Respiratory Medicine 211 (2023) 107193

Contents lists available at ScienceDirect

Respiratory Medicine

journal homepage: www.elsevier.com/locate/rmed

Review article

A scoping review of co-creation practice in the development of non-pharmacological interventions for people with Chronic Obstructive Pulmonary Disease: A health CASCADE study

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ARTICLE INFO

Keywords:
Co-creation
Non-pharmacological interventions
COPD
Participation
Stakeholder
Creativity

ABSTRACT

Background: Incorporating co-creation processes may improve the quality of outcome interventions. However, there is a lack of synthesis of co-creation practices in the development of Non-Pharmacological Interventions (NPIs) for people with Chronic Obstructive Pulmonary Disease (COPD), that could inform future co-creation practice and research for rigorously improving the quality of care.
Objective: This scoping review aimed to examine the co-creation practice used when developing NPIs for people with COPD.
Methods: This review followed Arksey and O'Malley scoping review framework and was reported according to the PRISMA-ScR framework. The search included PubMed, Scopus, CINAHL, and Web of Science Core Collection. Studies reporting on the process and/or analysis of applying co-creation practice in developing NPIs for people with COPD were included.
Results: 13 articles complied with the inclusion criteria. Limited creative methods were reported in the studies. Facilitators described in the co-creation practices included administrative preparations, diversity of stakeholders, cultural considerations, employment of creative methods, creation of an appreciative environment, and digital assistance. Challenges around the physical limitations of patients, the absence of key stakeholder opinions, a prolonged process, recruitment, and digital illiteracy of co-creators were listed. Most of the studies did not report including implementation considerations as a discussion point in their co-creation workshops.
Conclusion: Evidence-based co-creation in COPD care is critical for guiding future practice and improving the quality of care delivered by NPIs. This review provides evidence for improving systematic and reproducible co-creation. Future research should focus on systematically planning, conducting, evaluating, and reporting co-creation practices in COPD care.

1Introduction

Chronic Obstructive Pulmonary Disease (COPD) is one of the world's leading non-communicable causes of death [1], and nearly 10% of the global population above the age of 40 years is affected by the disease [2]. Guidelines for COPD management recommend both pharmacological and Non-Pharmacological Interventions (NPIs) [1]. NPIs are essential components that are effective and should be used in conjunction with pharmacological interventions [3,4]. A NPI is defined as any intervention, which is theoretically supported, targeted and replicable, performed on a patient or caregiver and potentially capable of improving health or well-being that does not involve the use of any drugs or medicine [5,6]. NPIs for people with COPD vary from self-management interventions, and multidisciplinary pulmonary rehabilitation to non-invasive positive pressure ventilation, and surgical interventions (given to a pre-selected, minority of the patient group) [7]. Pulmonary rehabilitation, as a form of NPI that is recommended to the majority of people with COPD, consists of educational programs,

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https://doi.org/10.1016/j.rmed.2023.107193
Received 3 November 2022; Received in revised form 28 January 2023; Accepted 4 March 2023
Available online 6 March 2023

exercise training, nutritional support and behavioral change interventions [8–12]. There is well-documented scientific evidence to suggest that NPIs can improve quality of life, slow down deterioration, relieve symptoms, improve self-efficacy for disease management and restore health at a low economic cost for people with COPD [8,13–16]. Despite this wealth of evidence, access to, participation in and compliance with the majority of NPIs are low [17–19]. NPIs may require behavior change from both people with COPD and healthcare professionals. For people with COPD, it is about keeping a health-promoting behavior and increasing the compliance with the treatment, while for healthcare professionals, it is about changing the way they work. Current one size fits all healthcare design relies on traditional expert-driven systems in which patients are not involved in the early stages of the design process [20]. Biased information and theoretical underpinning considered universal (ie. behavior change theories), limit the comprehension of the mechanism by which change occurs. The interventions developed in this manner are not tailored, and unfortunately many interventions proven to be effective in randomized control trials (RCTs), fail in the real world because they do not take into account the complexity of the real world and circumstances in which patients live [21–25]. With an increasing emphasis on patient-centered care, which focuses on patient needs and preferences, it is necessary to maximize and optimize the engagement of people with COPD and other stakeholders in the intervention development, as well as incorporating implementation considerations in the early stages [24,26].

Co-creation provides a promising way to involve people with COPD and other stakeholders in the design of NPIs and may contribute to increasing the adherence of people with COPD to treatment, which in turn yields better clinical outcomes and lower costs [27]. Co-creation is defined as "a branch of participatory research which indicates that 'end-users' can be co-creators whose experiences provide value and innovation" [28,29]. Arnstein's citizen involvement ladder has eight rungs that specify citizen participation in planning processes. From nonparticipation to citizen control, the spectrum is represented from bottom to top [30], and co-creation is defined here as located on level six and higher of Arnstein's citizen involvement ladder. This implies that planning and decision-making responsibilities are at least shared after power redistribution through negotiation between citizens (i.e., people with COPD) and power holders in the co-creation process [30,31]. It may have the potential to address immediate health-related outcomes from individual to system levels, including physical health, health-promoting behavior, self-efficacy for disease management, access to health services, and community relations including social support and networks [27,32]. Additionally, it has been demonstrated that co-creation practices could offer tailored functionalities, iterative improvements prior to launch, and opportunities to include stakeholders' tacit knowledge to outcome interventions [33–36]. Other terms that are frequently used in the literature include co-production and co-design [37,38]. Co-creation differs from co-design and co-production because of their varied emphasis placed in practice which is based on their different characteristics and origins [37,38]. Co-creation is focused on an iterative process, involving various stakeholders throughout the process, and creative problem solving. Co-design can be considered as a specific instance of co-creation and may also be considered as a collective design process between designers and those who are not trained in design, while co-production may place more emphasis on implementing determined solutions using existing resources [37,38]. But they are often reported interchangeably. There has been recent calls for moving towards authentic and meaningful co-form and the focus of this review is on the process of co-creation [39]. However, some of the research reported that co-creation practice appeared to limit the patient's role to functioning as an information provider rather than an active co-creator [40]. Thus, a synthesis of existing literature reporting on co-creation is required to contribute to further evidence-based practice in the relevant field.

Current reviews of NPIs for COPD are focused on intervention effectiveness [41–45] rather than examining the development process. With the growing development of NPIs for COPD care, a scoping review to examine the co-creation practice used when developing NPIs for people with COPD is needed to aid the planning and commissioning of future research.

2Objectives

The objective was to examine the reported co-creation practice when developing NPIs for people with COPD. Specifically, the review synthesize the study characteristics, methods and theories used in the co-creation practice and co-creation evaluation, facilitators and challenges faced in the co-creation practice, as well as the implementation considerations of the co-created NPIs. The review questions were as follows.

- What methods and theories have been employed to assist co-creation practices in development of NPIs for people with COPD?
- Which facilitators and challenges regarding the co-creation processes have been reported in the existing co-creation practices of developing NPIs for people with COPD?
- What are the implementation considerations for the co-created interventions reported in the co-creation practices of developing NPIs for people with COPD?

3Methods

This scoping review was conducted following the Arksey and O'Malley framework [46] and recommendations for clarification of the Arksey and O'Malley framework proposed by Levac et al. [47]. It is reported according to the PRISMA Extension for Scoping Reviews (PRISMA-ScR) checklist [48] (Appendix A). The protocol was registered at Zenodo (10.5281/zenodo.6684694) [49]. The search terms remained unchanged as they were in the registered protocol.

3.1Search Strategy

The following electronic databases were searched: PubMed, Scopus, CINAHL, and Web of Science Core Collection (all editions). We consulted a medical librarian to develop the literature search strategy. A key term search strategy was employed using selected terms that were iteratively developed in each database. All the above-mentioned databases were searched using combination of two groups of keywords: "co-creation" and "COPD" (Appendix B). The keywords for 'co-creation' were selected based on above definition for this scoping review. Appendix C contains the full search strategy for four databases. The search keywords differ between databases due to different search engines. All articles chosen for inclusion after full-text screening in the scoping review were used for identifying further references. We reviewed the bibliographies of included articles, and hand-searched the "similar studies" and "cited by" sections of included articles to identify additional studies. Relevant grey literature was manually searched for relevant reports, working papers, and conference proceedings in ProQuest and NICE Evidence Search for Health and Social Care.

3.2Study Screening

Studies were screened according to a three-step process that encompassed i) managing search results and removing duplicates using Mendeley and Rayyan; ii) title and abstract screening; and iii) full-text screening. Two pairs of reviewers (K.W., M.S., R.H., and Q.A.) independently screened the identified citations for eligibility through title and abstract screening. Two reviewers (D.A. and Q.A.) independently screened the identified citations for eligibility through full-text screening. Conflicts of both title and abstract screening and full-text screening between reviewers were resolved by a discussion among

reviewers. Two reviewers independently screened titles and abstracts of the relevant grey literature identified by a manual search for eligibility. The study screening process in the PRISMA flow diagram shows in Fig. 1. There are no limitaions on study design or geographic location for eligible studies. The inclusion and exclusion criteria which reviewers applied when screening shows in Table 1.

3.3Data extraction

Data were extracted into Microsoft Excel independently by two pairs of reviewers (D.A., L.McC., and Q.A.). Conflicts between reviewers were resolved by a discussion among all reviewers (K.W., M.S., R.H., L.McC., D.A., and Q.A.). Extracted data include study characteristics, methods and theories used in the co-creation practice and co-creation evaluation, facilitators and challenges faced in the co-creation practice, as well as implementation considerations for the co-created NPIs. In the tabulated extracted results, facilitators and challenges encountered by co-creation practice were grouped into themes based on similarity. Additionally, a narrative summary accompanies the tabulated extracted results, describing how the results relate to the review objective and research questions, as well as how the results may inform future co-creation practice in developing NPIs for people with COPD.

Table 1
Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
Studies published in English since 1970 with full-text availability.	Studies examining animal health and study protocols.
Studies reporting on the process and/or analysis of applying co-creation practice in developing NPIs, in-person as well as digital for people with COPD.	Studies involving patients who don't have COPD. (Studies on people with COPD who have comorbidities are included)
End-users are involved in the decision-making process (instead of functioning as an information provider). End users include patients, caregivers, and healthcare professionals.	Studies aiming to develop pharmacological interventions.
Detailed co-creation process is reported	Extended abstracts for conferences.

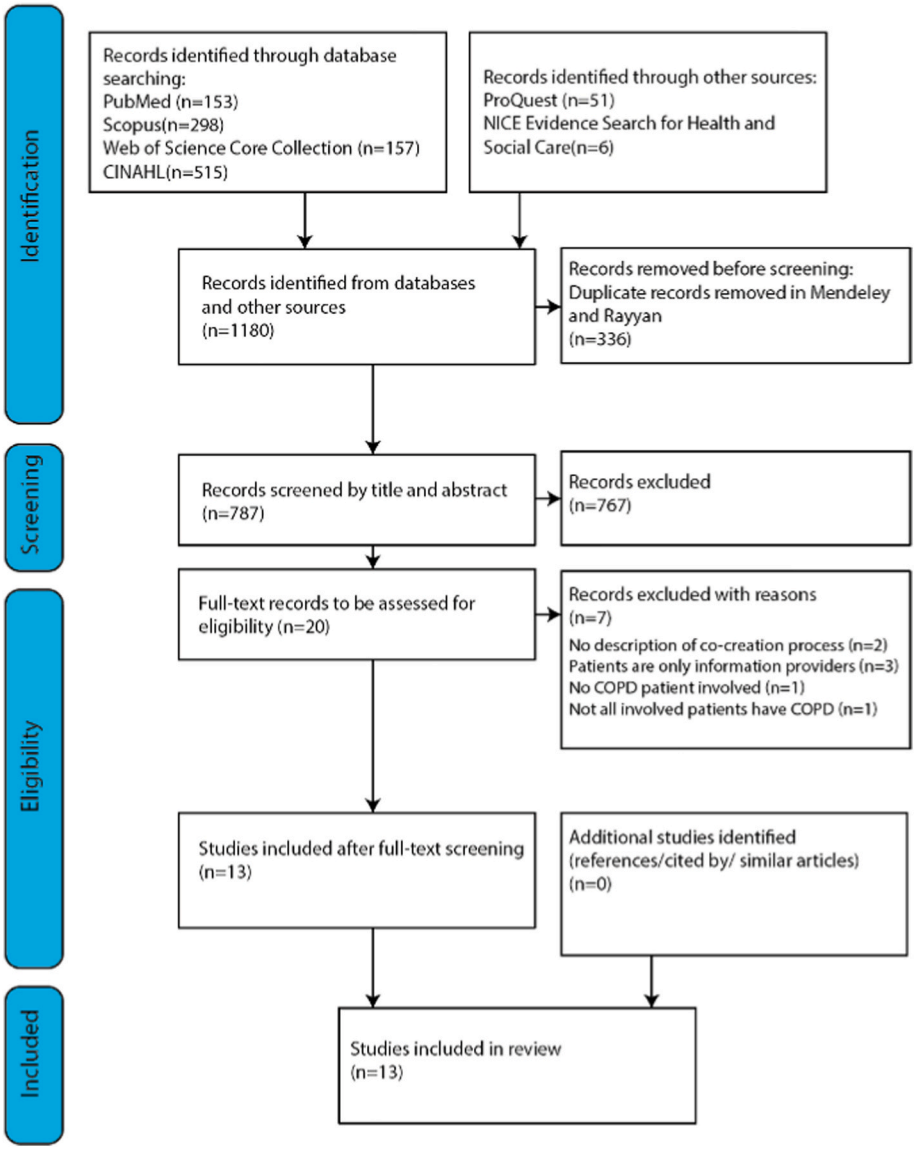

Fig. 1. PRISMA Flow Diagram for the scoping review process.

4Results

4.1Study selection

13 studies were finally included from 1180 retrieved citations from four databases, and identified additional studies (Fig. 1).

4.2Study characteristics

Characteristics of the 13 articles are shown in Table 2, including author/year/location, study aim, NPI, co-creators, data collection, and data analysis. Twelve co-creation practices as well as NPIs were included among these 13 studies because two of the included articles described the same co-creation practice (see Table 2). All included studies were published between 2014 and 2022. The included studies were geographically diverse, with four conducted in the United Kingdom [50–53], three in Sweden [33,54,55], and two in Nepal [56,57]. Additional studies were carried out in Canada (n = 1) [58], China (n = 1) [59], Norway (n = 1) [60], and the United States (n = 1) [61]. Eight of the 13 included articles were devoted to developing eHealth interventions, such as a virtual agent [50], a website [54,55], a mHealth intervention [51,55,59,60], a telehealth-delivered pulmonary rehabilitation intervention [61], and an eHealth tool [33]. Aside from the eHealth interventions, three of the articles were aimed at developing a new model of care for people with COPD [53,56,57]. One was to incorporate home-based exercise training into a Hospital at Home scheme for patients discharged from hospitals [53], while the other two were to provide biomedical and psychosocial care to support people with COPD's self-management [56,57]. For the remaining two articles, one aimed to create a tool that would allow patients to directly identify and express their support needs to healthcare professionals [52], the other one aimed to create educational materials for people with COPD from new immigrant communities in British Columbia, Canada [58]. In regard to the targeted stages, people with Acute Exacerbation of Chronic Obstructive Pulmonary Disease (AECOPD) were a target condition in one intervention [53]. One of the NPIs targeted people with advanced COPD [52]. Specification of stages of COPD in their sample were not explicitly discussed in the development of the other interventions. The comorbidities of recruited patients were not reported or discussed in any of the included articles. As to the composition of co-creators in each study, besides people with COPD, reported co-creators also included healthcare professionals, informal carers (relatives of patients and others), designers, community-based organizations, academic researchers, software engineers, local government officials, policy makers and media persons, and patient organization representatives (Table 2). Nearly all included articles reported the composition of the co-creators. Among the studies that provided specified numbers of co-creators, the majority of co-creators in five studies were people with COPD, with one study reporting only people with COPD involved [60]. Most studies used a purposive sampling (i.e. researchers rely on their own judgment to select the participants that are most likely to yield appropriate and useful information) for co-creators and varied the composition of group of co-creators in different workshops throughout the co-creation process depending on the goals of the various stages and the accessible resources.

4.3Methods and theories applied in co-creation practice

Two of the studies were conducted in a hybrid environment (some people were on the phone to participate and others were in-person) [53,54], one in virtual co-creation sessions [33], the others all took place in physical meetings. While the majority of the studies mentioned the people in charge of facilitating the co-creation processes, only two studies, Lundell et al. [33] and Shum et al. [58] mentioned the qualification of the facilitation team. Based on defining one co-creation session as one of a series of knowledge integration processes, the number of sessions in each co-creation process ranges from two [50,61] to nine [55]. Sessions were conducted in various workshop settings. Focus groups and interviews were the most used methods for data collection. When it comes to data analysis, the most common methods were content analysis and thematic analysis. Creative methods were used in four studies (Table 3). Easton et al. used creative methods such as day mapping, mood boards, and video-based scenario testing of acceptability to address many of the challenges in co-creation projects, such as power imbalances or deficits, language, trust, and time [50]. Davies et al. used an interactive method known as paper prototyping, which proved to be effective in establishing dialogues among co-creators [51]. An et al. used experience prototyping to improve the design output based on the input of co-creators [59]. Das et al. demonstrated the co-creators' feelings and future scenarios using creative methods aided by generative tools such as illustrations, pictures, and post-it notes [60]. There were no established theories reported in the studies to guide co-creation practice or behavior change theories mentioned to help to define NPI characteristics. Methodologies such as an experience-based co-design toolkit [53], a double diamond design process [50], community-based participatory research [58], human-centered design [59], reflective life-world research [54], and design thinking models [56,57] guided the co-creation practices in the included articles.

4.4Co-creation evaluation

Two included studies focused on reporting on the co-creation evaluation [56,61], while the others (n = 11) focused on reporting on the co-creation practice. For the two studies concentrated on evaluating co-creation, Yadav et al. evaluated co-creator satisfaction and ownership, and found that co-creators were actively involved in, and made a significant contribution to the co-creation process [56]. The authors also discovered the intrinsic and extrinsic factors that influence the stakeholder's engagement, engagement signs, and outcomes of engagement in developing countries like Nepal [56]. Lundell et al. presented the results of process validity as well as user satisfaction and ownership [33]. The co-creators reported high agreement between their individual perspectives and the group discussions' conclusions, and they were in general satisfied with the structure and content of the co-creation process. Participation in the workshops was described as interesting, pleasant, informative and rewarding [33]. Regarding the evaluation of the co-created NPIs, Barker et al. mentioned that the co-created NPI was being piloted within a single-centered mixed-method feasibility trial, so the specifics were not reported in the article [53]. Easton et al. evaluated the accessibility of the co-created virtual agent and reported that co-creators have generally positive feedback on the look and feel of it [50], while An et al. conducted a usability test for the developed mHealth application and found that most participants completed tasks successfully and were able to navigate smoothly throughout the app [59].

4.5Facilitators and challenges reported in co-creation practice

Diverse facilitating factors for co-creation sessions that were beneficial for data collection were reported in most of the included studies, including a) administrative preparations, b) diversity of stakeholders, c) cultural considerations, d) employment of creative methods, e) creation of an appreciative environment, and f) digital assistance.

a) Administrative preparations in recruitment, such as attracting potential participants through local newspaper advertisements and radio broad casting [58], appropriate workshop duration (typically up to 2 h [33,52–54,58,61]), and having a flexible schedule (letting the co-creators set the standard for how much time they require [60]) were all identified as facilitating factors for co-creation in the included literature.

Table 2
Characteristics of the 13 included studies.

First Author, Year, Location	Study Aim	NPI	Co-creators	Data Collection	Data Analysis
Barker, 2021, UK [53]	To enrol service users (people with COPD and informal carers) and healthcare professionals to co-design a model of care that integrates home-based exercise training within a HaH scheme for patients discharged from hospital following AECOPD.	A model of care	2 people with COPD; 1 care giver; 8 healthcare professionals	Co-design workshop	Inductive directed content analysis; the table of changes approach
Easton, 2019, UK [50]	To co-design the content, functionality, and interface modalities of an autonomous virtual agent to support self-management for patients with an exemplar long-term condition (LTC; COPD) and then to assess the acceptability and system content.	A virtual agent	17 people with COPD; 6 healthcare professionals	Workshop; day mapping; personas; mood board; video-based scenario testing; System Usability Scale (SUS)	Content analysis technique; thematic analysis
Shum, 2014, Canada [58]	1) To assess knowledge, attitudes, and beliefs related to COPD self-management practices within the target communities; 2) To investigate access and utilisation patterns of COPD-related information and care services among participant groups; 3) To examine the feasibility of involving family caregivers in the learning process and self-management practices.	Education al materials	30 people with COPD; 15 family members; 15 facilitators	Patient-oriented focus group session; individual interview	Thematic analysis
Kjellsdotter, 2021, Sweden [54]	To describe a developing process of a website as a part of a self-management education program for people with COPD.	A website	5 people with COPD; 11 healthcare professionals	Group & individual interview	Phenomenological research
An, 2021, China [59]	To develop a prototype app focused on PR for patients with COPD, and conduct a usability test of the prototype.	A mHealth app	15 people with COPD; 11 healthcare professionals; designers	Individual interview; zeltman metaphor elicitation technique; think aloud; experience prototyping	Thematic analysis
Tistad, 2018, Sweden [55]	To explore the aspects of an eHealth tool design and content that make it relevant and useful for supporting COPD-related self-management strategies from the perspective of health care professionals, people with COPD and their relatives, and external researchers.	A website	6 people with COPD; 13 healthcare professionals; 2 relatives of patients; 4 external researchers	Individual interview; focus group discussion; prototyping	Qualitative content analysis
Pekmezaris, 2020, US [61]	To analyze qualitative data from focus groups with key stakeholders to ensure the acceptability and usability of the telemonitoring COPD intervention.	A telehealth-delivered pulmonary rehabilitation intervention	(In total 20) one-third representing patients and caregivers; one-third representing providers (pulmonologists, researchers, and primary care physicians); one-third representing the other stakeholders (such as community-based organizations)	Focus group	Thematic analysis
Das, 2015, Norway [60]	To identify central aspects that the participants experienced to be of importance related to their health condition and disease using generative tools.	mHealth technology and healthcare services	5 people with COPD	Individual co-design session	Thematic analysis
Davies, 2020, UK [51]	To co-design a prototype mobile app for people with COPD.	A prototype mobile app	5 people with COPD; academic researchers; software engineers; healthcare professionals	Co-design workshop; paper prototyping; focus group; observation; individual interview; think aloud; SUS	thematic analysis
Gardener, 2019, UK [52]	To develop an evidence-based, designed-for-purpose, tool to enable patients to directly identify and express support needs to healthcare professionals.	The Support Needs Approach for Patients (SNAP) tool	(In total 57) people with COPD; care givers; healthcare professionals	Focus group; workshop; member check	Thematic analysis; content analysis
Yadav, 2021, Nepal [57]	Using co-design process to develop an integrated self-management intervention program for people with COPD in Nepal.	An integrated model	(In total 68) people with COPD; relatives of patients; healthcare professionals; local government officials; state- and central-level policy makers; academics;	Interview; observation; consultation; workshop	NR

(*continued on next page*)

Table 2 (*continued*)

First Author, Year, Location	Study Aim	NPI	Co-creators	Data Collection	Data Analysis
			representatives from NonGovernment Organizations		
Yadav, 2021, Nepal [56]	To understand the feasibility and acceptability of a co-design approach to developing an integrated model of healthcare for people with multi-morbid COPD in rural Nepal.	An integrated model	(In total 68) people with COPD; family members of patients; healthcare professionals; local government officials; state- and central-level policy makers; academics; representatives from NonGovernment Organizations	Workshop; interview; observation	Thematic analysis
Lundell, 2022, Sweden [33]	To describe the experiences of, and evaluate a digital co-creation process for developing an eHealth tool for people with COPD.	An eHealth tool	10 people with COPD; 5 healthcare professionals; 2 relatives of patients	Digital workshop; respondent validation; member check; questionnaire	Descriptive quantitative statistics; descriptive qualitative analysis

Note: COPD: Chronic obstructive pulmonary disease; AECOPD: Acute Exacerbation of Chronic Obstructive Pulmonary Disease; HaH: Hospital at Home; NR: Not reported.

Table 3
Description of reported creative methods.

Methods	Description in practice	References
Day mapping	Patients worked with healthcare professionals to map out a day in their life journey to gain a shared understanding of the lived experience of COPD.	[50]
Mood boards	Mood board aimed to define the ideal set of features for design outcomes.	[50]
Video-based scenario testing of acceptability	Researchers developed a short screenplay that introduced the design outcome and depicted how it might provide support to its user in typical domestic situations.	[50]
Paper prototyping	Participants drew on papers of their preferred app interface.	[51]
Experience prototyping	Experience prototyping emphasizes the experiential aspect of whatever representations are needed to successfully convey an experience with a product, space or system.	[59]
Creative methods aided by generative tools	The participants were given tools such as illustrations, post-it notes, pictures, or sets of expressive components, in order to create artifacts that express their thoughts, feelings, and ideas.	[60]

b) The diversity of stakeholders and involving a wide range of stakeholders [53], especially government officials [56] was reported as advantageous to the co-creation process. Moreover, Tistad et al. reported that it was critical to include both rural and urban areas, as well as people with COPD at various disease stages, to provide tailored interventions [55].
c) Cultural considerations and tailoring the co-creation process to local culture, particularly in the low and middle-income countries (LMICs), was a crucial element in the planning and execution of a co-creation practice [56]. Two studies that included participants from various linguistic groups both mentioned the use of translators as part of the co-creation process [58,61].
d) Employment of creative methods and the use of generative tools was considered useful and contributed positively to the co-creation process [50,60]. The creative methods described in the included literature were "A day in life" mapping, mood board [50], role play [50], video-based scenario testing [50], Reflective Life-World Research [54], experience prototyping [59], a workbook consisting of their current situation [60], employment of generative tools like illustrations, pictures, and post-it notes to demonstrate feelings and future scenarios [60], paper prototyping [51].
e) The creation of an appreciative environment was considered important and the co-creators asserted that the group's atmosphere of mutual respect and relaxation contributed to the participants' engagement [33,50,56]. As mentioned in the study by Lundell et al., "It was simple to speak one's mind when one felt accepted, heard, and seen" [33].
f) Some benefits of digital meeting formats included the elimination of travel and parking issues, reduced infection risks, the geographical diversity of participants, and the ability to accommodate the physical limitations of participants [33]. Davies et al. used digital assistance in the initial iteration of their NPI prototype by delivering it on a mobile device to gather input form users so that the next version can be optimized accordingly [51].

As for the main challenges, first, according to some studies, physical limitations, due to respiratory insufficiency, hypoxemia and ambulatory oxygen treatment, may affect patients' interaction with others, and complicate their participation [33,60]. Second, the composition of the co-creators is poorly understood in the planning stage and heavily dependent on readily available resources. For the studies aiming to develop digital NPIs, lack of research examining co-creator composition through a sociotechnical lens, which is used to understand the work system as it involves a complex interaction between humans, machines, and the surrounding environment, could lead to the omission of crucial viewpoints [50]. Third, co-creation workshops can be time-consuming, especially when researchers have to learn the social structure of the community and work around the schedules of various stakeholders [57]. Fourth, it can be difficult to engage patients from marginalized communities when the facilitators of the research group are from a different background than the participants [57]. Fifth, computer illiteracy and a lack of knowledge of digital technology and video communication platforms are hurdles to adopting digital meetings [33,60]. When performing digital co-creation sessions, Lundell et al. noted that assistance from Information and Communication Technology (ICT) professionals was beneficial [33].

4.6Implementation considerations of co-created NPIs

Three studies mentioned that it is critical that the development of co-created NPI is informed by contextual conditions, fits into existing routines, and does not threaten the existing hierarchy between healthcare professionals and patients [50,55,57]. Two NPIs were initially intended to be integrated into an existing service routine [53,54]. Barker et al. aimed to develop a model of care that incorporates home-based exercise training into a Hospital at Home scheme for patients discharged from the hospital after AECOPD [53]. Because the Hospital at Home scheme is an established system; much effort was put into discussing how to better integrate the proposed model of care into the existing scheme. Similarly, Kjellsdotter et al. developed a website based

on a COPD patient education project, but no implementation information was reported during the co-creation process [54]. Six studies discussed the implementation considerations of the NPIs in their co-creation processes [51,53,55–57,61]. Eight studies reported their future implementation plans [50–53,55–57,61]. Four studies did not include any implementation considerations in their report [33,58–60].

5Discussion

Based on the defined characteristics of co-creation, this review provides a summary of co-creation practice in NPI development in COPD care to date. The findings could inform future NPI development in COPD care.

5.1Summary of findings

The scoping review discovered 13 articles that described the co-creation process for developing NPIs for people with COPD. The composition of the group of co-creators varied and was reported in the majority of the studies. However studies did not discuss the rationale for the composition of the group of co-creators. eHealth interventions accounted for more than half of the co-created NPIs. There has been little research into the co-creators' experiences and the evaluation of the co-creation process. Surprisingly, only a few creative methods were used in the co-creation process, instead the majority of studies relied on consultative methods. Inadequate attention has been paid to reporting on the relationship between co-creation practice and intervention implementation. Moreover, there is a lack of reporting of COPD stages and comorbidities which may limit the scalability of research findings. Below we discuss some potential improvement that could be made to address the issues highlighted in this review to make co-creation more evidence-based.

5.2Toward evidence-based co-creation in COPD care

Leask et al. introduces a framework for co-creation that includes four stages, Planning, Conducting, Evaluating and Reporting [62].

5.2.1Planning stage

At the planning stage, the choice of suitable facilitators is important because building a strong, ongoing relationship with co-creators is critical, as their participation requires a significant time commitment, as well as physical and mental involvement [63]. It was mentioned that using experienced facilitators who share the same cultural norms and have previous experience working with local community, government officers, policy makers, clinicians and/or other stakeholders is important when conducting co-creation practice [58,61]. Moreover, the composition of the co-creation team needs careful consideration and must respond to a clear rationale which is unfortunately often absent from study reports. The demographics distribution of the co-creation team needs to be reported and regarded as strong evidence to prove the rigorousness of the research findings, which can be learned from strategies used in Delphi studies [64]. In terms of the team size, most of the included articles have a larger sample size in each session than the suggested ten to twelve [62]. A large sample size is important in some form of research, but it might be detrimental to the co-creation process because high-quality interactive dialogues among co-creators are required, and consensus might need to be reached at some point [62]. Nearly half of the studies included more people with COPD than other stakeholders. This could be positive because people with COPD are a vulnerable group in comparison to other co-creators, and because they are end users of NPI, their needs must be prioritized [65]. It's also possible that people with COPD are more likely to drop out due to exacerbations.

5.2.2Conducting stage

In the conducting stage, the development process of NPI should be a robust piece of research that is methodologically strong and incorporates existing evidence and stakeholders' experience and views [21]. Established guidance from the Medical Research Council (MRC) recommends incorporating stakeholder involvement and the use of theory into the process of complex intervention development [66]. Identification of a relevant theory or framework before practice may result in a more effective intervention than a purely empirical or pragmatic approach [66]. But no established theories for planning or conducting the co-creation process, assessing its efficacy and impact, or informing the functionality of co-created interventions were reported in the included articles [67]. Instead, the co-creation practice in the included articles was governed by a number of different methodologies. Using theory to guide intervention development helps identify potential factors that influence desired outcomes. As a result, this should be encouraged and adopted as common practice to increase the likeliness of desired outcomes. Since the included studies' main objectives were to report on co-creation practice, the possibility that some theories were incorporated but not reported cannot be completely ruled out.

As for the methods used in co-creation practice, Sanders classified interactive approaches to the intervention design process in terms of what people say, do, and make [68]. Das et al. placed co-creation in the last category (i.e., make), as the participants could present their idea by explaining their creations [60]. The majority of the methods used in the studies reviewed may be placed in the classification "say" or "do". These methods are generally consultative and routinely used in qualitative studies for the development of health interventions. This might be because developing interventions that funders could relate to is more important for applying fundings for the intervention development process, rather than innovative interventions that required new ways of thinking [21]. However, creative methods have also proven to be beneficial in the included studies. According to Easton et al., the explicit use of creative methods in co-creation aids in addressing challenges related to power imbalances or deficits, language, trust, and time, and fosters a nonhierarchical environment [50]. Therefore, novel, high-quality and more interactive methods and tools should be applied to aid co-creators' participation in decision making. Moreover, only three included studies mentioned that they paid attention to manifesting ownership of co-creators during the conducting stage, indicating a high potential for improvement. Ownership of co-creators may be facilitated in the context of co-creating NPIs for COPD care by a reasonable composition of co-creator's groups, comprehension of related knowledge prior to participation, team branding, and asking appreciative questions, for example.

5.2.3Evaluating stage

As mentioned by Leask et al., co-creation evaluation should be done in two ways: evaluating the process and evaluating the intervention [62]. This review uncovers a lack of research reporting on the evaluation of the co-creation processs, and the intervention effectiveness. Both of these are critical elements that must be carried out and structurally reported. All included studies were published on or after 2014, thus the co-creation projects included may be in an ongoing process, and the reported outcomes may be updated in the near future.

5.2.4Reporting stage

Reporting on the co-creation process in an understandable, reproducible, and systematic manner is important, as it assists clinicians and patients in reliably implementing effective interventions, and contributes to evidence-based co-creation [62,69]. We found that, based on the reported content, it is challenging to distinguish co-creation studies from other approaches, for example, qualitative studies in which informants only provide information, instead of reaching a consensus. Studies applying co-creation can be missed out by interested parties due to their unstandardized report. Appendix D contains the essential data outlining

the strategies used in the included papers to recognize their co-creation practices. Furthermore, the background of the facilitation team and theories that have been incorporated into co-creation practice may need to be disclosed in the report. One possible tool to use for planning and reporting the co-creation project is the PRODUCES framework (Problem, Objective, Design, (end-) Users, Co-creators, Evaluation, Scalability), which could be adopted to facilitate a systematic approach when using participatory methodologies in co-creation [62]. It could, for instance, be used in planning and reporting the co-creation project and is utilized in the existing protocol for COPD care [70]. However, this tool is not used in any of the included articles.

5.3Relationships between co-creation practice and the implementation of co-created NPIs

Implementation science and co-creation for public health may have complementary strengths [71]. Co-creation might be positioned at the start of the translational research pathway, with implementation science at its distal end, and it could also be regarded as a useful technique for optimizing and operationalizing implementation strategies [71]. In the included studies, the feasibility, acceptability, and effectiveness of NPIs were either tested in laboratory settings or subject of further plans. There seems to be a dearth of consideration about how to make those NPIs practicable within health care in clinical settings or non-clinical settings (i.e., homecare). The MRC guidance suggests early consideration of implementation in the framework for developing and evaluating complex interventions, which increases the likelihood that an intervention can be widely adopted and maintained in real-world settings [66]. How NPIs are implemented from bench to bedside and integrated into health care should be part of the co-creation process with relevant stakeholders included in the co-creation team. Additionally, Yadav et al., mentioned the issue of funding support to put the intervention into action in the real world [56]. Co-creation projects are typically regarded as long-term endeavors that may face challenges in adapting to updating surroundings and maintaining funder consistency. One co-creation project is likely to involve various funders to support various stages of the process, which could result in unforeseen delays that disrupt the project's plan [21]. More adaptable funding opportunities might be needed to deal with this.

5.4Scalability of NPI

Given the trend toward patient-centered care and the rising number of readily available NPIs in COPD care, we discovered from the literature that it is a relatively small number of articles reporting on co-creation practice. Among those, the majority of the studies were carried out in high and upper-middle-income countries, with two carried out in Nepal, a LMIC, but the researchers of the Nepal project came from institutions in high-income countries. The findings suggest that more work needs to be done in LMICs, as they account for nearly 90% of COPD deaths in people under the age of 70 [72]. Additionally, in some co-creation studies, it is preferable to include patients who are co-creators at various disease stages rather than a specific disease stage to gain a more comprehensive understanding of their requirements and expectations from various disease severity [55]. Depending on the purpose of the intervention, it is also acceptable to begin with a single intervention targeting specific stages of COPD. With the exception of one NPI that particularly targeted AECOPD [53] and the other on advanced COPD [52], other studies did not report which stages they were targeting or indicate that they were targeting all stages. NPIs such as PR are recommended to be given also to patients with AECOPD, in conjunction to a potential hospital stay. Only one study mentioned that the developed NPI can be utilized by people with AECOPD [53]. There is a gap in the existing literature regarding if and how NPIs can be adapted to AECOPD, which may be the period when people with COPD have the highest need to adhere to their treatment [73]. Additionally, comorbidities are common in people with COPD [74]. Despite this, the comorbidities of recruited patients are not discussed in any of the included articles. Knowledge of patients' comorbidities could aid in emergency preparedness and make patients' input more traceable. The diverse disease histories of people with COPD contribute to the bias in the development process. By considering any additional conditions that COPD patients may have, an NPI may find it more practical and useful to personalize care for patients. Additionally, if the co-creation process can be carried out systematically, it might produce some core interventions that could serve as a springboard for other subgroups of the population. A systematic co-creation process can also be used as an intervention itself to be adapted in further co-creation processes.

5.5Study limitations

A few limitations must be acknowledged. First, to reduce bias in the results, one of our exclusion criteria was to exclude studies involving patients who do not have COPD. As a result, studies involving a mixed group of people with COPD and people who have other diseases with similar symptoms as end users were excluded. However, some of them may provide useful recommendations for running co-creation sessions. Second, due to the non-standardized definition of co-creation in developing health interventions, we might have missed some studies that used different terminology. Our search terms might not be as thorough as they ought to be. Additionally, the following four electronic databases were searched: PubMed, Scopus, CINAHL, and Web of Science Core Collection (all editions). There might be additional studies that are not included in these four databases. Thus, some research relevant to co-creation may not have been captured. However, an effort was made to record as many processes as possible through iterations of keywords and search strategies. Third, as COPD care is the main focus of this scoping review, it would have been ideal to consult with COPD patients prior to conducting the scoping review, but that was not done. Though, one researcher (K.W.) in the author team has vast clinical experience of people with COPD. Despite these limitations, this scoping review identifies critical gaps in the related literature and lays the groundwork for future research.

6Conclusion

This review examines and summarizes the existing literature in terms of planning, conducting, evaluating and reporting on co-creation practice to provide evidence toward improving co-creation of NPI practice for people with COPD that is structured and reproducible. We discovered some indications of potential successful co-creation practice based on the identified facilitators and challenges. However, several issues might limit the efficacy and progress of the development of NPIs using co-creation. There is a lack of systematic theory guiding the co-creation process, the majority of methods used are consultative in nature and do not harness all the collective intelligence and creative potential, and the implementation into real world setting tends to be left out. The results of this review suggest a potential improvement for future research. First, systematically plan, conduct, evaluate and report the co-creation of NPIs for COPD care based on theory; Second, incorporate implementation considerations in all stages of the co-creation process; Third, identify and test new and more creative and interactive methods; Fourth, broaden the scope of co-created NPIs to include people with COPD with different disease severities and/or comorbidities.

Funding source

This work was funded by the European Union's Horizon 2020 research and innovation program under the Marie Skłodowska-Curie grant agreement 956501.

Declaration of competing interest

None of the authors have any actual or perceived conflicts of interest.

Acknowledgements

The authors acknowledge Mattias Lennartsson, a librarian at medical library unit of Umeå University library, for his assistance in constructing and refining our search strategy.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.rmed.2023.107193.

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