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REVIEW ARTICLE

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Mapping the role of patient and public involvement during the different stages of healthcare innovation: A scoping review

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Abstract

Background: Patient and public involvement (PPI) has become increasingly important in the development, delivery and improvement of healthcare. PPI is used in healthcare innovation; yet, how it is used has been under-reported. The aim of this scoping review is to identify and map the current available empirical evidence on the role of PPI during different stages of healthcare innovation.

Methods: The scoping review was conducted in accordance with PRISMAScR and included any study published in a peer-reviewed journal between 2004 and 2021 that reported on PPI in healthcare innovation within any healthcare setting or context in any country. The following databases were searched: Medline, EMBASE, CINAHL, PsycInfo, HMIC and Google Scholar. We included any study type, including quantitative, qualitative and mixed-method studies. We excluded theoretical frameworks, conceptual, scientific or grey literature as well as discussion and opinion papers.

Results: Of the 87 included studies, 81 (93%) focused on or were conducted by authors in developed countries. A wide range of conditions were considered, with more studies focusing on mental health (n = 18, 21%) and cancer care (n = 8, 9%). The vast majority of the studies focused on process and service innovations (n = 62, 71%). Seven studies focused on technological and clinical innovations (8%), while 12 looked at both technological and service innovations (14%). Only five studies examined systems innovation (5%) and one study looked across all types of innovations (1%). PPI is more common in the earlier stages of innovation, particularly problem identification and invention, in comparison to adoption and diffusion.

Conclusion: Healthcare innovation tends to be a lengthy process. Yet, our study highlights that PPI is more common across earlier stages of innovation and focuses mostly on service innovation. Stronger PPI in later stages could support the adoption and diffusion of innovation.

Victoria Cluley and Alexandra Ziemann are co-first authors.

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Patient or Public Contribution: One of the coauthors of the paper (S. S.) is a service user with extensive experience in PPI research. S. S. supported the analysis and writing up of the paper.

KEYWORDS

healthcare innovation, patient and public involvement, scoping review

1 | BACKGROUND

Patient and public involvement (PPI) is premised on the principle that healthcare should be patient-centred, involving patients and the public in the design, conduct and dissemination of research and improvement work. Since the mid-1990s, PPI has become increasingly integrated into research, delivery and improvement in health and social care systems across the globe[1] to the extent that it is now widely considered best practice.[2] This paper focuses on PPI in healthcare innovation. While many studies have focused on reporting the benefits and challenges of PPI, these studies have tended to focus on earlier stages of the research process, such as research design and conduct. In their systematic review of 66 studies reporting the impact of PPI on health and social care research, for example, Brett et al.[3] found little regarding the impact of PPI upon the implementation of innovations. These findings mirror other studies[4,5] that appear to have generated substantial evidence regarding PPI involvement in the early stages of research, but where less is known about PPI is the later stages such as implementation, spread and scale-up.[6]

Although there are many reviews on the role of PPI, they are often targeted within particular health services, including cancer care[7] and mental health,[8] or address a specific part of the research or innovation journey. Two previous scoping reviews have focused upon PPI in health research (the early stage of innovation)[9] and PPI in health policy-making.[10] To date, no reviews have been carried out to provide a holistic picture of PPI across all stages of innovation and across different areas of healthcare. In response to this evidence gap, this paper reports the findings of a scoping review to identify and map the currently available empirical evidence regarding the role of PPI during the different stages of healthcare innovation.

Before the scoping review is presented, we first outline our use of the terms PPI and innovation. Both are terms that lack a universal definition and so require clarification when used. Regarding PPI, we adapted the definition that the UK-based National Institute for Health Research (NIHR) Centre for Engagement and Dissemination[11] uses for PPI in research. This definition was chosen to reflect the scope of the innovation journey. Based on this, we define PPI in the innovation journey as an 'active partnership' between members of the public, patients and those supporting innovation in healthcare. Regarding innovation, we used Greenhalgh et al.'s[12] widely accepted definition: 'innovation in service delivery and organization [is] a novel set of behaviours, routines, and ways of working that are directed at improving health outcomes, administrative efficiency, cost effectiveness, or users' experience and that are implemented by planned and coordinated actions (p. 582)'. This definition is broad enough to include not only technological advances and new medical devices but also service innovation and quality improvement initiatives, reflecting the wide scope of innovation in healthcare.

Building on this, we considered four main stages of innovation as defined by Gabriel et al[13]: (1) *problem identification*, the identification and conduct of research into different health problems; (2) *invention*, the development of ideas for new services or products, or new ways of providing a service; (3) *adoption*, the implementation of new ideas into practice, including prototyping, piloting and evaluating safety and effectiveness; and (4) *diffusion*, the wider uptake of the ideas, services or products into use across the whole organisation/s. Also following Gabriel et al.,[13] we focused on three types of innovation: *technological and clinical innovations*, which include new drugs, diagnostic tests, medical devices, software and surgical techniques; *process and service innovations*, including new institutions, business models, service models, clinical pathways, roles, education and training; and *systems innovations*, including policy innovations and systems reforms. Such mapping sought to identify good practice as well as evidence gaps (if any) to inform future research objectives.

2 | METHODS

We conducted the scoping review in accordance with Tricco et al.[14] A protocol was developed, following Peters et al.,[15] and was revised by members of the research team and two experts in the field of healthcare innovation. The protocol is available upon request from the corresponding author.

2.1 | Inclusion and exclusion criteria

2.1.1 | Types of participants

We included studies that considered the involvement of the public or patients across healthcare innovations, often referred to as service users or expert patients.

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2.1.2 | Concept/phenomenon of interest

Our primary focus was to identify and map the involvement of the public or patients across any stage of healthcare innovation. As mentioned previously, our interest related to any practice innovation of the delivery of healthcare, including new medication, medical devices, care models, treatment programmes and service or quality improvement initiatives. To reflect our focus on healthcare delivery, we excluded innovations relating to healthcare financial management or governance, following the Cochrane Effective Practice and Organisation of Care taxonomy of health systems interventions.[16] Papers related to commissioning, educational and/or workforce development or those only focusing on evidence or knowledge utilisation were also excluded. While our definition of systems innovation includes policy innovation, we chose to exclude papers detailing policy to avoid duplicating a previous review.[10] This is discussed in further detail in the discussion and limitations sections.

2.1.3 | Context

The context for this review included peer-reviewed studies within any healthcare setting or context including the primary, secondary, acute or community setting, in any country.

2.1.4 | Types of studies

We included any empirical study type that reported on PPI in healthcare innovation within our inclusion criteria, including quantitative, qualitative and mixed-method studies. Theoretical frameworks, conceptual, scientific or grey literature such as case reports, evaluations, guidelines on how PPI should be conducted or service reviews as well as discussion and opinion papers were excluded.

There were no restrictions on language; the internal research team had the capacity to translate papers in Greek, Spanish, Italian, German, Dutch and Chinese. We aimed to use Google Translate for studies in other languages, but this was not required. Studies were limited from 2004, to reflect the publication of the definition of innovation used to shape the review.[12]

2.1.5 | Types of outcomes

Specific outcomes were not applicable in this study because our intention was to identify and map the empirical evidence in relation to PPI involvement across all stages of innovation—successful or unsuccessful.

2.2 | Search strategy

The search strategy followed Peters et al.'s[15] three-step process.

2.2.1 | Step 1

An initial search of Medline was carried out to identify the key words required for Step 2. However, due to the excessive number of hits (>70,000), a number of revised stages were carried out within the research team, to ensure a balance between adequate searching and unnecessary hits (see Appendix S1 for the revised version). As such, a second database was not searched and analysed to provide search terms. An example of the revised search terms included Delivery of health care; Patient or public or citizen or service user or lay or people; Involve* or participa* or co-crea* or co-design or co-produ*; Implement*or innovat* or spread or diffusion of innovation or evidence-based practice or quality improvement or adopt or translational medical research.

2.2.2 | Step 2

Using the key words and revised search strategy, the following bibliographic database sources were searched: Medline, EMBASE, CINAHL, PsycInfo, HMIC and Google Scholar. Data were limited from 2004 onwards; no language was excluded due to the translating capacity of the wider team. An initial search was conducted on 23 October 2019, and it was updated on 21 September 2021.

2.2.3 | Step 3

Citation checking was carried out for all included texts generated from the database sources to identify any additional papers that fulfilled our inclusion/exclusion criteria.

2.3 | Review screening process and results

All searches were carried out by C. F. For the bibliographic database search results, the citations were uploaded to Mendeley, deduplicated and uploaded to Rayyan, a systematic review screening software. A. Z. and C. S. carried out the initial screening, where titles and abstract were screened against the inclusion criteria. For papers that fulfilled the criteria, C. F. obtained the full texts and uploaded them to Rayyan. Full-text screening was carried out in a blinded manner by A. Z. and C. S. They screened the papers independently from each other and then met to discuss and resolve potential conflicts. Following this, C. F. carried out citation checking of all the included papers that captured additional papers. A. Z. and C. S. double-screened the papers from citation checking. C. F. carried out a Google Scholar search to cross-check against our included papers, which were double-screened by A. Z. and C. S.

Five papers were found in incidental searches during the initial phase, when C. F., who ran the searches, familiarized herself with the project. These papers were double-screened by A. Z. and C. S., and all were included in the final review.

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2.4 | Data charting process

A data extraction tool was adapted from the Joanna Briggs Institute and refined with input from the research team to meet the specific needs of this review. C. F. charted the data from the main searches, and C. S. updated and refined the form. V. C. and E. O. conducted a blinded double-check of the data extraction. Any discrepancies were resolved between C. S., V. C. and E. O.

A critical appraisal of individual papers was beyond the scope of this study.[17]

2.5 | Synthesis of data

We first summarized the studies by the type and stage of innovation. Studies were then grouped by the innovation stage that they focused on, and narrative synthesis was used to identify the main findings that they presented.

3 | RESULTS

The PRISMA diagram below (Figure 1), developed following the updated guidelines for reporting systematic reviews,[18] provides an overview of our search and screening process.

3.1 | Characteristics of the included studies

The key characteristics of the included studies are summarized in Table 1. Of the 87 studies included in this review, 48 (55%) used qualitative methods, 2 (2%) used quantitative methods and 14 (16%) used mixed methods. Eighteen (21%) were case studies and five (6%) were randomized-controlled trials.

The vast majority of the studies focused on or were conducted by authors in developed countries: Australia ($n = 6$, 7%), Canada ($n = 11$, 13%), Denmark ($n = 2$, 2%), Finland ($n = 1$, 1%) Germany ($n = 1$, 1%), Ireland ($n = 1$, 1%), New Zealand ($n = 1$, 1%), Norway ($n = 1$, 1%), Sweden ($n = 5$, 6%), The Netherlands ($n = 2$, 2%), the United Kingdom ($n = 31$, 36%) and the United States ($n = 16$, 18%). Three studies (3%) had international focus or compared more than two countries, one was conducted in Colombia (1%), one in India (1%), two in India and Pakistan (2%), one in Kenya (<1%) and one in Uganda (1%).

The studies considered a wide range of conditions. The conditions that were seen more frequently among the 87 studies included were mental health ($n = 18$, 21%) and cancer care ($n = 8$, 9%). Other areas included human immunodeficiency virus (HIV) ($n = 4$, 5%), services for older people ($n = 3$, 3%), young patients ($n = 3$, 3%), cardiovascular conditions ($n = 2$, 2%), dementia ($n = 2$, 2%), muscular–skeletal health ($n = 2$, 2%), paediatrics ($n = 2$, 2%) and rheumatology ($n = 2$, 2%). A number of

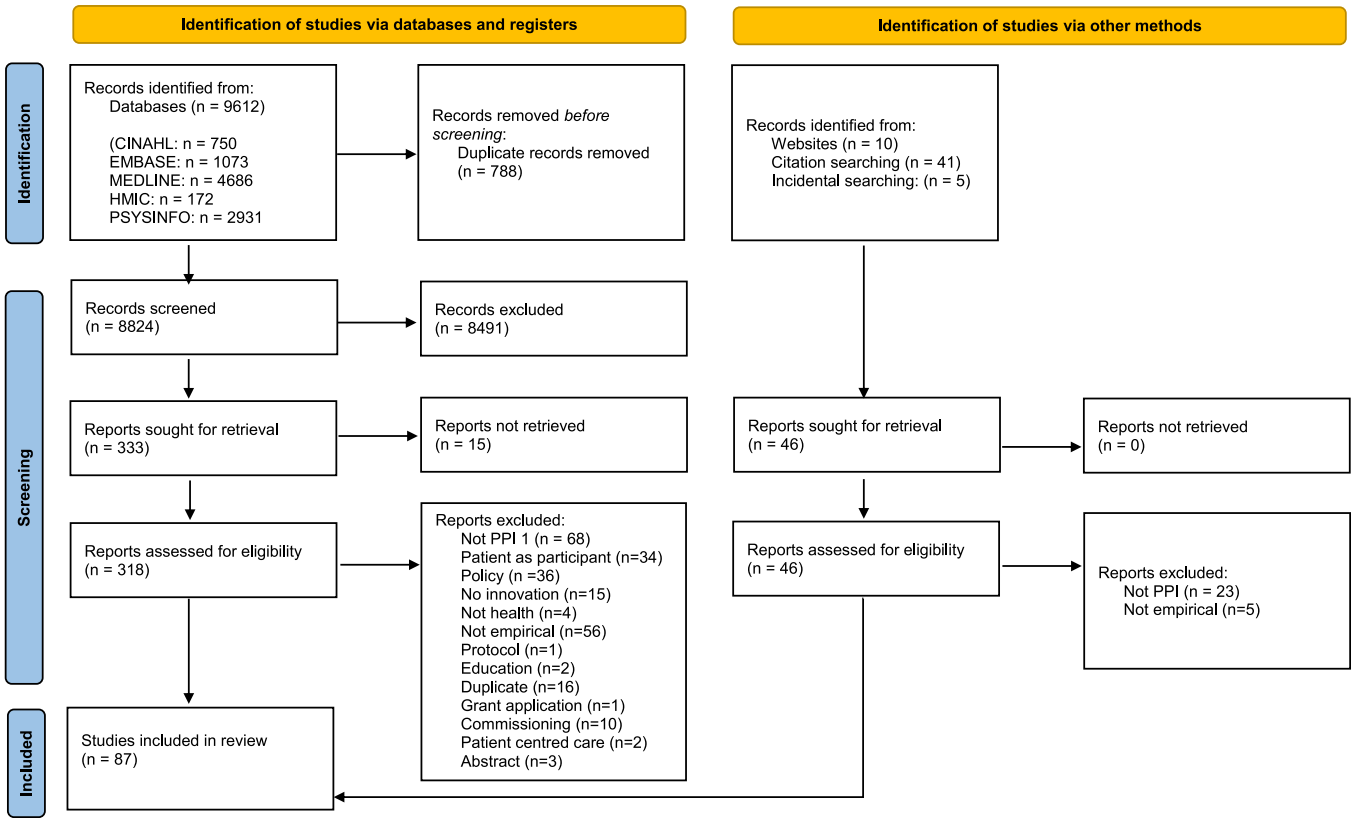


FIGURE 1 PRISMA flow chart. PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses

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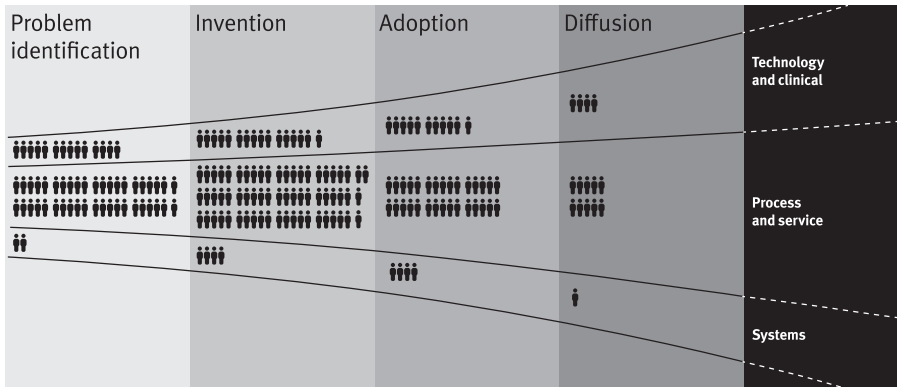


FIGURE 2 Patient and public involvement across the innovation journey

them did not focus on a specific disease and are classified as general in Table 1.

3.2 | Type of innovation

Following the definition of Gabriel et al.,[13] the vast majority of the studies focused on process and service innovations ($n = 62$, 71%). Seven studies focused on technological and clinical innovations (8%), while 12 looked at both technological and service innovations (14%). Only five studies examined systems innovation (6%). One study focused on all types of innovation (1%). The studies detailing process and service innovation-focused predominantly on quality improvement. Of the seven studies on technological and clinical innovations, two looked at digital health,[19,20] one at clinical platforms[21] and one at patient-recorded outcomes.[22]

3.3 | Stages of innovation

Mirroring research on PPI in general, it is evident from this review that PPI is more common in the earlier stages of innovation, particularly problem identification and invention, in comparison to adoption and diffusion.

Five studies focused on problem identification in healthcare research.[23–27] Fourteen studies focused on the invention. One involved consent processes;[28] five focused on quality improvement using 'living labs',[29] patient surveys,[30] patient forums[31] or a combination of different methods.[32,33] Twenty-seven studies looked at both problem identification and invention, the majority of which were quality improvement initiatives. Twenty-seven studies considered adoption, while only six analysed PPI in wider diffusion or scaling up of innovations. Finally, only five studies looked at all stages of the innovation process.

A summary of studies by stage and type of innovation is presented in Table 2 below. The data are also presented using an infographic developed by a design company (Design Science: bring knowledge to life. https://design-science.org.uk/) to facilitate interpretation by different audiences (Figure 2).

3.4 | Methods of PPI engagement

The majority of the studies included in the review ($n = 32$, 37%) described public and patient involvement and engagement in quality improvement initiatives.

The review included 24 studies (28%) involving PPI in codesign or codevelopment of health services. The methods used included patient journey mapping, surveys and workshops,[20,45,55,100,102] expert panels of patients and carers,[56,81] a user board,[57] PPI in the format of a conference,[36] Delphi methods to reach consensus,[28] living laboratories for technology innovation,[29] stakeholders activities[22,35,101] and interviews with patients.[58] Two studies presented codevelopment of clinical guidelines using qualitative methods.[40,82] Other studies used various methods.[19,37,49,83–85]

Participation in research activities was described in 14 studies (16%).[24–27,34,59–66,83] Patients and the public participated in various ways, through advisory and face-to-face discussion groups,[34,62,63] virtual steering groups,[59] online surveys and workshops[26] and network activities.[65] Some innovative initiatives included video-reflexive ethnography that allowed clinicians to explore the needs of patients and their families in end-of-life care.[60]

Eleven studies described the direct involvement of patients and the public in health service delivery either via peer-led activities or volunteering.[38,39,52,67,86–91] Peer-service delivery was predominantly described in mental health services and considered eating disorders,[67,89] maternal depression in South Asia,[87,88,91] a service-user-led computerized cognitive behavioural therapy in the United Kingdom[52] and an addiction recovery programme in the United States.[38] The studies presenting volunteering activities all focused on hospital settings in the United Kingdom.[39,86,90]

4 | DISCUSSION

To summarize, two main trends are evident across the review. First, PPI in healthcare innovation has taken a number of approaches, and the majority of the studies reviewed focused on process and service innovation ($n = 62$, 71%), while only seven studies (8%) focused on technological

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TABLE 1 Key characteristics of the included studies

Author (year)	Country	Study design	Area	Type of innovation	Process of innovation	Methods of PPI engagement
Abelson et al. (2019)	Canada	Mixed methods	General	Technological and clinical/process and service	All	QI initiatives (other)
Absolom et al. (2015)	UK	Case study	Cancer	Technological and clinical/process and service	Problem identification/invention	Research participation (advisory group)
Adams et al. (2015)	UK	Qualitative study	Cancer	Process and service innovation	Problem identification/invention/adoption	QI initiative (filmed patient narratives-storytelling)
Alvis et al. (2020)	Colombia	Qualitative study	Coagulapathies	Systems	Invention	Consensus conference
Amirkhanyan et al. (2019)	US	Qualitative study	Nursing homes	Process and service innovation	Invention	QI initiatives (other)
Andersson and Olheden (2012)	Sweden	Qualitative study	General	Process and service innovation	Problem identification	QI initiatives (variety of methods)
Armstrong et al. (2013)	UK	Case study	General	Process and service innovation	Problem identification/invention	QI initiatives (variety of methods)
Ashby et al. (2007)	UK	Case study	Services for older people	Process and service innovation	Problem identification/invention	Research participation (virtual steering group)
Ashford et al. (2019)	US	Mixed methods	Substance use disorder	Process and service innovation	Invention/adoption/diffusion	Peer-led service delivery
Atif et al. (2017)	Pakistan and India	Qualitative study	Mental health	Process and service innovation	Invention/adoption	Peer-led service delivery
Baim-Lance et al. (2019)	US	Qualitative study	HIV	Process and service innovation	Invention	Coproduction (various methods)
Baker et al. (2016)	Canada	Case study	General	Process and service innovation	Problem identification/invention	QI initiatives (variety of methods)
Bakibinga et al. (2020)	Kenya	Qualitative study	General	Technological and clinical	Invention/adoption	Codevelopment (various methods)
Berg et al. (2015)	Norway	Case study	HIV	Process and service innovation	Problem identification/invention/adoption	Codesign (user board)
Bichel et al. (2009)	Canada	Case study	General	Process and service innovation	Problem identification/invention	Codesign (conference model)
Boelens et al. (2014)	Europe	Qualitative study	Cancer	Process and service innovation	Invention	Codesign (consensus process using the Delphi method)
Boivin et al. (2009)	UK	Qualitative study	General	Systems	Invention/adoption	Codevelopment of clinical guidelines (qualitative study with patients)
Bouchard et al. (2020)	Canada	Qualitative study	Cardiovascular	Process and service innovation	Invention	Codevelopment (steering committee, patient/carer experiences)
Boustani et al. (2012)	US	Case study	Dementia	Technological and clinical/process and service	All	QI initiatives (network participation)
Boyd et al. (2012)	New Zealand	Qualitative study	Cancer	Technological and clinical/process and service	Problem identification/invention	Codesign (patient journey mapping, surveys, workshops)

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TABLE 1 (Continued)

Author (year)	Country	Study design	Area	Type of innovation	Process of innovation	Methods of PPI engagement
Brighton et al. (2018)	UK	Qualitative study	Palliative care	Process and service innovation	Problem identification	Research participation (online forum for palliative care and rehabilitation research)
Bygholm and Kanstrup (2017)	Denmark	Qualitative study	Services for older people	Technological and clinical/process and service	Invention	Codesign of technology innovation (living laboratories)
Carlsson et al. (2006)	Sweden	Qualitative study	Cancer	Process and service innovation	Problem identification/invention	QI initiatives (network participation)
Cavanagh et al. (2011)	UK	Case study	Mental health	Technological and clinical/process and service	Invention/adoption/diffusion	Peer-led service delivery
Cheng et al. (2021)	Australia	Qualitative study	Mental health	Technological and clinical	Adoption	Workshops
Cheetham et al. (2013)	UK	Case study	Services for young people	Technological and clinical/process and service	Invention/adoption	QI initiatives (variety of methods)
Collier and Wyer (2016)	Australia	Qualitative study	End-of-life and infection control	Process and service innovation	Problem identification/invention	Research participation (video-reflexive ethnography)
Crocker et al. (2016)	UK	Qualitative study	General	Technological and clinical/process and service	Problem identification	Research participation (various activities)
De Souza et al. (2016)	UK	Case study	Rheumatology	Technological and clinical/process and service	Problem identification/invention/adoption	QI initiative (independent patient advisory group)
Desai et al. (2019)	US	Case study	Mental health	Process and service innovation	Problem identification/invention	Research participation (stakeholders engagement and training)
Farmer et al. (2018)	Australia	Qualitative study	General	Systems	All	Codesign (community activities and workshops)
Finn et al. (2018)	UK	Quantitative	General	Process and service innovation	Invention	QI initiatives (questionnaire, email communication, public meetings)
Forbat et al. (2009)	UK	Qualitative study	Cancer	Process and service innovation	Invention/adoption	QI initiatives (variety of methods)
Gillard et al. (2010)	UK	Qualitative study	Mental health	Process and service innovation	Problem identification	Research participation (coresearch)
Godfrey et al. (2020)	UK	Mixed methods	Mental health	Process and service innovation	Invention/adoption	Volunteering in healthcare delivery
Gustavsson (2014)	Sweden	Qualitative study	Neonatal	Process and service innovation	Problem identification/invention/adoption	QI initiatives (variety of methods)
Gustavsson and Andersson (2019)	Sweden	Qualitative study	Paediatric	Process and service innovation	Invention	QI initiatives (variety of methods)
Gustavsson et al. (2016)	Sweden	Qualitative study	Paediatric	Process and service innovation	Problem identification/invention	QI initiatives (variety of methods)
Hackett et al. (2018)	Canada	Qualitative study	Mental health	Process and service innovation	Problem identification/invention	Codesign (experience maps and focus groups)

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TABLE 1 (Continued)

Author (year)	Country	Study design	Area	Type of innovation	Process of innovation	Methods of PPI engagement
Hester et al. (2015)	Ireland	Mixed methods	Mental health	Technological and clinical/process and service	Problem identification/invention	QI initiatives (focus groups)
Holland et al. (2019)	UK	Qualitative study	General	Process and service innovation	All	Coproduction (various methods)
Howson et al. (2018)	UK	Qualitative study	General	Process and service innovation	Invention/adoption	Volunteering in healthcare delivery
Kanstrup et al. (2015)	Denmark	Qualitative study	Diabetes	Technological and clinical	Problem identification/invention	Codesign (variety of methods)
Kendall et al. (2006)	UK	Qualitative study	Cancer	Process and service innovation	Problem identification/invention	Research participation (patient and carer discussions group)
Khodyakov et al. (2017)	US	Qualitative study	General	Process and service innovation	Problem identification/invention	QI initiatives (expert panel including patients)
Khodyakov et al. (2019)	US	Mixed methods	Muscular-skeletal	Process and service innovation	Problem identification/invention	QI initiatives (key stakeholders group)
Kiracho et al. (2020)	Uganda	Mixed methods	General	Systems	Adoption	Community score cards
Lai et al. (2020)	UK	Mixed methods	Cardiovascular	All	Problem identification	Research participation (online surveys and workshops)
Laurance et al. (2014)	International	Case study	General	Technological and clinical/process and service	Problem identification/invention/adoption	QI initiatives (community engagement strategies)
Lavoie-Trembla (2016)	Canada	Qualitative study	General	Process and service innovation	Problem identification/invention	Codesign (patient interviews)
Louch et al. (2019)	UK	Qualitative study	General	Process and service innovation	Invention/adoption	Volunteering in healthcare delivery
Ma et al. (2020)	Canada	Mixed methods	Physiotherapy	Process and service innovation	Problem identification/invention	Codevelopment of intervention (participation in expert panel)
Ma et al. (2019)	Canada	RCT	General	Technological and clinical	Problem identification/invention	Codevelopment (stakeholder engagement activities)
Mamary et al. (2004)	US	Qualitative study	HIV	Process and service innovation	Problem identification/invention	QI initiatives (focus groups)
Maxwell et al. (2008)	UK	Qualitative study	HIV	Systems	Invention/adoption	QI initiatives (variety of methods)
McKevitt et al. (2017	UK	Qualitative study	Stroke	Process and service innovation	Invention/adoption	QI initiatives (consultation exercises; lay membership; and elicitation of patient perspectives)
Omeni et al. (2014)	UK	Mixed methods	Mental health	Process and service innovation	Unclear/varied	QI initiatives (variety of methods)
Ottman et al. (2011)	Australia	Mixed methods	Services for older people	Process and service innovation	Problem identification/invention	Research participation (users & carer focus groups)
Patel et al. (2019)	US	Qualitative study	End-of-life care	Process and service innovation	Problem identification/invention	QI initiatives (community engagement strategies)
Palukka et al. (2021)	Finland	Qualitative study	Opioid substitution treatment	Process and service innovation	Invention	Meetings with stakeholders

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TABLE 1 (Continued)

Author (year)	Country	Study design	Area	Type of innovation	Process of innovation	Methods of PPI engagement
Patterson et al. (2009)	UK	Qualitative study	Drug misuse	Process and service innovation	Problem identification/invention/adoption	QI initiatives (variety of methods)
Peeters et al. (2014)	The Netherlands	Qualitative study	General	Process and service innovation	Invention	QI initiatives (variety of methods)
Pollard et al. (2014)	UK	Qualitative study	General	Process and service innovation	Problem identification/invention	QI initiatives (patient reference groups)
Prothero et al. (2017)	UK	Qualitative study	Rheumatology	Process and service innovation	Adoption	Codesign (workshops)
Raue et al. (2021)	USA	Quantitative study	Depression	Process and service innovation	Invention	Lay-delivered intervention
Renedo and Marston (2011)	UK	Qualitative study	General	Process and service innovation	Unclear/varied	QI initiatives (variety of methods)
Renedo et al. (2015)	UK	Qualitative study	General	Process and service innovation	Unclear/varied	QI initiatives (variety of methods)
Roennow et al. (2020)	International	Qualitative study	Scleroderma	Process and service innovation	Invention	Community advisory board
Rowe et al. (2020)	Australia	Qualitative study	Mental health	Technological and clinical	Invention/adoption	Codesign (workshops and usability testing sessions)
Sanger et al. (2007)	Germany	Case study	General	Process and service innovation	Invention/adoption/diffusion	Cocreation of guidelines (patient forum)
Shklarov et al. (2017)	Canada	Mixed methods	Chronic conditions	Process and service innovation	Problem identification/invention/adoption	Research participation (peer-to-peer research
Singh et al. (2018)	Canada	Case study	General	Process and service innovation	Problem identification/invention	Research participation (research networks)
Singla et al. (2014)	Pakistan and India	Qualitative study	Mental health	Process and service innovation	Invention/adoption	Peer-led service delivery
Singla et al. (2020)	India	Qualitative study	Mental health	Process and service innovation	Invention/adoption	Peer-led service delivery
Sprague Martinez et al. (2020)	USA	Mixed methods	Health for young	Process and service innovation	Problem identification/invention	Survey and photovoice
Stice et al. (2020)	US	RCT	Mental health	Process and service innovation	Problem identification/invention	Peer-led service delivery
Stice et al. (2013)	US	RCT	Mental health	Process and service innovation	Invention/adoption	Peer-led service delivery
Stover et al. (2019)	US	Case study	General	Technological and clinical	Invention/adoption	Codesign (stakeholder engagement activities)
Strudwick et al. (2021)	Canada	Mixed methods	Mental health	Process and service innovation	Invention	Codesign (stakeholders engagement)
Toncinic et al. (2020)	The Netherlands	Mixed methods	General	Technological and clinical	Problem identification/invention	QI initiatives (stakeholders analysis)
Walsh et al. (2016)	Australia	Case study	Muscular–skeletal healthcare	Process and service innovation	Invention/adoption/diffusion	QI initiatives (variety of methods)

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TABLE 1 (Continued)

Author (year)	Country	Study design	Area	Type of innovation	Process of innovation	Methods of PPI engagement
Walshe et al. (2019)	UK	RCT	Dementia	Process and service innovation	Problem identification/invention/adoption	Research participation (various activities)
Whiting et al. (2016)	UK	Qualitative study	Services for young people	Process and service innovation	Invention	QI initiatives (patient forum)
Wilson et al. (2015)	UK	Qualitative study	Mental health	Technological and clinical/process and service	All	Research participation (various activities)
Wilson et al. (2018)	UK	Case study	Mental health	Process and service innovation	Invention/adoption	Codevelopment (various methods)
Yeary et al. (2011)	US	Case study	Cancer	Process and service innovation	Adoption/diffusion	Coproduction activities (community and academic partners collaborated)
Young et al. (2005)	US	RCT	Mental health	Process and service innovation	Invention/adoption/diffusion	Coproduction (various methods)

Abbreviation: HIV, human immunodeficiency virus; RCT, Randomised Clinical Trial; QI, Quality Improvement.

TABLE 2 Synthesis of evidence across different types and stages of innovation

		Stages of innovation			
		Problem identification	Invention	Adoption	Diffusion
Type of innovation	Technological and clinical	14[21,25,26,29,34–43]	16[19–22,34,35,44–53]	11[19,20,22,44,46,48,50–54]	4[44,50–52]
	Process and service	42[23–27,29,34,36,37,44–48,50,51,55–80]	64[28,30–34,36–39,44–48,50–53,55–99]	30[37–39,44,46,48,50–53,57,64,66,71,76,80,82–84,86–94,100,101]	10[37,38,44,50–52,82,84,92,101]
	Systems	2[26,102]	4[40–42,102]	4[40,41,43,102]	1[102]

Note: Some studies described more than one type of innovation or fell across different stages of innovation, so the total number does not add up to the final number of studies included.

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innovation and five (6%) on systems innovation. In terms of technological innovation, this trend is reflected in Gagnon et al.'s[103] review of PPI in health technology assessment, where the use of PPI in the development of technology is recognized as a relatively recent growth area. Second, the studies reviewed focused on PPI in earlier stages of the innovation journey in comparison to later stages, reflecting PPI trends in general.[4,5] Drawing on the studies reviewed and the literature in the field, we next discuss why these trends might be prevalent.

4.1 | PPI is most frequently used in service improvement innovation

As outlined, the majority of the studies reviewed focused on service innovation ($n = 62$, 71%). Armstrong et al.,[68] for example, presented three case studies to highlight the role of PPI in quality improvement work. Similarly, Khodyakov et al.[69] explored how PPI can be used to improve outpatient care. Various methods were used to achieve this. Traditional methods such as interviews,[58] focus groups[70] and surveys[45] were frequently used; however, more innovative and participatory methods were also found. Hacket et al.,[55] for example, used experienced-based codesign to include young people in the improvement of youth mental health services. Collier and Wyer[60] used reflexive video ethnography to improve end-of-life care.

One reason for this trend could be that process and service innovation is an aspect of healthcare innovation that has long been associated with patient inclusion. Coproduction, experienced-based codesign and other patient-centred methods for improvement have an evidence-based background for effective healthcare improvement work.[104,105] The use of these participatory methods to carry out PPI work in service innovation is reflected in the studies reviewed. Across the studies, these approaches were used to improve HIV care in Norway[57] and United States of America[85]; access to primary care in Canada[36]; services for cancer care across Europe[28]; mental health services in Canada,[55] England[24,83] and the United States of America[84]; secondary care in Canada[58]; colorectal cancer screening in the United States of America[101]; management of rheumatoid arthritis[100]; rehabilitation services for people with spinal cord injury[56]; and to develop patient guidelines in Germany.[82]

PPI was found to be used least in technology ($n = 7$, 8%) and systems ($n = 5$, 6%) innovation. Various studies addressing the use of PPI in technological innovation have also identified this trend. Caution and ambivalence towards the use of PPI in health technology development have long been noted.[106] Recently, it was identified that the use of PPI is increasing in this area of innovation; however, challenges continue, including lack of public knowledge/awareness and lack of guidance on how to use PPI in health technology innovation.[103] It has been suggested that the slow take-up of PPI in this field of innovation is due to the dual roles of the health technology community to contribute to both research and policy-making.[107] Where PPI is well established and accepted in health research, studies have shown that the lack of a universal and rigorous approach to PPI is perceived to be unreliable by policy-makers.[106,107]

While PPI was found in fewer studies detailing technology innovation, interestingly, the use of PPI in these studies tended to be grounded in participatory approaches rather than traditional research methods with a participatory angle such as interviews and surveys. Codesign was a particularly common approach to PPI in this area of innovation. Codesign techniques were used to develop the use of technology in nursing homes,[29] to develop diabetes technology[49] and to develop an online mental health support platform.[20] This is perhaps a reflection of the design element involved in these methods and the parallels found in the design of technology. Additionally, such methods tend to focus on the earlier stages of innovation, perhaps going some way towards explaining the trend to utilize PPI at the beginning of the innovation journey rather than the end.

4.2 | PPI is most frequently used at the beginning of the innovation journey

In the introduction, we set out the innovation journey to include four stages: problem identification, invention, adoption and effectiveness and diffusion.[13] The majority of studies concentrated on one or two of these stages and these tended to focus on the earlier stages of problem identification, invention and adoption. As outlined, only six studies focused specifically on the use of PPI at the final diffusion stage.[38,52,82,84,92,101]

Significantly, only five studies addressed PPI at all stages of the innovation journey.[37,44,50,83,102] PPI is intended to be a whole-process approach, meaning that PPI is included at all stages of the research or innovation journey. The 'nothing about us, without us' slogan borrowed from disability studies and often used to describe the ethos of PPI summarizes this aim well. Despite this, PPI work is often criticized for its limited use. Other studies have identified that PPI work tends to take place at the beginning of a project to aid planning and agenda-setting and then dwindle off.[3,9,10] A similar trend has been observed in technological innovation in healthcare,[108] whereby, it has been identified that PPI is more likely to be found at planning and implementation stages in comparison to monitoring and dissemination stages. This has led to PPI being criticized as a tick-box exercise to fulfil funding requirements,[109] and as virtue signalling.[110]

It has recently been suggested that 'what gets done is what can be measured'.[111] This claim is based on the increasing call to measure the impact of PPI and how this is prescribed by funding bodies. Russel et al.[111] use the NIHR as an example and show that reporting the impact of PPI is typically focused on things that can be measured quantitatively, such as the number of events and participants. Here, we suggest that this observation goes some way towards explaining why PPI tends to be used at earlier stages in the innovation process.

Related to this point, research and innovation tend to be lengthy processes. To include PPI throughout requires commitment and support, time and resources from both researchers and patient and public participants.[112] There are numerous evidence-based strategies to support effective PPI and retention of participants; however, as illustrated in this review and others, PPI is seldom used in the later stages of research.[113,114] Another reason for this trend is that PPI work is notoriously underfunded and often delegated to junior staff members, who are more likely to move onto other roles within the course of a project.[115]

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Those tasked with facilitating PPI work often do so in addition to existing roles, which can lead to PPI activity falling by the way side when other work has to be prioritized.[109] In response to these limiting issues, Boylan et al.[109] call for 'a dedicated initiative aimed at solidifying involvement as part of research culture' (p. 729). To date, this has not happened, although the UK Standards for Public Involvement could be a step in the right direction.[116] It must be acknowledged, however, that these standards have been developed with the United Kingdom in mind and may not be transferable to countries with alternative healthcare systems or to those with differing cultural values addressing healthcare.

4.3 | Limitations

The studies found reflected our search terms and inclusion and exclusion criteria. These terms and criteria limited the study as follows. First, our search terms reflected the language commonly used in our definition of PPI, chosen for its broad scope and popular use. Although this definition is well used in the PPI literature, the process of doing PPI work has been variously described and not all countries use the same terminology. Indeed, the term 'engagement' is often used in Canada and Scandinavian countries. The exclusion of wider terms may go some way towards explaining why the vast majority of the papers found took place in high-income countries. PPI is a particularly western concept and activity and is not well used in low- and middle-income countries.[117] Wider search terms may have yielded more geographically varied studies; however, as Miah et al.[117] point out, the premise of PPI itself is western in nature and can be challenging to implement in countries where professional and patient relationships are structured hierarchically.

Second, our exclusion criteria limit the scope of findings in our review. Examples of PPI used in innovations in healthcare policy were excluded so as not to duplicate the findings of a recent review of PPI in healthcare policy.[10] This had the effect of limiting the number of studies found to address systems research. For this reason, our findings will be less relevant to those exploring health systems innovation, specifically policy innovation. To reflect our focus on healthcare delivery, we also excluded papers addressing finance and governance. Although not explicitly part of healthcare delivery, these issues do of course impact on the delivery of healthcare, and further research into the use of PPI in these areas would be useful. In addition to this, we also excluded studies addressing service reviews and evaluations. Including such studies may have had the effect of providing more studies detailing PPI at the later stages of innovation.

Finally, the focus of this review was to identify and map how PPI is used in healthcare innovation. Consequently, we did not comment on the success or impact of the PPI work nor did we comment on the inclusivity or diversity of the PPI work being reported.

4.4 | Recommendations/future research

Our recommendations and future research findings are based on both the review findings and their limitations. As outlined, our main findings showed first that PPI was most commonly used in service improvement innovations and least used in technological and systems innovation; second, PPI is most often used in the earlier stages of the innovation journey. Building on these findings, we recommend the following:

1. Further research should be conducted to explore why PPI is not as well used in health technology and systems innovation.
2. More research should be done to promote the use of and improve the accessibility of PPI, especially for use in health technology and systems innovation.
3. A whole-system approach to PPI is adopted in all forms of healthcare innovation work to ensure that PPI is used throughout the innovation journey rather than just at the early stages. In a recent systematic review of barriers and enablers of PPI,[118] it was found that a whole-system approach will increase the buy-in and partnership working necessary to support successful PPI work.

Based on our study limitations, we make the following observations and recommendations. While the benefits of PPI in healthcare research and delivery are widely accepted, PPI has also been subject to wide-ranging critique. PPI activity is significantly under-evaluated, resulting in a poor evidence base and limited understanding of how PPI can improve research processes and outcomes.[119] Where the impact of PPI is reported, the attention tends to focus on improvement and delivery outcomes. The impact on the participants themselves is underexplored.[120] As outlined, we did not comment on this based on our research purpose to identify and map PPI in healthcare innovation. In addition to this, PPI work is increasingly being criticized for its lack of inclusivity and diversity.[121] The typical PPI participant has been described as white, middle class and male.[122] Based on these criticisms and the limitations of our search, we recommend that further research is needed to explore the impact of PPI in healthcare innovation, particularly focusing on patient and public experience. We also recommend that further research is needed to explore and promote diversity in PPI work in healthcare innovation.

In addition to this, as observed in our review findings and limitations, the majority of the studies found were conducted in high-income countries. With the exception of a few published papers,[123,124] there has been limited exploration of why PPI is seldom used in low- and middle-income countries nor how PPI could be used in these countries. Building on this, we recommend that further research is needed to explore the use of PPI or similar engagement strategies in healthcare innovations in low- and middle-income countries.

5 | CONCLUSION

At the time of conducting this scoping review, no reviews had been carried out to provide a holistic picture of PPI across all stages of innovation and across different areas of healthcare. This scoping

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review set out to address this evidence gap by identifying and mapping the use of PPI work in healthcare innovation. In doing this, we have highlighted two main findings that are generally consistent with the PPI and healthcare innovation literature: first, PPI is used most frequently in service improvement innovations and the least in system and technology innovations and, second, PPI is most used in the early stages of innovation.

At present, PPI in healthcare innovation runs the risk of being described as a tick-box exercise or virtue signalling. As outlined above, we have set out a range of recommendations in response to this. What is most important, however, is that if PPI is accepted to be as beneficial as it is often reported to be, that there are systems of support in place to guide its use and ensure its accessibility and inclusivity across the whole innovation journey. While PPI should not be a one-size-fits-all approach,[114] it has been identified that the lack of measurable variables and the lack of a universal definition or approach render evidence gained from PPI work unpalatable to certain and influential audiences such as policy-makers. As suggested earlier, the UK Standards for Public Involvement could be a step in the right direction.[116]

To support this conclusion, as outlined in our recommendations, we advocate for a whole-system approach to PPI to ensure that PPI is used across the whole innovation journey, not just at the earlier stages. Stronger PPI in later stages is likely to support the adoption and diffusion of innovation.

AUTHOR CONTRIBUTIONS

Claire Feeley carried out all the searches. Claire Feeley, Alexandra Ziemann, Victoria Cluley, Ellinor K. Olander and Charitini Stavropoulou were involved in the data extraction and analysis. All authors were involved in the interpretation of the results, contributed to the writing up of the manuscript and approved the submitted version.

DATA AVAILABILITY STATEMENT

All data generated or analysed during this study were included in this published article and/or its Supporting Information Materials.

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