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Research Involvement and Engagement

REVIEW

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Measuring impacts of patient and public involvement and engagement (PPIE): a narrative review synthesis of review evidence

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Abstract

Introduction Patient and public involvement and engagement (PPIE), in its various forms, offers a wide range of potential benefits to research, health services and systems, and to those involved in this collaborative process. As PPIE has expanded over the years, so too have expectations regarding the evaluation of its effects and impacts.

Methods We conducted a narrative review synthesis of review articles around measurement of PPIE impact – conceptualising 'impact' to include any type of effect on people or processes, both proximate and longer-term. We searched PubMed, Cochrane Library of Systematic Reviews, and CINAHL electronic databases and conducted hand searches. Inclusion criteria comprised: public involvement, reporting impacts of public involvement, and using a review methodology. This yielded 27 review articles based on studies in the UK, US, Canada and Australia.

We employed a three-part analysis process: 1) extracting all subcategories of impact reported into Excel (n = 37); 2) combining and categorising this list into primary and subcategories of impact based on thematic analysis; and 3) cross-checking these categories with the original review.

Results Our review of reviews indicates that studies often do not report impacts of PPIE activities and when they do, they report a wide range, with little consistency across studies. We classified four broad types of PPIE impacts on: people (PPIE contributors, researchers, healthcare staff and policymakers), different phases of the research process, services and systems and on PPIE processes themselves. Across these categories, the most commonly documented impacts relate to impacts on PPIE collaborators, including individual empowerment and recovery, on researchers, improving their understanding of and collaboration with people typically excluded from research and on earlier phases of the research process. Studies reported both positive and negative impacts. Methodologically, previous evaluations of PPIE impact predominantly relied on retrospective self-reporting, with little triangulation from other data sources or prospective data collection over time.

Conclusion The impacts of PPIE appear to be under- and inconsistently reported. More robust evaluation of PPIE impact, drawing on the broad categories we present, offers opportunities for PPIE contributors, researchers and funders to better understand the effects of these investments.

Keywords PPIE, Impact, Outcomes, Narrative review, Synthesis of evidence

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Plain English Summary

Where did we start?

Patient and public involvement and engagement (PPIE) is a common way of making research more relevant to members of the public. The amount of PPIE that researchers do has increased in the last two decades, yet what the impact is of these activities is less clear. Recording impacts helps us keep track of how PPIE shapes people and research on this bigger scale.

What did we do?

We searched for academic review articles that mentioned impacts of PPIE. Out of 35,335, we identified how previous studies have defined and measured different types of impacts.

What did we find?

We identified four broad types of PPIE impacts on: people (PPIE contributors, researchers, healthcare staff and policymakers), different phases of the research process, services and systems and on the ways in which PPIE is done. Studies reported both positive and negative impacts. They measured change most often by asking researchers and PPIE contributors what they thought the impacts had been.

Introduction

Setting the stage – PPIE and impact

Patient and public involvement and engagement (PPIE) can democratise research by applying patients, carers, and service-users' experiences and needs to research questions, designs, and processes [1–5]. There are various synonyms for and analogous approaches to PPIE (i.e., co-design, co-creation, co-production). The most relevant and popular definition for PPIE professionals in the UK comes from the National Institute of Health and Care Research (NIHR) [1–6]. This defines PPIE as doing research "with" or "by" patients or members of the public, instead of "about" or "on" them [1–6].

Some of the clearest conceptual origins for conducting research "with" patients lie in Arnstein's "ladder of citizen participation," [6–10]. This is a typology developed in community organising amongst the civil rights and social movements of 1960s America "to make target institutions responsive to…[the] views, aspirations, and needs [of those without power]" [6–10]. It uses a hierarchical spectrum of approaches in which citizen power increases as the steps move up the ladder from "nonparticipation" (steps 1 Manipulation, 2 Therapy) to "tokenism" (steps 3 Informing, 4 Consultation, 5 Placation), to "degrees of citizen power" (steps 6 Partnership, 7 Delegated, 8 Citizen Control) [9]. The ladder can apply to various contexts where power is exercised, but for PPIE, the "partnership" and "citizen control" steps highlight the opportunity to democratise research and shift power to be more collectively held amongst community members [9, 10].

Increasingly, many PPIE professionals and research management teams consider what the "impacts" are of the effects and changes that PPIE activities have supported [11–13]. Impact most commonly refers to the changes, effects, contributions, or benefits of PPIE or research on society, stakeholders, public services, or end users [14]. However, what illustrates these changes and benefits of PPIE on research are and how to describe them can vary greatly [15].

The evidence for the impact of PPIE has been described as 'weak' and 'anecdotal', with many calling for more reporting on the context in which PPIE was conducted to understand and compare its impacts and build a more robust evidence base [11, 12, 16–19]. Such contextual factors can include what collaborators are invited to contribute, how their feedback is adopted by researchers, what skills and knowledge public collaborators bring to PPIE activities, what skills, values, and knowledge or assumptions researchers bring to PPIE activities, and what mutual learning emerges from it for researchers and public collaborators [11, 12, 16–19].

The evolution of PPIE, the marketisation of health services and consequent tensions

The conceptual and historical origins of PPIE's purpose to improve research quality can be attributed to two factors: 1) the consumerism of healthcare whereby patients are viewed as consumers who can help improve the value for money of research and efficiency of services [13, 17]; and 2) the mandated, top-down approach where PPIE is a requirement of funding conditions [11, 17, 20, 21].

Guidance requiring consumer involvement through PPIE was established in 1993 by the UK's NHS Research and Development Programme [17]. During the eighties, the Thatcher government transformed the NHS and UK health research through a more commercial approach to public management [13, 22, 23]. Patients were considered consumers with a right to choose where treatment was provided, and public services were reorganised

with more top-down management and significant public service cost cuts [13, 22, 23]. Despite the various governments since Thatcher and the corresponding organisational changes to what is now the National Institute of Health and Care Research (NIHR), "consumer involvement" was a prominent and common term throughout the 90 s and 2000 s [17, 24–26].

The NIHR issues guidance on PPIE taking a top-down approach mandating that all its funding recipients conduct PPIE [12, 23, 27–29]. The NIHR alongside other national funding bodies require grant applications, academic publishing and organisational operating practices to include PPIE [12, 17, 27, 28]. Researchers are recommended to follow the UK Research and Innovation (UKRI) Standards of Public Involvement and NIHR PPIE guidance to plan for and demonstrate impact on the effects of PPIE on research [6–8].

Ocloo and Matthews argue that viewing patients as consumers has blunted PPIE's potential as it focuses on insights from patients which are reported at board meetings, as opposed to goals of shared decision making and community involvement in research processes [17, 21]. This can limit public collaborators' contributions and potential impact of PPIE as the added value to research is measured through simple quantitative assessments of PPIE activity, improved uptake or recruitment, or better support of a study [14, 15, 17, 30]. This results in less easily quantifiable/abstract PPIE experiences being left out of the assessment [14, 15, 17, 30].

While mandating PPIE has increased activity, this does not guarantee more democratised research or improved power sharing [10, 17, 20, 31], and can lead to tokenism [17, 21] defined as "asking for involvement but not taking it seriously or enabling it to be effective" [21]. Essentially tokenising PPIE resembles disingenuous practices to fulfil funder requirements, rather than substantive collaboration between researchers and the public, leading to a tick-box exercise [11, 17, 20, 21].

The top-down pressure to conduct PPIE often with time and resource/capacity constraints can lead to tokenistic PPIE practices [13, 22, 23, 32]. This leads to pressures on PPIE professionals to deliver meaningful and engaging PPIE activities [13, 22, 23, 32]. Genuine PPIE requires long-term relationship- and trust-building with public collaborators and community organizations, albeit within a research culture whose logic of deliverables requires maximised impact and value for money on rigid and shorter time schedules [13, 22, 23, 32].

Aims

To support our commitments to impacts of PPIE as NIHR-funded centres (Applied Research Collaboration (ARC), Health Determinants Research Collaboration (HDRC)), we accessed the PPIE evidence base to frame our PPIE strategies and activities. Thus, we approached this review from a pragmatic perspective, intending to inform practice. We aim to understand how PPIE impacts are currently being measured. We understand "how they are measured" as including the broad categories, specific indicators, methods, time frames, and the trade-offs concerning different approaches to measuring PPIE impacts.

Methods

Narrative Review

We conducted a narrative review of reviews on PPIE, then analysed these peer reviewed reviews to complete an evidence synthesis on the impacts of PPIE [21, 33–37]. Our narrative review, like others, was not meant to be systematic, but instead, pragmatic to support relevant professionals such as PPIE leads, PPIE officers, and researchers [21, 33–36, 38]. Our intention was to identify themes identified in the academic literature on PPIE impacts, then synthesize these for practical consideration, rather than undertake a traditional systematic review of all possible PPIE impacts [34–37, 39, 40].

Search process

The search terms selected were framed by our professional expertise in PPIE and included terms common and relevant to working in PPIE [21, 37]. For example, this included commonly used terms synonymous with PPIE, such as public involvement, co-production, co-creation, and co-design (see Table 1).

We searched the PubMed, Cochrane Library of Systematic Reviews, and CINAHL electronic databases. Our search had no beginning date, though it was capped at April 2024. We did not set language restrictions, although all articles identified were written in English. Searches were completed with two, i.e., "impact AND PPIE" or three factor phrasings, i.e. "impact AND PPIE AND review". If a database included a "review" and "systematic review" filter, these were toggled on and off to compare results. If a filter was not included, then, "review," "systematic," and "reviews" were all searched alongside the other terms.

The overall search followed an iterative process in which we clarified our understandings of our review while familiarizing ourselves with the literature, leading us to develop some of our search terms post-hoc [38, 41]. We completed three iterations, each using the following three step process: a) search, b) review literature and reflect on the search scope c) update the search based on findings [38, 41]. In the second iteration, we adopted the terms "consumer involvement," "consum," "consumer," and "outcomes" [41]. In the third and final iteration, we reviewed bibliographies of relevant articles, searched

Table 1 Search Terms

First term – Impact and synonyms
• "impact"
• "outcomes"
• "outcom"
• "result"
Second term – PPIE and synonyms:
• "PPIE"
• "public"
• "public involvement"
• "public involvement and engagement"
• "involvement"
• "involv"
• "consumer involvement"
• "consumer"
• "consum"
• "codesign"
• "co-design"
• "coproduction"
• "co-production"
• "coproduc"
• "co-produc"
• "cocreat"
• "co-creation"
• "co-creat"
• "collaborat"
Third term – Review and synonyms
• "review"
• "reviews"
• "systematic"

citation lists, and backward citation searches [40]. This also provided validation to our included citations.

Inclusion and Exclusion criteria.

Tables 2 and 3 list the inclusion and exclusion criteria which were subject to refinement [41]. Abstracts that met the inclusion criteria were selected for review. Essential to inclusion were both the use of a review methodology including multiple studies' PPIE activities and impacts or outcomes of a PPIE activity.

In the first iteration, we sought review articles that included "impact" in the title and abstract, as opposed to reviews that focus on PPIE but might include some insights on impact categorised in other ways. We sought reviews that provided a broad or overarching perspective on PPIE impacts, i.e., Brett et al. [42], as opposed to area-specific impacts, i.e. PPIE impacts on cardiology research.

Table 3 Exclusion Criteria

1) Article focuses on a single PPIE study or project
2) Does not use a review method
3) Does not review multiple studies
4) Does not report the impacts that emerged from PPIE activities
5) Reporting only on procedural aspects of PPIE without describing the impacts of PPIE

In the second iteration, our perspective shifted from overarching considerations of PPIE to include topic-specific reviews. We found that articles might not mention impact in their title or abstract, but they might still include relevant impacts in the paper.

Collectively this process yielded 27 reviews. We illustrate article processing details by source in Fig. 1.

Analysis

We employed a three-part analysis process for the 27 articles: 1) data extraction, 2) data synthesis, and 3) creation of an impact framework. During data extraction, sometimes called charting, we used a Microsoft Excel spreadsheet to note key characteristics across reviews i.e., title, year of publication, authors, review method, number of papers included in the review, research questions, inclusion/exclusion criteria. [43–45] (see Table 4) [42–68]. Building on Modigh et al.'s method of extracting and reporting on categories and subcategories of impact, these were also included in our charting [45]. In total, we charted 37 total subcategories of impact, and we have included a complete list in Supplement 1.

In the data synthesis phase, we reviewed which categories were redundant or overlapped/linked with others, which recurred across reviews, and which were thematically connected [38, 43–45]. Based on feedback with our local PPIE panel, we collapsed and combined these recurring categories, then cross-checked them with the original review to assure their validity [38, 43–45].

In our final phase of analysis, we built on Gupta et al.'s method of combining a review with creation of a conceptual framework [38]. We reviewed the synthesized subcategories and categories of impact and identified

Table 2 Inclusion Criteria

1. Analysing involvement activities by any relevant involvement-related term (i.e., public involvement, PPIE, consumer involvement, co-production) in research, service development, or service delivery
2. Reporting impacts or outcomes that emerged from PPIE activities from multiple studies
3. Use of a review method to consider impacts of multiple projects on PPIE, i.e. systematic review, scoping review, bibliometric review

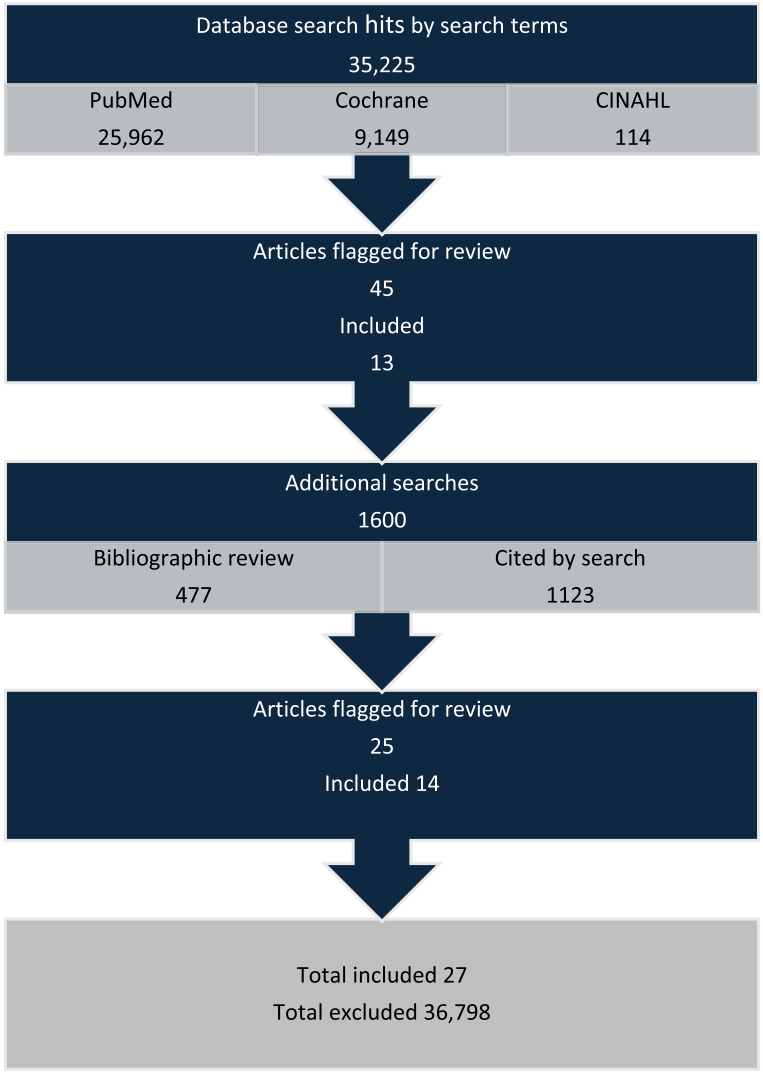

Fig. 1 Search data

how these related to one another to understand what connected them and how their variety and complexities could be conveyed visually [38].

PPIE on this project

We held regular meetings with the NIHR ARC North Thames Research Advisory Panel (RAP) public patient collaborators [69] to assure that the topic and questions were relevant for them. We held three discussion sessions with 12 panel members at the conception of the idea, at the project plan stage and at the completion of the literature review. Following the final meeting, we revised this manuscript and shared it again with panel members for additional feedback. The RAP members used several definitions to conceptualize PPIE's impacts, including "outcomes," "the way the research will be different due to PPIE", "the thing you haven't thought of before," and "the lightbulb moment brought by the [PPIE] panel."

We did not secure ethical approval for our PPIE activities, as per the NIHR, ethical approval is not required for these activities [4, 5, 70], but public collaborators gave consent for their involvement.

Results

We provide an overview of all articles reviewed in Table 4 (including topic area, methodology, country of origin, journal, terminology, exclusion criteria, and inclusion criteria; Table 4). This review of reviews revealed four key findings, discussed in turn below. First, studies often do not report impacts of PPIE activities and when they

Table 4 Articles summary

Citation	Topic area	Methodology	Country of Origin	Journal	Terminology	Exclusion Criteria	Inclusion criteria
Modigh et al. 2021 [45]	PPIE impacts in health research versus healthcare	Scoping review of reviews	Sweden	Health Policy	PPI, patient and public involvement, co-production, public participation, patient engagement	Studies presenting no summary of empirical results from other studies; Studies other language than English; published before the year of 2000, book chapters, debate articles; studies not using a review-method; no demonstration of impact of PPI activities	Human participants; any age; any sex; Studies reviewing the literature on the impact of PPI activities in both health research and healthcare; Studies published in the English language; published between years 2000–2020, using a review-method, and aiming to demonstrate impact of PPI activities (at least in part of the article)
Cluley et al. 2022 [46]	PPIE role in healthcare innovation	Scoping review	UK	Health Expectations	PPI, patient and public involvement	Innovations or papers relating to healthcare financial management or governance, commissioning, educational and/or workforce development or those only focusing on evidence or knowledge utilisation	Studies that considered the involvement of the public or patients across healthcare innovations, often referred to as service users or expert patients
Brett et al. 2014 [42]	PPIE impacts on service users, researchers, communities	Systematic review	UK	Patient	PPI, patient and public involvement, user involvement	Not reported	Not reported
Vanderhout et al. 2023 [47]	PPIE impacts in child health research	Scoping review	Canada	The Journal of Pediatrics	Patient and family engagement	Not reported	(1) peer-reviewed journal articles that described at least 1 impact of patient and family engagement on child health research, defined as a qualitative or quantitative impact on the research process (any element related to study design, research operations/execution, or knowledge transfer and implementation), research teams, or patient and family partners; (2) a research population age range of birth to 18 years; and (3) English language publications
South et al. 2016 [48]	PPIE impacts on trials	Purposive sampling	UK	Trials	PPI, patient and public involvement	Not reported	Not reported
Van Schelven et al. 2020 [49]	PPIE impacts on health and social care research, young people with chronic conditions	Scoping review	Netherlands	Health Expectations	PPI, patient and public involvement, user involvement, service user involvement	not reported	not reported

Table 4 (continued)

Citation	Topic area	Methodology	Country of Origin	Journal	Terminology	Exclusion Criteria	Inclusion criteria
Baines et al. 2022 [44]	PPI impacts on digital health innovation, implementation, and evaluation	Systematic review	UK	Health Expectations	PPI, patient and public involvement, coproduction, codesign	Protocols, conference proceedings, letters or theses, articles not available in the English language and articles published before 2010 that do not involve patients and/or the public in the innovation, implementation and/or evaluation of digital health technologies were excluded	Articles of any study design except for protocols, conference proceedings, letters or theses published in the English language, between 2010 and 2020, that involved patients and/or the public in the innovation, implementation and/or evaluation of digital health technologies were included

Table 4 (continued)

Citation	Topic area	Methodology	Country of Origin	Journal	Terminology	Exclusion Criteria	Inclusion criteria
Brett et al. 2010 [50]	PPI impacts on health and social care research	Systematic review	UK	University of Warwick	PPI, patient and public involvement, user involvement	Foreign language unless deemed a critical study to include in the systematic review; Children and adolescent services; Letters, opinions, editorials If the study had a fatal flaw, in terms of quality, which compromised its results	Definition of user involvement in health (public and primary) and social care research; Conceptualisation of user involvement for health (public and primary) and social care research; Methods for capturing user involvement data and measurement of user involvement in health (public and primary) and social care research (reliability and validity reported); Impact of involvement at all stages of health (public and primary) and social care research (e.g. protocol, ethic approval, advisory, data collection, analysis, dissemination); Impact of the research on individual users or research team members (e.g. personal development/new skills/financial gain or work load/emotional journey), on groups (e.g. communities, user groups, teams), on organisations (e.g. communities, NHS, Council, Funders, Ethics committee), and on policy (local and national); Outcomes of research (results of the research study); Economic evaluation of user involvement in Health (public and primary) and social care research; Evidence from 1995 to 2009; English language; Users involved are adults; The article/report contained a substantial amount of critical analysis or reflection on the impact of public involvement in research (a "substantial" amount is defined as a separate or distinct section within the report); The article/report discussed public involvement in health and social care research; The article/report was publicly available as a report form; The grey literature searches will be from 1995 onwards, in line with the dates searched for the published literature
Burton et al. 2019 [51]	PPI impacts on dementia research	Scoping Review	UK	Current Opinion in Psychiatry	PPI, patient and public involvement, co-production	Not reported	Not reported

Table 4 (continued)

Citation	Topic area	Methodology	Country of Origin	Journal	Terminology	Exclusion Criteria	Inclusion criteria
Chambers et al. 2019 [43]	PPI impacts on palliative care research	Synthesis review	UK	Palliative Medicine	Patient and carer involvement, user involvement	Other areas of research Palliative care in service provision at individual level with no involvement, No guidelines or standards, No experience of patient/carer involvement in palliative care research, No involvement, Aged under 18 years, Non-Western populations, Non-English	Palliative care research, Palliative care in other settings (e.g. education, service provision) if it relates to involvement at a higher level than the individual patient/carer, includes guidelines or standards, or is a key text of relevance to the review; Anyone with experience of patient/carer involvement in palliative care research (e.g. patients, carers, clinicians, academics) Involvement; Any evidence on the effects of involvement, either on outcome or process (e.g. impact, benefits, barriers) Aged 18 years and older; Evidence concerning Western populations only English only; Any evidence or literature, including grey literature; Any design, including reviews, qualitative, quantitative, mixed methods, text or opinion; Any year

Table 4 (continued)

Citation	Topic area	Methodology	Country of Origin	Journal	Terminology	Exclusion Criteria	Inclusion criteria
Crocker et al. 2018 [52]	PPI impacts on enrolment and retention in clinical trials	Systematic review and meta-analysis	UK, Spain	BMJ	PPI, patient and public involvement	Studies of trials with a behavioural or other non-clinical primary outcome were excluded;	The primary outcome had to be a measure of health status; We included papers that quantitatively evaluated the impact of a PPI intervention, compared with no intervention or another non-PPI intervention, on enrolment and/or retention rates in a clinical trial or trials in any patient population. We defined "PPI intervention" as an intervention that was, or included as an active component, any form of PPI consistent with the INVOLVE definition of public involvement: "research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them," where the term public includes patients, potential patients, carers, and people who use health and social care services, as well as people from organisations that represent people who use services. This included interventions not necessarily labelled or conceptualised as "PPI" by the study authors (for example, user testing, peer recruitment, and community based participatory research). We included interventions in which PPI was integrated with additional components inseparable from the PPI (such as involvement of other stakeholders) because this is consistent with the way patients are often involved in practice (for example, being part of an advisory group). Hereafter, we refer to such components as "non-PPI components" of interventions

Table 4 (continued)

Citation	Topic area	Methodology	Country of Origin	Journal	Terminology	Exclusion Criteria	Inclusion criteria
Domecq et al. 2014 [53]	Best ways to identify, engage, and observe patient engagement; risks, benefits, harms, barriers of patient engagement	Systematic review	UK	BMC Health Services Research	Patient engagement	Other non-original studies (non-systematic literature reviews, comments, opinions, letters and editorials etc.)	All original studies of any design, size, or patient population published in the English language in which patients or their surrogates provided feedback, had input, or took part in the design, con- duct and dissemination of research. Systematic re- views were also included to supplement the findings from original studies Studies in which patients were actively engaged in de- signing research Participation in surveys was only considered to be research engagement when the main purpose of the survey was to obtain patients' values and preferences that relate to research prioritization or research design
Hyde et al. 2016 [54]	Investigate the process and impact of collaborating with members of a patient Research User Group (RUG) on a systematic review	Systematic review	UK	Health Expectations	PPIE, patient and public involvement and engagement	Not reported	Not reported
Lloyd et al. 2021 [55]	PPI impacts on health service outcomes	Systematic review	Australia	BMC Health Services Research	Public involvement, user involvement	Outcomes for participating individuals or evaluations of how public involvement was conducted were not the focus of this review. Articles unavailable in the English language due to time and cost limitations	Original research published in academic peer-reviewed journals with evidence of public involvement in health service design or re-design, with reported health service outcomes
Mathie et al. 2014 [56]	Consumer involvement impacts on research in cystic fibrosis, diabetes, arthritis, dementia, intellectual and developmental disabilities, and public health	Scoping review and survey	UK	International Journal of Consumer Studies	Consumer involvement, PPI, patient and public involvement, user involvement	Excluded studies that were more than 2 years old (end date of recruitment before 1 September 2009)	Studies most likely to have been designed since the embedding of PPI in the research governance framework (Department of Health, 1999)
Mockford et al. 2012 [57]	Impact of PPI on NHS health care	Systematic review	UK	International Journal for Quality in Health Care	PPI, patient and public involvement, service user involvement, user involvement	Discussion papers, think pieces or editorials were excluded	All types of user/patient activity which involved patients, carers and the public working: (a) in a collaborative way with health professionals or management, e.g. as lay members of NHS committees or in condition-specific groups or (b) in a user-led way where the service user was leading the involvement activity
Nilsen et al. 2006 [58]	Consumer involvement impacts on healthcare policy and research	Systematic review	Norway, UK	Cochrane Database of Systematic Reviews	Consumer involvement	Not reported	Not reported

Table 4 (continued)

Citation	Topic area	Methodology	Country of Origin	Journal	Terminology	Exclusion Criteria	Inclusion criteria
Shippee et al. 2013 [59]	Evidence-based frameworks for patient and service user engagement in research	Systematic review and synthesized framework	USA	Health Expectations	Patient and service user engagement, PSUE	Did not evaluate how to incorporate patients' voice into research, information was not extractable. Duplicates; Non-English publication	English-language studies, commentaries, grey literature and other sources (including systematic and non-systematic reviews) pertaining to patient and public involvement in biomedical and health services research; Studies of any design, size and patient age or morbidity status, published in English, in which patients, surrogates, caregivers or other service user stakeholders participated in planning or conducting biomedical and health services research
Smith et al. 2022 [60]	Changes in co-production to improve application of co-production	Scoping review	UK	Health Research Policy and Systems	Co-production, co-creation, co-design, user involvement, PPI/E, patient and public involvement/engagement,	Limit = United Kingdom, Limit = English language; Limit to year = "2010–2020;" Subsequently limited to 2018–2020 given the large number of hits from initial searches	Any stakeholders involved in applied health research (e.g. researchers, patients, public); Co-production approach or methodology; United Kingdom literature: research conducted in or relevant to United Kingdom context (e.g. systematic reviews that included studies conducted in the United Kingdom); Definitions, typologies or conceptualization of co-production Key outcomes (conceptual, methodological, impact, health, experiential) Research implications, Any type of published literature including systematic reviews, literature reviews, empirical research (evaluations of co-production or co-produced intervention research), guidelines, opinion or comment pieces English language only; From 2010 onwards, when "co-production" started to appear in the health literature

Table 4 (continued)

Citation	Topic area	Methodology	Country of Origin	Journal	Terminology	Exclusion Criteria	Inclusion criteria
Halvorsrud et al. 2019 [61]	Effectiveness of Co-creation/-production	Systematic review and meta analysis	UK	Journal of Public Health	Co-creation/production, co-creation, co-production, co-design,	Excluded co-creation with only adolescents and children, because structural differences between child and adult health services, including regulations on the involvement of parents and carers in children's care, mean that the form of co- creation substantially varies across these settings	Reviews of research with sufficient post-treatment or post- exposure data or estimations available for quantitative pooling (i.e. experimental designs including randomized control trials (RCTs), quasi-experimental and pre-post evaluations; all relevant observational studies such as cohort, case–control, cross-sectional) Research literature of co-creation approaches applicable to health policy and health service research (e.g. public health or community interventions) relating to any health conditions or diseases in adult populations

Table 4 (continued)

Citation	Topic area	Methodology	Country of Origin	Journal	Terminology	Exclusion Criteria	Inclusion criteria
Dawson et al. 2018 [62]	Black and minority ethnic peoples involvement in PPI in health and social care research	Systematic review	UK, USA	Health Expectations	PPI, patient and public involvement, user involvement	If studies exclusively focused on majority groups or a combination of minority ethnic and majority groups where the data from minority ethnic groups was not clearly identifiable, then they were excluded; PPI in service development and clinical audit; Editorials, letters, commentaries, opinion pieces, theses and reviews, although the latter was used to identify other relevant studies for inclusion; Studies discussing the role of people from ethnic minority back- grounds as research participants; Studies not published in English; Grey literature	Population—a BME group(s) explicitly by the authors of the study within the paper itself. Members of any BME groups as defined by the authors of the studies themselves and from any country were included. Studies focusing on migrants including refugees, asylum seekers of different nationalities identified by authors as minority ethnic groups, are included even if detailed descriptors of their ethnicities were not available. In these cases, the population was defined based on "countries of origin."While the populations identified in this review as BME may be different (e.g., indigenous peoples) due to characteristics such as language, ethnicity, culture, migration, all of these groups share similar key characteristics in that they are all likely to experience health inequalities, discrimination, racism and stigmatisation that can marginalize these populations and therefore are included in this review. Types of studies—All study designs reporting empirical, primary health or social care research regarding PPI of the population of interest as outlined above were eligible for inclusion. Published between 1990–2016. Settings in primary or secondary health care setting, at interface of these settings, and/or social care research context
Greenhalgh et al. 2016 [63]	Models of co-creation in community-based health services	Narrative review	UK, Australia	Milbank Quarterly	Co-creation, co-production, co-design	Not reported	Not reported

Table 4 (continued)

Citation	Topic area	Methodology	Country of Origin	Journal	Terminology	Exclusion Criteria	Inclusion criteria
Slattery et al. 2020 [64]	Co-design in health	Rapid overview of reviews	Australia	Health Research Policy and Systems	Co-design, co-production	Primary studies Non-health settings Reviews describing research user engagement: a. in non-research processes or projects (e.g. engagement in healthcare) b. only outside the study planning phase (i.e. after the point at which the research question has been finalised); Reviews describing engagement with non-research stakeholders where there is no identified interest in a specific research project (e.g. public submissions on research priorities)	Systematic or narrative reviews (quantitative or qualitative studies) of research co-design (as defined above). Reviews had to address at least one of the following (adapted from PCORI classifications [19]) a. Examples of research co-design (e.g. review of primary studies where engagement took place); and/or b. Description of research co-design methodologies (e.g. synthesis and presentation of framework for research engagement); and/or c. Evaluation of research co-design (e.g. a meta- analysis of engagement effectiveness in influencing patient outcomes or experiences); English language; Peer-reviewed journal publications or publicly available reports
Smith et al. 2008 [65]	Evidence of service user involvement in nursing, midwifery, health visiting	Multi-method review	UK	International Journal of Nursing Studies	Service user involvement, user involvement	Not reported	Not reported
Boote et al. 2012 [66]	Public involvement in health research	Bibliometric review	UK	Health Expectations	Public involvement	Not reported	Not reported
Brett et al. 2012 [67]	PPI impacts on health and social care research	Systematic review	UK	Health Expectations	PPI, patient and public involvement, user involvement, service user involvement	Those papers that were quality-assessed as not adequate on the CASP checklist or three or less on the Dixon-Woods checklist were excluded	All study types that were in English language and reported data on the involvement of adult service users were included

Table 4 (continued)

Citation	Topic area	Methodology	Country of Origin	Journal	Terminology	Exclusion Criteria	Inclusion criteria
Staley et al. 2009 [68]	Impacts of public involvement on health and social care research	Structured literature review	UK	National Institute of Health and Care Research (NIHR) INVOLVE	Public involvement, user involvement	Not reported	The article/report contained a substantial amount of critical analysis or reflection on the impact of public involvement in research. (A 'substantial' amount was defined as a separate or distinct section within the report or article. Where an article or report only contained one or two paragraphs on the impact of user involvement as part of the conclusion/discussion, this was not considered to be substantial, and the article or report was not included); The article/report discussed public involvement in NHS, public health and/or social care research. Some studies of public involvement in service development were included when the lessons could be generalised; The article/report was publicly available as a journal publication, project report, book or book chapter, thesis, or as an editorial in a journal. Comments, letters and opinion pieces were not included

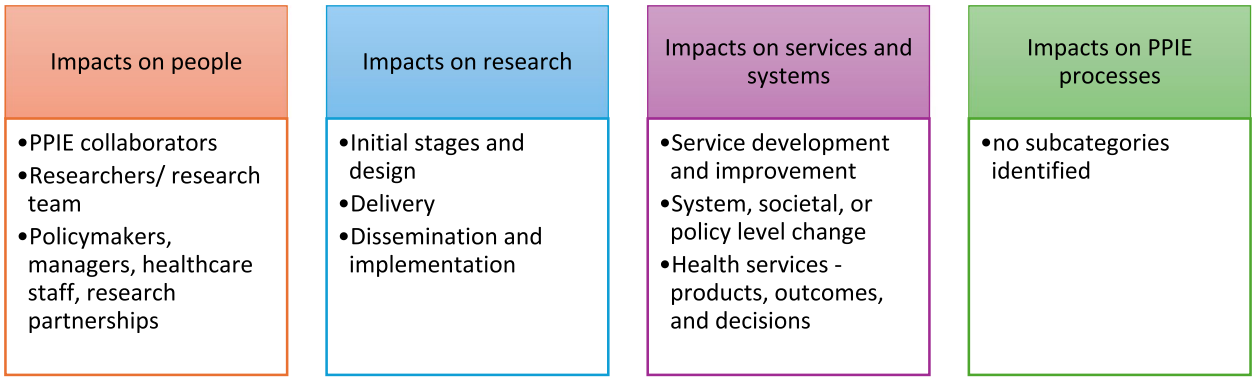

Fig. 2 Categories of PPIE Impact

do, they report a wide range of impacts, with little consistency in the indicators selected and how impact is categorised [47, 53, 62, 64, 68]. Two meta-analyses that attempted to analyse and condense large amounts of PPIE data [52, 59], found difficulties in synthesis due to high variability of PPIE data. Through our qualitative synthesis of impact categories, we classify four broad types of impacts of PPIE on: people, research processes, services and systems and on PPIE processes themselves.

Second, across these categories, the most commonly documented impacts relate to impacts on 1) PPIE collaborators, including individual empowerment and recovery [42, 43, 45, 47, 49, 50, 59–61, 66, 68], 2) on academic researchers, improving their understanding of and collaboration with minoritised peoples and those typically excluded from research [42, 44, 47, 57, 64, 66]; and 3) on earlier phases of the research processes, assuring the relevance of research to specific stakeholder groups, and improving studies' reach in recruitment and involvement of affected populations [43, 44, 47–52, 56–59, 61, 64–68]. Reported impacts on services, systems and subsequent PPIE processes were less common [44, 55, 61].

Third, several studies reported both negative and positive impacts [42, 49, 50, 52, 64, 65, 68]. The most common positive impacts included making studies more applicable or accessible to members of the public and creating practical and social benefits for members of the public. Common negative impacts included additional time and monetary cost, frictions and disagreements between members of the public and researchers, and disingenuous or tokenized collaboration.

Finally, in terms of methods, previous evaluations of PPIE impact predominantly relied on retrospective self-reporting, with little triangulation from other data sources or prospective data collection over time [42, 49, 50, 52, 64, 65, 68].

Types of PPIE impacts

In the subsequent sections, we provide specific examples of the most and least commonly reported measures of impact (summarized in Fig. 2 and Table 5).

PPIE impacts on people

One of the most reported impacts of PPIE is how it shapes, affects, and facilitates the experiences of those involved.

PPIE impacts on PPIE collaborators

The benefits for PPIE collaborators centred on experiences often described as "empowering and therapeutic" [42, 43, 45, 47, 49, 50, 66, 68]. For example, practical benefits to PPIE collaborators included "learn new skills," "learn new knowledge," "understand research" and "[improved] knowledge and understanding of their condition, illness, or treatment" [42, 45, 47, 49, 50, 68]. Other more distal impacts focused on social and emotional benefits that collaborators gleaned from the PPIE experiences: "feeling empowered," [43, 50, 59, 60, 66] "participating in a change or update to services," [43, 51] "supporting their personal recovery," [43, 50], and "shared experience of conditions, working with peers, new relationships," [42, 43, 45, 47, 49, 66, 68]. Finally and, perhaps, most strongly, PPIE in palliative care gave collaborators "new or added motivation in life," literally making them want to live longer [43, 59].

Finally, were impacts specifically on research collaboration, including "greater understanding and knowledge of research in the community," "community building," "collaborators become research advocates," and "community ownership of research" [42, 47, 50, 61, 63, 68].

Four reviews described negative impacts for PPIE collaborators [42, 43, 50, 60]. These included interpersonal dynamics with researchers, such as frustration at "rigid" or "limited beliefs" on the part of experts [42, 50],

Table 5 Categories of Impact with Examples of Impact

Impacts on people
• Public collaborators"feeling empowered"[43, 50, 59–61, 66]
• Public collaborators'improved"knowledge and understanding of their condition, illness, or treatment" [42, 45, 47, 49, 50, 68]
• Improved relationships between researchers and patients/families [47]
• Deeper empathy between researchers and "research subjects" [64]
• Changes to "health professionals' attitudes, values and beliefs about the value of user involvement [57]
Impacts on research processes
• Shifting the research agenda or focus to the public [67, 68]
• Improving research feasibility [50, 68]
• Frictions and disagreements between members of the public and researchers, [42, 44, 45, 49, 50, 52, 60, 66, 68]
• Improved informed consent [50, 64, 67, 68] and recruitment processes [51, 52, 67, 68]
• Materials for dissemination included more lay language, relevance to local communities, and validity in both its data and means of reporting [50]
Impacts on services, systems
• Increase[d] overall effectiveness of systems" [44]
• General improvement for quality [61], including: "improved usability" with 'insight into 'patients'needs and preferences' [44]
• Changes to provide more "health-promoting behaviour" [61]
• "Improvements to service processes, e.g., Record keeping, data sharing, medication dispensing, care pathways, and appointment and recall systems," [55]
Impacts on PPIE processes
• A lack of support or interest [56]
• Spread of experience-based co-design processes to other services and organisations," [56]
• "Formation of local health action groups, steering groups, or committees" [56]

"researcher insensitivity" [42], feeling "not listened to" or "not taken seriously" [42, 50], pressure [43, 60], "distrust of the research being conducted" [50], or stress from the involvement due to "power imbalances" between the public and researchers [43].

Other issues also included difficulties in collaborating with researchers, feeling uncomfortable sharing thoughts [42], feeling marginalized [50], disempowered [43], intimidated [43], anxious [50], or isolated [42]; assumptions from researchers that public collaborators "lack knowledge" [50]; limited preparation or training from researchers or the project [42, 50]; "disappointment" that the research did not provide "additional support to help them manage their condition" [42]; burdened by serving as a "bridge to health care systems in the community" [42]; and frustrations at dealing with "formal procedures of research," [50]. Finally, other difficulties included reliving difficult experiences, related to care, services, loss, trauma, illness, etc. [43, 50].

Other skills and knowledge-based negative impacts included limited clarity around PPIE collaborators' roles and difficulties contributing to the research [50]; limited understanding of research and limited feedback from researchers [42, 50]; "poor communication," including being omitted from research teams communications [42, 50], lack of familiarity with research processes and jargon, and privileging public collaborators with particular communication styles [42]. The time burden of PPIE included overburdening with tasks, the time-consuming nature of PPIE, unrealistic time expectations of PPIE collaborators, and limited time to review documents [42, 43, 50]. Financial burdens of PPIE included funding needs for travel and carers or having to self-finance one's own involvement [50], difficulties with travel, employment, and lack of conventional worker rights (appraisal, professional development, etc.) [51].

PPIE impacts on researchers

Benefits of PPIE on researchers and research teams included shifts to more team-oriented and skills-based ways of working [42, 44, 47, 64, 66]. Specifically, positive impacts included improvements to working relationships, such as robust networking and teambuilding [42, 47], new skills [42, 47], especially around the ability to "resolve differences" [47]; improved relationships between researchers and patients/families [47], and deeper empathy between researchers and "research subjects" [64]. PPIE also created changes in researchers' thinking, such as gaining new insights around problems [42], challenging researchers' beliefs and perspectives, and new understandings of public involvement [66]. Importantly, PPIE created a renewed and more in-depth community and person-centred focus for researchers [42, 44, 47, 64, 66]. This included more benefits for and better links with communities [42, 47], greater diversity in projects [42], "cultural competency" [47], more successful recruitment response rates, informed participants, and "recruitment from seldom heard groups" [64]. Finally, reviews noted an improvement to workload and work processes, such as a lighter workload [42], better

commitment from researchers towards the project [44], and increased confidence amongst researchers to conduct a study [66].

However, several negative impacts on researchers were reported, especially on workload and work processes [42, 68]. For example, PPIE directly increasing researchers' workload [68], creating difficulties with changing typical working patterns to create spaces of collaboration with members of the public [42], tokenizing PPIE activities and relationships [42], and doubts as to whether PPIE was worth the resources and effort [42] were named.

Reviews described pressures and tensions on research teams [42, 47]. For example, PPIE impinged on researchers' time and funding [42, 47], teams faced tension in PPIE activities and interactions, feelings of "constant criticism," and tension between PPIE collaborators and researchers around "what constitutes a good research study" [42]. Another tension centred on teams' and members' of the public need to explain to host organisations why PPIE was necessary [42].

PPIE impacts on policymakers, managers, healthcare staff, research partnerships

The impact of PPIE on healthcare staff, policymakers, and research partnerships were considered by the fewest papers reviewed [45, 57, 60, 61, 66]. One paper noted that PPIE had changed "health professionals' attitudes, values and beliefs about the value of user involvement" [57]. Another referred to changes in practices, attitudes, beliefs, and knowledge and skills for healthcare staff, policymakers and managers [45].

Unique elements attributed to policymakers and managers were including democratic elements in PPIE, societal values, legitimacy and trust, and responsiveness [45]. Negative impacts, by contrast, included slower and more expensive team productivity, participants representing individual agendas instead of broader public ones, and poorer policy plans and priorities [45]. Regarding research partnerships, PPIE yielded different models for partnerships and strengthened relationships [61, 66].

A notable absence in the discussion of PPIE impacts relating to people were mentions of PPIE professionals, staff who coordinate PPIE activities, recruit, train and mentor PPIE collaborators and often serve as the interlocutors between researchers and PPIE collaborators. This further illustrates what Mathie et al. have described as the 'invisible work' of PPIE, in which the work, advice, and contributions of PPIE professionals, frequently go overlooked [67].

PPIE impacts on research processes

The widest ranging and clearly reported impacts of PPIE on research focused on what changes had taken place within research processes, which we have synthesised to three phases: initial stages, design and delivery, and dissemination and implementation [43, 44, 47–52, 56–59, 61, 64–68]. We refer to the research cycle in this section, but we do not report discretely along all elements of the NIHR's depiction of the research cycle [1], as reviewers did not always follow this version of the research cycle, and they often used the terms interchangeably and in different ways than the NIHR.

PPIE impacts on research initial stages and design

"Initial stages and design" refers to the earliest stages of the research cycle, identification and prioritisation of the topic, design, and grant application. PPIE impacts reported during the initial research stages included identifying and prioritising topics [50], providing "motivation and momentum they, [researchers], needed to get started" [68], obtaining ethical approval [45, 48, 50], shifting the research agenda or focus to the public [67, 68] and improving research feasibility [42, 68].

Design-focused impacts described improving research design with the public, end-users, or study participants in mind, usually describing research designs as "more applicable," "acceptable," or "easier for people to participate" because of PPIE activities [59, 64–68]. It could also describe more relevant research topics [47, 50, 64, 65, 67] or research questions [47, 49, 56, 64, 68]. Some reviews cited studies where PPIE was credited with helping secure funding [47, 68].

PPIE Impacts on research delivery

"Delivery" refers to mid stage research cycle processes, including, recruitment and data collection, and analysis and interpretation.

For delivery-related impacts, authors focused on PPIE collaborators shaping language in research projects in various ways [50, 64, 67, 68]. For example, adapting "researcher language" to "suit the lay audience" [50], making language "accessible," or "culturally appropriate," or making it specific to "patient information and invitation letters" [50]. These tied to improved informed consent [50, 64, 67, 68] and recruitment processes [51, 52, 67, 68], usually with higher recruitment numbers [66], higher "response rates" [66], success in "reaching seldom heard groups in research" [66], and more study participants coming from "specific…communities such as ethnic minorities" [59].

Impacts on data collection included both changes to language in data collection instruments (including questionnaires, interview topic guides, and others) [50, 60, 64, 66–68], and the ways that instruments were used with or by members of the public in the research process [50, 51, 64]. Specifically, reviews reported that PPIE activities

yielded improved data quality, relevance to community members, and validity of the instruments or data collected [42, 47, 50, 68]. Impacts on analysis and report writing likewise attributed higher levels of validity and relevance to community members and the public [42, 47, 50, 68].

PPIE Impacts on research dissemination and implementation

"Dissemination and implementation" refers to the final stages of the research cycle, disseminating or sharing findings, and applying research findings into practice. PPIE-related dissemination impacts included more lay language in dissemination materials [50], overall stronger engagement between communities and project results [68], and higher chances that research findings will be applied [64, 68]. Authors described knowledge sharing events as positive impacts of PPIE, including co-delivered or co-produced training sessions [57], communication forums [58], and conference presentations [50, 66]. Articles noted that PPIE made these presentations more "poignant" [50], "lay user-friendly," [50], or "accessible" [66].

Negative impacts of PPIE on research

Frequent negative impacts included additional time and monetary cost, frictions and disagreements between members of the public and researchers, disingenuous or tokenized collaboration which alienates or disempowers public collaborators, or difficulty implementing and taking on public suggestions [42, 44, 45, 49, 50, 52, 60, 66]. Others included challenges with academic publishing, such as findings from PPIE-related work being perceived as unimportant, word counts being incompatible in length with the breadth of PPIE activities, and anxieties around public collaborators sharing results prior to publication [68].

PPIE impacts on services and systems.

The impact of PPIE on services and systems were less often reported than those on people and research. Nevertheless, these are synthesised into three domains: service development and improvement; system, societal, or policy level change; and health services, including products, outcomes, and decisions.

PPIE Impacts on service development and improvement

Services impacts focused on general improvement for quality [61], including: "improved usability" with 'insight into 'patients'needs and preferences' [44], building in desired changes for services for mental health [50], and creating prioritisation activities to support plans around services and means to evaluate services [56].

PPIE Impacts on system, societal, or policy level change

Systems and policy impacts reported an "increase[d] overall effectiveness of systems" [49], building workforce diversity [50], and strategy creation to further support service development [55]. One review highlighted several community-focused impacts, including community plans for wider systems changes, better access to care and social supports, health literacy, and "self-efficacy" of systems [61].

PPIE impacts on health services—products, outcomes, and decisions

The most extensive service/system subcategory was for health services and its constituent parts. Some impacts focused specifically on medical elements, such as clinical outcomes [45, 61] or physical health providers' and patients' knowledge or satisfaction with care [45], creating a "conceptual model of recovery" [56], increased trust, improved decision-making, and decision-making infrastructure with staff and clinicians [55, 56].

Other impacts centred on changes to the service elements of healthcare, such as "record keeping, data sharing, medication dispensing, care pathways, and appointment and recall systems" [55]. This also included, "health-promoting behaviour[s]" [61] (i.e., giving patients educational or wellness materials), new or expanded clinical services [55], creating patient feedback processes [55], easier to read records and documents [58], using summary letters [55], staff personnel procedures [55], and updated clinical spaces [55, 56].

Two reviews described negative impacts [45, 58], including one in which patient-facing documents produced through PPIE activities did not reduce anxiety around"patient-controlled analgesia" [58].

Impacts on PPIE processes

The smallest category was impacts on PPIE, itself. This category included specific positive impacts from one review, i.e., "Spread of experience-based co-design processes to other services and organisations," and the "formation of local health action groups, steering groups, or committees" [56].

This review also offered negative impacts, which focused on "negative experiences rather than negative outcomes," with one specific example citing "a lack of support or interest," from researchers, due to "inappropriate" PPIE techniques [56].

Methodological approaches in measuring PPIE impact

The review articles suggest that evidence of impact is limited or weak [56, 57, 60, 64, 67, 68]. Impacts are often not measured in the cases in which they are reported, and the

specific methods indicating how impacts were measured are reported least of all [45, 51, 55, 59, 64, 66–68]. In several studies, there appears to be a strong confirmation bias, where PPIE impacts are reported as a reflection on experiences, opinions, and perceptions, rather than more robust measures [48–51, 54, 57, 59].

When methods were reported, qualitative approaches – predominantly interviews, focus groups, and observations – were used most frequently to evaluate PPIE impacts, and authors call for strengthening and standardizing qualitative methods for PPIE evaluations [44, 48, 50, 53, 57, 60]. Other articles evaluated PPIE through questionnaires and recruitment data [46, 51, 57, 63, 68]. Several authors have called for additional quantitative and comparative methods, with control studies [43, 47].

Reviews referred to existing tools for evaluating PPIE: the Patient Involvement Research Impact Tool (PIRIT), the Public Involvement Impact Assessment Framework (PiiAF), the National Coordinating Centre for Public Engagement's (NCCPE) Embryonic, Developing, Gripping, Embedding (EDGE) tool, the Public and Patient Engagement Evaluation Tool (PPEET), the Principles, Purpose, Presence, Process Impact tool (4Pi), and the Patient Engagement In Research Scale (PEIRS) [71–75]. Therefore, the challenge is not a lack of measurement tools, but rather a lack or inconsistent use of these instruments and a lack of transparent reporting of what was measured and how.

Discussion

There is a growing emphasis on PPIE, mandated by many funders, [11, 17, 20, 21] and growing pressures for researchers to report impact. However, this review of reviews reveals a fragmented landscape of PPIE impacts, with absent or inconsistent measurement and reporting of impacts of weak methodological quality. The institutionalisation of PPIE and attention to impact offers an opportunity to invest in more intentional and consistent measurement of PPIE over longer timeframes and across multiple dimensions of impact [11, 13, 23].

Impacts on research processes were most common, likely linked to required reporting to funders [13]. Existing studies also suggest additional compelling positive impacts of PPIE for people, such as PPIE contributors and researchers involved in the PPIE processes. These included increased confidence and will to live, to shifts in thinking about a project and finding a new cause and community around research. The category of impacts on research processes and systems was comparably shorter but still illustrated that PPIE impacts can offer increased effectiveness and quality to systems, services, and processes. Finally, the PPIE impacts on the actual PPIE processes included overall growth of PPIE – more of it getting done and more groups emerging dedicated to it and its related family of practices.

Negative impacts overlapped thematically across all four categories, people, research processes, services and systems, and PPIE processes. They touched on difficulties with communication between researchers and public collaborators, time and workload burdens for all involved, tensions or pressures on people or projects, and changes made to projects as limited. This echoes what Russell et al. argue, in addition to "being empowering or emancipatory," PPIE "runs the danger of having precisely the opposite effect" [11].

Across types of impacts, there are clear gaps. The relative lack of more downstream and medium to longer-term impacts on health care staff and policymakers and on health systems and policy may reflect the short-term, reflective nature of current measurement approaches. The relative lack of impacts on subsequent PPIE processes may be attributed to reporting practices. For example, PPIE collaborators and researchers might be regularly changing their approaches in practice, without tracking and publicising these changes. RAP members also observed two notable omissions in current subcategories of PPIE impact: the costs and savings of PPIE involvement on research budgets and the impacts on patients' direct experiences of healthcare services. As Papoulias and Brady note, there remains a need to openly and safely consider the impacts that are reported less often, or not at all around PPIE [13].

Taken together, the incomplete and wide variation in how PPIE impacts have been measured to date makes it difficult to understand the individual and collective effects of increased investments in PPIE, and how these effects vary across different contexts, types of research and PPIE contributor backgrounds. For example, "empowerment" of public collaborators as a PPIE impact, as Schilling and Gerhardus argue, can be a vaguely defined descriptor, at times completely undefined by a project, and usually described in conflicting ways between projects [76]. Specific PPIE impact measures will obviously need to be tailored to each study and assessing an exhaustive set of impacts is infeasible; however, the typology we present here offers a consistent menu of options from which people can identify those which are most relevant. Existing studies also underscore the importance of measuring both positive and negative impacts.

Methodologically, there remains much room for improvement, shifting from self-reported author and collaborator perceptions to more robust, empirical measures. Larger studies with substantive PPIE involvement and research infrastructure grants with standing PPIE

panels, whose members take part in multiple studies over time, offer the opportunity for longer-term follow-up of impacts over time. Funders who require PPIE and impact reporting could help to bring structure to PPIE impact measurement, using the typology we present here or an established PPIE measurement tool to guide reporting templates. They will also be instrumental in ensuring there is adequate funding to more robustly assess PPIE impacts, including to coproduce PPIE impact measurement standards based on existing measurement tools.

RAP panel members also saw value in improved assessment of PPIE impact. In their own experience, they observed "I've been looking into this for a lot of time – since 5–6 years ago, [during which I saw]…a progression from a tick box kind of PPI to a more coequal coproduction." They were eager to understand, "Where is it that we get better involvement?" "Where is it that we should get involved in a deeper way?" and "Where do we have the most impact?" Improved measurement and understanding of their contributions could potentially have positive knock-on effects in increasing involvement and retention among PPIE collaborators.

Strengths and limitations

The greatest limitation to this review is our geographical limitation. Our review of review identifies types of impacts reported from research based in the UK, US, Australia, Sweden, Norway, Spain, and the Netherlands. All papers focussed on communities in the UK, USA, Canada, or Australia. Importantly, each of these latter four countries has their own institution supporting patient and public involvement – the NIHR in the UK [29], Patient Centred Outcomes Research Institute (PCORI) in the USA [77], The Canadian Institutes of Health Research's Strategy for Patient-Oriented Research (SPOR) [78], and the National Health and Medical Research Council in Australia [79]. One review had examples of PPIE evaluations from Colombia [46] and India [46].

It is extremely important to note that differing variations of PPIE take place around the world. For example, Colombia [80], Ghana [81], and India [82] have all shown compelling recent examples of ways of engaging members of the public in health research, albeit with differing terms or conceptual traditions. Some of these vary slightly as, "PPE" or "patient-public engagement" [80] or "community engagement" [80], while others are more different, "community based health planning" [81] and "participatory learning and action" [82]. Exploring PPIE impact in a range of settings may expand and help to refine the initial typology we present here.

Conclusion

We conducted a narrative review of reviews to complete a pragmatic evidence synthesis of categories of impacts of PPIE. We included 27 review articles and have found that categories of impact fall most clearly along the lines of who or what changes because of PPIE. We have found that there is widespread variation in how PPIE is measured, how measurements are reported, what impacts occur, and how impacts are conceptualised. As PPIE and impact measurement becomes more common, PPIE researchers and collaborators must keep pace and indeed, have much to offer the measurement of research impact more broadly. The four categories of impact of PPIE we have identified in this project can guide future research, impacts on people, impacts on research processes, impacts on services and systems, and impacts on PPIE processes.

Abbreviations

PPIE	Patient and Public Involvement and Engagement
NIHR	National Institute of Health and Care Research
ARC	Applied Research Collaboration
HTA	Health Technology Assessment
MS	Multiple Sclerosis
RAP	Research Advisory Panel
PCORI	Patient Centred Outcomes Research Institute
SPOR	Strategy for Patient Oriented Research
PIRIT	Patient Involvement Research Impact Tool
PiiAF	Public Involvement Impact Assessment Framework
NCCPE	National Coordinating Centre for Public Engagement
EDGE	Embryonic, Developing, Gripping, Embedding
PPEET	Public and Patient Engagement Evaluation Tool
4Pi	Principles, Purpose, Presence, Process Impact
PEIRS	Patient Engagement In Research Scale

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Author contributions

WL: conceptualisation; investigation; funding acquisition; writing—original draft; methodology; validation; writing—review and editing; software; formal analysis; project administration; data curation. AB: conceptualisation; data curation; writing—original draft; writing—review and editing; supervision; project administration. DM: conceptualisation; funding acquisition; writing—original draft; writing—review and editing; validation; methodology; data curation; supervision; project administration.WL: conceptualisation; investigation; funding acquisition; writing—original draft; methodology; validation; writing—review and editing; software; formal analysis; project administration; data curation. AB: conceptualisation; data curation; writing—original draft; writing—review and editing; supervision; project administration. DM: conceptualisation; funding acquisition; writing—original draft; writing—review and editing; validation; methodology; data curation; supervision; project administration.

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Data availability
No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate
As this project included a narrative review of reviews using PPIE activities, it does not require ethical approval, per the NIHR [4, 5, 70]. As previously stated, public collaborators consented to involvement activities.

Consent for publication
Not applicable. Names mentioned in Acknowledgements are printed with consent.

Competing interest
The authors declare no competing interests.

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References

1. National Institute of Health and Care Research (NIHR). Briefing notes for researchers-public involvement in NHS, health and social care research. 2024. https://www.nihr.ac.uk/briefing-notes-researchers-public-involvement-nhs-health-and-social-care-research https://www.learningforinvolvement.org.uk/.
2. National Institute of Health and Care Research (NIHR) Biomedical Research Centre (BRC) Patience Experience Research Centre (PERC). A Rough Guide to Public Involvement. (2021). Version 1.5. March 2025. https://www.imperial.ac.uk/media/imperial-college/medicine/perc/PERCs-Rough-Guide-to-Public-Involvement---March-2025-mp---clean.pdf.
3. INVOLVE, N. Patient and Public Involvement in Research and Research Ethics Committee Review. NIHR INVOLVE. 2009. https://www.invo.org.uk/wp-content/uploads/2011/12/INVOLVENRESfinalStatement310309.pdf.
4. Lammons W, Silkens M, Hunter J, Shah S, Stavropoulou C. Centering Public Perceptions on Translating AI Into Clinical Practice: Patient and Public Involvement and Engagement Consultation Focus Group Study. J Med Internet Res. 2023;25:e49303.
5. Lammons W, Nobility L, Markham S, Saloniki EC. PPIE in a technical research study: Using public involvement to refine the concept and understanding and move towards a multidimensional concept of disability. Health Expect. 2024;27(3):e14072.
6. UK Public Involvement Standards Development Partnership. UK Standards for Public Involvement. *NIHR* 12 (2019).
7. National Institute of Health and Care Research (NIHR). Guidance for applicants on working with people and communities. 2024. https://www.nihr.ac.uk/research-funding/application-support/working-with-people-and-communities.
8. UK Research and Innovation (UKRI). Shared commitment to improve public involvement in research – UKRI. 2022. https://www.ukri.org/news/shared-commitment-to-improve-public-involvement-in-research/.
9. Arnstein SR. A Ladder Of Citizen Participation. J Am Plann Assoc. 1969;35:216–24.
10. Tritter JQ. Revolution or evolution: The challenges of conceptualizing patient and public involvement in a consumerist world. Health Expect. 2009;12:275–87.
11. Russell J, Fudge N, Greenhalgh T. The impact of public involvement in health research: what are we measuring? Why are we measuring it? Should we stop measuring it? Res Involv Engagem. 2020;6:1–8.
12. Staley K. 'Is it worth doing?' Measuring the impact of patient and public involvement in research. Res Involv Engagem. 2015;1:1–10.
13. Papoulias S, Brady LM. "I am there just to get on with it": a qualitative study on the labour of the patient and public involvement workforce. Health Res Policy Syst. 2024;22:1–13.
14. Morgan Jones M, Manville C, Chataway J. Learning from the UK's research impact assessment exercise: a case study of a retrospective impact assessment exercise and questions for the future. J Technol Trans. 2022;47:722–46.
15. White CD, Phillips A, Sajonia-Coburgo-Gotha B. Retrospectively evidencing research impact using online data mining. Res All. 2022;6(1). https://doi.org/10.14324/RFA.06.1.07.
16. Staley K, Barron D. Learning as an outcome of involvement in research : what are the implications for practice, reporting and evaluation ? Res Involv Engagem. 2019;1:1–9.
17. Russell J., Greenhalgh T. & Taylor M. Patient and Public Involvement in NIHR Research 2006–2019: Policy Intentions, Progress and Themes. National Institute for Health Research (NIHR), Oxford Biomedical Research Centre (BRC) (2019).
18. Petit-Zeman S, Locock L. Bring on the evidence. Nature. 2013;501:160–1.
19. Boivin, A. *et al.* Evaluating patient and public involvement in research. BMJ (Online). 2018;363:k5147.
20. Green, G. Power to the people: To what extent has public involvement in applied health research achieved this? Research Involvement and Engagement vol. 2 Preprint at https://doi.org/10.1186/s40900-016-0042-y (2016).
21. Ocloo J, Matthews R. From tokenism to empowerment: Progressing patient and public involvement in healthcare improvement. BMJ Qual Saf. 2016;25:626–32.
22. Mathie E, et al. The role of patient and public involvement leads in facilitating feedback: 'invisible work.' Res Involv Engagem. 2020;6:1–12.
23. National Institute of Health and Care Research (NIHR). NIHR Annual Report 2023/24. 2024. https://www.nihr.ac.uk/about-us/who-we-are/reports-and-performance/annual-report-202324.
24. Telford, R., Boote, J. D. & Cooper, C. L. What does it mean to involve consumers successfully in NHS research? A consensus study. Health Expectations vol. 7 209–220 (2004) Preprint at https://doi.org/10.1111/j.1369-7625.2004.00278.x.
25. Deldot, M. *et al.* Consumer Involvement in the Design and Development of Medication Safety Interventions or Services in Primary Care: A Scoping Review. Health Expectations review article open access (2024) http://doi.org/10.17605/OSF.IO/DQM7G.
26. National Institute of Health and Care Research. NIHR changes name to emphasise long-term commitment to social care research. National Institute of Health and Care Research. 2022. https://www.nihr.ac.uk/news/nihr-changes-name-emphasise-long-term-commitment-social-care-research.
27. Jagosh J. *et al.* Uncovering the Benefits of Participatory Research: Implications of a Realist Review for Health Research and Practice. Milbank Q. 2012;90(2):311-46.
28. Johns, T., Whibley, C. & Crossfield, S. Closed Study Evaluation: Measuring Impacts of Patient and Public Involvement and Research Quality and Performance. 2015 https://www.researchgate.net/publication/321431525.
29. National Institute of Health and Care Research (NIHR). Involve patients. https://www.nihr.ac.uk/career-development/health-and-care-research-introduction/involve-patients.
30. Research Excellence Framework. Research Excellence Framework REF 2029. 2015. https://www.2029.ref.ac.uk/guidance/section-1-overview/#section-engagement-and-impact-e-amp-i.
31. Polanco A, Al-Saadi R, Tugnait S, Scobie N, Pritchard-Jones K. Setting international standards for patient and parent involvement and engagement

in childhood, adolescent and young adult cancer research: A report from a European Collaborative Workshop. Cancer Rep (Hoboken). 2022;5(6):e1523. https://doi.org/10.1002/cnr2.1523. Epub 2021 Aug 12. PMID: 34383382; PMCID: PMC9199507.
32. Papoulias S, Callard F. 'A limpet on a ship': Spatio-temporal dynamics of patient and public involvement in research. Health Expect. 2021;24:810–8.
33. Guy Paré & Spyros Kitsiou. Methods for Literature Reviews. in Handbook of eHealth Evaluation: An Evidence-based Approach (eds. Lau, F. & Kuziemsky, C.) 157–180 (University of Victoria, Victoria, Canada, 2016).
34. Edbrooke-Childs J, Deighton J. A narrative review of reviews of interconnecting risks (IR) of mental health problems for young people. J Fam Ther. 2021;43:748–72.
35. Sukhera J. Narrative Reviews in Medical Education: Key Steps for Researchers. J Grad Med Educ. 2022;14:418–9.
36. Sukhera J. Narrative Reviews: Flexible, Rigorous, and Practical. J Grad Med Educ. 2022;14:414–7.
37. Green BN, Johnson CD, Adams A. Writing narrative literature reviews for peer-reviewed journals: secrets of the trade. J Chiropr Med. 2006;5:101–17.
38. Gupta, V. *et al.* Understanding the identity of lived experience researchers and providers: a conceptual framework and systematic narrative review. Res Involv Engagem. 2023;24;9(1):26. https://doi.org/10.1186/s40900-023-00439-0.
39. Goedhart, N. S. *et al.* Engaging citizens living in vulnerable circumstances in research: a narrative review using a systematic search. Res Involv Engagem. 2021; 7(1):59. https://doi.org/10.1186/s40900-021-00306-w.
40. 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.
41. Arksey H, O'Malley L. Scoping studies: Towards a methodological framework. International Journal of Social Research Methodology: Theory and Practice. 2005;8:19–32.
42. Brett J, et al. A Systematic Review of the Impact of Patient and Public Involvement on Service Users. Researchers and Communities Patient. 2014;7:387–95.
43. Chambers E, Gardiner C, Thompson J, Seymour J. Patient and carer involvement in palliative care research: An integrative qualitative evidence synthesis review. Palliat Med. 2019;33:969–84.
44. Baines R, et al. Meaningful patient and public involvement in digital health innovation, implementation and evaluation: A systematic review. Health Expect. 2022;25:1232–45.
45. Modigh A, Sampaio F, Moberg L, Fredriksson M. The impact of patient and public involvement in health research versus healthcare: A scoping review of reviews. Health Policy (New York). 2021;125:1208–21.
46. 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;25:840–55.
47. Vanderhout SM, et al. The Impact of Patient and Family Engagement in Child Health Research: A Scoping Review. J Pediatr. 2023;253:115–28.
48. South A, et al. Models and impact of patient and public involvement in studies carried out by the Medical Research Council Clinical Trials Unit at University College London : findings from ten case studies. Trials. 2016;17:1–13.
49. van Schelven F, Boeije H, Mariën V, Rademakers J. Patient and Public Involvement of young people with a chronic condition in projects in health and social care: A scoping review. Health Expect. 2020;23:789–801.
50. Brett, J. *et al.* The PIRICOM Study : A Systematic Review of the Conceptualisation, Measurement, Impact and Outcomes of Patients and Public Involvement in Health and Social Care Research. University of Warwick. 2010. https://www.ukcrc.org/wp-content/uploads/2014/03/Piricom+Review+Final+2010.pdf.
51. Burton A, Ogden M, Cooper C. Planning and enabling meaningful patient and public involvement in dementia research. Curr Opin Psychiatry. 2019;32:557–62.
52. Crocker JC, et al. Impact of patient and public involvement on enrolment and retention in clinical trials: Systematic review and meta-analysis. BMJ. 2018;363:1–17.
53. Domecq JP, et al. Patient engagement in research: A systematic review. BMC Health Serv Res. 2014;14:1–9.
54. Hyde C, Dunn KM, Higginbottom A, Chew-Graham CA. Process and impact of patient involvement in a systematic review of shared decision making in primary care consultations. Health Expect. 2016;20:298–308.
55. Lloyd N, Kenny A, Hyett N. Evaluating health service outcomes of public involvement in health service design in high-income countries: a systematic review. BMC Health Serv Res. 2021;21:1–13.
56. Mathie E, et al. Consumer involvement in health research: A UK scoping and survey. Int J Consum Stud. 2014;38:35–44.
57. Mockford C, Staniszewska S, Griffiths F, Herron-marx S. The impact of patient and public involvement on UK NHS health care: a systematic review. Int J Qual Health Care. 2012;24:28–38.
58. Nilsen ES, Myrhaug HT, Johansen M, Oliver S, Oxman AD. Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material (Review). Cochrane Database Syst Rev. 2006;3:CD004563.
59. Shippee ND, et al. Patient and service user engagement in research: A systematic review and synthesized framework. Health Expect. 2013;18:1151–66.
60. Smith H, et al. Co-production practice and future research priorities in United Kingdom-funded applied health research: a scoping review. Health Res Policy Syst. 2022;20:1–43.
61. Halvorsrud K, et al. Identifying evidence of effectiveness in the co-creation of research : a systematic review and meta-analysis of the international healthcare literature. J Public Health (Bangkok). 2019;43:197–208.
62. Dawson, S., Campbell, S. M., Giles, S. J., Morris, R. L. & Cheraghi-Sohi, S. Black and minority ethnic group involvement in health and social care research : A systematic review. Health Expect. 2018;21:3–22. https://doi.org/10.1111/hex.12597.
63. Greenhalgh T, Jackson C, Shaw S, Janamian T. Achieving Research Impact Through Co-creation in Community-Based Health Services: Literature Review and Case Study. Milbank Q. 2016;94:392–429.
64. Slattery P, Saeri AK, Bragge P. Research co-design in health: a rapid overview of reviews. Health Res Policy Syst. 2020;18:1–13.
65. Smith E, et al. Service user involvement in nursing, midwifery and health visiting research: A review of evidence and practice. Int J Nurs Stud. 2008;45:298–315.
66. Boote J, Wong R, Booth A. 'Talking the talk or walking the walk?' A bibliometric review of the literature on public involvement in health research published between 1995 and 2009. Health Expect. 2012;18:44–57.
67. Brett J, et al. Mapping the impact of patient and public involvement on health and social care research: a systematic review. Health Expect. 2012;17:637–50.
68. Staley, K. Exploring Impact: Public Involvement in NHS, Public Health and Social Care Research. NIHR INVOLVE. 2009. https://www.www.invo.org.uk.
69. National Institute of Health and Care Research (NIHR) Applied Research Collaboration (ARC) North Thames. Meet our RAP and VDRP panel members. 2024. https://www.www.arc-nt.nihr.ac.uk/about-us/.
70. Hickey, G. (INVOLVE) et al. Draft Guidance on Co-producing Research. 2021;1–11. https://www.learningforinvolvement.org.uk/wp-content/uploads/2021/04/NIHR-Guidance-on-co-producing-a-research-project-April-2021.pdf.
71. Popay, J., Collins, M. & PiiAF Study Group. The Public Involvement Impact Assessment Framework (PiiAF) Guidanc. 2014. https://piiaf.org.uk/documents/piiaf-guidance-jan14.pdf.
72. Engagement, N. C. C. for P. Introducing the EDGE Tool Self-Assessing Your Support for Public Engagement. 2023. https://www.publicengagement.ac.uk/sites/default/files/2023-08/introducing_the_edge_tool.pdf.
73. Public and Patient Engagement Collaborative. Public and Patient Engagement Evaluation Tool (PPEET). McMaster University vol. 10. 2018 https://www.ppe.mcmaster.ca/.
74. Faulkner, A. *et al.* 4Pi National Involvement Standards: Involvement for Influence. 2015 http://www.nsun.org.uk/assets/downloadableFiles/4PiNationalInvolvementStandardsFullReport20152.pdf.
75. Hamilton CB, et al. Shortening and validation of the Patient Engagement In Research Scale (PEIRS) for measuring meaningful patient and family caregiver engagement. Health Expect. 2021;24:863–79.
76. Schilling I, Gerhardus A. Is this really Empowerment? Enhancing our understanding of empowerment in patient and public involvement within clinical research. BMC Med Res Methodol. 2024;24:205.

77. Patient-Centered Outcomes Research Institute (PCORI). Patient-Centered Outcomes Research Institute (PCORI). https://www.pcori.org/.
78. Canadian Institutes of Health Research (CIHR). Strategy for Patient-Oriented Research. https://cihr-irsc.gc.ca/e/41204.html.
79. National Health and Medical Research Council (NHMRC). Consumer and community engagement. https://www.nhmrc.gov.au/about-us/consumer-and-community-involvement/consumer-and-community-engagement.
80. Vélez, C. M. *et al.* What should be publicly funded in the Colombian health system? A mixed methods study of citizens' perceptions. BMJ Open. 2025;15:e085866.
81. Baatiema L, Skovdal M, Rifkin S, Campbell C. Assessing participation in a community-based health planning and services programme in Ghana. BMC Health Serv Res. 2013;13:233.
82. Chakraborty, P. *et al.* Using Participatory Learning and Action in a Community-Based Intervention to Prevent Violence Against Women and Girls in Mumbai's Informal Settlements. Int J Qual Methods. 2020;19:1609406920972234.

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