



BMJ Open Quality Patient engagement in the development and delivery of healthcare services: a systematic scoping review

Joachim Støren Sagen ^{1,2}, Geir Smedslund,^{1,3} Ann Elisabeth Simonsen,⁴ Andreas Habberstad,⁵ Ingvild Kjekken,^{1,2} Hanne Dagfinrud,^{1,6} Rikke Helene Moe ¹

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¹NKRR, Center for treatment of Rheumatic and Musculoskeletal Diseases (REMEDY), Diakonhjemmet Hospital, Oslo, Norway

²Oslo Metropolitan University, Faculty of Health Sciences, Oslo, Norway

³Norwegian Institute of Public Health, Oslo, Norway

⁴Røysumtunet Rehabilitation Centre, Oslo, Norway

⁵The Norwegian Federation of Organisations of Disabled People, Oslo, Norway

⁶University of Oslo, Faculty of Medicine, Oslo, Norway

Correspondence to

Joachim Støren Sagen;
joachim.sagen@diakonsykk.no

ABSTRACT

Background Patient engagement (PE) is required to improve future healthcare services. PE in the development and delivery of healthcare services is likely to be complex but is scarcely described.

Objectives The objective of this scoping review was to summarise primary studies on mesolevel PE regarding structure, process and outcomes. More specifically, the aim was to explore barriers and facilitators to successful PE, how persons are engaged in the process and summarise reported consequences.

Method A systematic scoping review was conducted, searching the MEDLINE, EMBASE, Cochrane and PsycINFO databases. Primary studies, published between 7 July 2005 and 4 October 2022, were considered for inclusion. Two reviewers extracted data about PE (eg, attributes of PE settings, facilitators and barriers, and outcomes to PE) and the first author coded the extracted data into structural, processual and outcome themes.

Results Of 8588 identified records, 37 studies were eligible. Most of the included studies were conducted in Europe (n=19; 51%) and North America (n=13; 35%). Structures that ensure sufficient stakeholder representativeness and PE knowledge through education may facilitate the PE process further, regardless of the environmental setting. Interpersonal relationships with uneven power dynamics were reported as noteworthy processual barriers to meaningful PE, while clearly described roles and tasks were reported as important facilitators. In contrast to hard outcomes with operationalised PE effects, the most noteworthy outcomes of PE were reported as soft processual consequences such as patient representatives improving their self-esteem and feeling valued.

Conclusions Unfortunately, there is a dearth of studies exploring hard and operationalised PE outcomes on healthcare services and patients receiving healthcare. The PE process may be facilitated by dedicated finances to PE education and by ensuring sufficient stakeholder representativeness.

INTRODUCTION

Rationale

The implementation and evaluation of patient engagement (PE) includes a number of concepts and dimensions with multiple possible terms and definitions.¹ In this review, the term (PE) will be used when referring to

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ The existing literature suggests possible procedural mechanisms and structural attributes for evaluating the quality of mesolevel patient engagement (PE) and its consequences. This study is needed to provide knowledge on current PE and the influence of procedural mechanisms present in current healthcare structures, including approaches, practices and outcomes.

WHAT THIS STUDY ADDS

⇒ Sufficient finances, earmarked PE education and training, and stakeholder representativeness are of great structural importance to facilitate meaningful PE approaches, which in turn may improve all stakeholders' processual experiences.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ The findings from this review shed light on structural attributes that hinder and facilitate meaningful PE processes and may serve as a basis for the development of educational initiatives targeting mesolevel PE to ease the distribution of future PE responsibilities. The results may also help guide future research aiming to test the rigour of outcome measures used to evaluate and compare PE initiatives in, and across, healthcare services.

comanagement of healthcare services. PE can be understood as patients, patient representatives or patient organisations engaging with stakeholders at different levels of care.² PE is highlighted as an important part of healthcare services and as a criterion for quality.^{3,4}

PE can take place at the microlevel, mesolevel and the macrolevel. At the microlevel, patients are coproducers of self-management, while the comanagement of political incentives on a governmental level can be referred to as the macrolevel. At the mesolevel, patient representatives engage as coproducers in the development and delivery of healthcare services, aiming to improve these services for a larger group of individuals.² As illustrated in [figure 1](#), PE is suggested

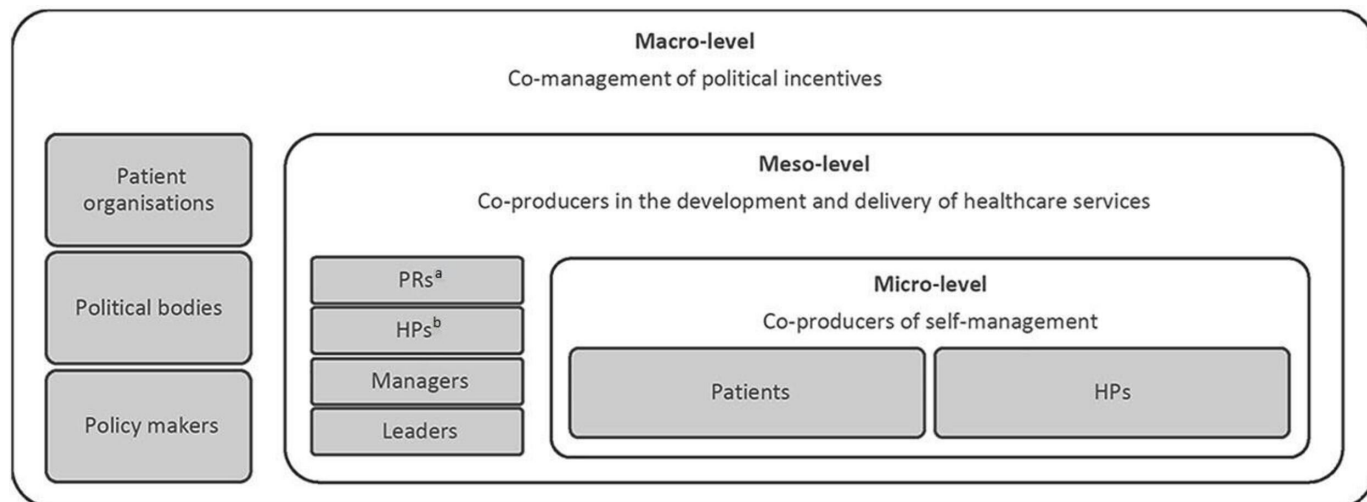


Figure 1 A brief overview of PE stakeholders at the microlevels, mesolevels and macrolevels in healthcare services, inspired by Andreassen.² ^aPRs, patient representatives, including carers. ^bHPs, healthcare professionals.

to involve one or more of the professionals working in healthcare services in addition to patient representatives such as patients and carers.¹

Historically, PE initiatives have focused on patients as coproducers of their own care. Over the last decades, there has been increasing attention on PE in the design, implementation and delivery of healthcare services at the mesolevel. PE at this level is often organised as collaborative working groups, patient councils or patient advisory boards. The outcomes of PE are likely to be complex and may, in different ways, influence both the healthcare service and the persons involved.^{5,6} PE has the potential to improve shared decision-making, person-centred care and organisations' communication.⁷⁻⁹ It has also been argued that PE may decrease hospital admissions and reduce costs if performed as a meaningful cocreation process.¹⁰

To inform future research and practice, a scoping review was performed to systematically identify and map existing gaps in knowledge regarding the structure, process and outcome of PE. We used a PE-adapted version of Donabedian's model to evaluate the quality of healthcare services to increase the understanding of current worldwide PE practices.¹¹ This review will focus on PE structures (the characteristics of settings or contexts in which PE occurs), PE processes (what PE practices and mechanisms are actually performed) and outcomes (the consequences on healthcare services, stakeholder relationship and experiences as a consequence of PE practices). PE regarding peer support initiatives, research and records focusing on patient or staff education as single PE practices will not be considered.

Objectives

The objective of this scoping review was to identify, summarise and map primary studies on mesolevel PE regarding structure, process and outcomes, following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist for scoping reviews.¹²

The scoping process was guided by the following research questions:

- ▶ How are different stakeholders engaged in the process?
- ▶ What hinders and facilitates successful PE?
- ▶ What are the reported PE outcomes?

METHODS

A systematic scoping review was conducted based on the framework by Arksey and O'Malley and Levac *et al.*^{13,14} following the required five stages: (1) identifying the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data and (5) collating, summarising and reporting the results.

Patient and public involvement

One patient representative (AH) affiliated with the Norwegian Federation of Organisations of Disabled People (FFO) and one representing the patient advisory board at Røysumtunet Rehabilitation Centre (AES) were actively involved as patient research partners. They were engaged from the very beginning and were dedicated to the importance of the research topic during all stages of the research stages. Moreover, they participated in developing the project plan and study design, helped interpret the findings, prepare the manuscript, and will contribute to the dissemination of results to patient organisations and policy-makers.

Protocol and registration

The protocol was drafted using the PRISMA-Protocols¹⁵ applicable to the scoping review methodology. The protocol was registered prospectively in the Open Science Network on 8 October 2020 (10.31219/osf.io/ysa9v) and revised by the research team due to increased familiarity with the research area.

Identifying the research question

Because of the broadly defined research purpose, we identified key elements by using frameworks such as

(but not limited to) Population, Context and Concept.¹⁶ Population criteria included patient representatives and healthcare providers. Context criteria comprised practices and motives, whereas concept criteria were PE in the development and delivery of healthcare services.

Identification of studies

Eligibility criteria

Primary studies published between 7 July 2005 and 4 October 2022 that matched the inclusion criteria were considered. Studies in English, Norwegian, Swedish or Danish were eligible. The studies could indirectly or directly involve patients, including carers, as well as other representatives from the health service (eg, healthcare professionals, managers, leaders). Studies were included if participants were 16 years or older with adequate consent competence.

After a preliminary search performed in 2019, databases were prioritised through team discussion. The search strategies were refined through team discussion and drafted by an experienced medical librarian. A comprehensive search was performed from 1 January 2005 to 6 July 2020 in the following bibliographic databases: MEDLINE, EMBASE, Cochrane and PsycINFO to identify potentially relevant primary studies. To manage our findings according to available resources and to explore the latest developments in PE, our primary focus was on publications from the previous fifteen years. A new search was performed for 1 June 2020 to 4 October 2022 to ensure the inclusion of the newest published studies. The search strategy for the last search is attached as online supplemental file 1.

Selection of studies

After duplicates were removed, the remaining records underwent title and abstract screening by two researchers (GS and JSS), and in cases of disagreement, a third reviewer was consulted (RHM). When inclusion or exclusion could not be determined based on the title and abstract, the article was screened in full text. Three reviewers performed the full text screening (GS, RHM and JSS).

Data

A data-charting form was developed and adjusted to the included studies by two reviewers using Covidence¹⁷ (GS and JSS). When a primary study was found eligible, data were extracted independently by two authors (GS and JSS). In case of conflicts, the first author (JSS) made the final decision. The reviewers extracted data about PE characteristics and mechanisms (eg, facilitators, and barriers to PE, including structural attributes, and stakeholder behaviours and experiences). The environmental setting (health and longevity, citizens' knowledge and standard of living) of the study's country of origin were compared using reports from the Human Development Index (HDI),¹⁸ which measures key dimensions of human development.

The first author (JSS) coded the extracted PE characteristics into themes using Quirkos V.2.4.1.¹⁹ The themes were guided by the proposed framework¹¹ for evaluating PE initiatives at the mesolevel. Included studies were quality assessed by two independent reviewers in pairs (RHM, GS and JSS) using the nine first questions of Critical Appraisal Skills Programme,^{20 21} which is suitable for randomised controlled studies²⁰ and qualitative studies.²¹ The Mixed Methods Appraisal Tool²² was used to assess quality for mixed method studies, cross-sectional studies and case reports, and disagreement was solved by group discussion. The response categories C=Can't tell and N=No were collapsed to No. Based on the number of yeses and noes for each primary study, an overall assessment was performed (presented in [table 1](#)). Robvis²³ was used to create visual quality assessment tables as shown in online supplemental file 2.

RESULTS

Selection of sources of evidence

Initial searches detected 8588 records about PE at the mesolevel, of which 145 were duplicates. After title and abstract screening, 192 records were assessed for full text review, of which 37 studies met the eligibility criteria. Most of the excluded records (n=72) did not address the mesolevel and forty records did not involve comanagement between patient representatives, healthcare professionals, managers or leaders. Twenty-one records were excluded due to out-of-range settings (eg, research, peer support or education as single PE initiatives). Reasons for excluding records were no full text available (n=8), wrong study design (n=8) (protocol, review or pilot), or inaccurate patient population (n=6) (inadequate consent competence, target population younger than 16 years) ([figure 2](#)).

Sources of evidence

Of the 37 included studies, 33 (89%) were conducted in countries that scored 'very high' on the HDI over the last decade. As shown in [table 1](#), 24 (65%) studies were qualitative; of these, 3 used an action research design (8%) and 2 (5%) used a case-study design. Four (11%) studies used mixed methods, three (8%) studies were randomised controlled trials, three (8%) were cross-sectional studies and one (3%) was a case report. Most studies (n=34;92%) were published within the last 10 years, with the largest share deriving from Europe (n=19;51%) and 13 (35%) originating from North America. The countries with the most included studies were the UK (n=8;22%) and the USA (n=8;22%). Two (5%) studies were developed in Lebanon, one (3%) in India, and another in Nepal (3%). The Quality appraisal detected 15 good quality, 9 fairly good and 12 poor quality studies. A summary of grading of the quality of evidence is included in online supplemental file 2.

The aims of the included studies were to explore PE at the mesolevel to increase knowledge and understanding

**Table 1** Characteristics of the included studies

Study, ref	Country	Method/design (intervention/comparator)	Study PE aim	Participants (N=2992)	Quality*
Experiences, attitudes or opinions					
Amann <i>et al</i> 2018 ²⁴	Switzerland	Qualitative	How HP/management experience PE.	HP/management (22)	●
Brouwers <i>et al</i> 2017 ²⁵	Canada	Mixed	Attitudes towards practice guideline development.	PR (41)	●
Gagliardi <i>et al</i> 2008 ²⁶	Canada	Qualitative	Indicator selection.	PR (15), HP (10), Management (5)	●
Gurung <i>et al</i> 2017 ²⁷	Nepal	Qualitative	System strengthening.	PR (24)	●
Lindblom <i>et al</i> 2021 ²⁸	Sweden	Qualitative	Codesign process	PR (4), HP (10)	●
Livingston <i>et al</i> 2013 ²⁹	Canada	Mixed	Improve care.	PR (25), HP (27)	●
Neech <i>et al</i> 2018 ³⁰	UK	Qualitative	Experiences of involvement.	PR (13)	●
Rise <i>et al</i> 2014 ⁵¹	Norway	Qualitative	Implementation of a comprehensive development plan.	PR (4), HP, managers/leaders (13)	●
Samudre <i>et al</i> 2016 ⁵⁶	India	Qualitative	Experiences, barriers and facilitators.	PR (8), HP (3) managers/leaders (16)	●
Development of recommendations					
Armstrong <i>et al</i> 2017 ³¹	USA	Qualitative	Guideline development.	PR (15)	●
Armstrong <i>et al</i> 2018 ³²	USA	RCT (patients and physicians/physicians)	Guideline question formation.	PR, HP (19)	●
Fraenkel <i>et al</i> , 2016 ⁶⁰	USA	Case report	Develop clinical practice guideline recommendations	PR, HP (10)	●
Goodman <i>et al</i> 2017 ⁴⁷	USA	Qualitative	Clinical practice guideline development.	PR (11)	●
Boivin <i>et al</i> 2014 ⁵²	Canada	RCT (priority setting with PE/not PE)	Assess the impact.	PR (83), HP (58), management (31)	●
Impact					
de Souza <i>et al</i> 2017 ⁵³	UK	Qualitative/case report	Development of innovative strategies	PR (10)	●
Daouk-Öyry <i>et al</i> 2018 ⁵⁴	Lebanon	Qualitative/action research	Engaging the patient in cocreating.	PR (18)	●
Dickinson <i>et al</i> 2020 ⁵⁷	USA	RCT (standard/plusPE)	Adoption of evidence-based guidelines	Other (Practices) (211)	●
O'Donnell <i>et al</i> 2019 ³³	Ireland	Qualitative	Quality improvement initiatives.	PR (10), HP (8)	●
Greene <i>et al</i> 2018 ³⁴	USA	Mixed	Influence on quality improvement.	Focus group/survey: PR (17)/(47), leaders (11)/(56)	●
Gremyr <i>et al</i> 2018 ⁵⁹	Sweden	Quantitative/Cross-sectional	Radicality of improvement	HP (155)	●
Omeni <i>et al</i> 2014 ³⁵	UK	Mixed	Views on impact.	PR (302), HP (143)	●
Scholtes <i>et al</i> 2021 ³⁶	UK	Quantitative/cross-sectional	Occurrence and influence	HP (35), management (29)	●
Exploring, understanding and knowledge					
Anderson <i>et al</i> 2021 ³⁷	Canada	Qualitative	Approaches and strategies	PR (20) HP (10), managers/leaders (10)	●

Continued

Table 1 Continued

Study, ref	Country	Method/design (intervention/comparator)	Study PE aim	Participants (N=2992)	Quality*
Carlsson <i>et al</i> 2007 ⁴⁸	Sweden	Qualitative	Generate knowledge about quality improvement.	PR (16), HP (10)	●
Dayekh <i>et al</i> 2022 ³⁸	Lebanon	Qualitative	Benefits and barriers	PR (41), HP (27)	●
Fudge <i>et al</i> 2008 ³⁹	UK	Qualitative	Policy.	PR (158), HP (18)	●
Galvin <i>et al</i> 2020 ⁴⁰	UK	Qualitative Action research	Insights and benefits	PR (12), HP (17)	●
Hashem <i>et al</i> 2018 ⁴⁹	UK	Qualitative	Decisions about funding medicines.	PR, HP, other (41)	●
Hwang and Warshaw, 2019 ⁴¹	USA	Cross-sectional	Clinical settings.	HP (829)	●
McKeivitt <i>et al</i> 2018 ⁴²	UK	Qualitative	PE in major system changes.	PR, HP, managers/leaders, other (45)	●
Rise <i>et al</i> 2013 ⁵⁰	Norway	Qualitative	Service users' and service providers' own definitions.	PR (4) HP (33), management (44)	●
Sharma <i>et al</i> 2018 ⁴³	USA	Qualitative	Define roles and understand recruitment.	Managers/leaders (19)	●
Steffensen <i>et al</i> 2022 ⁵⁸	Denmark	Qualitative	Practices and influence	PR (3), HP (1), management (8)	●
van der Meide <i>et al</i> 2015 ⁴⁴	The Netherlands	Case report	The client council.	PR (9)	●
Weiste <i>et al</i> 2021 ⁴⁵	Finland	Qualitative	Workshop contributions	PR (9), HP (38), management (7),	●
Whiston <i>et al</i> 2019 ⁴⁶	Ireland	Qualitative	Intensity and implementation	PR (22), HP (9)	●
Woelders and Abma 2019 ⁵⁵	The Netherlands	Qualitative action research	Alternatives to formal involvement	PR (10), management (1), HP (2)	●

*Judgement: ● Poor quality ● Fair quality ● Good quality. The response categories C=Can't tell and N=No used for the Critical Appraisal Skills Programme and the Mixed Methods Appraisal Tool were collapsed to No, <2 'no'=good quality, <3 'no'=fair quality and ≤3 'no'= poor quality. HP, health professionals; PE, patient engagement; PR, patient representatives; RCT, randomised controlled trial.

about how PE was performed (n=15;41%), the impact of PE initiatives (n=8;22%), or experiences, attitudes or opinions of PE (n=9;24%). All studies aiming to assess the

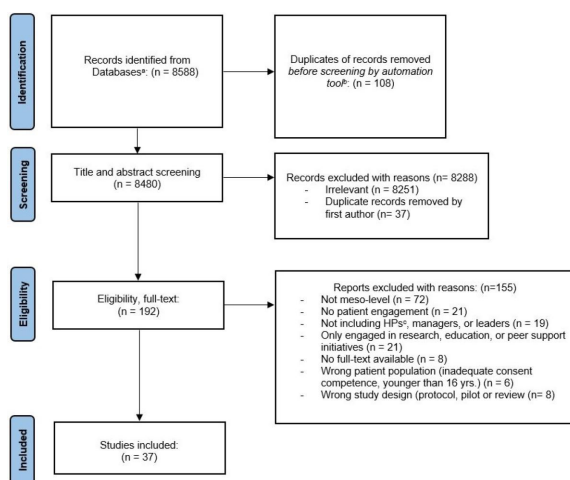


Figure 2 Flow chart for identification of studies via databases. ^aMEDLINE, EMBASE, Cochrane and PsycINFO. ^bCovidence. ^cHPs, healthcare professionals.

outcome of involving patient representatives in the development of treatment recommendations originated from North America (n=5;14%). The aim in most studies was to increase knowledge about PE activities in the field of mental healthcare (n=8;20%). Three studies (8%) were developed in the setting of cancer treatment, three (8%) in the setting of stroke care and two (7%) within rheumatology. Single studies were developed in the setting of cardiovascular disease, dermatology, hip and knee surgery, geriatrics, and spinal cord injury. Sixteen (43%) studies were conducted in a more general setting and did not focus on specific diagnoses (table 1).

PE structure

As described by others,¹¹ structure can be understood as the attributes of a PE setting, such as PE education, resources and the organisation of PE initiatives. PE knowledge, recruitment, resources and physical environment were the most prominent structural attributes reported. Organisation of PE initiatives, including timing and consistency of PE initiatives referred to as the organisational structure, was reported in all studies.

Table 2 Studies highlighting structural attributes as facilitating, hindering or both for PE*†‡

Structural attribute	PE barrier	PE barrier and facilitator	PE facilitator
PE knowledge			
Recruitment and/or representativeness			
Time and resources			
Physical environment			
Ref study			
Amann <i>et al</i> 2018 ²⁴	Armstrong <i>et al</i> 2017 ³¹	Scholtes <i>et al</i> 2021 ³⁶	Hwang and Warshaw, 2019 ⁴¹
Brouwers <i>et al</i> 2017 ²⁵	Armstrong <i>et al</i> 2018 ³²	Anderson <i>et al</i> 2021 ³⁷	McKevitt <i>et al</i> 2018 ⁴²
Gagliardi <i>et al</i> 2008 ²⁶	Boivin <i>et al</i> 2014 ⁵²	Carlsson <i>et al</i> 2007 ⁴⁸	Sharma <i>et al</i> 2018 ⁴³
Gurung <i>et al</i> 2017 ²⁷	de Souza <i>et al</i> 2017 ⁵³	Dayekh <i>et al</i> 2022 ³⁸	van der Meide <i>et al</i> 2015 ⁴⁴
Lindblom <i>et al</i> 2021 ²⁸	Daouk-Öyry <i>et al</i> 2018 ⁵⁴	Fudge <i>et al</i> 2008 ³⁹	Weiste <i>et al</i> 2021 ⁴⁵
Livingston <i>et al</i> 2013 ²⁹	O'Donnell <i>et al</i> 2019 ³³	Galvin <i>et al</i> 2020 ⁴⁰	Whiston <i>et al</i> 2019 ⁴⁶
Neech <i>et al</i> , 2018 ³⁰	Greene <i>et al</i> , 2018 ³⁴	Hashem <i>et al</i> , 2018 ⁴⁹	
Rise <i>et al</i> , 2014 ⁵¹	Omeni <i>et al</i> 2014 ³⁵		

Affected stakeholder: , multiple stakeholders: , public or patients; , HP's managers, leaders; , policy-makers.

Study participants and healthcare setting: (a) HP; (b) PR; (c) HP and PR; (d) HP, managers/leaders, PR. (1) acute care; (2) regional care; (3) specialised care; (4) national/general care.

Study method: Qualitative; mixed; cross-sectional; action-research; case study; RCT.

*Bar height represents number of participants: Small bar = ≤ n 10, medium bars = > n 10, and highest bars = > n 49.

†Study ref.

‡Blue numbers=study ref.

PE, patient engagement; RCT, randomised controlled trial.

PE knowledge

In 23 studies (62%), there was a focus on knowledge and capability on how to engage PE stakeholders.^{24–46} Out of these, a lack of competence was reported as a barrier in nine studies (24%).^{26 28 29 31 34 39 40 42 45} Lack of technical skills,³⁹ lack of insight in appropriate PE methods,²⁶ lack of understanding legal constraints³⁴ and uncertainty on how to incorporate patient experiences,³² were also reported as PE barriers. PE knowledge was described as a factor with the potential to work as both a facilitator and a barrier in nine (24%) studies.^{24 25 27 32 33 38 41 43 44} Among the 18 (49%) studies of which lack of PE knowledge was mentioned as a barrier, 8 (22%) reported that multiple stakeholders such as patients, healthcare professionals and/or managers could benefit from increasing their PE knowledge on how to incorporate PE as part of the structure.^{27 31 32 34 38 39 44 47} Similar results were reported in four (11%) studies where PE knowledge was endorsed as a facilitator (table 2).^{30 35 37 46}

Recruitment and representativeness

As shown in table 2, according to 16 (43%) studies, representativeness and/or recruitment had the

potential of being both a facilitator and a barrier to meaningful cocreation.^{25–28 31 34 36 37 39–41 43–45 48 49} Of these studies, nine (24%) took place in the setting of specialised care,^{25–27 31 34 39–41 44} three (8%) in regional care^{28 43 45} and four (11%) in the setting of national care.^{36 37 48 49} Insufficient representativeness was reported as only being a PE barrier in six (16%) studies.^{34 36 39 40 43 45} As examples, old age,^{37 39} small numbers of patient representatives with time to spare,^{36 39 40} and professionals recruiting already known patient representatives⁴⁵ were described as a restriction for sufficient representativeness. Sufficient representativeness was highlighted as a facilitator in six (16%) studies,^{25 26 31 41 44 49} and representativeness among multiple PE stakeholders were underlined as a facilitator in four (11%).^{31 41 44 49} Representativeness could be facilitated by recruiting a sufficiently number of engaged stakeholders with the ability to provide general perspectives related to specific PE purposes.^{26 27 31 34 37 39 41 43 44 49} Gender distribution was described in most studies, some of these sought or described a balance of gender.^{26 28 35 37 42 44 50} However,

an over-representation of women was described in one study,⁴⁴ and men was described to be more experienced in the role as patient representative in another study.³⁵

Time and finances

As seen in [table 2](#), time, human resources and/or finances were reported as important structural characteristics in some of the studies. In six (16%) studies, lack of time and/or finances were listed as a barrier.^{31 32 36 40 41 46} For instance, patient representatives could be too overwhelmed by their illness,⁴¹ or having logistical challenges.³⁶ Limited economical resources dedicated to PE from policy-makers was also reported as a PE barrier.^{46 51} Time and/or finances were reported as both a facilitator and a barrier in six (16%) studies.^{25 27 38 51-53} Investing time and resources into training service providers about PE were reported to be facilitators in one (3%) study.²⁹ In 7 (19%)^{27 31 32 41 51-53} of the 13 studies in which time and/or finances were addressed, these structural attributes applied to multiple stakeholders.

Physical environment

The physical environment was reported as a PE barrier in one (3%) study,²⁴ and outlined as a combination of facilitator and barrier to PE in another.⁵⁴ In two (5%) studies, the physical environment was specifically reported to affect patient representativeness,^{24 41} and described in two (5%) to influence multiple stakeholders ([table 2](#)).^{40 54} The physical environment, including services and equipment such as transportation and IT systems, was reported as PE facilitators by being innovative in one (3%) study.⁴¹ In another study, using a room with surroundings where people felt safe and at ease was reported to facilitate PE.⁴⁰

Organisational structure

Using combined PE initiatives (eg, patient panel, focus groups and surveys) representing the broader organisational PE activity were frequently reported.^{24 25 29 34 37-39 41 42} Standing committees, boards, councils or panels were often more consistently engaged in PE tasks and integrated as part of the structure than other PE initiatives (online supplemental file 3). However, patient advisory councils were reported in one study to address day-to-day clinical challenges, while governing board patient members tended to handle decisions on a higher operational level.⁴³ Of the 17 studies reporting focus groups, workshops and forums, 10 studies associated these initiatives with operationalised PE tasks.^{28 29 31 32 34 38 42 50 53} Consultation meetings were reported as a PE initiative without regular meetings in two studies^{33 52} and action research was used as a framework to organise PE initiatives in three studies (online supplemental file 3).^{40 54 55} Other ways of conducting PE, such as surveys and interviews, were described as more passive forms of engagement,^{26 39} often including undecipherable tasks.

The PE phase refers to when PE was initiated and the consistency of engagement during a PE process. As

seen in online supplemental file 3, patient representatives organised in focus groups, workshops or forums were more likely to participate in an earlier phase of the engagement process than for other PE formats. Early, ongoing PE initiatives were endorsed as preferable over single and passive PE activities,^{25 26 36 46 56 57} with active visible dissemination from PE contributions,^{30 32 46 53 58} and patient representatives taking an active role through the entire PE process.^{25 26 31 38 58}

Process

Process can be understood as activities, tasks, approaches and mechanisms that are performed in a PE structure.¹¹

PE task

Regarding the studies that comprised a preoperationalised PE task(s), a frequently mentioned task was to share experiences and assist healthcare professionals in the process of prioritising issues of patient concerns.^{26 33 37 42 44 49 50 55 59} It was highlighted that the overall PE purpose was to improve patient experiences of care,^{9 28 29 38 40 53 54} or to contribute to the identification of outcome measures and practice guidelines.^{25 31 32 47 60}

PE approach

Engagement approaches can be described as heterogeneity of models used in dynamic ways to engage various stakeholders.¹¹ Overall, review findings indicate various mechanisms, including interpersonal relationships acting as part of the engagement approach.

Negative interpersonal relationships and experiences were reported as barriers to meaningful PE. Consequently, patient representatives are affected both directly and indirectly in their PE process,^{31 32 48} creating a sense of tokenism and differences in power balance between patients and healthcare professionals.^{25 28 30 35 42 44 51 53 55 56} Examples of barriers to meaningful cocreation were professionals' taking control over the PE agenda and how patient representatives participated in the engagement process.^{39 42 51} Mutual respect and values, creating a meaningful partnership based on equity among stakeholders, were emphasised as facilitators for PE.^{29 31 40 42 44 46 48 50 53} In some studies, equity was reported in the setting of easily understandable language and respectful communication.^{28 33 38 43 53 55}

Role clarity

Patient representatives' desired roles and tasks did not necessarily correspond with the actual role and tasks they ended up performing.^{28 40} Professionals were reported to assume patient representatives to take a consultative role rather than taking part in final decision-making.²⁶ A clear description of roles and the importance of accepting different roles and backgrounds was reported as keys to meaningful PE.^{25 28 31 33 58} Training patient representatives in leadership roles,⁴³ and in the language and mindset of hospital governance could also facilitate PE.⁴⁴

PE outcomes

In contrast to hard and operationalised outcomes with clearly defined and measurable effects of PE, the most prominent results of PE were reported as soft outcomes or consequences. Examples of soft outcomes are stakeholder experiences, relationships and capacity building acting as intermediary stages to reach hard outcomes such as improved healthcare quality and cost-effectiveness.⁶¹

Patient representativeness was described to have an intrinsic value⁴² that may influence decision-making processes in shaping policies, services, guidelines and programmes.^{9 32 34 37–39 52 57 60} Patient representatives can contribute to an increased focus on patient-centred care and argue for other priorities than healthcare professionals traditionally do.^{47 53 54 60} Patient representatives tend to focus more on patient perspectives, such as patient-relevant topics, than healthcare professionals working alone.^{47 48 60} As an example, a patient panel assigned higher importance to avoiding infection than experiencing a disease flare than a physician panel did.⁴⁷ Moreover, patient representatives would focus more on remission than health professionals.⁶⁰ Studies reported that the codesign processes may facilitate mesolevel change by organising varying PE initiatives suitable for certain tasks and process phases.^{28 37} Early involvement of patient representatives was described as facilitating PE and further associated with the greatest impact at the mesolevel.^{34 59}

The PE process in itself was reported as a barrier with stigmatising attitudes and power differences as a processual consequence.^{26 30 45 49 50 55 56} Conversely, PE as an adapting process was commented on as important regarding the positive impact on experiences for various PE stakeholders.^{24 28 34 36 38 57} Outcomes such as patient representatives improving their self-esteem and feeling valued when supported by health professionals were emphasised.^{29 30 35 42} Positive experiences resulting from democratic dialogue, mutual respect and equality were reported as outcomes facilitating a meaningful process.³³ To facilitate a meaningful process, the importance of a common understanding of what PE should contain, clarifying the criteria for success and the timing of involvement were endorsed.^{25 50 51 59} Furthermore, the importance of clarifying types of knowledge contributions expected was embraced.⁵⁸

DISCUSSION

Summary of evidence

The objectives of this review were to explore current knowledge about the persons engaged in healthcare cocreation and delivery, investigate facilitators and barriers to PE, and to report PE outcomes. The overall findings suggest that the PE process itself may both promote discrimination and increase stakeholder self-esteem. As supported by others,⁶² structures ensuring sufficient diversity and PE knowledge among all stakeholders, including healthcare

professionals, managers and patient representatives, seems to be especially important to facilitate a PE process.

The finding that professional control and prominent use of too-advanced language hinder PE can assist current education and training materials such as The Principles of Community Engagement,⁶³ PE Trainings,⁶⁴ ethics frameworks such as PRO-Ethics,⁶⁵ and current PE evaluation tools such as The Public and Patient Evaluation Tool.⁶⁶ The findings may also serve as a basis for the development of new education materials targeting mesolevel PE.

In this review, no studies originated from countries with a low HDI score, implying a possible need for exploring PE processes in developing countries in particular. Both Nepal and India scored 'medium' (0.588, 0.630) on the HDI when the studies were conducted and Lebanon had a 'high' HDI score (0.747) at the time when the studies were published in 2022³⁸ and 2018.⁵⁴ This review may have failed to detect unpublished reports, studies reporting on unfamiliar PE processes, or structures uncommon in western countries possibly detected by a more HDI specific search. Findings suggest that patients and carers from countries with a medium HDI and in a mental health setting describes internalised stigmatising attitudes.^{27 56} Findings described in the study from Nepal imply within-group stigma among patient representatives.²⁷ Similar findings are shown in the study from India which reported that PE at microlevel was prioritised over mesolevel by all stakeholders, including policy-makers.⁵⁶ Working towards user centric healthcare services, free from competing interests among stakeholders are described as important first steps to reduce stigmatising attitudes.^{27 56}

Structure

Results indicate that stakeholders' knowledge regarding the incorporation of PE as part of a healthcare organisation may be an essential structural attribute to facilitate change in practice. This is supported by a recent study on PE within health profession education influencing the microlevel,⁶⁷ where the development and use of context-specific education tools and programmes empowered patients' to participate in shared decision-making. As part of the organisational structure, the findings further suggest that PE education and training may benefit from focusing on the use of different PE initiatives suitable for specific PE tasks, for instance, by having a standing patient board, which conducts surveys or workshops when needed. In addition to insufficient PE knowledge, uneven power relations are frequently described as hindering PE. Sometimes healthcare professionals and managers perceive PE as a threat.⁵³ This threat may serve as a 'sticky floor' which holds on to provider-centric structures with unequal stakeholder responsibility and influence. These structures may foster power inequalities and are frequently reported in studies originating from countries with medium, high and very high HDI scores.^{30 49 54–56 58}

Process

In line with a previous study,⁶⁸ included studies indicate that processual experience, such as stakeholder relationships may be difficult to change through education, but may develop as part of the engagement process itself. Studies report that different PE expectations and values among the different stakeholders can serve as an important barrier to PE and that PE stakeholders in some cases tend to place a symbolic value on the decision-making process.^{39 42 43 49 50} In studies where the PE process was described as a barrier, patient representatives tended to be underestimated due to their lack of professional knowledge. It was also reported that the PE process could trigger health difficulties, generate self-stigma and hinder a meaningful cocreation process.^{26 30 45 49 50 56} A recent scoping review concludes that all stakeholders should take on a more progressive role to convert from a pro-forma PE approach to meaningful levels of cocreation.⁶ A meaningful level of engagement embraces empowerment to participate with equity as a core value.^{38 44 69}

Outcome

Even if our findings indicate that patient representatives engaged in the cocreation process may contribute to improved care, there is a lack of research reporting this as hard outcomes. More specifically, a paucity of research report changes in service delivery, improved healthcare quality, cost-effectiveness, health status or overall well-being at the microlevel. On the other hand, soft outcomes such as a change in experiences, stakeholder relationships and stakeholder capacity building were described in the majority of the included studies. These soft outcomes and consequences were similar across PE tasks and organisation of the PE initiatives.

Strengths and limitations

A strength of our study is the critical appraisal of all included studies, to our knowledge, not applied in scoping reviews before. This may ease the use of the results for future hypothesis generating processes. A limitation is that we only included primary studies published in English, Swedish, Danish or Norwegian. A wide scoping area made the review process long and time consuming. We screened an extensive amount of studies selected from comprehensive searches in the predefined databases, but important studies in other databases may have been missed.

Future research

Extended hypothesis testing when evaluating rigour in outcome measures is suggested in a previous study.⁷⁰ The findings from this review may work as a fundament when considering additional variables to test. Future research is proposed to explore how consistent and diverse PE initiatives engaging multiple stakeholders may promote respect and equity among PE stakeholders. An important next step could also be to explore HDI scores related to PE by including more specified searches for this purpose.

In addition, mesolevel PE may benefit from research focusing on structured PE education and training with possible outcomes at different levels of care and how these outcomes may be experienced by stakeholders. Studies have reported diversity among stakeholders as a facilitator of PE, but few have reported on gender differences among stakeholders in general, or patient representatives in particular.

CONCLUSIONS

This scoping review demonstrates a lack of research describing clearly defined outcomes identifiable for patient representatives, healthcare professionals, managers and patients. The PE process may flourish further through education, training, experience and stakeholder diversity. Sufficient stakeholder representativeness and PE knowledge are reported as the most noteworthy structural attributes to facilitate equity and a meaningful cocreation process. Overall, earmarked finances ensuring sufficient PE representativeness and knowledge among all stakeholders is a cornerstone of integrating PE as a part of a healthcare structure in any setting.

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ORCID iDs

Joachim Støren Sagen <http://orcid.org/0000-0001-5252-1770>
Rikke Helene Moe <http://orcid.org/0000-0001-7601-5346>

REFERENCES

- Halabi IO, Scholtes B, Voz B, *et al.* "Patient participation" and related concepts: a scoping review on their dimensional composition. *Patient Educ Couns* 2020;103:5–14.
- Andreassen TA. Service user involvement and repositioning of healthcare professionals: a framework for examining implications of different forms of involvement. *Nordisk Vålfördsforskning | Nordic Welfare Research* 2018;3:58–69.
- World Health Organization. World report on disability [Online document]. Geneva WHO; 2011. Available: <https://www.who.int/publications/i/item/9789241564182> [Accessed 01 Sep 2021].
- European Commission. *Patient involvement, Eurobarometer Qualitative study*. European Commission, 2012.
- Crawford MJ, Rutter D, Manley C, *et al.* Systematic review of involving patients in the planning and development of health care. *BMJ* 2002;325:1263.
- Fearnley J, Joseph L, Vasanthan L, *et al.* Methods of engagement and levels of involvement of stakeholders in the management of work-related musculoskeletal disorders: a systematic scoping review. *J Public Health (Berl)* 2022;30:2761–76.
- Scholl I, LaRussa A, Hahlweg P, *et al.* Organizational- and system-level characteristics that influence implementation of shared decision-making and strategies to address them - a scoping review. *Implementation Sci* 2018;13.
- Sandvin Olsson AB, Strom A, Haaland-Øverby M, *et al.* How can we describe impact of adult patient participation in health-service development? A scoping review. *Patient Educ Couns* 2020;103:1453–66.
- Sharma AE, Knox M, Mleczo VL, *et al.* The impact of patient advisors on healthcare outcomes: a systematic review. *BMC Health Serv Res* 2017;17:693.
- Bombard Y, Baker GR, Orlando E, *et al.* Engaging patients to improve quality of care: a systematic review. *Implement Sci* 2018;13:98.
- Hamilton CB, Dehnadi M, Snow ME, *et al.* Themes for evaluating the quality of initiatives to engage patients and family caregivers in decision-making in healthcare systems: a scoping review. *BMJ Open* 2021;11:e050208.
- Tricco AC, Lillie E, Zarin W, *et al.* PRISMA extension for Scoping reviews (PRISMA-SCR): checklist and explanation. *Ann Intern Med* 2018;169:467–73.
- Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol* 2005;8:19–32.
- Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. *Implement Sci* 2010;5:69.
- PRISMA-P Group, Moher D, Shamseer L, *et al.* Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Syst Rev* 2015;4.
- Peters MDJ, Godfrey CM, Khalil H, *et al.* Guidance for conducting systematic scoping reviews. *Int J Evid Based Healthc* 2015;13:141–6.
- Covidence systematic review software Melbourne, Australia: Veritas health innovation. 2023. Available: <https://www.covidence.org/> [Accessed 30 Jul 2020].
- Human development reports [Human Development Index (HDI)]. Available: <https://hdr.undp.org/data-center/human-development-index#/indicies/HDI> [Accessed 08 Aug 2022].
- Quirkos. Qualitative analysis software made simple 2023. 2023. Available: <https://www.quirkos.com/> [Accessed 01 Aug 2022].
- Critical Appraisal Skills Programme. CASP randomised controlled trial checklist. 2018. Available: <https://casp-uk.net/images/checklist/documents/CASP-Randomised-Controlled-Trial-Checklist/CASP-RCT-Checklist-PDF.pdf> [Accessed 26 Oct 2022].
- Critical Appraisal Skills Programme. Qualitative studies checklist 2018. Available: https://casp-uk.net/images/checklist/documents/CASP-Qualitative-Studies-Checklist/CASP-Qualitative-Checklist-2018_fillable_form.pdf [Accessed 04 Apr 2021].
- Hong QN, Fàbregues S, Bartlett G, *et al.* The mixed methods appraisal tool (MMAT) version 2018 for information professionals and researchers. *EFI* 2018;34:285–91.
- McGuinness LA, Higgins JPT. Risk-of-bias visualization (Robvis): an R package and shiny web app for visualizing risk-of-bias assessments. *Res Synth Methods* 2021;12:55–61.
- Amann J, Brach M, Rubinelli S. How Healthcare professionals experience patient participation in designing healthcare services and products. A qualitative study in the field of spinal cord injury in Switzerland. *Patient Educ Couns* 2018;101:1452–9.
- Brouwers MC, Vukmirovic M, Spithoff K, *et al.* Understanding optimal approaches to patient and caregiver engagement in the development of cancer practice guidelines: a mixed methods study. *BMC Health Serv Res* 2017;17:186.
- Gagliardi AR, Lemieux-Charles L, Brown AD, *et al.* Barriers to patient involvement in health service planning and evaluation: an exploratory study. *Patient Educ Couns* 2008;70:234–41.
- Gurung D, Upadhyaya N, Magar J, *et al.* Service user and care giver involvement in mental health system strengthening in Nepal: a qualitative study on barriers and facilitating factors. *Int J Ment Health Syst* 2017;11:30.
- Lindblom S, Flink M, Elf M, *et al.* The manifestation of participation within a co-design process involving patients, significant others and health-care professionals. *Health Expect* 2021;24:905–16.
- Livingston JD, Nijdam-Jones A, Lapsley S, *et al.* Supporting recovery by improving patient engagement in a forensic mental health hospital: results from a demonstration project. *J Am Psychiatr Nurses Assoc* 2013;19:132–45.
- Neech SGB, Scott H, Priest HM, *et al.* Experiences of user involvement in mental health settings: user motivations and benefits. *J Psychiatr Ment Health Nurs* 2018;25:327–37.
- Armstrong MJ, Mullins CD, Gronseth GS, *et al.* Recommendations for patient engagement in guideline development panels: a qualitative focus group study of guideline-naïve patients. *PLoS ONE* 2017;12:e0174329.
- Armstrong MJ, Mullins CD, Gronseth GS, *et al.* Impact of patient involvement on clinical practice guideline development: a parallel group study. *Implement Sci* 2018;13:55.
- O'Donnell D, Ní Shé É, McCarthy M, *et al.* Enabling public, patient and practitioner involvement in co-designing frailty pathways in the acute care setting. *BMC Health Serv Res* 2019;19:797.
- Greene J, Farley D, Amy C, *et al.* How patient partners influence quality improvement efforts. *Jt Comm J Qual Patient Saf* 2018;44:186–95.
- Omeni E, Barnes M, MacDonald D, *et al.* Service user involvement: impact and participation: a survey of service user and staff perspectives. *BMC Health Serv Res* 2014;14:491.
- Scholtes B, Breinbauer M, Rinnenburger M, *et al.* Hospital practices for the implementation of patient partnership in a multi-national European region. *Eur J Public Health* 2021;31:73–9.
- Anderson NN, Baker GR, Moody L, *et al.* Approaches to optimize patient and family engagement in hospital planning and improvement: qualitative interviews. *Health Expect* 2021;24:967–77.
- Dayekh AY, Naseridine M, Dakroub F, *et al.* Impact, obstacles and boundaries of patient partnership: a qualitative interventional study in Lebanon. *PLoS ONE* 2022;17:e0270654.
- Fudge N, Wolfe CDA, McKeivitt C. Assessing the promise of user involvement in health service development: ethnographic study. *BMJ* 2008;336:313–7.
- Galvin KT, Pound C, Cowdell F, *et al.* A Lifeworld theory-led action research process for humanizing services: improving "What matters" to older people to enhance humanly sensitive care. *Int J Qual Stud Health Well-Being* 2020;15:1817275.
- Hwang A, Warshaw G. Joint AGS-CCEHI survey offers insights into patient engagement in geriatric clinical settings. *J Am Geriatr Soc* 2019;67:1791–4.
- McKeivitt C, Ramsay AIG, Perry C, *et al.* Patient, carer and public involvement in major system change in acute stroke services: the construction of value. *Health Expect* 2018;21:685–92.
- Sharma AE, Huang B, Knox M, *et al.* Patient engagement in community health center leadership: how does it happen. *J Community Health* 2018;43:1069–74.
- van der Meide H, Olthuis G, Leget C. Patient participation in hospital care: how equal is the voice of the client council. *Health Care Anal* 2015;23:238–52.
- Weiste E, Stevanovic M, Uusitalo L-L. Experiential expertise in the co-development of social and health-care services: self-promotion and self-dismissal as interactional strategies. *Social Health Illn* 2022;44:764–80.
- Whiston L, Barry J, O'Keane V, *et al.* Patient, family and clinician preferences for the intensity and implementation of patient and family participation in healthcare design and delivery in psychiatry. *Eur J Psychiatry* 2019;33:8–16.
- Goodman SM, Miller AS, Turgunbaev M, *et al.* Clinical practice guidelines: incorporating input from a patient panel. *Arthritis Care Res (Hoboken)* 2017;69:1125–30.
- Carlsson C, Segesten K, Nilbert M, *et al.* Captured voices in cancer: experiences from networking between individuals with experiential and professional knowledge. *BMC Health Serv Res* 2007;7:23.

- 49 Hashem F, Calnan MW, Brown PR. Decision making in NICE single technological appraisals: how does NICE incorporate patient perspectives? *Health Expect* 2018;21:128–37.
- 50 Rise MB, Solbjør M, Lara MC, *et al.* Same description, different values. How service users and providers define patient and public involvement in health care. *Health Expect* 2013;16:266–76.
- 51 Rise MB, Solbjør M, Steinsbekk A. Experiences from the implementation of a comprehensive development plan for user involvement in a mental health hospital: a qualitative case study. *Int J Soc Psychiatry* 2014;60:387–95.
- 52 Boivin A, Lehoux P, Lacombe R, *et al.* Involving patients in setting priorities for healthcare improvement: a cluster randomized trial. *Implementation Sci* 2014;9:24.
- 53 de Souza S, Galloway J, Simpson C, *et al.* Patient involvement in rheumatology outpatient service design and delivery: a case study. *Health Expect* 2017;20:508–18.
- 54 Daouk-Öyry L, Alameddine M, Hassan N, *et al.* The catalytic role of mystery patient tools in shaping patient experience: a method to facilitate value co-creation using action research. *PLoS ONE* 2018;13:e0205262.
- 55 Woelders S, Abma T. Participatory action research to enhance the collective involvement of residents in elderly care: about power, dialogue and understanding. *Action Research* 2019;17:528–48.
- 56 Samudre S, Shidhaye R, Ahuja S, *et al.* Service user involvement for mental health system strengthening in India: a qualitative study. *BMC Psychiatry* 2016;16:269.
- 57 Dickinson WP, Nease DE, Rhyne RL, *et al.* Practice transformation support and patient engagement to improve cardiovascular care: from Evidencenow Southwest (ENSW). *J Am Board Fam Med* 2020;33:675–86.
- 58 Steffensen MB, Matzen CL, Wadmann S. Patient participation in priority setting: co-existing participant roles. *Soc Sci Med* 2022;294:114713.
- 59 Gremyr I, Elg M, Smith F, *et al.* Exploring the phase for highest impact on radicality: a cross-sectional study of patient involvement in quality improvement in Swedish healthcare. *BMJ Open* 2018;8:e021958.
- 60 Fraenkel L, Miller AS, Clayton K, *et al.* When patients write the guidelines: patient panel recommendations for the treatment of rheumatoid arthritis. *Arthritis Care Res (Hoboken)* 2016;68:26–35.
- 61 A practical guide to measuring soft outcomes and distance travelled. Department for Work and Pensions, Welsh European Funding Office; 2003.
- 62 Ocloo J, Garfield S, Franklin BD, *et al.* Exploring the theory, barriers and enablers for patient and public involvement across health, social care and patient safety: a systematic review of reviews. *Health Res Policy Syst* 2021;19:8.
- 63 Centers for Disease Control and Prevention (CDC). Principles of community engagement. 2011. Available: https://www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_508_FINAL.pdf [Accessed 24 Oct 2022].
- 64 The European Patients' Academy on Therapeutic Innovation. Patient engagement trainings. 2022. Available: <https://eupati.eu/training/patient-engagement/> [Accessed 10 Dec 2022].
- 65 Cruz Rivera S, Aiyegbusi OL, Ives J, *et al.* Ethical considerations for the inclusion of patient-reported outcomes in clinical research: the PRO ethics guidelines. *JAMA* 2022;327:1910–9.
- 66 McMaster University. Faculty of health science 2018. Available: <https://ppe.mcmaster.ca/resources/public-and-patient-engagement-evaluation-tool/> [Accessed 20 Dec 2020].
- 67 Romme S, Smeets HWH, Bosveld MH, *et al.* Involving patients in undergraduate health professions education: what's in it for them? *Patient Educ Couns* 2022;105:2190–7.
- 68 Laker DR, Powell JL. The differences between hard and soft skills and their relative impact on training transfer. *Hum Resour Dev Q* 2011;22:111–22.
- 69 Aguilar-Gaxiola S, Ahmed SM, Anise A, *et al.* Assessing meaningful community engagement: a conceptual model to advance health equity through transformed systems for health: organizing committee for assessing meaningful community engagement in health & health care programs & policies. *NAM Perspect* 2022;2022.
- 70 Garratt A, Sagen J, Børøsund E, *et al.* The public and patient engagement evaluation tool: forward-backwards translation and cultural adaption to Norwegian. *BMC Musculoskeletal Disord* 2022;23:556.