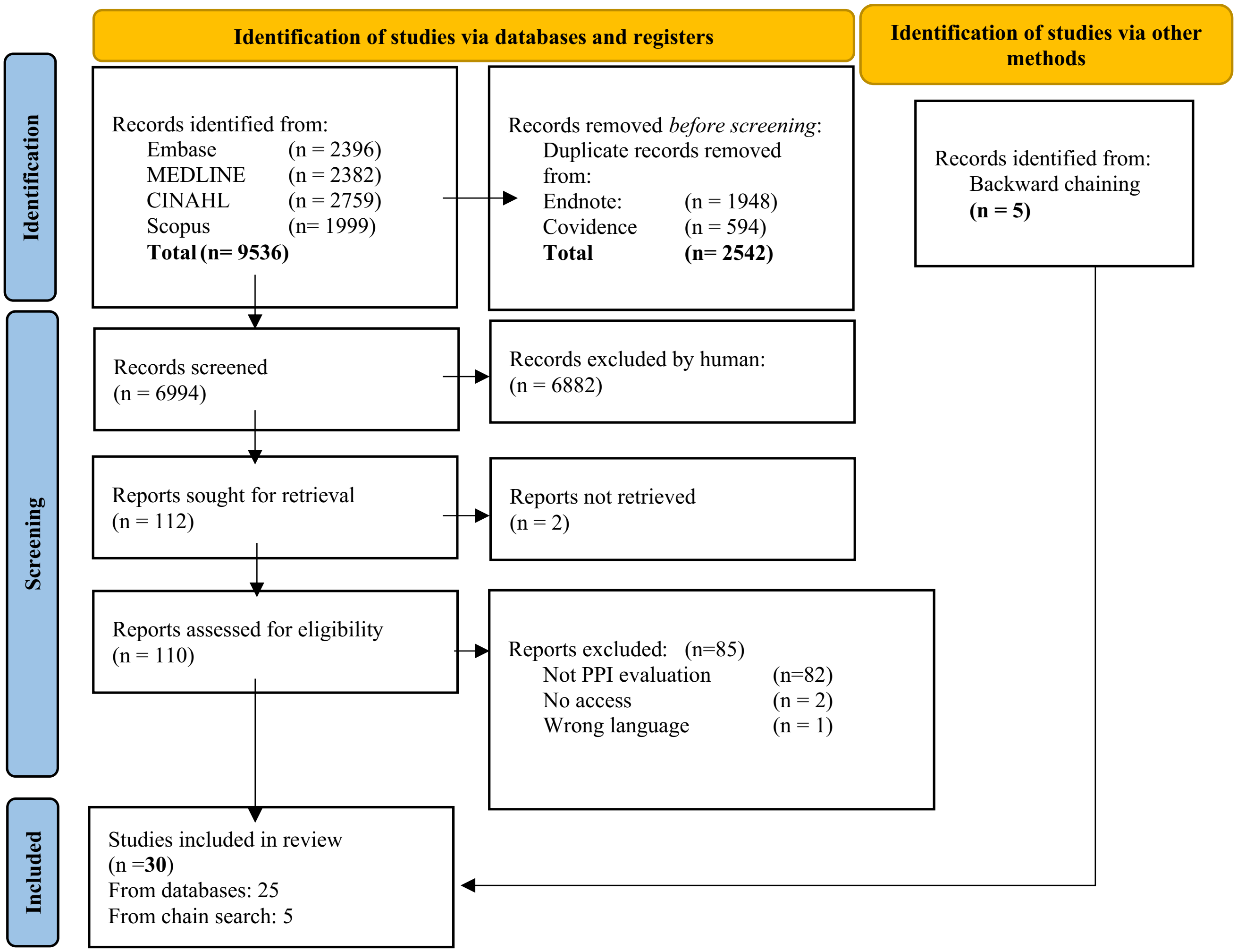


Fig. 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 flowchart (including updated search June 2025). *PPI* patient and public involvement. Source: Page MJ, et al. BMJ 2021;372:n71. https://doi.org/10.1136/bmj.n71.

four specified whether they used the short or long form and included the GRIPP2 checklist as an attachment: three used the short form [49, 58, 59] and one used the long form [55].

Five articles either used GRIPP2 to inform their evaluation or mentioned/provided a link to it, but none included the checklist or specified whether PPI was reported in accordance with GRIPP2 guidelines [38, 45–47, 63]. Further details are presented in Table 2.

Each study used different terminology, highlighting a lack of consistency in the approaches employed for evaluation. Thirteen studies included tables or figures to illustrate PPI activities within the research process [41, 45–48, 50, 54–56, 58, 60, 61, 63], while the remaining studies described the PPI activities in varying levels of detail within unspecified sections of the text. Patient and public involvement activities were reported across multiple stages of the research process, including study planning, data interpretation and dissemination. These activities predominantly reflected collaboration with contributors actively involved in shaping research questions, co-designing methods, interpreting findings and co-developing dissemination strategies. In some cases, consultation was also evident; particularly in terms of feedback on study materials and decisions. See Table 2 for further information.

3.3 Evaluation Tools Used in Practice

A total of 22 methods for data collection were identified across the included studies (see Table 3). These methods were subsequently categorised into 13 distinct evaluation methods such as singularly applied tools, surveys, questionnaires and interviews (see Fig. 2), encompassing 71 individual tool types. Among these, a small number, for example frameworks, models and rubric, were not used directly for data collection but rather served as frameworks

Table 2 Characteristics of the included studies

#, Ref.	PPI role according to NIHR	PPI in research process	Partners	Research area	GRIPP	Subject/evaluator	Type of evaluation	Time of evaluation (intended)
1 [38]	Collaboration	Co-design of evaluation, analysis and knowledge mobilisation	Older adults [60-80]	Ageing	No	PP/PP and R	Process, impact	After 6–12 months
2 and 3 [39, 40]	Collaboration, consultation	Development of grant proposal and project set0up, study design, undertaking of research, dissemination of study findings	Patients and caregivers	COVID-19	Yes	PP and R/R	Impact, process, outcome	At the end
4 [41]	Collaboration	Reaction to program data, set priorities, development and pilot testing of maintenance activities, participation in grant development tasks	Parents and caregivers	Paediatrics (obesity)	No	PP/R	Process	Continuously
5 [42]	Collaboration	Identification of research problem, literature review, research design, data collection and analysis, interpretation and discussion, knowledge dissemination	Patients	Implementation research / hospitalised medical patients	No	PP and R/R	Process, outcome, impact	Continuously
6 [67]	Consultation	Support of recruitment strategies, interpretation of patient and caregiver interviews, ensuring outcome definitions	Public	Brain cancer	No	PP/R	Impact	
7 [43]	Collaboration Consultations	Establishment of research goals, recruitment of participants, collection of data, planning of analyses, formulation of dissemination strategies.	Representatives	Environmental health research	No	PP/R	Process	

Table 2 (continued)

#, Ref.	PPI role according to NIHR	PPI in research process	Partners	Research area	GRIPP	Subject/evaluator	Type of evaluation	Time of evaluation (intended)
8 [44]	Consultation Collaboration	Help scope or design projects, preparation of grant applications, development of surveys, planning of focus groups, recruitment of study participants, building of networks, planning for dissemination. PPI with research experience: help shape projects, development of processes, support of other members.	Patients and individuals	Asthma and COPD	No	PP/R	Process	After 1 year (continuously)
9 [45]	Consultation Collaboration	Evaluation planning, co-design of methods (survey/interview guide), pilot testing, data interpretation, and dissemination.	Parents	Paediatrics (palliative care)	No	PP and R/R	Process, outcome, Impact	At the end
10 [46]	Consultation Collaboration	Grant development and research governance, ethical approval, intervention development, recruitment and treatment delivery, data collection and analysis, dissemination.	Patients and carer	Mental health	No	PP/PP and R	Process, outcome, impact	Continuously
11 [47]	Collaboration	Proposal development, study design, recruitment of study participants, retention of study participants, preliminary analysis of findings.	Patients/caregivers, organisational and financial stakeholders	Palliative care	No	PP/R	Process, outcome, impact	Continuously
12 [48]	Consultation Collaboration	Co-development of research questions, methods, interpretation, dissemination	Community representatives, health professionals, public sector managers	Primary healthcare	No	PP/R	Process, outcome, impact	Continuously

Table 2 (continued)

#, Ref.	PPI role according to NIHR	PPI in research process	Partners	Research area	GRIPP	Subject/evaluator	Type of evaluation	Time of evaluation (intended)
13 [49]	Consultation Collaboration	Terms of reference for the group, advise on recruitment strategies, reviewing of results from projects, interpretation of findings from the patient perspective, development of materials for dissemination	Patients	Ambulatory surgery and imaging	Yes	PP and R/R	Process impact	At the end
14 [50]	Consultation, collaboration	Feedback on KT tools (videos, infographics, eBooks), discussions on dissemination and development of tools, input on new grants	Parents	Paediatrics (child health)	No	PP/R	Process, impact, outcome	Continuously
15 [51]	Consultation, collaboration	Feedback, advice	Youths (aged 12–25 years) Committee members	Health services research (youth)	No	PP and R/R	Process, impact, outcome	
16 [52]	Collaboration	Reflection on PRP involvement; planning for future evaluation of engagement	Individual with lived experience with a rheumatic or musculoskeletal condition	Rheumatology	No	PP and R/R	Exploratory; intended to assess process, outcome and impact	
17 [53]	Collaboration	Consultation, co-design, co-producer, decision making and processes, engaged in tokenistic manner	Individual with lived experience with a rheumatic or musculoskeletal condition	Rheumatology	No	PP/R	Process	
18 [54]	Collaboration	Identification of the research problem, literature review, development of the research design, grant development, data collection, data analysis, knowledge dissemination, decision-making and governance	Patients, family/caregivers, public	Patient-oriented research (non-specified)	No	PP/R	Process, outcome, impact	At the end

Table 2 (continued)

#, Ref.	PPI role according to NIHR	PPI in research process	Partners	Research area	GRIPP	Subject/evaluator	Type of evaluation	Time of evaluation (intended)
19 [55]	Collaboration	Problem formulation, theory and literature review, hypothesis and research questions, research design, data collection, data analysis, dissemination of results	Older people aged 55+ years/service providers	Public health research/health equity research	Yes	PP/PP and R	Process, impact	Continuously
20 [56]	Co-production	Study conceptualisation, refinement of research questions, co-design of materials, recruitment, data collection, data analysis, interpretation of results and dissemination	Individuals with lived experience of inflammatory bowel disease, researchers, clinicians	Gastroenterology	No	PP and R/R	Process, outcome, impact	Continuously
21 [57]	Collaboration	Research design, evaluation tool development, data collection, data analysis, dissemination of results	Patient advocates, professional and non-informal caregivers, clinicians, researchers, hospital and health systems, and policy makers	Dementia (quality of life)	No	PP/R	Process, outcome, impact	Continuously
22 [58]	Collaboration with co-productive approach	Co-design and run two workshops, Co-design an evaluation for each workshop	Young people (aged 13–17 years)	Mental health	Yes	PP/PP and R	Process, impact	Continuously
23 [59]	Consultation Collaboration	Research design, content development, tool and platform selection, data collection and evaluation, dissemination and future involvement	Parents	Paediatrics (disability)	Yes	PP and R/R (PP reviewed)	Process, impact	

Table 2 (continued)

#, Ref.	PPI role according to NIHR	PPI in research process	Partners	Research area	GRIPP	Subject/evaluator	Type of evaluation	Time of evaluation (intended)
24 [60]	Collaboration	Planning and implementation of research methods, including grant writing, relationship building, data collection, analysis, engagement activities and dissemination	Community leaders, citizen partners, knowledge users and connectors from connector organisations, and methods researchers	COVID-19 (public health)	No	PP and R/R	Process, outcome, impact	After 1 year
25 [61]	Consultation Collaboration	Research design, content development, data collection, data analysis, dissemination and evaluation	Patients	Mental health	Yes	PP and R/PP and R	Process, outcome	Continuously
26 [62]	Collaboration in a co-production way	Research design, literature review, hypothesis and research questions, research design, data collection, data analysis, dissemination and utilisation	Public	Rehabilitation	No	PP and R/PP and R	Process, impact, outcome	Continuously
27 [63]	Collaboration	Design, recruitment, data handling, analysis, co-authorship, and dissemination across review and qualitative phases	Public advisor	Doctoral research	No	PP and R/PP and R	Process	At the end
28 [64]	Collaboration	Consortium meetings, co-creating communication materials for patients, collectively interpreting data and making joint decisions including co-authorship on several scientific publications	Patient representatives	COVID-19 (kidney research)	No	PP and R/PP and R	Process, outcome, impact	Continuously

Table 2 (continued)

#, Ref.	PPI role according to NIHR	PPI in research process	Partners	Research area	GRIPP	Subject/evaluator	Type of evaluation	Time of evaluation (intended)
29 [65]	Collaboration	Team meetings via Zoom to discuss data collection, staff engagement strategies, data analysis, manuscript preparation and conference presentations	Patient and family partners	Dementia	No	PP/R	Process, outcome, impact	Continuously
30 [66]	Consultation	Planning stages, designing the interview topic guide	Services users, carers and public	Mental health	No	PP and R/R	Process	At the end

COPD chronic obstructive pulmonary disease, *COIVD-19* coronavirus disease 2019, *GRIPP2* Guidance for Reporting Involvement of Patients and the Public (long form and short form), *NIHR* National Institute for Health and Care Research, *PP* patient/public partner, *PPI* patient and public involvement, *R* researcher, *Ref.* reference

to guide or support the evaluation process. These were included in the mapping to reflect their functional role in shaping data collection strategies, even though they do not themselves generate data.

Of the 71 tool types, 32 were named (see Table 3), including 25 based on pre-existing tools and seven that were de novo custom designed for individual studies. In addition, four studies developed custom-designed evaluation tools but did not assign them a specific name; these are listed in Table 3 by author. The most frequently used tools were PPEET and PEIRS22, each applied in six studies. Despite the validation of both PPEET [68, 69] and PEIRS22 [70], these tools were not employed in their original forms; rather, they were adapted or supplemented with additional evaluation tools or open-ended questions.

Seven studies employed a single type of data collection method, i.e. questionnaire ($n = 4$), model ($n = 1$), interview ($n = 1$) and survey ($n = 1$) [44, 49, 54, 59, 61, 63, 66] while 15 studies used surveys or questionnaires in combination with other methods [38–42, 45–48, 50, 53, 55–57, 60, 64, 65]. Further details of the included studies are presented in Table 3.

Existing evaluation tools were used with adaptations and in various combinations (see Table 3). While validated and non-validated evaluation tools were identified, all included studies, except one [63] found it necessary to either combine or adapt existing tools; several chose to develop entirely new tools [45, 46, 48–50, 57, 62, 66, 67], which calls for future adaptations [62]. The adaptations and combinations of tools were implemented to accommodate specific contexts and purposes of the evaluation [38, 41, 44, 51, 54–56, 59, 65, 66].

3.4 Outcomes of Involvement in Research

Patient and public involvement directly resulted in various changes in the included studies, manifesting both as modifications to the project and personal changes for those involved [38–67]. Patient and public involvement evaluations informed the related changes throughout the process [45–51, 53, 55–57, 59, 60, 64, 65, 67]. The personal changes experienced were diverse and occurred primarily among PPI partners but were reported to be uniformly positive. Patient and public involvement partners reported increased mental and physical well-being and the development of new transferable owing to their involvement in the research [39, 40, 42, 45, 46, 48, 50, 51, 54, 56, 58, 62, 64–66]. For patients acting as PPI partners, the research became a way of coping with their illness. However, the impact evaluations were restricted to short-term outcomes and aligned more closely with the output such as the content, language and design of illustrations in the flyer.

Table 3 Description of evaluation tools

Tool name	Pre-existing/de novo	Data collection methods	Description/features	Author (year), nation
Public and Patient Engagement Evaluation Tool (PPEET)	Pre-existing	Survey	(1) Participant questionnaire Module A: one-time engagement activities Part (A) Communication and supports for participation Part (B) Sharing your views and perspectives Part (C) Impacts and influence of the engagement initiative Part (D) Final thoughts Module B. Ongoing/long-term engagement initiatives + Module A (2) Project questionnaire Module A: planning the engagement component of your project Part (A) Integrity of design and process Part (B) Collaboration, common purpose and partnerships Part (C) Final reflections Module B: Assessing the engagement component of your project + Module A Additional part: influence and impact Module C: assessing the impact of the engagement component of your project (3) Organisation questionnaire Part (A) Policies and practices that support public and patient engagement Part (B) Participatory culture Part (C) Influence and impact Part (D) Collaboration and common purpose Part (E) Final thoughts PEET by: Abelson et al. (2016 and 2019) in combination with interview	Babatunde et al. (2023), GB [42]
		Interview	Semi-structured based on survey response	
PPEET	Pre-existing	Survey	Participant questionnaire version 2.0 PPEET by: Abelson et al. (2018) in combination with Photovoice and focus group	Abousifein et al. (2024), CA [38]
		Photovoice	Partners were encouraged to create or capture images that reflect their perspectives and to critically analyse images selected by others	

Table 3 (continued)

Tool name	Pre-existing/de novo	Data collection methods	Description/features	Author (year), nation
		Focus group	Focus group guide: (1) Overview and impact of participation within the collaborative (2) Partnership challenges and successes	
PPEET - Modified	Pre-existing	Questionnaire	PPEET version 2. Module B for both parent-partners and researchers Three open-ended questions were added (1) impact, (2) barriers and (3) Facilitators Adapted from: Abelson et al. (2019)	Ogourtsova et al. (2021), CA [59]
PPEET	Pre-existing	Questionnaire	PPEET, Version 2 **Participant** Questionnaire **Module A**. One-time engagement activities **Module B**. Ongoing/long-term engagement initiatives Participant Questionnaire Module B. Ongoing/long-term engagement initiatives Project Questionnaire Module B. Assessing the engagement component of your project PPEET by: Abelson et al. (2019) translated to German versions and in combination with "Short scale for teaching evaluation"	Seeralan et.al. (2021), DE [61]
PPEET - Adapted to developmental evaluation	Pre-existing	Questionnaire	Assesses the level of agreement, linked to the patient/public partners' understanding, support, possibility of expressing and possibility of participating, and what perspective the patient/public partner brings to the EMBOLDEN's Strategic Guiding Council Adapted from: Abelson et al. (2019)	MacNeil et al. (2023), CA [55]
		Focus group	13 prompts adapted from the WE-ENACT tool from: P.C.O.R. Institute (PCORI)	
		Meeting notes	From 16 strategic guiding council meetings	
PPEET - Adapted	Pre-existing	Questionnaire	Participant tool (one-time engagement) to capture stakeholders' assessments of the key features of the engagement activity 19 closed and open-ended questions across four domains: (1) communications and supports for participation; (2) sharing your views and perspectives; (3) impacts and influence of the engagement initiative; (4) final thoughts Adapted from: Abelson et al. (2019) in combination with: PEIRS-22 and WE ENACT	Marshall et al. (2023) CA, [56]

Table 3 (continued)

Tool name	Pre-existing/de novo	Data collection methods	Description/features	Author (year), nation
Patient Engagement In Research Scale (PEIRS-2) - Adapted	Pre-existing	Questionnaire	(1) Procedural requirements, (2) convenience, (3) contributions, (4) team environment and interaction, (5) support, (6) feeling valued, (7) benefits Used to measure the quality/degree of meaningful patient engagement in the project from all stakeholders By: Hamilton et al. (2021) In combination with WE-ENACT and PPEET	
PEIRS-2 - Adapted	Pre-existing	Questionnaire	By: Hamilton et al. (2021) By: Hamilton et al. (2021) Questions on the experiences of online engagement, added	Li et al. (2022), CA [54]
PEIRS-22 - Modified	Pre-existing	Questionnaire	(1) Procedural requirements, (2) convenience, (3) contributions, (4) team environment and interaction, (5) support, (6) feeling valued, (7) benefits PEIRS-22 by: Hamilton et al. (2021) Two open ended questions added	Barn et al. (2022), CA [44]
PEIRS-22 - Modified	Pre-existing	Questionnaire	(1) Procedural requirements, (2) convenience, (3) contributions, (4) team environment and interaction, (5) support, (6) feeling valued, (7) benefits Digitised. Numerical rating scale of the PEIRS-22 supplemented with emojis Comment boxes added to each question for contextual or additional information	Wong et al. (2024), CA [65]
		Interview	One-on-one conversations to understand what aspects of the team's engagement were successful and which were not	
		Reflective sessions	Guided by Rolfe et al.'s (2001) reflective model	

Table 3 (continued)

Tool name	Pre-existing/de novo	Data collection methods	Description/features	Author (year), nation
PEIRS-22 - Modified	Pre-existing	Questionnaire	Part one, PEIRS-22: (1) Procedural requirements, (2) convenience, (3) contributions, (4) team environment and interaction, (5) support, (6) feeling valued, (7) benefits In combination with: OMERACT involvement information (type of disease, age, sex, self-rated level of participation in OMERACT, number of years with OMERACT, self-rating of personal engagement in OMERACT working group or OMERACT community processes and decisions)	Jones et al. (2025), AUS [53]
		Reflections	Part two, reflections of components of the PEIR framework Context and examples in a free-text format to elaborate response on the seven subdomains of the PEIRS-22	
PEIRS-22 - Adapted	Pre-existing	Questionnaire	(1) Procedural requirements, (2) convenience, (3) contributions, (4) team environment and interaction, (5) support, (6) feeling valued, (7) benefits The term “community” was adopted in place of “patient”	Porchak et al. (2025), CA [60]
		Interview	To understand (1) partnership quality, (2) engagement processes, (3) group collaboration and perceived contribution value, (4) satisfaction with operations, (5) unique partnership achievements and (6) commitment to future collaboration Interview conducted as individual and focus group interviews	

Table 3 (continued)

Tool name	Pre-existing/de novo	Data collection methods	Description/features	Author (year), nation
Public Involvement Impact Assessment Framework Guidance (PiiAF)	Pre-existing	Framework	Provides guidance to researchers who wish to design an assessment of the impact of public involvement in their research Focus on researchers' reflection on values, approaches to involve the public in research, focus and study design, practical issues and impact of public in research and reflections of foundations, intervention theory, context and design of impact assessment By: Popay and Collins (2014) In combination with "The Research Contributions Framework"	Aiyegbusi et al. (2023 and 2024) GB [39, 40]
The Research Contributions Framework	Pre-existing	Framework	Three domains: uptake, use and impact Constructed from empirical findings about how impact occurs, and operationalising alongside concepts from the literature, used for development of evaluation plans By: Morton (2015) In combination with PiiAF	
		Discussion	With patient partners	
		Interview	Of researchers	
		Engagement log	Of activities	
		Survey	To assess the situation	
PEIR Plan Guide	Pre-existing	Workbook	Facilitates high-quality partnerships between researchers and patient partners Main focus on "Feel valued"	Hofstetter et al. (2024), CA [52]
		Templates	Each component of the PEIR Framework is detailed with corresponding templates to guide completion, ensuring all aspects are addressed. Additionally, three templates support documentation of key items, roles and responsibilities, and work planning	
		Discussion	Breakout groups with patient research partners, researchers, fellows, clinicians and industry representatives Based on PEIR Plan guide and templates	

Table 3 (continued)

Tool name	Pre-existing/de novo	Data collection methods	Description/features	Author (year), nation
Community Capacity Evaluation Plan	Pre-existing	Survey	Seven dimensions selected by members: (1) communication, (2) problem assessment, (3) participation and personal influence, (4) leadership, (5) community power, (6) collective efficacy, (7) overall satisfaction Quantitative items and 3 open-ended questions Based on: Goodman et al., 1998; Sandoval et al., 2012; Zoellner, Hill, Brock, et al., 2017	Alexander (2021), USA [41]
		Interview	Semi-structured, conducted via telephone	
		Engagement log	Meeting minutes, PAT outputs, document review	
Principles and dimensions the conceptual logic model of community-based participatory research (CBPR) - Adapted	Pre-existing	Model	(1) Context, (2) group dynamics/equitable partnerships, (3) intervention and research, (4) outcomes By: Wallerstein et al. (2017)	Baldwin et al. (2021), USA [43]
	Pre-existing	Interview	Telephone and in-person Dimensions based on the CBPR conceptual logic model by Wallerstein et al. (2017)	
Patient-Centred Outcomes Research Institute (PCORI) Stakeholder Engagement Survey	Pre-existing	Survey	(1) Assess the amount of influence patients/public had on the project, (2) what to improve when engaging with researchers, (3) personal learning when engaging with researchers, (4) experiences with the project, (5) additional thoughts, (6) challenges with engaging with researchers, (7) how have these challenges been addressed?, (8) other challenges that have not already been captured and how and to what extent could these challenges have been resolved? By: PCORI In combination with PCORI Rubric	de Forcrand et al. (2021), USA [47]
PCORI Engagement Rubric	Pre-existing	Rubric	Used as a guide to mobilise Study Advisory Committee members and evaluate their engagement By: PCORI	
		Engagement log	Qualitative reviews of meeting transcripts, and the administration of the embedded PCORI Stakeholder Engagement Survey	

Table 3 (continued)

Tool name	Pre-existing/de novo	Data collection methods	Description/features	Author (year), nation
Ways of Engaging- ENgagement ACtivity Tool (WE-ENACT) - patients and stakeholders 3.0 item pool	Pre-existing	Survey	28 open and closed-ended questions to measure: Preparation and readiness to engage, roles and responsibilities, engagement in specific research tasks, group process and dynamics, perceived influence and outcomes By: PCORI (2016) In combination with PPEET and PEIRS-22	
WE-ENACT tool - adapted	Pre-existing	Focus group	13 prompts Adapted from: PCORI	MacNeil et al. (2023), CA [55]
RE-AIM model	Pre-existing	Model	Used as a framework to inform the development of the topics of the interview guide By: Glasgow, Vogt and Boles (1999)	Hilverda et al. (2025), NL [51]
		Interview	Semi-structured interviews with five topics (1) reach, (2) effectiveness, (3) adoption, (4) implementation and (5) maintenance, addressing the advantages and disadvantages, as well as the barriers and facilitators, of involving youth Based on: Glasgow, Vogt and Boles (1999)	
The Cube evaluation framework	Pre-existing	Model	Four dimensions (1) Voice: strong voice influences decision making vs weak voice, little influence in decision making (2) Contribute: one way vs many ways to be involved (3) Agenda: organisation's concerns vs public concerns (4) Change: organisation changes (ability and willingness to respond) vs organisation resists changes Question asked to map experiences of being involved: (1) Did you feel like your voice was heard? (2) Did you feel like there were enough activities to get involved in? (3) Did you feel like the event was based on things that mattered to you? (4) Did you feel like the facilitators listened to you? By: Gibson, Welsman, Britten (2017)	Moult et al. (2025), UK[58]

Table 3 (continued)

Tool name	Pre-existing/de novo	Data collection methods	Description/features	Author (year), nation
		Video blogging	Four questions to capture the experiences of the young people: 1) What did you learn from today's workshop? 2) Do you have any new insights from today's workshop? 3) What was your favorite part of the workshop? 4) What would you like to see us do at the next workshop?	
		Notes	Anonymous written feedback and reflections	
The Cube evaluation framework	Pre-existing	Model	1) Voice: strong voice influences decision making vs weak voice, little influence in decision making 2) Contribute: one way vs many ways to be involved 3) Agenda: Organisation's concerns vs public concerns 4) Change: Organisation changes (ability and willingness to respond) vs organisation resists changes To map experiences, involvement interactions and evaluating public involvement and reflect on: (1) the strength of the public voice, (2) the number of ways in which public advisors had an opportunity to get involved, (3) whether the discussion was about the public or organisation's (doctoral researcher, university or funder) concerns and (4) if the organisation changed or resisted feedback Gibson, Britten and Lync (2012) and Gibson, Welsman and Britten (2017)	Teodorowski et al. (2024), UK [63]

Table 3 (continued)

Tool name	Pre-existing/de novo	Data collection methods	Description/features	Author (year), nation
Patient Engagement Monitoring and Evaluation (PEME) framework-– adapted	Pre-existing	Framework	Six domains: (1) objectivity, (2) input, (3) activities and the process of patient engagement, (4) learnings and changes, (5) impact, (6) context Selected subcomponents: Expectations, preparations, resources, representativeness of stakeholders, management, interactions, satisfaction, learnings, changes, research relevance, study quality and efficiency, reputation and trust and embedding of patient engagement, policy, community and decision-making context Adapted from: Vat et al. (2021) and in combination with Reflexive Monitoring Action approach by Van Mierlo et al. (2010)	Vervoort et al. (2024), NL [64]
		Participant observation		
		Questionnaire	With open-ended questions	
		Interactive reflection sessions		
Public Involvement in Research Impact Toolkit (PIRIT)	De novo		Consist of a checklist and a tracking tool	Baddeley et al. (2023), GB [67]
		Checklist	(1) Planning tool: a checklist of potential public involvement-related activities	
		Spreadsheet	(2) Tracking tool: record public contributions, the difference they make to the project and related public involvement standards available — predefined questions/statements	
Patient and Public Involvement (PPI) Questionnaire	De novo	Questionnaire	Summative questionnaire Seven questions to assess whether participation as a public contributor has had a positive and/or negative impact, and to determine if they would choose to participate again	Capobianco et al. (2023), UK [46]
		Telephone calls	An offer to raise concerns that would not normally be raised in a larger group	
		Feedback meetings		
Patient Partner Experience Survey	De novo	Survey	(1) motivations, (2) opinion on engagement in the research project, (3) opinion on the partnership council, (4) final thoughts and suggestions about engagement in this project	Etchegary et al. (2023), CA [49]

Table 3 (continued)

Tool name	Pre-existing/de novo	Data collection methods	Description/features	Author (year), nation
Research Team Experience Survey	De novo	Survey	(1) Opinion about the patient engagement in the research project and (2) Final open items about engagement	
Stakeholder-Centric Instrumentation Process (SCIP)	De novo	Process	Consists of seven steps to customise an evaluation: (1) determine best practice for evaluating stakeholder engagement, (2) complete target review of the evaluation tool by the research team, (3) invite targeted review of the evaluation tool by stakeholders, (4) present the evaluation tool to stakeholders for approval, (5) administer evaluation tool and capture data on face validity and acceptability, (6) share evaluation tool results with stakeholders, (7) determine need for further tailoring of evaluation tool (repeat or stop the process accordingly)	Martínez et al (2021), USA [57]
Stakeholder-Centric Engagement Evaluation Tool	De novo	Survey	"Quantitative measurement of community engagement" by Goodman et al. (2017) and the SCIP was integrated (1) Focus on issues important to the (study population) from the advisory committee, (2) respect and value advisory committee perspectives, (3) seek advisory committee input, (4) act on advisory committee input, (5) the advisory committee and the research team learn from one another's expertise, (6) deal with conflicts and disagreements effectively, (7) communicate with advisory committee members' concerns or disagreement in dissemination activities, (8) use a clear organisational structure, (9) be transparent and informative, (10) involve the advisory committee in dissemination activities	
The Participatory Research Partnership (PaRe) model	De novo	Model	Five phases Phase (1) starting the research partnership, Phase (2) building a research team, Phase (3) reciprocal co-planning of researcher life, Phase (4) co-production of new research data, Phase (5) utilisation of research data in everyday life	Sipari et.al. (2023), FIN [62]

Table 3 (continued)

Tool name	Pre-existing/de novo	Data collection methods	Description/features	Author (year), nation
		Templates	Six templates: (1) getting to know your research partners, (2) agency in the research partnership, (3) defining the practices of the research partnership, (4) agreeing on tasks in the research partnership, (5) planning in the research partnership, (6) developmental evaluation of the research partnership	
Worsley et al.	De novo	Interview	Semi-structured with four themes: (1) route in and personal motivations, (2) sense made of the research proposal, (3) appreciation of the process, (4) feedback and impact	Worsley et al. (2022), USA [66]
Barret et al.	De novo	Spreadsheet	PPI activities including funding, type of activity, who was involved and impact on the study Engagement log and spreadsheet was informed by Guidance for Reporting Involvement of Patients and the Public (GRIPP2) and PiiAF GRIPP2 by Staniszewska et al. (2017) PiiAF By: Popay and Collins (2014). Stage one: Review of engagement log Stage two: Qualitative exploration that covered (1) participants understanding of PPI, (2) personal experiences of involvement with the centre and (3) ideas for improvement of how the centre conducts PPI Identical set of questions was used to both the surveys and the interviews	Barret et al. (2024), UK [45]
		Interview	Allowed PPI partners to provide more depth	
		Focus group	Allowed PPI partners to provide more depth	
		Survey	Survey was offered to meet the needs of PPI partners who felt uncomfortable being interviewed and to provide an opportunity for them to share negative experiences freely	

Table 3 (continued)

Tool name	Pre-existing/de novo	Data collection methods	Description/features	Author (year), nation
Hartling et al.	De novo	Survey	Assess (1) outcomes of membership, (2) experience with the Pediatric Parent Advisory Group (P-PAG), (3) interactions with the research team, (4) perceptions of P-PAG management Opportunity to add questions, comments and concerns at the end of the survey via an open-ended/free-text response box	Hartling et al. (2024), CR [50]
		Interview	One-on-one semi-structured interviews: parallel questions to those used in the survey P-PAG members experience in the group and to contextualise survey findings	
Dos Anjos et al.	De novo	Meeting notes	The suggestions, criticisms and comments shared during and after the meetings were analysed	Dos Anjos et al. (2025), BR [48]
		Questionnaire	Post-activity questionnaire to assess participants' satisfaction and confidence	

Across the included studies, PPI partners reported that their perspectives were not always acknowledged, risking an imbalance between PPI partners and researchers [38, 51, 66] creating an 'us vs them' scenario. This was evident in the proportion of evaluation tools designed for PPI partners only [38, 41, 43, 44, 46–48, 50, 53–58, 65, 67]. Additionally, the terminology used to describe evaluations is notable. Only a minority of studies used terminology aimed at a partnership [38, 56, 58, 59, 63, 67], while the majority described the evaluation with a focus on "PPI" [39–41, 43, 44, 47, 48, 50–52, 55, 58–60, 62, 64, 66]. This raises the question of whether it is equitable to only evaluate one collaborating partner, rather than conduct an evaluation of the partnership and collaboration as a whole.

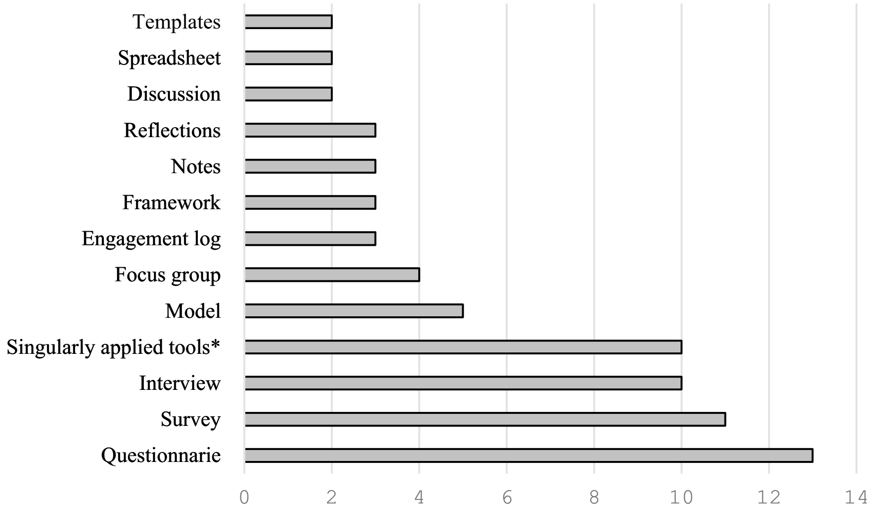
The motivation of PPI partners to participate was often explicitly expressed, whereas it was not possible to identify researchers' motivations [42, 43, 45, 49–51, 63, 65]. One study indicated that researchers did not feel adequately prepared for collaboration with PPI partners, which created unfavourable conditions for a partnership [65]. This highlights the importance of training for both PPI partners and researchers. Despite the provision of training [39, 40, 48, 51, 55, 56, 59, 60, 62], both partners and researchers reported feeling insufficiently equipped for the collaboration [41, 44, 45, 50, 51, 53, 64]. Thus, a picture of an increased need for training individuals in the research group was seen.

3.5 Themes Across Studies

3.5.1 Roles

Despite widespread agreement on the importance of involving PPI partners at every stage, [38–41, 47, 49, 51, 56, 60], few studies explicitly acknowledged that PPI input was not always feasible or appropriate in practice [45, 63]. Project teams often disregarded professions and titles and emphasised working as equal partners. Consistent with this, emphasis was placed on respecting the diverse expertise individuals possess whether academic or "expert-by-experience" [39–47, 51, 54–56, 60, 63, 64]. Partnership also necessitates the clarification of roles and responsibilities, something described as of critical importance [44, 45, 49–53, 56, 60, 62–64]. In contrast, others described suboptimal role clarification as posing a risk of adversely affecting the work conducted [41–45, 51, 53, 54, 56, 60, 61, 64, 65]. Bridging the gap between researchers and PPI partners to foster a cohesive research team can be achieved through listening and mutual understanding. This is essential, and a strong emphasis was placed on shared responsibility and learning from one another regardless of expertise, ultimately strengthening the bond and sense of unity [42, 43, 45, 46, 48, 49, 51, 52, 56, 59–61, 63, 64].

Fig. 2 Evaluation tool types



* Participant observation, checklist, feedback meetings, video blogging, telephone calls, photovoice, rubric, workbook, process, scale

3.5.2 Communication

Communication was described as a crucial element and was reported to be both a facilitator and barrier in partnership, role definition, outcomes and evaluation [39, 40, 42, 45, 46, 48, 49, 51, 53, 54, 56, 60, 63, 64, 66]. Evaluation and communication were closely related, contributing to the optimisation of the research process and outcomes; for this reason, both communication and evaluation should be continuous [39, 40, 42, 43, 46–51, 56, 57, 59, 60, 62–64]. Two of the included studies specifically addressed the concept of “developmental evaluation”, viewing evaluation as an integral part of the research process [55, 62]. Continuous reflections resulting from communication and evaluation may help to bridge the gap between researchers and PPI partners. In most cases, PPI partners reported feeling like an integral part of the research group when they felt seen, heard and valued.

3.5.3 Addressing Diversity

A strong focus on diversity was highlighted from the perspectives of both PPI partners and researchers, with the intention of including as diverse a group of individuals as possible within the project group [38, 42–46, 49, 51, 56, 58–60, 62, 64, 65]. However, assembling a diverse research team was described as challenging [42, 45–47, 50, 51, 58, 59, 62]; one study [42] describes uncertainty regarding the definition of diversity. Attention to diversity among participants necessitated tailored adaptations to both evaluation tools and engagement with individual PPI partners to meet their specific needs [42, 43, 45–47, 50, 51, 55, 58, 62]. Meanwhile, diversity among PPI partners underscores the need for the clarification of roles, which should be considered in light of the group’s varied expertise and requirements [62]. Despite the significant emphasis on diversity, we observed a lack of sufficient diversity in the composition of research groups. For instance, women were over-represented, and paradoxical inclusion criteria favour PPI partners with experience [42, 45–47, 51, 53, 56–62, 64, 65]. By prioritising experienced individuals, these criteria inadvertently excluded PPI partners without established experience, or individuals from under-represented groups, thus undermining the goal of fostering true diversity.

3.5.4 Additional Results

Across the studies, it became evident that evaluations are not consistently completed by either PPI partners or researchers [39, 40, 46, 49, 53, 56, 58–62, 64, 65] with only a minority of studies achieving full (100%) response rates. In some cases, response rates varied between researchers and PPI partners in survey-based evaluations with researchers less likely to complete the distributed questionnaires [39, 40, 42, 49, 59]. While limited participation from PPI partners may be understandable given various contextual factors, the lack of engagement from researchers is more striking. Given their central role in shaping PPI activities, one might expect researchers to contribute to evaluation processes—especially as continuous reflection and self-assessment are integral to evidence-based research practice.

Based on interviews, discussions and the documentation of user activities, one study developed a questionnaire to define key considerations for PPI and engagement. Based on the responses from this questionnaire, lists of “key” and “desirable” considerations were compiled. Evaluation of PPI and engagement only appeared on the desirable considerations list and was thus not regarded as critical for PPI and engagement [39, 40].

4 Discussion

In the 30 included studies, a total of 32 named evaluation tools were identified (alongside 39 that were not named); 24 of these were pre-existing instruments. There was a tendency to adjust already validated tools or create new tools to meet the specific requirements of the local setting. Both PPI partners and researchers consistently showed a higher response rate compared with researchers in cases where both parties were being evaluated. Only a few studies utilised the GRIPP2 framework for reporting, despite it being the only available reporting guideline explicitly mentioning evaluation.

Patient and public involvement typically occurs in the forms of consultation and collaboration, although the goal and intentions are often stated as co-production. Ongoing communication and evaluation are described as essential for sustaining the partnership and are recommended to be integrated as a continuous part of the project. We observed that PPI partners often contributed to changes in project outputs and outcomes. Additionally, positive impacts are noted, with PPI partners experiencing personal growth, while researchers, to a lesser extent, acknowledging new skills that can be applied in future projects.

We found a substantial number of evaluation tools for PPI in health research, many of which were developed de novo or adapted to address key aspects identified by both PPI partners and researchers. Greenhalgh et al. suggest that embracing diversity may offer a solution to the perceived lack of robust evaluations, which is consistent with the findings of this review [71]. However, creating a common framework for evaluation that is adaptable to specific contexts, user populations and research teams would be challenging; we found that the idea of diversity was embraced, but did not manifest in the actual partnerships as this would mean accommodating changes in both tool adaptation and team composition [71].

The tendency to combine multiple evaluation tools indicates the difficulty of capturing all necessary aspects in a single method. This trend was also highlighted by Shahid et al., who found that the combination of tools is a common approach [24]. Additionally, most evaluation tools primarily focus on the perspective of the PPI partners on the research process, rather than evaluating the partnership between partners and researchers. This seems paradoxical given the shift towards research being conducted *with* or *by* PPI partners, as outlined in the “UK Standard for Public Involvement” [30]. This lack of consistent evaluation makes it difficult to gauge the true impact of PPI — both on the research process and for the individual and society. The quest for evidence and understanding of the impact of PPI has been criticised for missing the underlying values of PPI, such as democratic inclusion and ethical imperatives [72]. Others have questioned whether PPI is implementable and can be assessed against measurable outcomes, or if it is rather a social practice of dialogue and learning [73]. If considered the latter, the reflection of practices is more important than evaluation tools.

The distinction between different roles in research teams persists, reflecting an underlying ‘us vs them’ dynamic. This suggests that the collaboration between PPI partners and researchers may not be truly equal. Evaluations should assess teams as a whole, or as Aguilar-Gonzalez et al. suggest, allow PPI partners to evaluate the researchers’ contributions [74]. This aligns with the findings of this review where few tools were designed to evaluate both PPI partners and researchers, and researchers demonstrated low response rates.

As mentioned in the introduction, Malterud and Elvbakken [21] and Grindell et al. [22] have raised concerns about the quality of involvement and evidence in research conducted with PPI [21]. They question the claim that PPI leads to enhanced quality of research, as they found a lack of adequate evaluation in their sample and highlight that this absence of evaluation undermines the quality and evidence of study findings [21, 22].

While an international standardised checklist (GRIPP2) exists for reporting user involvement to ensure quality and evidence, this review found its use inconsistent. Only seven out of 30 studies employed GRIPP2, and most used the shorter GRIPP2-SF version. This gap in reporting quality is consistent with multiple reviews [33, 34, 75], with some debate over whether certain studies should have used the more detailed GRIPP2-LF, particularly those focusing heavily on user involvement, such as Sipari et al. and Marshall et al. [56, 62]. Another review found that GRIPP2 was only used in the UK and Scandinavian countries, adding a geographic challenge to the comparison on PPI evaluations [33]. Similarly, Rouncefield-Swales et al. highlight both the lack of evaluation and the need for its greater prioritisation. They conducted a scoping review focusing on PPI and engagement activities with children and young people in health-related research. Using an adapted version of the GRIPP2 to collect data, they found that only 11 out of the 40 reviewed studies included evaluations of impact, with just seven of these being formal [75]. This underlines the persistent gap between the potential of tools like GRIPP2 and their actual implementation, particularly in ensuring a thorough and systematic evaluation of PPI. Thus, while GRIPP2 offers a structured approach for reporting and evaluation, its under-utilisation signals a broader issue with the consistent application of evaluation practices in user-involvement research. The inclusion of GRIPP2 in this context, despite it not being an evaluation tool, is particularly relevant given that it contains a specific focus on evaluation, an essential component for optimising the quality of user involvement in research.

Andrew Booth emphasises the importance of researchers evaluating their own performances for improving evidence-based practice and research quality [13]. While this is a recommendation for all research, and not PPI specific, the low rate of researcher participation in evaluations suggests that it is not common practice for researchers. Others highlight the importance of developing reflective skills for researchers if PPI is to be an integral part of research [76, 77]. In contrast with previous reviews, we found nine studies emphasising ongoing evaluation. This could be a way to improve the PPI process and impact, as adjustments could be made in the course of research. Others advocate this together with a dialogical approach [78, 79]. A clear disconnect exists between the emphasis on evaluating PPI and the actual practice. Despite the call for robust evaluation tools, the implementation of evaluation is often deprioritised, and existing checklists are underutilised [10, 40, 75, 80]. This could relate to our finding of researchers feeling unprepared for such collaborations. Only one included study explicitly reported that researchers felt unprepared for user involvement [49], but several discussed a need for further training. This highlights the need for greater support and training for researchers as PPI becomes more widespread in health research. Similar concerns are raised by Agyei-Manu et al., who found that researchers recognised their lack of skills in integrating PPI partners into the research process [81].

Malterud and Elvbakken describe instances in which PPI partners were involved in data and analysis without academic training, leading to compromises in academic rigour [21]. This suggests a gap in knowledge on how to effectively involve PPI partners in research, potentially owing to a lack of training or guidance. These findings suggest that researchers may lack confidence in involving PPI partners effectively, underscoring the need for greater attention to researchers' perspectives, learning and evaluation in relation to user involvement [21, 49].

4.1 Strengths and Limitations

This scoping review was conducted in accordance with the PRISMA-ScR guidelines, with a search strategy developed iteratively alongside an information specialist experienced in PPI. The review offers new insights by emphasising the low response rates of researchers in evaluations, a scarcity of tools for both PPI partners and researchers, and low prioritisation of these processes. These findings provide a foundation for future research and potentially explain why some studies lack sufficient quality of involvement. Data extraction by one reviewer, with validation by another, may be considered a limitation. The PRISMA-ScR guidelines by Tricco et al. do not mandate the use of two reviewers but emphasise transparency and rigour in reporting [31]. Similarly, Mak and Thomas, along with Levac et al., recommend but do not require the involvement of two reviewers for data extraction [28, 82]. To ensure that the data extracted by the primary reviewer aligned with the research question and purpose, a second reviewer validated the extracted data [28]. This study has some limitations that should be acknowledged. First, the dataset was relatively small, which limits the generalisability of findings and highlights the need for further research. Second, no quality assessment was conducted, in line with scoping review guidelines that consider this step optional when including diverse methodologies [28, 31, 82, 83]. Third, stakeholder consultation — recommended by Levac et al. to enhance the relevance of findings — was not conducted, as the aim was limited to mapping and synthesising the existing literature [28]. Finally, the search strategy was limited to English-language terms, which may have excluded relevant non-English sources.

5 Conclusions

Evaluation tools are often developed de novo, combined or adapted from pre-existing tools. These developments or modifications are typically aimed at tailoring tools to the specific context in which they are applied, suggesting that a standardised validated evaluation tool may not always be suitable. Only a few studies included both PPI partners and researchers as evaluators, and researchers often displayed low response rates. An important, potentially overlooked challenge relates to researchers' readiness to conduct research involving PPI partners; this suggests a further need for skill building and training with regard to PPI activities, the development of partnerships and reflective evaluations.

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Consent to Participate Not applicable.

Consent for Publication Not applicable.

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