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REVIEW ARTICLE

How are pain management interventions co-designed? A scoping review

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Abstract

Aim Pain is a common public health concern and the primary reason for seeking healthcare. Co-design is a promising approach for developing person-centred pain management interventions. This review aims to explore the characteristics of co-design in pain management interventions and research.

Subject and methods This scoping review was conducted following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews guidelines. Systematic searches were conducted in MEDLINE, EMBASE, CINAHL, PsycINFO, Web of Science, and Scopus using key concepts related to pain, co-design, and intervention. Descriptive, thematic, and narrative synthesis were used to present the findings.

Results Forty-seven peer-reviewed articles ($n=44$; 94%) from high-income and ($n=3$; 6.0%) from low- and middle-income countries were analysed. Thirteen different terminologies were used to describe the collaborative process in the studies. Co-design was commonly conducted among older adults with chronic pain ($n=34$). Self-management strategies ($n=18$), educational interventions ($n=6$), multimodal interventions ($n=3$), and palliative care ($n=2$) were the co-designed interventions developed through co-design studies. The majority ($n=16$) were technology-based interventions.

Conclusion The review highlights the significant variability in terminology and how co-design is utilised in pain management studies. Low- and middle-income countries were underrepresented in the included studies. The results of this review underscore the need for a standardised co-design guide for future research, engaging co-design partners more meaningfully, and expanding co-design interventions and research in low- and middle-income countries to address global disparities in pain management.

Keywords Co-design · Pain management · Scoping review · Intervention · Collaborative approach

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Introduction

Pain is a common experience and the main reason for seeking healthcare in the general population (Wierzbicka 2012; Williams and Craig 2016). The revised International Association for the Study of Pain (IASP) definition of pain is 'an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage' (Raja et al. 2020). While pain often resolves as tissue heals, it can persist beyond the normal healing time, becoming chronic (Feizerfan and Sheh 2015; Orr et al. 2017). Chronic pain affects billions of people globally (Zimmer et al. 2022), with one in five people experiencing it regularly (Van Hecke et al. 2013). In low- and middle-income countries (LMICs), the prevalence is even higher, impacting 20–40% of the population (Jackson et al. 2016).

Despite advancements in pain research, effective pain management remains complex and challenging for clinicians and researchers (Ugwu 2020; Wang and Tsai 2010; Haroutounian et al. 2022). Barriers such as the subjective nature of pain, patient preferences, and healthcare provider beliefs influence pain management (Wagner et al. 2005; Aboumatar et al. 2022; Austrian et al. 2005; Carr 2007). This complexity highlights the importance of involving people with lived experience (PLE) of pain and health service users directly in pain management interventions and research, as their knowledge and perspectives provide important contextual insights that cannot be captured through traditional approaches alone (de Wit et al. 2013; Frampton and Hughes-Webb 2011). Previous studies have demonstrated that engaging PLE of pain and clinicians in the development and evaluation of interventions improves outcomes, optimises resources, and ensures interventions align with the needs and contexts of real-world settings (Louise and Annette 2019; Greenhalgh et al. 2016). However, many pain management interventions and pain research studies are designed without PLE input, which limits the relevance, efficacy, and applicability of interventions and research findings (Lin et al. 2015).

One way to effectively engage PLE in interventions and research development is through a co-design approach. Co-design is a collaborative and iterative process that involves PLE, clinicians, researchers, and other interest holders in designing and developing health interventions, products, services, and policies (Carroll et al. 2017; de Wit et al. 2013). Co-design of interventions involves equitable and collaborative decision-making with PLE and other key interest holders through one or all stages of co-planning, co-design, co-implementation, and/or co-evaluation of an intervention (O'Cathain et al. 2019; Elbers et al. 2021; Burkett 2012; Eyles et al. 2016; Slattery et al. 2020). It is distinguished from co-designed research, which describes a continuum of participation in all stages of the research cycle, including co-planning, co-designing, co-conducting, and/or co-disseminating research with PLE and key interest holders, but may or may not include co-design or evaluation of an intervention (Bellingham et al. 2023). This active partnership fosters equity in the research and intervention development process, leading to outcomes more tailored to user needs, preferences, and contexts.

While co-design methodologies have been widely used across various disciplines (Webber et al. 2022; Yates et al. 2023; Bray et al. 2022; Patchwood et al. 2023; Schiffler et al. 2023), there is considerable variation in the terminology, types of, and levels of co-design partner involvement (Webber et al. 2022; Magee et al. 2022; Devan et al. 2021; Yates et al. 2023). Despite these inconsistencies, there is increasing interest in using co-design methodologies in both pain management research and in the development of pain interventions, particularly in the development of technology-based solutions, self-management strategies, and complex interventions (Greenhalgh et al. 2016; Cooke et al. 2021; Ledel Solem et al. 2020; Goff et al. 2023; Wylde et al. 2018). However, there is a lack of comprehensive reviews on how co-design processes have been conceptualised or used to develop pain management interventions, or more broadly, in pain management research. Therefore, we aimed to identify the terminology, characteristics, and components of co-design in pain management interventions and research to guide future co-design of pain management interventions and research.

Methods

Design and protocol registration

This scoping review was conducted using the methodological framework described by Arksey and O'Malley (2005). Our results are reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Review (PRISMA-ScR) reporting guidelines (Supplementary file 1). The protocol was prospectively registered on Open Science Framework at https://osf.io/tbvy9/ (Gashaw et al. 2024).

Data source and search strategies

Three key concepts (pain, co-design, and intervention) were developed to generate search terms. Search strategies were initially drafted for MEDLINE (Ovid) in consultation with a health librarian at the University of Technology Sydney (UTS), and subsequently adapted for other electronic databases. Searching was conducted from inception to March

2024 across six databases. The search was conducted across MEDLINE (Ovid), Embase (Ovid), CINAHL (EBSCOhost), PsycINFO, Web of Science, and Scopus, without restrictions on publication year, type, and language. Additionally, the reference lists of review articles on co-designed interventions and research in pain management were manually checked. Detailed search terms, strategies, and results for each database are provided in Supplementary file 2.

Eligibility criteria

We aimed to synthesise and map available co-design studies on pain management interventions conducted in any setting. We considered primary peer-reviewed studies with quantitative, qualitative, and mixed-method designs. We excluded conference abstracts, review articles, editor letters, and expert opinions. Eligibility criteria were described using the participant, concept, and context (PCC) framework for scoping review, as follows:

Population We included co-design studies conducted among individuals of all ages with any pain condition. Pain was operationalised as an unpleasant sensory and emotional experience associated with or without potential tissue damage, encompassing acute and chronic, specific and nonspecific pain conditions, and pain related to medical conditions or procedures (Raja et al. 2020; Kumar and Elavarasi 2016).

Concept Our review centred on two concepts: co-design research and pain management intervention. We included studies that described co-design and collaboration between people with lived experience of pain, researchers, and other key stakeholders, characterised by partnerships, shared responsibility, and meaningful participation, regardless of whether the term 'co-design' was explicitly used or claimed. Because co-design is frequently used interchangeably with related terms such as collaborative approaches, co-creation, and co-production (Slattery et al. 2020).

To operationalise the level of participation, we used the International Association of Public Participation (IAP2) spectrum, which outlines participation in interventions and research across five levels: inform, consult, involve, collaborate, and empower (Sheridan et al. 2017; Participation 2018), with levels of participations described as collaborate and empower, more consistent with contemporary definitions of co-design (O'Cathain et al. 2019; Elbers et al. 2021; Burkett 2012; Eyles et al. 2016; Slattery et al. 2020).

We included peer reviewed studies that applied co-design or collaboration at any stage of the research process related to pain management, including determining pain research needs, priorities, or questions (co-decide); planning and study design (co-planning); intervention design (co-design); and co-evaluation, dissemination, and implementation (co-evaluating). We excluded co-design studies that were not on pain management or did not include pain management components.

Context We included peer-reviewed studies from any country and therapeutic setting (e.g. healthcare setting, community, and home-based interventions).

Study selection

The search results were imported into Covidence for deduplication and screening (Covidence systematic review software, Veritas Health Innovation, Melbourne, Australia.). Two independent reviewers (MG, TK) screened for eligibility based on titles and abstracts. Full texts were then retrieved for the remaining articles and independently evaluated against the inclusion criteria by the same reviewers. Any disagreements and discrepancies during the screening process were resolved by a third reviewer (LJ). The search results and study screening process were detailed and presented using the PRISMA-ScR diagram (Rethlefsen and Page 2022) in Fig. 1.

Data extraction and charting

The first author (MG) developed a data extraction form in Microsoft Excel in consultation with BST and LJ. All authors revised and approved the data extraction form. The data extraction form was then piloted by extracting the data from five (10%) randomly selected articles (MG and TK) to ensure consistency. The clarity and the agreement of the piloted data were checked by the senior author (BTS). Data items extracted were study and participant characteristics such as lead authors, publication year, study country, study aims, design and settings, sample size, study population description (e.g., age, sex), and strengths and limitations of the included studies. Additionally, data extracted included the co-design or collaborative process, including methodology, terminology, interest holders engaged and their role, type of intervention or research developed, evaluation and outcome of interventions or research, and reported theoretical frameworks.

Synthesis of results

The data were synthesised using both narrative and quantitative approaches. Study characteristics such as publication year, country, study design, and study population were described using frequency and percentage. To explore the available evidence on co-design research for pain management in low- and middle-income countries, we categorised the countries of the included studies as low-income, lower-middle-income, upper-middle-income, and higher-income

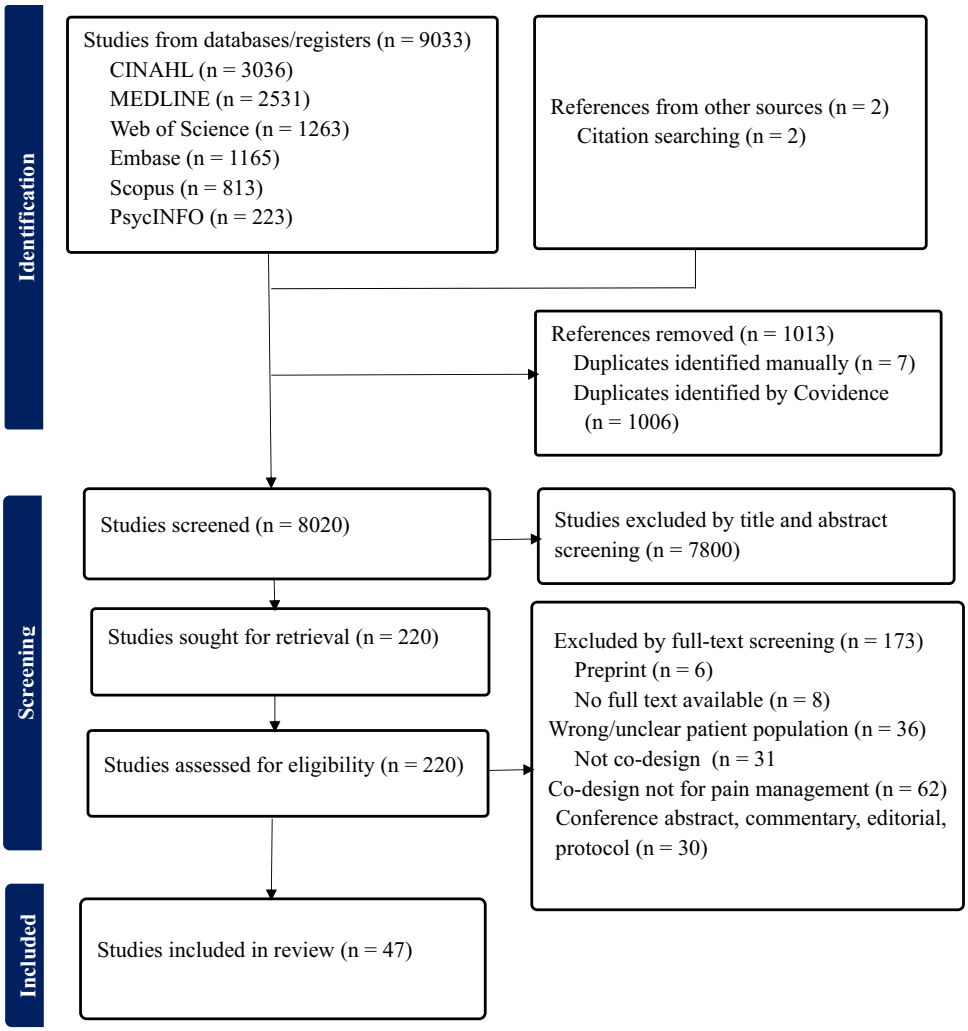

Fig. 1 The PRISMA flow diagram summarises the study selection process

based on the World Bank's recent classification (The World). Given the diverse pain types in the study populations, we further categorised the pain conditions as acute and chronic pain based on their duration or as reported in the studies, and classified by age groups: adult (age 18 years and above) and pediatric populations (children and youth under 18 years).

The review aimed to explore the description and characteristics of co-design methodology for developing pain management interventions and research. This was mapped by examining across studies the co-design and collaborative terminology, partners and roles, methods and activities, interventions and research, evaluation, and outcome of interventions and research, and theoretical frameworks. Challenges in co-design and collaborative studies were also examined. A qualitative narrative synthesis was used to describe the co-design and collaborative participants, their level of engagement, evaluation strategies, and the reported limitations and strengths of the co-design studies.

Results

Selection of sources of evidence

Our search identified 9031 records from six electronic databases and two additional articles from manual reference list searches. A total of 7800 records were excluded during title and abstract screening, and 220 articles were selected for full-text screening, of which 47 were included in this review (see Fig. 1).

Study and study population characteristics

The 47 included studies covered 14 countries across five continents, with 94% ($n = 44$) conducted in high-income countries (Cooke et al. 2021; Ahern et al. 2022a; Ahern et al. 2022b; Braithwaite et al. 2023; Yates et al. 2023; Magee et al. 2022; Fernon et al. 2016; Fritsch et al. 2021; Goff et al. 2023; Marcelo et al. 2023; Sherman et al. 2022; Slater et al.

2012; Slater et al. 2020; Tacey et al. 2023; Bedson et al. 2019; Bostrøm et al. 2020; Ledel Solem et al. 2020; Donnelly et al. 2021; Fränkl et al. 2024; Grønning et al. 2018; Hochstenbach et al. 2017; Lyng et al. 2023; Morcillo-Muñoz et al. 2021; Primdahl et al. 2024; Turesson et al. 2022; Carr et al. 2019; Godziuk et al. 2022; Lalonde et al. 2015; Mrklas et al. 2020; Shewchuk et al. 2021; Zaslawski et al. 2023; Jinks et al. 2009; Liu et al. 2019; Patel et al. 2019; Prothero et al. 2017; Sandhu et al. 2022; Webber et al. 2022; Wylde et al. 2018; Al-Mondhiry et al. 2022; Hommel et al. 2020; Leach et al. 2019; Schemer et al. 2023), including Australia ($n=14$; 30%) (Cooke et al. 2021; Ahern et al. 2022a; Ahern et al. 2022b; Braithwaite et al. 2023; Yates et al. 2023; Magee et al. 2022; Fernon et al. 2016; Fritsch et al. 2021; Goff et al. 2023; Marcelo et al. 2023; Sherman et al. 2022; Slater et al. 2012; Slater et al. 2020; Tacey et al. 2023), United Kingdom ($n=8$;17.0%) (Bedson et al. 2019; Jinks et al. 2009; Liu et al. 2019; Patel et al. 2019; Prothero et al. 2017; Sandhu et al. 2022; Webber et al. 2022; Wylde et al. 2018), Canada ($n=6$; 12.8%) (Carr et al. 2019; Godziuk et al. 2022; Lalonde et al. 2015; Mrklas et al. 2020; Shewchuk et al. 2021; Zaslawski et al. 2023), and the United States of America ($n=4$; 8.5%) (Al-Mondhiry et al. 2022; Hommel et al. 2020; Leach et al. 2019; Schemer et al. 2023). Only three studies ($n=3$; 6.0%) were conducted in LMICs, where one study was conducted in Ethiopia and two studies in Iran (Carey et al. 2023; Namnabati et al. 2017; Mehdizadeh et al. 2022). Despite no restrictions on the publication year, all included studies were published from 2009 onwards (Fig. 2). Most studies ($n=29$; 61.7%) were qualitative, followed by mixed methods designs ($n=15$; 31.9%).

The study populations varied in age and pain conditions, with sample sizes ranging from 5 to 50 people involved in the collaboration. The majority of studies were conducted among people with non-specific chronic pain ($n=16$; 34.0%) (Bedson et al. 2019; Bostrøm et al. 2020; Ledel Solem et al. 2020; Cooke et al. 2021; Grønning et al. 2018; Lalonde et al. 2015; Lyng et al. 2023; Magee et al. 2022; Morcillo-Muñoz et al. 2021; Sandhu et al. 2022; Schemer et al. 2023; Slater et al. 2020; Turesson et al. 2022; Wylde et al. 2018; Yates et al. 2023; Zaslawski et al. 2023), arthritis-related pain ($n=13$; 27.7%) (Braithwaite et al. 2023; Carr et al. 2019; Donnelly et al. 2021; Fernon et al. 2016; Godziuk et al. 2022; Goff et al. 2023; Marcelo et al. 2023; Mrklas et al. 2020; Shewchuk et al. 2021; Primdahl et al. 2024; Prothero et al. 2017; Tacey et al. 2023), low back pain ($n=6$; 12.8%) (Ahern et al. 2022a; Ahern et al. 2022b; Fritsch et al. 2021; Liu et al. 2019; Slater et al. 2012; Webber et al. 2022), and cancer-related pain ($n=6$; 12.8%) (Carey et al. 2023; Leach et al. 2019; Mehdizadeh et al. 2022; Schmidt et al. 2020; Al-Mondhiry et al. 2022; Hochstenbach et al. 2017). For a detailed summary of the study and participant characteristics, see Table 1.

Overall, $n=33$ (70.2%) studies focused on the design of pain management strategies, tools, research priorities, and interventions, which were not evaluated. In contrast, one-third of the included studies ($n=14$) focused on evaluating interventions (Table 3).

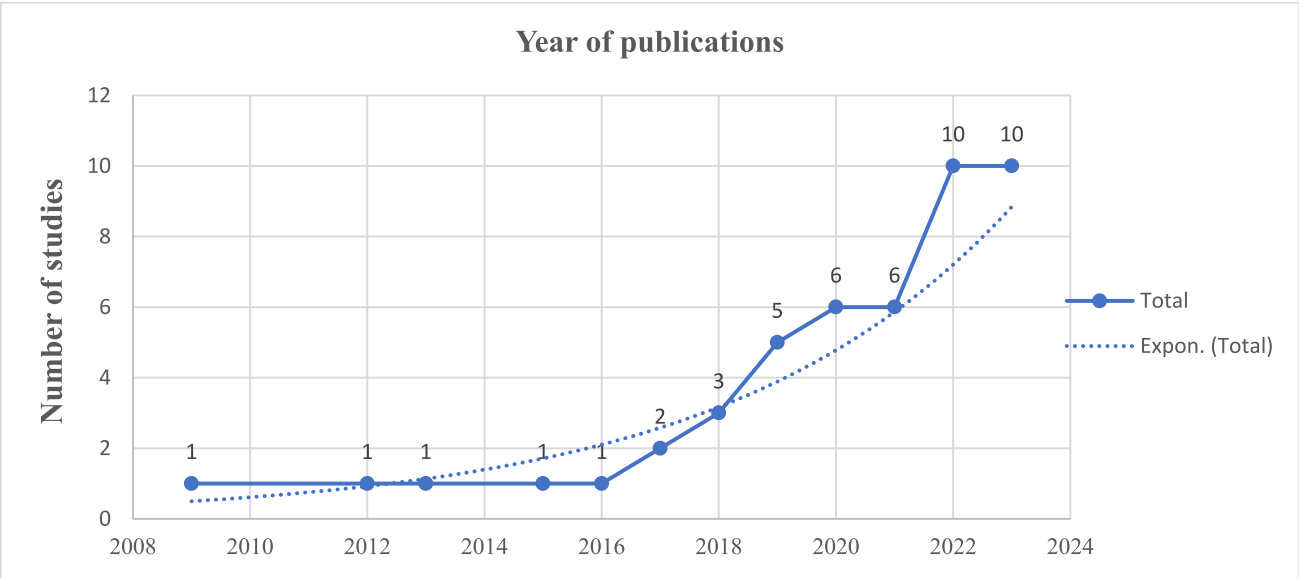

Fig. 2 Publication Trends in Co-design Research Over Time ($n=47$)

Table 1 Study and participant characteristics of the included studies ($n = 47$)

Authors (year)	Country	Target population	Study design	Study setting	Age of study population	Sample size	% of female
Ahern et al. (2022a)	Australia	Acute LBP	Mixed study	Primary care	≥18 years; mean (44)	Focus goup = 13 Survey = 426	NR
Ahern et al. (2022b)	Australia	Acute LBP	Pilot trial	Primary care	Mean (± SD) (40.5 (± 13.2)	14	50
Bedson et al. (2019)	UnitedKingdome	MSK chronic pain	Qualitative	Primary care	≥18 years Not specified	NR	NR
Blödt et al. (2013)	German	Women with menstrual pain	Mixed study	College	Range (16 to 25)	NR	100
Bostrøm et al. (2020)	Norway	Chronic pain	Pilot trial	Healthcare facilities and online	≥18 years Not specified	50	NR
Ledel Solemet al. (2020)	Norway	Chronic pain	Qualitative	Online through eHealth	≥18 years; mean (51)	17	88
Al-Mondhiry et al. (2022)	USA	Cancer pain	Qualitative	Academic and community centres	≥18 years Not specified	11	NR
Braithwaite et al. (2023)	Australia	Osteoarthritis (OA)	Qualitative	Arthritis Foundation headquarters	Mean (± SD) 68.7 (± 9.8)	6	33.30
Carey et al. (2023)	Ethiopia	People in palliative care (cancer pain)	Qualitative	Hospital and non-governmental organization centre	Range (30–50) years	Phase I: ($n = 40$), phase II ($n = 10$)	NR
Carr et al. (2019)	Canada	People with arthritis (OA and RA)	Qualitative	Healthcare organization	NR	NR	NR
Cooke et al. (2021)	Australia	Chronic pain	Qualitative	Pediatric chronic pain clinic	Range (10–14) years	Phase I = 14; phase II = 3 and phase II = 6	NR
Donnelly et al. (2021)	Ireland	People with RA	Qualitative	Community	Range (37–83)	11	72.70
(Fernon et al. 2016)	Australia	Gout arthritis	Qualitative	Hospital	Range (39–79)	13	15.40
Frankl et al. (2024)	German	Persistent somatic pain	Qualitative	University Medical centre	Mean (± SD) 48.3 (± 14.8) years	12	66.70
Fritsch et al. (2021)	Australia	LBP	Qualitative	Community and primary care	NR	15	NR
Godziuk et al. (2022)	Canada	Knee OA	Qualitative	Online	≥40 Years Not specified	Survey ($n = 20$ and interview ($n = 10$)	100
Goff et al. (2023)	Australia	OA	Qualitative	Mixed (online and health care)	Median (range) 68(63–78)	15	73.30
Grønning et al. (2018)	Norway	Chronic pain	Qualitative	Primary healthcare centre	Range (31–61) years	7	85.70
Hochstenbach et al. (2017)	Netherlands	Cancer pain	Qualitative	Outpatient setting	Range (53–60) years	5	NR
Hommel et al. (2020)	USA	Adolescent with migraine	Qualitative	Multidisciplinary headache centre	Range (11–18) years	40	75
Jinks et al. (2009)	UnitedKingdome	Knee pain	Qualitative	University research centre	NR	13	76.90
Lalonde et al. (2015)	Canada	Chronic non-cancer pain	Qualitative	Primary care centres	NR	53	NR
Leach et al. (2019)	USA	People with cancer pain	Qualitative	Clinics	Mean (± SD) 61 (± 14) years	40	65
Liu et al. (2019)	Unitedkingdom	LBP	Mixed study	Phone call	NR	NR	NR

Table 1 (continued)

Authors (year)	Country	Target population	Study design	Study setting	Age of study population	Sample size	% of female
Lyng et al. (2023)	Denmark	MSK chronic pain	Mixed study	Online	≥18 years Not specified	NR	92.80
Magee et al. (2022)	Australia	Chronic pain	Mixed study	Online	NR	12	NR
Marcelo et al. (2023)	Australia	LBP, hip and knee OA	Mixed study	Online	Mean (±SD) 73.4 (±5.7) years	30	57
Mehdizadeh et al. (2022)	Iran	Children with cancer pain	Qualitative	Treatment and research centre	Mean (9) Range (7–14) years	5	60
Morcillo-Munoz et al. (2021)	Spain	Chronic non-malignant pain	Mixed study	Community province centres	NR	28	NR
Mrklas et al. (2020)	Canada	Knee OA	Qualitative	Academic health centre	NR	28	53.60
Shewchuk et al. (2021)	Canada	Knee OA	Mixed study	Arthritis Alliance centre and healthcare	≥20 years Not specified	18	61
Memarzadeh et al. (2017)	Iran	Post-surgical pain	Qualitative	Hospital	NR	50	90
Patel et al. (2019)	UnitedKingdom	Chronic headache	Mixed study	Community (home to home)	≥18 years Not specified	7	NR
Primdahl et al. (2024)	Denmark	People with Inflammatory arthritis	Qualitative	Outpatient clinics	Median (range): 52.4 (8–65)	38	71
Prothero et al. (2017)	UnitedKingdom	People with RA	Qualitative	Health research centre	>18 years Not specified	7	NR
Sandhu et al. (2022)	Unitedkingdom	Chronic pain	Qualitative	University Hospital	>18 years Not specified	19	NR
Schemer et al. (2023)	USA	Youth with chronic pain	Qualitative	Clinics	Mean (±SD) 13 (±3.12) Range (8–20)	26	77
Schmidt et al. (2020)	Switzerland	Cancer pain	Qualitative	Online	NR	26	100
Sherman et al. (2022)	Australia	People with endometriosis	Mixed study	Online	≥18 years Not specified	22	100
Slater et al. (2012)	Australia	Back pain	Quantitative	Community	Mean (±SD) 62.3 (±15.1) years	51	68.80
Slater et al. (2020)	Australia	Chronic MSK pain	Mixed study	Community	Mean (±SD) 20.5 (±3.3) years	15	80
Tacey et al. (2023)	Australia	OA	Mixed study	Tertiary Hospital	Mean (±SD) 64.3 (±7.2) years	11	64
Turesson et al. (2022)	Sweden	Chronic pain	Mixed study	NR	NR	7	NR
Webber et al. (2022)	UnitedKingdom	LBP	Qualitative	Community setting and healthcare centre	NR	8	NR
Wylde et al. (2018)	UnitedKingdom	Chronic pain	Mixed study	Orthopaedics centre	NR	NR	NR
Yates et al. (2023)	Australia	Chronic pain	Mixed study	Community setting	Mean (±SD) 54.9 (±15.74) years	Qualitative ($n=22$) and survey ($n=186$)	69.90
Zaslawski et al. (2023)	Canada	Chronic pain	Qualitative	Online	Range (15–18) years	9	53.30

LBP Low back pain; *MSK* Musculoskeletal; *NR* Not reported; *OA* Osteoarthritis, *RA* Rheumatoid arthritis

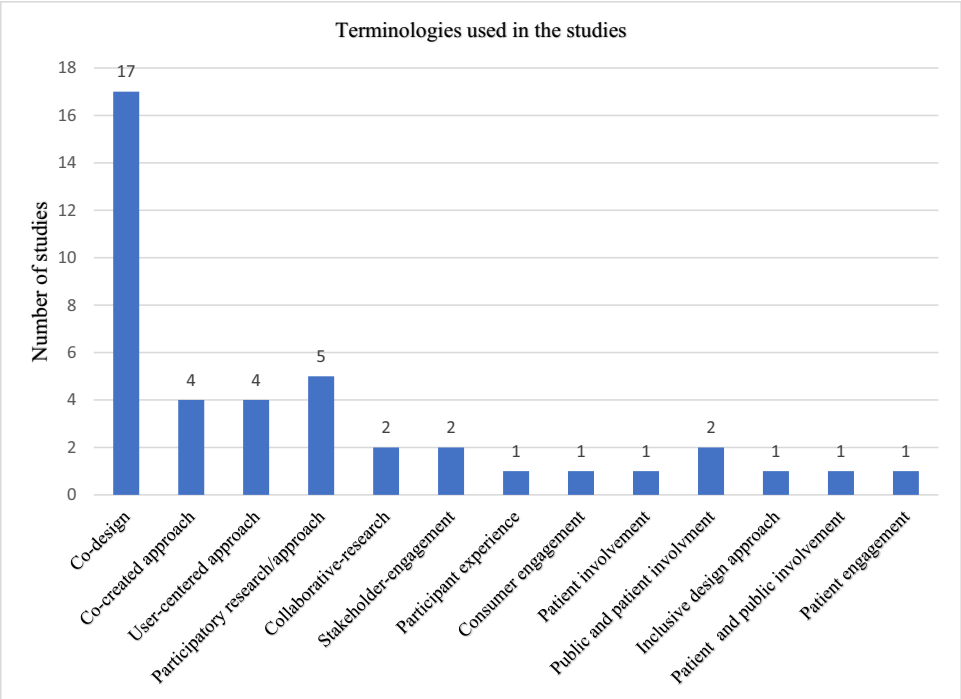

Fig. 3 Terminologies used in the co-design studies ($n=41$)

Characteristics of studies in developing pain management interventions

Terminologies used across studies

Thirteen different terminologies were identified across 41 studies (87.2%) to describe participation, collaboration, and partnerships among researchers, PLEs, and interest holders (Fig. 3). Six studies (12.8%) did not specify the terminology to describe the collaborative process; however, they met the selection criteria. The term 'co-design' was the most frequently used terminology by the included studies ($n=17$; 36.2%), followed by 'participatory research' ($n=5$; 10.6%), and some were described as 'user-centred' ($n=4$; 8.5%). However, only nine studies defined their terminologies by citing other sources (Bedson et al. 2019; Braithwaite et al. 2023; Carr et al. 2019; Goff et al. 2023; Jinks et al. 2009; Liu et al. 2019; Schemer et al. 2023; Schmidt et al. 2020; Tacey et al. 2023).

Co-design partners and their role

Studies described involving PLE and multidisciplinary clinicians (e.g. general practitioners, physiotherapists, nurse practitioners, psychologists, medical and pain specialists, and other allied health professionals) and various other interest holders. Over one-third ($n=16$; 34.0%) of the included studies involved carers, family, and patient advocacy groups (Bedson et al. 2019; Ledel Solem et al. 2020; Al-Mondhiry et al. 2022; Carey et al. 2023; Carr et al. 2019; Fritsch et al. 2021; Hommel et al. 2020; Lalonde et al. 2015; Lyng et al. 2023; Marcelo et al. 2023; Mehdizadeh et al. 2022; Morcillo-Muñoz et al. 2021; Memarzadeh et al. 2017; Primdahl et al. 2024; Sherman et al. 2022). Studies were also conducted with healthcare managers, social workers, technicians, software developers, community representatives, and representatives from (e.g. pain associations, health insurance, and digital health companies) (Bedson et al. 2019; Ledel Solem et al. 2020; Fränkl et al. 2024; Tacey et al. 2023; Turesson et al. 2022). The role of PLE and interest holders was varied and not clearly stated across the studies.

The level of involvement of PLE and interest holders varied across studies. While some ($n=11$) studies involved PLE and interest holders as study partners and co-researchers throughout the research process, meeting contemporary definitions of co-design (Fernon et al. 2016; Godziuk et al. 2022; Donnelly et al. 2021; Hochstenbach et al. 2017; Hommel et al. 2020; Leach et al. 2019; Lyng et al. 2023; Prothero et al. 2017; Schemer et al. 2023; Al-Mondhiry et al. 2022; Bedson et al. 2019), other partners appeared to be involved via steering and advisory committees and the level of participation was unclear. However, the majority ($n=20$) of studies that stated they were co-designed, only appeared to engage PLE and interest holders for insights and feedback, which would be equivalent to the level of consultation rather than co-design (Braithwaite et al. 2023; Cooke et al. 2021; Godziuk et al. 2022; Lalonde et al. 2015; Liu et al. 2019; Magee et al. 2022; Marcelo et al. 2023; Morcillo-Muñoz et al. 2021; Memarzadeh et al. 2017; Sandhu et al. 2022; Slater et al. 2020; Turesson et al. 2022; Yates et al. 2023;

Zaslawski et al. 2023; Wylde et al. 2018; Sherman et al. 2022; Grønning et al. 2018; Fränkl et al. 2024; Donnelly et al. 2021; Table 2).

Methods and collaborative activities

The included studies described a wide range of approaches to co-design or collaboration, with over half of the studies (24; 51.0%) describing various processes and activities (Ahern et al. 2022a; Bedson et al. 2019; Blödt et al. 2013; Al-Mondhiry et al. 2022; Carey et al. 2023; Donnelly et al. 2021; Fritsch et al. 2021; Hommel et al. 2020; Jinks et al. 2009; Liu et al. 2019; Mehdizadeh et al. 2022; Mrklas et al. 2020; Memarzadeh et al. 2017; Patel et al. 2019; Schemer et al. 2023; Sherman et al. 2022; Slater et al. 2020; Tacey et al. 2023; Turesson et al. 2022; Wylde et al. 2018; Yates et al. 2023), including workshops, working groups, interviews, surveys, and focus groups. Specifically, co-design workshops were mentioned in 19 studies (40.4%). Additionally, 10 studies (21.3%) described meetings with interest holders, expert panels, consultations, or patient working groups. Others conducted research activities like interviews (18 studies; 38.3%), online and self-administered surveys (10 studies; 21.3%), and focus groups (7 studies; 14.9%). While these research methodologies have generated data, their capacity for true collaboration were not fully established. Furthermore, detailed descriptions of the frequency and duration of these activities were not adequately described across the studies. However, some studies did indicate that the frequency of co-design or collaborative activities ranged from one to seven, with durations lasting from 20 min to a day (Zaslawski et al. 2023; Webber et al. 2022; Tacey et al. 2023; Schemer et al. 2023; Lalonde et al. 2015; Fränkl et al. 2024; Table 2).

Types of interventions co-designed

The interventions developed across the studies were broad. Studies commonly reported on the design of pain management interventions, strategies, tools, apps, protocols, and educational material (Fernon et al. 2016; Cooke et al. 2021; Braithwaite et al. 2023). More than one-third ($n = 18$; 38.3%) of the interventions focused on empowering self-management programs with ($n = 11/18$; 61.1%) digital and app-based strategies, and another one-third of interventions ($n = 14$; 29.8%) (Bedson et al. 2019; Ledel Solem et al. 2020; Carey et al. 2023; Cooke et al. 2021; Fernon et al. 2016; Fernon et al. 2016; Goff et al. 2023; Hochstenbach et al. 2017; Hommel et al. 2020; Leach et al. 2019; Magee et al. 2022; Mehdizadeh et al. 2022; Mrklas et al. 2020; Turesson et al. 2022) were technology-based interventions. The most common types of pain management interventions developed through co-design and collaborative studies were self-management interventions ($n = 18$), educational interventions ($n = 6$), self-care and self-efficacy interventions ($n = 4$), complex and multimodal interventions ($n = 3$), and palliative care management ($n = 2$).

Evaluations and outcomes of interventions

One-third ($n = 14$; 29.8%) of the included studies evaluated the acceptability and feasibility of interventions in real-world settings (Ahern et al. 2022b; Bedson et al. 2019; Bostrøm et al. 2020; Al-Mondhiry et al. 2022; Cooke et al. 2021; Hommel et al. 2020; Shewchuk et al. 2021; Patel et al. 2019; Sandhu et al. 2022; Slater et al. 2012; Slater et al. 2020; Tacey et al. 2023; Wylde et al. 2018; Yates et al. 2023). Twelve studies used pre- and post-pilot testing, and two studies used prospective cohorts and mixed methods to assess the interventions, with follow-up durations ranging from two days to 6 months. The studies used patient-reported outcome measures to evaluate primary outcomes such as feasibility, acceptability, usability, and deliverability, and secondary outcomes focused on the clinical and functional impact of the interventions. These outcome measures are important to assess the subjective experiences and objective health outcomes of the study population (Table 3).

Theoretical frameworks used in the studies

Most studies ($n = 38$; 86.0%) did not report or use a theoretical framework to guide the development of co-design or collaboration. The biopsychosocial model ($n = 1$), blended care model ($n = 1$), integrated conceptual framework ($n = 1$), behavioural change model ($n = 1$), Medical Research Council framework ($n = 3$), and chronic care model ($n = 2$) were the commonly reported theoretical framework guides used in some studies (Ahern et al. 2022a; Bostrøm et al. 2020; Patel et al. 2019; Primdahl et al. 2024; Sandhu et al. 2022).

Limitations and strengths of co-designing as reported in the included studies

Studies included in the review discussed their limitations and potential strengths within their co-design or collaborative process. The most common limitations reported were the representativeness and generalizability of the results (Bedson et al. 2019; Al-Mondhiry et al. 2022). For example, studies were conducted in a single setting, with an underrepresentation of men with lived experience in collaborative processes and a lack of partners with lived experience (Leach et al. 2019; Ledel Solem et al. 2020; Godziuk et al. 2022). Researchers also noted that the appropriateness and transferability of the study findings were related to the representativeness of multiple study participants and 'end users', including PLE, and healthcare professionals with different ages, settings,

Table 2 Characteristics of co-design studies in developing pain management interventions ($N=43$)

Aim of co-design	Co – designparticipants		Phase of co-design participants engaged	Terminologies	Co-design methods/ activity	Frequency of co-design activities
	Consumers (patients and carers) involved	Other interest holders involved				
To develop My Back My Plan (MBMP) primary care program for acute LBP (Ahern et al. 2022a)	People with LBP	primary care clinicians (GPs, PTs, practice managers)	Co-deciding, co-planning, co-designing,	Co-design	Focus group and survey	3 = focus group
To develop and validate the pain-monitoring app (Keele pain recorder) for patients with MSK pain (Bedson et al. (2019)	Patient advisor group	Clinical advisor group (GP, PT, research nurses, primary care researchers, research facilitators, & information technology managers)	Co-deciding, co-planning, co-evaluation	Collaborative-research	Interview, and workshop	2 = workshops
To design a study on the effectiveness of additional self-care acupressure for menstrual pain comparing usual care alone using different methods of stakeholder engagement (Blödt et al. 2013)	Women with menstrual pain	Stakeholder advisor group (acupuncture expert, gynecologist, lived experience teacher, and mind–body medicine expert)	Co-planning, co-designing, co-deciding	Stakeholder-engagement	survey, focus group, stakeholder meeting	1 = focus group and 3 = stakeholder meetings
To design and develop a user-centred, evidence-based eHealth self-management intervention for people with chronic pain (Ledel Solem et al. 2020)	People with chronic pain and their Spouses	Health care providers, health care manager, eHealth research psychologist, editors, software developers, and user representative	Co-planning, co-designing, co-deciding	User-centred	Workshops	5
To use community-partnered participatory research to co-design and pretest a mobile app on palliative care priorities of clinicians and patients with advanced cancer (Al-Mondhiry et al. 2022)	People with cancer and their carers	Physicians and nurse practitioners	Co-planning, co-deciding, co-evaluation	Co-created approach	Interview and patient working group meetings	4

Table 2 (continued)

Aim of co-design	Co – designparticipants		Phase of co-design participants engaged	Terminologies	Co-design methods/ activity	Frequency of co-design activities
	Consumers (patients and carers) involved	Other interest holders involved				
To identify translational research solutions to improve the uptake of core management strategies that are grounded in consumers' lived experience of OA (Braithwaite et al. 2023)	Patients with OA	Pain researchers	Co-planning, co-deciding, co-designing	Co-design	Workshop	3
To co-design, develop, and evaluate a mobile phone-based remote monitoring system for use by palliative care patients (Carey et al. 2023)	People in palliative care and family care	Healthcare provider	Co-planning, co-designing, co-deciding, co-evaluate	Co-design	Interviews and workshop	Interview ($n=2$) and workshop ($n=1$)
To describe the process of patient engagement to co-design a patient experience survey for people with arthritis (Carr et al. 2019)	Patient representatives	Researchers	Co-deciding, co-planning	Co-design	Online meeting	NR
To co-create a mHealth app with consumers and healthcare professionals and evaluate the acceptability and feasibility of the resulting mHealth app (Cooke et al. 2021)	Children with chronic pain, parents	Healthcare providers	Co-designing, co-evaluating, co-implemting	Co-created approach	Interview	2
To understand how individuals with RA self-managing their illness through the involvement of stakeholders (Donnelly et al. 2021)	People with rheumatoid arthritis	Research advisory group (people with lived experience, HCP), multidisciplinary academic team	Co-decing, co-planning	Participatory approach	Interview, photograph, and workshop	Workshop ($n=2$)
To involve end-user patients in the design of a gout self-management eTool (Fernon et al. 2016)	People with Gout	NR	Co-planning, co-designing	User-centred	Focus group	4

Table 2 (continued)

Aim of co-design	Co – designparticipants		Phase of co-design participants engaged	Terminologies	Co-design methods/ activity	Frequency of co-design activities
	Consumers (patients and carers) involved	Other interest holders involved				
To identify the need for internet-based guides and to evaluate public and patient involvement for persistent somatic symptoms (Fränkl et al. 2024)	People with persistent somatic pain	Health insurance and digital health agency representatives, healthcare providers, self-help organizations	Co-planning, co-designing	Public and patient involvement	Workshop	4
To develop a bank of text messages for a lifestyle-based self-management intervention for people with low back pain (Fritsch et al. 2021)	Consumer representative (people with LBP and pain community)	Multidisciplinary clinicians, and researchers	Co-designing, co-deciding	Co-design	Workshop and expert review	1
To connect and consult people with knee OA in the design and delivery of a multimodal intervention Godziuk et al. (2022)	People with knee OA	NR	Co-planning, co-designing	Patient engagement	Survey and interview	1
To develop the web-based Translating Research Evidence and Knowledge (TREK) 'My Knee' education and self-management toolkit for people with knee osteoarthritis (Goff et al. 2023)	People with knee OA	Healthcare providers (physiotherapists, exercise physiologists, nurse practitioners)	Co-deciding, co-designing	Co-design	Workshops	3
To explore participants' experiences with a chronic pain self-management intervention (Grønning et al. 2018)	People with chronic pain	Healthcare providers (physiotherapists, lifestyle coaches), service user representative	Co-designing, co-deciding	Participant experience	Interview	NR

Table 2 (continued)

Aim of co-design	Co – designparticipants		Phase of co-design participants engaged	Terminologies	Co-design methods/ activity	Frequency of co-design activities
	Consumers (patients and carers) involved	Other interest holders involved				
To describe a co-creative method in the development of an eHealth intervention delivered by registered nurses to support self-management in outpatients with cancer pain (Hochstenbach et al. 2017)	People with cancer pain	Healthcare practitioners and researchers	Co-designing, co-evaluation	Co-created approach	Interview	NR
To design, code, and pilot test the feasibility and preliminary efficacy of a self-management digital therapeutic tool for migraine headaches (Hommel et al. 2020)	People with migraine headaches, parents/ caregivers	Clinicians	Co-designing, co-deciding, co-evaluation	Co-design	Focus group and interview	NR
To establish a community knee pain forum to engage stakeholders in the design, dissemination, and prioritization of knee pain research (Jinks et al. 2009)	Arthritis care members	GPs, PTs, fitness instructors, social service workers, researchers	Co-designing, co-dissemination	Stakeholder-engagement	Meeting and interview	Meeting ($n=3$)
To explore the perceptions of key actors regarding the challenges and priority interventions to improve CNCP management in primary care (Lalonde et al. 2015)	People with chronic pain and family members	Physicians, pharmacists, nurses, physiotherapists, psychologists, pain specialists, patients, family members, decision-makers and managers, and pain researchers	Co-planning, co-designing,	Participatory research	Focus group	7
To evaluate user testing for an eHealth program designed for cancer survivor self-management (Leach et al. 2019)	People with different forms of cancer	NR	Co-develop, co-evaluation	User-centred	Action decks	NR

Table 2 (continued)

Aim of co-design	Co – designparticipants		Phase of co-design participants engaged	Terminologies	Co-design methods/ activity	Frequency of co-design activities
	Consumers (patients and carers) involved	Other interest holders involved				
To apply Inclusive Design methods in pain self-management and propose ways to increase people's access to a 'Physio-Direct' service (Liu et al. 2019)	People with low back pain	Physiotherapists	Co-deciding, co-planning, co-design,	Inclusive design approach	Survey and interview	NR
To establish research priorities for chronic musculoskeletal (MSK) pain (Lyng et al. 2023)	People living with chronic MSK pain, and their relatives	Healthcare providers, researchers	Co-planning, co-deciding	Participatory research	Survey and workshop	1
To evaluate and improve the content of a mHealth intervention for chronic pain (Magee et al. 2022)	People with chronic pain	Healthcare providers (pain specialist physician, clinical psychologist, PTS)	Co-planning, co-designing, co-evaluation	Co-design	Online survey	NR
To develop and evaluate two educational consumer leaflets to support opioid tapering in older people with low back pain (LBP) and hip or knee osteoarthritis (Marcelo et al. 2023)	People with LBP and their carers	Healthcare providers included physiotherapists, pharmacists, orthopedic surgeons, rheumatologists, nurse practitioners, and general practitioners	Co-planning, co-designing, co-deciding, co-evaluation	Co-design	Survey	NR
To develop and preliminary evaluation of a cancer self-management system (CanSelfMan) (Mehdizadeh et al. 2022)	Children with acute leukemia, and their parents	Clinicians	Co-planning, co-designing, co-evaluation,	Collaborative-research	Focus group and expert panel meeting	3
To select best evidence recommendations for chronic non-malignant pain and to prioritize self-care (Morcillo-Muñoz et al. 2021)	People with chronic pain, and caregivers	Healthcare providers and researchers	Co-planning, Co-designing	Participatory research	Workshops	NR

Table 2 (continued)

Aim of co-design	Co – designparticipants		Phase of co-design participants engaged	Terminologies	Co-design methods/ activity	Frequency of co-design activities
	Consumers (patients and carers) involved	Other interest holders involved				
To describe the co-design process for developing a knee osteoarthritis minimum viable product (MVP) mHealth app with patients, family physicians, and researchers that facilitates self-management and patient-physician communication (Mrklas et al. 2020)	People with knee osteoarthritis	Family physicians, and researchers	Co-planning, co-designing, co-deciding	Co-design	Focus group and Co-design workshop	3
To improve pain management in children with post-surgery pain (Memarzadeh et al. 2017)	Parents (mothers)	Nurses, doctors, anesthesiologists, anesthesia assistants, secretaries, researchers	Co-planning, co-evaluation	Participatory research	Workshop and interview	1
To develop and pilot self-management education interventions for chronic headaches (Patel et al. 2019)	People living with chronic headaches	Neurologists, general practitioners, leaders of headache charities, psychologists, academics, and researchers	Co-planning, co-deciding, co-evaluate	Patient and public involvement	Meeting and interview	NR
To develop a complex interdisciplinary Nurse-coordinated self-management (INSELMA) intervention for patients with Inflammatory Arthritis (Primdahl et al. 2024)	Patient representatives	Rheumatology nurses, physicians, rheumatologists, physiotherapists, occupational therapists, social workers, managers of a rehabilitation centre, psychologist	Co-planning, co-deciding	NR	Workshops	6
To develop a handbook to support intensive self-management for people with RA (Prothero et al. 2017)	People living with rheumatoid arthritis	Researchers	Co-deciding, co-evaluation	Patient involvement	Workshop	1

Table 2 (continued)

Aim of co-design	Co – designparticipants		Phase of co-design participants engaged	Terminologies	Co-design methods/ activity	Frequency of co-design activities
	Consumers (patients and carers) involved	Other interest holders involved				
To describe the design, development, and pilot of a multicomponent intervention for people with chronic non-malignant pain (Sandhu et al. 2022)	People with chronic pain	Healthcare providers and researchers	Co-developing, co-evaluation	NR	Consultation meeting	3
To explore and validate treatment change processes, prioritize and develop interventions for youth with chronic pain Schemer et al. (2023)	People with chronic pain, and caregivers	Researchers	Co-planning, co-designing, co-deciding	Co-design	Interview, co-design meeting	Co-design meeting ($n=6$)
To adapt a peer-led self-management program for female breast cancer survivors (Schmidt et al. 2020)	Women with breast cancer, and patient's advocacy	Healthcare providers, international research experts	Co-deciding, co-evaluation, co-dessemination	Co-created approach	Online workshop, conference	Workshop ($n=3$); conference ($n=2$)
To co-design and evaluate a bank of supportive SMS text messages (EndoSMS) for individuals with endometriosis (Schmidt et al. 2020)	Patient representatives	Healthcare providers, clinician researchers	Co-designing, co-evaluating	Co-design	Online workshops, and online survey	Workshop ($n=3$)
To test the acceptability and need for adaptation of extant digital technologies, the pain HEALTH website and the I Can Cope with Pain app, for use with musculoskeletal pain (Slater et al. 2020)	People with chronic pain	Clinicians	Co-conducting, co-evaluation	Co-design	Interview, app testing, and questionnaire	NR

Table 2 (continued)

Aim of co-design	Co – designparticipants		Phase of co-design participants engaged	Terminologies	Co-design methods/ activity	Frequency of co-design activities
	Consumers (patients and carers) involved	Other interest holders involved				
To co-design and test the feasibility of a digital health intervention for patients with OA (Tacey et al. 2023)	People with OA	Physiotherapist, occupational therapist, psychologist, language services manager, general practice adviser, rheumatologist, orthopedic surgeon, osteopath, representative of research design development agencies	Co-planning, co-designing, co-evaluation	Co-design	Workshop, feedback, and interview	1
To describe the development of a digital support application with evidence-based content for chronic pain (Turesson et al. 2022)	Patient representative	Healthcare researcher, and software team	Co-deciding, co-planning, co-designing	User-centred	Workshops and interview	NR
To use creative co-design to produce prototype evidence-based back pain educational resources Webber et al. (2022)	People with back pain	Healthcare providers, and researchers	Co-planning, co-designing, co-disseminating	Co-design	Workshops, and a co-design meeting	Workshops ($n=2$)
To refine the design of a complex intervention for chronic pain before rigorous evaluation (Wylde et al. 2018)	People with chronic pain	Orthopedic surgeons, physiotherapists, pain specialists, rheumatologist, and pain nurse	Co-planning, co-evaluation	NR	A co-design meeting, and surveys	NR
To co-design accessible interventions to increase pain self-efficacy, social connection, pain-related outcomes, and quality of life for chronic pain (Yates et al. 2023)	People with chronic pain	NR	Co-planning, co-designing	Co-design	Online survey and interview	NR
To gain perspectives from youth in the co-development of clinical trial design research related to chronic pain (Zaslawski et al. 2023)	Youth with chronic pain	Researchers	Co-deciding, co-planning, co-designing	Co-design	Online Focus group	2

CNCP Chronic non-cancerous pain; *GP* General practitioner; *LBP* Low back pain; *MSK* Musculoskeletal; *NR* Not reported; *OA* Osteoarthritis; *PT* Physiotherapist, *RA* Rheumatoid arthritis

educations, incomes, and gender compositions (Ahern et al. 2022a; Braithwaite et al. 2023). The small number of PLEs involved in co-design or collaborative processes was another reported limitation among the five studies (Al-Mondhiry et al. 2022; Grønning et al. 2018; Ahern et al. 2022b; Bedson et al. 2019; Hommel et al. 2020). A small sample size reduced participant diversity and made the findings less applicable to larger populations. Participant recruitment strategies (such as purposive and convenient selection of the study participants) and lack of follow-up due to logistical challenges were also less commonly mentioned limitations across the studies (Cooke et al. 2021; Zaslawski et al. 2023).

There were fewer strengths reported compared to limitations. Studies listed the use of co-design or collaborative methodology, including involvement of PLE and a broad range of interest holders, as strengths (Ledel Solem et al. 2020; Primdahl et al. 2024; Prothero et al. 2017). The iterative process and the use of theory-informed co-design were also reported as strengths in some studies (Wylde et al. 2018; Cooke et al. 2021).

Discussion

Our review found that co-design methodologies have been increasingly used in chronic pain research to develop self-management strategies and technology-based interventions in the past 5 years. However, the level of collaboration with PLE and interest holders across studies varied considerably. While some studies met contemporary criteria for co-design, namely equitable and collaborative decision-making with PLE and other key interest holders through one or all stages (O'Cathain et al. 2019; Elbers et al. 2021; Burkett 2012; Eyles et al. 2016; Slattery et al. 2020), the majority ($n=20$) of studies only appeared to engage PLE and interest holders at the level of consultation. The review identified a significant lack of co-design studies in LMICs to develop pain management interventions. Findings from this review showed that co-design approaches are increasingly employed in pain research. However, there is a need for detailed reporting and standardised terminology to describe the co-design process, as well as to expand co-design and collaborative studies in LMICs aimed at developing pain management interventions and strategies.

We identified 47 studies on diverse pain conditions, with the majority conducted on chronic pain. Of the included studies, only three studies were from LMICs, with the majority conducted in high-income countries. This review showed the underrepresentation of LMICs in co-designed pain management research. A possible reason for this gap could be the lack of resources and research funding, which limits interest holders' involvement and the ability to compensate co-design participants for their time (Singh et al. 2023). Furthermore, co-design practised in high-income countries has pre-established patient advocacy networks, an ethical review process that accommodates participatory methods, and a clear powersharing mechanism; however, in LMICs, community structure, cultural norms, a lack of structural support, and poor relationships between community researchers shape how the co-design process unfolded in this setting. The limited representation of LMICs and their high concentration in high-income countries is not merely a bibliometric observation but also has substantive implications for the transferability, equity, and real-world applicability of co-design approaches in these underrepresented countries with a high burden of chronic pain. This finding highlighted a fundamental equity and transferability issue that extends beyond research representation, as the interventions being developed and evaluated in the co-designed studies may be structurally and functionally unsuited to the underrepresented population that needs them most. Therefore, future research should prioritise not only the conduct of co-designed pain management research in LMIC settings but also the adaptation of co-design methodologies for development, documentation, and evaluation to these settings.

This review also found substantial variability in the terminology used to describe the co-design or collaborative process, participants, and methods, as well as significant differences in the levels of engagement of interest holders across the studies. This finding aligns with the previous co-design reviews on developing nutrition interventions (Meloncelli et al. 2023), stroke interventions (Singh et al. 2024), physical activity interventions (Constantin et al. 2022), co-design in health (Slattery et al. 2020), and multimorbidity care (Sumner et al. 2024). Terms such as 'co-design', 'co-production', 'co-creation', 'participatory action research', 'user-centred design', 'public involvement', and 'patient engagement' are often used interchangeably to describe interest holders' engagement in co-design studies (Barham 2011; Frank et al. 2015). Similarly, health researchers have referred to co-design partners using terms such as patients, patient partners, research partners, the public, end-users, consumers, and PLE (Holzer et al. 2022). This variability presents significant challenges to implementing and reproducing co-design approaches. These issues have also been identified in other fields, including physical activity intervention, stroke care, multimorbidity management, and mental health challenges (Sumner et al. 2024; Constantin et al. 2022; Talevski et al. 2023; Singh et al. 2024). The absence of standardised terminology and conceptual definitions has been a reporting challenge in collaborative research. Prior evidence highlights these inconsistencies as barriers to retrieving relevant literature and comparing findings across studies. This may also challenge search strategies to limit the scope of literature searches and increase the number of missing relevant studies (Drahota et al. 2016).

Table 3 Summary of studies evaluating co-designed pain management interventions ($n = 14$)

Authors	Description of intervention	Study type	Participants	Duration of follow-up	Mode of assessment	Outcomes	Outcome measure used	Findings/results
Ahern et al. (2022b)	Piloting My Back My Plan (MBMP) co-designed primary care program program for acute LBP	Pre-post pilot testing	Acute LBP patient Clinician (GPs, PTs)	3 months	In-person	Feasibility, acceptability of MBMP, Pain severity, recovery from LBP, and functional outcomes	A self-administered questionnaire, qualitative feedback, numerical pain rating scale, global back recovery scale, and Brief pain inventory questionnaire	MBMP is highly acceptable and feasible to improve patient understanding of LBP, practice of self-management, and functional recovery
Bedson et al. (2019)	Acceptability and clinical utility of the 'Keele pain recorder'	Pre-post pilot study	Patients GPs Nurse practitioners	1 month	In-person	Validity, acceptability, usefulness pain recorder	Baseline and post-study questionnaires	Promising in validity, acceptability, and clinical usefulness in clinical and self-management of musculoskeletal conditions
Bostrøm et al. (2020)	To assess the feasibility of a digital self-management program (EPIO), an app-based cognitive-behavioral pain self-management intervention program for patients living with chronic pain	Feasibility pilot study	People with chronic pain	3 months	Telehealth (app-based)	The usefulness and use of the EPIO program for Pain and psychosocial Outcome	A study-specific use/usability questionnaire, Brief Pain Inventory, health-related quality of life scale, Hospital Anxiety and Depression Scale, Self-Regulatory Fatigue scale, Pain Catastrophizing Scale, and Chronic Pain Acceptance Questionnaire	The digital self-management program showed an acceptable program completion rate and was rated as useful and easy to use, with excellent user satisfaction. It may be of use and support for patients living with chronic pain

Table 3 (continued)

Authors	Description of intervention	Study type	Participants	Duration of follow-up	Mode of assessment	Outcomes	Outcome measure used	Findings/results
Al-Mondhiry et al. (2022)	To determine the feasibility and acceptability of the My Wellness App for advanced cancer pain	Pilot testing study	People with advanced cancer	6 months	In-person and telephone	Acceptability and usability of the app and Pain-related disability in palliative care	Feedback in the form of interviews, and digital health preferences. Brief Pain Inventory-Interference scale, & patient empowerment scale	Feasible of applying co-created palliative care apps for a patient with cancer and their clinician
Cooke et al. (2021)	Acceptability and feasibility of myPainPal app for young people to self-management chronic pain	Qualitative feasibility study	People with chronic pain	1 week	Mobile app	Acceptability, feasibility, and useability of myPainPal app	Questionnaire	The app is an acceptable and feasible platform to facilitate young people's self-management of chronic pain
Hommel et al. (2020)	Pilot the feasibility and preliminary efficacy of a self-management digital therapeutic tool for adolescents with migraine	Piloting study	People with migraine headache	2 months	Online	Acceptability and feasibility of Migraine Manager app; duration of migraine, Health-related quality of life; and medication barriers	Daily Diary; Pediatric Quality of Life Inventory (PedsQL 4.0); Parent and Adolescent Medication Barriers Scales (PMBS/AMBS)	Migraine Manager self-management tool demonstrated the feasibility and preliminary efficacy in reducing headache days and improving patient physical functioning and quality of life reported by both patients and parents
Shewchuk et al. (2021)	Usability, quality, and effectiveness of the mHealth app prototype for aiding knee OA self-management	Mixed method pilot trial	Patients and healthcare providers	6 weeks	In-person and phone	Likeability and usefulness, effectiveness on quality of life, and patient activation of the mHealth app	European Quality-of-Life 5-Dimension 5-Level Questionnaire [EQ-5D-5L]) and patient activation measure [PAM])	Positive impressions of the app prototype features and functionalities related to likeability and usefulness and the potential use of self-management mHealth to improve outcomes

Table 3 (continued)

Authors	Description of intervention	Study type	Participants	Duration of follow-up	Mode of assessment	Outcomes	Outcome measure used	Findings/results
Patel et al. (2019)	Education and self-management intervention for chronic headache	Pilot study	Patients, healthcare providers, and other stakeholders	2 days	In-person (Qualitative feedback)	Feasibility of the intervention	Participants feedback	Education and self-management intervention are feasible to deliver and acceptable for use for chronic headache
Sandhu et al. (2022)	Telephone consultations and a final face-to-face consultation to offer continual support for chronic pain	Pilot study	People with chronic pain and Nurses	2 days	In-person and phone	Feasibility and Self-management support to reduce opioid use	Participants feedback	The intervention is feasible and describes the development of an opioid reduction intervention package
Slater et al. (2012)	Evaluate the effectiveness of a modified self-training educative pain session program for consumers with persistent LBP	Prospective cohort study	People with persistent low back pain	3 months	Not specified	Deliverability and evaluate the effectiveness of the intervention	Back Pain Beliefs Questionnaire (BBQ); Fear Avoidance Beliefs Questionnaire (FABQ)	Most consumers reported the intervention as very useful in health literacy and elements of positive health behaviors in self-managing their persistent LBP
Slater et al. (2020)	To test the acceptability and need for adaptation of self-management digital technologies for musculoskeletal pain	Feasibility study	Young individual with musculoskeletal pain	Not specified	App-based	Acceptability and usability of the iCanCope with Pain app	Semi-structured questionnaire	Digital tools, with appropriate user-informed adaptations, can help to build capacity tailored to support young people's self-management of musculoskeletal pain
Tacey et al. (2023)	Feasibility testing of the digital health intervention for OA	Pitot study	People with OA	2 weeks	electronics-based (phone, desktop, tablet)	Usability and feasibility of digital health	System Usability Scale	The usability of digital intervention is an excellent category in the System Usability Scale

Table 3 (continued)

Authors	Description of intervention	Study type	Participants	Duration of follow-up	Mode of assessment	Outcomes	Outcome measure used	Findings/results
Wylde et al. (2018)	Usability test of digital application for chronic pain	Feasibility test	People with chronic pain	NR	Web application and questionnaire	Usability of digital application	System Usability Scale and questionnaire	The application has the potential to be a valuable tool for supporting the individual in self-management of chronic pain
Yates et al. (2023)	Evaluation of digital peer-delivered intervention and acceptability to patients with chronic pain	Pilot survey	People with chronic pain	4 weeks	In-person	Deliverability and usability	Questionnaire	The content of the intervention was acceptable and appropriate

GP General practitioners; *LBP* Low back pain; *MBMP* My back my plan; *NR* Not reported; *OA* Osteoarthritis

The roles and levels of engagement of PLEs and interest holders varied across the included studies. Interest holders also collaborated with researchers throughout the co-design process to develop and refine the prototypes of interventions, apps, materials, leaflets, and text messages through co-design meetings and workshops (Schemer et al. 2023; Al-Mondhiry et al. 2022; Bedson et al. 2019). However, most PLEs were involved at the consultation level, with data collection methods used to gather their insights, needs, and experiences through interviews, surveys, and focus groups, or they were involved as consultants on advisory and steering committees. Some provided feedback on the early version of the intervention, apps, model of care, and prototype development (Fritsch et al. 2021; Goff et al. 2023; Mrklas et al. 2020), or evaluated the usability and acceptability through feedback and surveys (Ahern et al. 2022b; Bedson et al. 2019; Bostrøm et al. 2020; Al-Mondhiry et al. 2022). However, engaging PLE and interest holders beyond the consultation level is needed to achieve a level consistent with co-design and to improve the quality of healthcare and intervention outcomes (Slater et al. 2012, 2020).

The co-design methods identified in this review include workshops, interviews, surveys, and focus groups with digital and non-digital platforms. However, it is uncertain to what degree these methods are usually used for data collection and sufficiently support the collaborative processes (O'Cathain et al. 2019; Elbers et al. 2021; Burkett 2012; Eyles et al. 2016; Slattery et al. 2020). Indeed, data collected through such mechanisms is usually examined by researchers to determine key findings and next steps in a program of researchers, and the researchers and not PLE or interest holders are the key decision-makers. Many of these activities rely on digital technologies, reliable internet access, personal devices, even funded health research infrastructure, accessible venues and communities with prior experience of health research engagement that may not exist or may function differently in LMIC settings, present transferability challenges and may be the reason for the lack of studies in these settings.

Other challenges noted across studies include the iterative nature of the co-design methodology and the extended time required, which can be perceived as burdensome for researchers, PLEs, and interested holders, and meaningful engagement can be challenging (Wylde et al. 2018; Cooke et al. 2021). However, it is uncertain whether these challenges reflect structural barriers to collaboration, which have been noted in rehabilitation studies (Bourke et al. 2024), including a lack of funding and resources in academic and clinical settings (Farr et al. 2021). Tailoring co-design activities to meet the needs of PLE with different types of pain is important, as pain is a highly personal experience, and people may have different needs for accommodation and inclusion in co-design processes

(de Wit et al. 2013; Frampton and Hughes-Webb 2011). Researchers should consider how to engage PLEs and interested parties by allocating sufficient resources and time to maintain regular contact and meaningfully engage in co-design activities.

The mode of co-design delivery might also be a consideration. Researchers in the included studies ran co-design or collaborative activities using online, in-person, and hybrid modalities (Goff et al. 2023; Lyng et al. 2023; Turesson et al. 2022; Magee et al. 2022). Despite online co-design having benefits in reducing the burden of time, travel, and resources, researchers should consider the partners' digital skills, internet access, and the availability of adequate technology in low-resource settings. A hybrid co-design method allowed the co-design partners to choose which platform would be convenient, have greater accessibility, and reduce resources (Shewchuk et al. 2021; Wylde et al. 2018).

Studies in this review utilised co-design or collaborative approaches in the development and evaluation of various pain management interventions. Our findings indicated a shift towards interventions that empower individuals with the knowledge and skills to actively manage their pain (Stepanian et al. 2023). Self-management interventions and strategies emerged as the most common focus of co-design studies, followed by educational, self-care, self-efficacy, and multimodal complex interventions. The development of self-management programs across the included studies is consistent with global trends towards patient-centred care, where individuals need skills and resources to manage their conditions.

One-third of the co-design or collaborative interventions were technology-based. The result indicates an increasing use of technology to enhance and make pain management solutions more accessible. There are many benefits of digital health for people with pain, including real-time monitoring, interactive features, and personalised interventions, which make it suitable for diverse populations, including those in remote areas (Hadjiat and Arendt-Nielsen 2023). However, the application of digital technology in pain management should take into account the level of digital literacy and accessibility in low-resource and remote areas. Furthermore, the application of co-design to develop educational, self-care, and self-efficacy interventions has a significant role in enhancing PLE understanding of pain and fostering informed decision-making. At the same time, the increasing use of co-design for developing complex and multimodal interventions indicates its perceived importance in addressing the multifaceted nature of pain and complex health challenges that require multidisciplinary collaboration approaches (Sumner et al. 2024).

Finally, only one-third ($n = 14$) of the studies included in our review evaluated co-designed, collaborative interventions to assess their feasibility and preliminary effectiveness. Studies that evaluated interventions demonstrated positive outcomes in feasibility, acceptability, and usability (Ahern et al. 2022b; Bostrøm et al. 2020; Al-Mondhiry et al. 2022; Cooke et al. 2021; Patel et al. 2019). Evaluation of co-design interventions is essential to ensure they are practically applicable to targeted populations. A lack of robust evaluation limits the ability to draw conclusive insights about the real-world impact and applicability of these interventions.

Strengths and limitations

We conducted the review using state-of-art methods for conducting scoping reviews. We followed a pre-established, preregistered protocol on the Open Science Framework for transparency and to reduce the likelihood of publication or selection bias. We conducted a comprehensive search in partnership with experts in chronic pain, co-design methods, and health research librarians.

There are some noteworthy limitations that should be considered for future research. Firstly, our search strategy did not include grey literature. As a result, relevant works exist in the report, service documentation, and other non-indexed sources that may have been missed. Therefore, our findings should be interpreted with this in mind, and future reviews should consider including grey literature to provide a more comprehensive understanding of co-design in pain management. Secondly, there is no standardised definition or terminology for co-design in the literature; studies use a range of terms, often interchangeably, with varying levels of participant engagement. As a result, studies included studies labelled as 'co-design' may not reflect genuine partnership or a higher level of participation. While this presents a limitation, it also reflects a key finding of this review. Third, although we employed a comprehensive search strategy across multiple databases, using a wide range of search terms and forward–backward reference checking, our search may not have captured all studies. We attempted to mitigate this by broadening our search terms and inclusion criteria, some relevant studies may still have been missed. Lastly, consistent with the methodology of scoping reviews, we did not formally assess the quality of the included studies. Therefore, we are unable to comment on the quality of the included studies, the effectiveness, or the methodological robustness of co-design interventions, which need further exploration. Future research should include systematic reviews with quality appraisal to further assess the impact of co-designed interventions in pain management.

Research gap and implications

This scoping review revealed that co-design is increasingly being used in the development and evaluation of pain management interventions, particularly in high-income countries. The review highlighted a significant research gap in the underrepresentation of co-design research conducted in LMICs, despite a disproportionate burden of chronic pain. Future research should prioritise expanding co-design approaches in LMICs, with consideration of context-specific factors, to address global disparities in pain management. Furthermore, our review reveals substantial variability in how co-design is defined, conceptualise and implemented. Many studies labelled as 'co-design' reflect lower levels of stakeholder participation, such as consultation, rather than genuine partnership characterised by collaboration or empowerment. Addressing this issue requires the development of standardised terminology, a clear definition and practical guidance or frameworks to support consistent and meaningful application of co-design in pain research. The review also identifies self-management and technology-based interventions commonly developed through the co-design pain studies. Future research should explore their applicability in different contexts and evaluate their effectiveness in pain management.

Overall, our review provides foundational evidence that moves beyond descriptive observation by systematically identifying conceptual, geographical and methodological gaps. The findings of this review inform a clear future research gap, including the need for more equitable global representation, improved conceptual clarity and the development of a rigorous framework to guide co-design in pain management. Strengthening these gaps will critically advance the quality, relevance, and global applicability of co-designed pain management interventions.

Conclusion

This scoping review provides the first systematic mapping and characterisation of co-design approaches in pain management research. There is wide variability in terminology and in how co-design is conceptualised and utilised to develop pain interventions. Many studies do not appear to meet the required level of participation to be considered co-design, though they are often described as co-design. Self-management strategies and technology-based interventions were the co-designed interventions commonly developed among the included studies in people with chronic pain. Despite a disproportionate burden of chronic pain in LMICs, they were underrepresented in the current review. In summary, the review provides a comprehensive overview of how co-design is currently being utilised in pain studies.

Abbreviations CNCP: Chronic non-cancerous pain; GP: General practitioner; LBP: Low back pain; LMICs: Low and middle-income countries; MBMP: My back my plan; MSK: Musculoskeletal; NR: Not reported; OA: Osteoarthritis; PCC: Population concept context; PLE: People with lived experience; PRISMA-ScR: Prefered Reporting Systematic and Meta-Analysis extension for Scoping Review; PT: Physiotherapist; RA: Rheumatoid Arthritis

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Data availability All data relevant to our findings are included in the manuscript. Further requests on the dataset shall be arranged based on a reasonable request to the corresponding author.

Declarations

Conflicts of interest The authors declare no conflicts of interest in this work.

Ethical approval This study is based on previously conducted studies and does not contain any new data from human participants or animals. Therefore, ethical approval was not required.

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