

## Implementation Status of Patient-Centered COPD Patient Participation in Healthcare Quality Improvement: A Scoping Review Postprint

**Authors:** Chu Hongling, Li Shurun, Li Xinlin, Chen Yahong, Chen Yahong

**Date:** 2024-05-27T00:00:00+00:00

### Abstract

**Background** In patient-centered healthcare quality improvement, patients are transformed from recipients of medical services to collaborators, integrating patients' experiences and needs throughout the entire medical process into healthcare practice to enhance the effectiveness, efficiency, and quality of healthcare services. However, how to implement proven effective patient-centered patient engagement strategies in healthcare quality improvement in the field of chronic obstructive pulmonary disease (COPD) in China remains to be explored. **Objective** To conduct a scoping review of the implementation status of patient engagement strategies in healthcare quality improvement for COPD patients domestically and internationally, aiming to provide references for constructing COPD patient engagement implementation strategies suitable for the Chinese context. **Methods** The Joanna Briggs Institute's scoping review guidelines were adopted as the methodological framework. Computerized searches were conducted in PubMed, Embase, Cochrane Library, CNKI, Wanfang Data Knowledge Service Platform, and Chinese Medical Journal Full-Text Database, with the search period from database inception to November 29, 2022. Thematic analysis was used to organize the implementation status of COPD patient engagement. **Results** A total of 37 articles were included. According to engagement categories, they were divided into three types: direct participation in diagnosis and treatment, participation in organizational-level design and management, and participation in clinical research. According to engagement intensity, they were divided into three levels: consultation, involvement, and partnership and leadership. The cross-tabulation of engagement intensity and categories formed a matrix of 9 engagement behavior types. COPD patient engagement implementation was mainly reflected in 5 categories and 8 specific behaviors: including involvement in direct diagnosis and treatment (patients expressing preferences and wishes for treatment plans); consultation at the organizational management

level (surveying and understanding patient treatment experiences, organizing patient discussions on issues of concern to them) and involvement (participating in the development of healthcare quality improvement tools); and consultation at the clinical research participation level (listening to patient needs) and involvement (expressing preferences and wishes for intervention measures, participating in the development of assessment tools, participating in research design and implementation discussions). Surveying patient treatment experiences (10/37, 27.03%) and collecting patient preferences and wishes regarding research interventions (10/37, 27.03%) were the two most frequently implemented COPD patient engagement behaviors. Conclusion There are numerous behavioral measures for patient engagement in healthcare quality improvement, but few have been implemented in practice in the COPD field, and patient participation in the evaluation of improvements in clinical outcomes and quality of life is rarely seen. How to promote the implementation of COPD patient engagement in healthcare quality improvement in China and globally remains to be further explored.

## Full Text

### Title

Current Status of Implementation of Patient-Centered Patient Involvement in Healthcare Quality Improvement for COPD: A Scoping Review

Chu Hongling<sup>1</sup>, Li Shurun<sup>2</sup>, Li Xinlin<sup>2</sup>, Chen Yahong<sup>2\*</sup>

<sup>1</sup>Research Center of Clinical Epidemiology, Peking University Third Hospital/Key Laboratory of Epidemiology of Major Disease (Peking University), Ministry of Education, Beijing 100191, China

<sup>2</sup>Department of Respiratory and Critical Care Medicine, Peking University Third Hospital, Beijing 100191, China

\*Corresponding author: Chen Yahong, Professor/Chief physician; E-mail: chenyahong@vip.sina.com

### Abstract

**Background:** In patient-centered healthcare quality improvement, patients transform from passive recipients to collaborators in medical services by integrating their experiences and needs throughout the entire healthcare process into clinical practice, aiming to enhance the effectiveness, efficiency, and quality of healthcare services. However, how to implement proven patient-centered strategies for patient involvement in quality improvement within the COPD field in China remains to be explored.

**Objective:** This scoping review systematically examines the implementation status of patient involvement strategies in healthcare quality improvement

among COPD patients worldwide, aiming to provide references for developing implementation strategies suitable for the Chinese context.

**Methods:** Employing the scoping review guidelines of the Joanna Briggs Institute in Australia as the methodological framework, we systematically searched PubMed, Embase, Cochrane Library, CNKI, Wanfang Database, and the Chinese Medical Journal Full-Text Database from inception to November 29, 2022. A thematic analysis was applied to synthesize the implementation status of patient involvement in COPD.

**Results:** A total of 37 articles were included. Patient involvement was categorized into three types: direct involvement in clinical care, organizational-level design and management, and involvement in clinical research. Based on intensity, involvement was classified into three levels: consultation, engagement, and collaborative leadership, forming a nine-category matrix of involvement behaviors. Implementation of COPD patient engagement was primarily reflected in five categories encompassing eight specific behaviors: (1) direct involvement in clinical care (patients expressing preferences and wishes regarding treatment plans); (2) consultation at the organizational management level (surveying patient treatment experiences and organizing discussions on patient concerns) and engagement (participating in healthcare quality improvement tool development); and (3) consultation (listening to patient needs) and engagement (expressing preferences for interventions, participating in assessment tool development, and involvement in research design and implementation discussions) in clinical research. Surveying patient treatment experiences (10/37, 27.03%) and collecting patient preferences and wishes regarding interventions (10/37, 27.03%) were the two most frequently implemented behaviors.

**Conclusion:** While numerous measures for patient involvement in healthcare quality improvement exist, limited practice has been implemented in the COPD field, with very few studies evaluating the impact of patient involvement on clinical outcomes and quality of life. How to promote the implementation of patient involvement in healthcare quality improvement for COPD patients in China and globally requires further exploration.

**Keywords:** Chronic obstructive pulmonary disease; Patient involvement; Medical quality; Implementation; Scoping review

## Introduction

Chronic obstructive pulmonary disease (COPD) is a common chronic disease that severely impacts patients' quality of life and prognosis. The "China Pulmonary Health Study" reported that the prevalence rate among people over 40 years old in China is as high as 13.7%, with an estimated nearly 100 million patients nationwide [1]. Although multiple effective treatments and management methods exist to alleviate COPD progression, problems such as insufficient patient knowledge about COPD, poor treatment adherence, and suboptimal medication or device usage remain widespread. A potential solution is to further

implement patient-centered care by designing new roles for patients, transforming them from passive recipients to collaborators in healthcare services. This involves incorporating patient needs, experiences, and preferences from early development and evaluation of quality management measures through consultation, hospitalization, and follow-up, enabling patients to actively participate in healthcare processes and quality improvement to enhance service effectiveness, efficiency, and quality. However, the specific strategies and methods for patient involvement in healthcare quality improvement in the COPD field require further systematic examination. Therefore, this study employs the scoping review guidelines of the Joanna Briggs Institute in Australia [2] as the methodological framework to systematically review existing key measures and intensity levels of patient involvement in COPD, analyze current implementation status worldwide, and provide references for developing implementation strategies suitable for Chinese COPD patients.

## Methods

### 1.1 Research Question Formulation

Based on the patient involvement framework [3], this study addresses the following questions: (1) What are the practice behaviors of COPD patient involvement in healthcare quality improvement? (2) What methods are used to collect feedback information from COPD patients regarding healthcare quality improvement?

### 1.2 Literature Inclusion and Exclusion Criteria

**Inclusion criteria:** (1) Studies with the theme of patient involvement; (2) Study subjects were COPD patients; (3) Literature types included randomized controlled trials (RCTs), non-randomized controlled trials, cohort studies, cross-sectional studies, qualitative studies, mixed-methods studies, expert opinions, case studies, and case series reports.

**Exclusion criteria:** (1) Duplicate publications; (2) Conference abstracts; (3) Literature with unavailable full text.

### 1.3 Search Strategy

We systematically searched PubMed, Embase, Cochrane Library, CNKI, Wanfang Database, and the Chinese Medical Journal Full-Text Database. A combination of subject headings and free-text terms was used, with the search period from database inception to November 29, 2022.

**English search terms** included: patient participation, patient preference, patient need, patient insight, patient perspective, patients' experience, pulmonary disease, chronic obstructive.

**Chinese search terms** included: 慢阻肺 (COPD), 慢性阻塞性肺疾病 (chronic

obstructive pulmonary disease), COPD, 患者参与 (patient involvement), 以患者为中心 (patient-centered), 患者偏好 (patient preference).

The English search strategy for PubMed is shown in . The Chinese search strategy for CNKI was: SU= “慢阻肺” + “慢性阻塞性肺疾病” + “COPD” AND SU= “患者参与” + “以患者为中心” + “患者偏好” .

#### 1.4 Literature Screening and Data Extraction

Two researchers independently conducted literature screening and data extraction. The first step involved reading titles and abstracts to exclude literature that did not meet inclusion criteria, retaining those that met criteria or were uncertain. The second step involved full-text reading to exclude ineligible literature. Disputed literature was discussed with a third researcher. A customized form was used to extract data including authors, publication year, country of research institution, patient involvement behaviors, methods for collecting and analyzing patient involvement data, and other specific study content. The literature screening process is shown in [Figure 1: see original paper].

#### 1.5 Data Analysis

Based on the patient involvement framework, we analyzed the behaviors of patient involvement and their depth and intensity in the included literature, and described the methods used for collecting and analyzing patient involvement data.

### Results

#### 2.1 Literature Screening Process and Basic Characteristics of Included Studies

A total of 2,331 articles were retrieved. After screening according to inclusion and exclusion criteria, 37 articles were finally included, comprising 35 English articles and 2 Chinese articles. The literature screening process is illustrated in [Figure 1: see original paper].

#### 2.2 Basic Characteristics of Literature on COPD Patient Involvement

We analyzed the included literature by country, year, type of patient involvement, and methods for collecting patient involvement information. In terms of country distribution, the United Kingdom published the most literature on COPD patient involvement. Publications on patient involvement have increased annually in recent years. Regarding the purpose categories of patient involvement, 54.05% of literature used patient involvement to provide feedback for clinical research, while 45.95% aimed to provide feedback for medical practice. Among the included literature, 51.35% of studies used interview methods for data collection. Details are shown in .

### 2.3 Implementation of COPD Patient Involvement in Healthcare Quality Improvement

Using thematic analysis, we further analyzed the included literature and synthesized the implementation behaviors of patient involvement in healthcare quality improvement, as shown in . Patient involvement categories included: (1) direct involvement in clinical care processes, (2) organizational-level design and management, and (3) involvement in research. The intensity of involvement ranged from consultation, engagement, to deeper collaboration and collaborative leadership.

**2.3.1 Patient Involvement in Direct Clinical Care** Direct patient involvement in clinical care primarily manifests as actively providing information feedback during prevention, diagnosis, and treatment processes, communicating actively with healthcare professionals, and engaging in shared decision-making. Three included articles (8.11%) [4-6] focused on treatment preferences and wishes of COPD patients. Among them, Leung et al. [7] conducted a quantitative survey analyzing whether patients reported discussing end-of-life plans with physicians, finding that patients who reported such discussions were more likely to rate healthcare quality as optimal (OR=2.07, 95%CI: 1.05-4.09) and were very satisfied with care (OR=1.98, 95%CI: 1.10-3.55). This demonstrates that patient involvement in clinical discussions helps improve healthcare quality and satisfaction.

**2.3.2 Patient Involvement in Organizational-Level Design and Management** Patient involvement in organizational-level design and management primarily manifests as surveying patient treatment experiences (10 articles [7-16], 27.03%) or organizing patient discussions on their concerns (2 articles [17,18], 5.41%) to integrate patient values, experiences, and preferences into healthcare institution management. Deeper involvement includes participating in healthcare quality improvement tool development (2 articles [19,20], 5.41%) or incorporating patients as hospital management consultants or advisory committee members to discuss issues directly relevant to patients. The most intensive involvement at the organizational level would be engaging patients in quality improvement committees and participating in decisions on health resource allocation, though no such literature was identified.

Van Harlingen et al. [19] incorporated patients in co-designing a communication toolkit for patients, informal caregivers, and healthcare professionals. The toolkit development process involved 19 patients, 10 informal caregivers, and 13 healthcare professionals across 8 discussion rounds, resulting in a toolkit containing communication scenario settings, standardized communication statements, and corresponding communication aids. The toolkit identified 4 statements based on different communication scenarios, including 11 design criteria and 10 selection criteria. This study, through patient involvement, provided an effective and feasible tool for improving patient-provider communication and further

enhancing healthcare quality and quality of life for COPD patients.

**2.3.3 Patient Involvement in Research** Patient involvement in research transforms patients from mere research subjects to research collaborators who provide feedback at various research stages. This represents a substantial proportion of patient involvement in healthcare quality improvement literature. Researchers can listen to patient needs to conduct clinical research addressing patient priorities. During research design and implementation, organizing patient discussions on study design and implementation processes can improve feasibility and compliance. Deeper collaboration in clinical research includes involving patients in recommending research funding priorities and participating in intervention application decisions. In the included literature, patient involvement in research primarily manifested as listening to patient needs (4 articles [21-24], 10.81%), expressing preferences and wishes for interventions (10 articles [25-34], 27.03%), participating in assessment tool development (4 articles [35-38], 10.81%), and involvement in research design and implementation discussions (2 articles [39-40], 10.81%).

Caron-Flinterman et al. [39] organized COPD patients to discuss their health research priorities through 7 focus groups, 1 feedback session, and 1 questionnaire survey. The study found that this consultation process successfully elicited patient-prioritized research areas, some of which were not currently included in Dutch research agendas, demonstrating that patient involvement can expand research priority setting.

Bourne et al. [32] conducted a randomized controlled trial evaluating the feasibility, acceptability, and clinical effectiveness of providing and supporting COPD self-management programs in primary care. In this trial, researchers included intervention group participants in 9 focus group discussions to deeply understand the feasibility and acceptability of the intervention and potential facilitators/barriers to implementation in clinical practice. Including patients in evaluating intervention implementation in clinical trials helps provide patient-centered reference for clinical decision-making and develop more feasible implementation strategies.

## Discussion

This scoping review examined the current status of patient involvement in healthcare quality improvement in the COPD field, aiming to develop new COPD patient management models to improve healthcare quality. Although patient involvement is a relatively new concept, it has been widely practiced in the COPD field. Nilsen et al. [41] mentioned in a Cochrane systematic review that patient involvement may produce interventions that are easier for patients to understand and implement, helping patients learn COPD-related information such as treatment explanations, strategies to reduce dyspnea, timing for seeking help, and decision-making during exacerbations. Acquiring knowledge and skills forms the basis for patients' willingness to actively cooperate with treatment.

COPD patient involvement in healthcare quality improvement can be further divided into two categories: one directly providing feedback on clinical practice measures, and the other focusing on patient involvement in COPD-related clinical research. Based on existing literature, our research team refined and adapted a practical strategy matrix framework for COPD patient involvement in healthcare quality improvement. We found that most literature involved organizing patient discussions on their concerns, with no identified examples of deep involvement developing into collaborative or leadership relationships. Although existing practice strategies typically treat patient involvement as a behavior, patient involvement actually encompasses multiple complex organizational activities with varying intensity levels, organizational difficulties, resource requirements, and demonstrated values.

This scoping review found that surveying patient treatment experiences during healthcare delivery and collecting patient preferences and wishes regarding interventions in clinical research are the two most common forms of patient involvement implementation in the COPD field. However, these two forms can be summarized as collection, analysis, and application of patient needs and experience data. With the continuous development of patient-centered healthcare service concepts and practices, obtaining patient experiences, insights, and needs during treatment and effectively integrating them into patient management plans has gained increasing attention. GOLD [42] proposes that one fundamental principle for selecting appropriate inhaler devices includes assessing and considering patient acceptability, satisfaction, and preferences. Involving patients in developing individualized treatment plans can improve adherence [43], and meeting patient needs is the premise for guiding clinical practice, management, and research—a practical implementation measure of patient-centered care that has been actively pursued domestically and internationally.

**Limitations and Future Directions:** This scoping review primarily examined patient involvement in healthcare quality improvement from the perspective of patient participation behaviors. Although shared decision-making is a direct manifestation of patient involvement in clinical care and has matured with the development of evidence-based medicine, with existing researchers having conducted specialized reviews on this topic, this scoping review excluded literature on shared decision-making in direct clinical processes. Additionally, this review focused on multifaceted behaviors of COPD patient involvement rather than specifically evaluating the effectiveness of patient involvement. Consequently, only one quantitative survey study was identified that analyzed the impact of patient-reported discussions with physicians about end-of-life plans on patient-reported healthcare quality and satisfaction. Other literature did not specifically evaluate the effects of patient involvement models, so this scoping review did not focus on effectiveness evaluation. Future research should further explore effective and implementable behavioral strategies within the COPD patient involvement framework to improve clinical outcomes and quality of life for COPD patients.

## References

- [1] Chinese Medical Association Respiratory Disease Branch COPD Group, Chinese Thoracic Society COPD Working Committee. Guidelines for the diagnosis and management of chronic obstructive pulmonary disease (revised version 2021) [J]. Chinese Journal of Tuberculosis and Respiratory Diseases, 2021, 44(3): 170-205. DOI: 10.3760/cma.j.cn112147-20210109-00031.
- [2] LOCKWOOD C, DOS SANTOS K B, PAP R. Practical guidance for knowledge synthesis: scoping review methods [J]. Asian Nurs Res, 2019, 13(5): 287-294. DOI: 10.1016/j.anr.2019.11.002.
- [3] CARMAN K L, DARDESS P, MAURER M, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies [J]. Health Aff (Millwood), 2013, 32(2): 223-231. DOI: 10.1377/hlthaff.2012.1134.
- [4] LEWIS H B, SCHROEDER M, GUNSOY N B, et al. Evaluating patient preferences of maintenance therapy for the treatment of chronic obstructive pulmonary disease: a discrete choice experiment in the UK, USA and Germany [J]. Int J Chron Obstruct Pulmon Dis, 2020, 15: 595-604. DOI: 10.2147/COPD.S221980.
- [5] MIDDLEMASS J B, VOS J, SIRIWARDENA A N. Perceptions on use of home telemonitoring in patients with long term conditions - concordance with the Health Information Technology Acceptance Model: a qualitative collective case study [J]. BMC Med Inform Decis Mak, 2017, 17(1): 89. DOI: 10.1186/s12911-017-0473-5.
- [6] MANISCALCO M, MARTUCCI M, FUSCHILLO S, et al. Portable oxygen concentrator versus oxygen cylinder in chronic lung disease: patient preferences and psychological implications [C] // Rehabilitation and chronic care. European Respiratory Society, 2020: 56. DOI: 10.1183/13993003.congress-2020.407.
- [7] LEUNG J M, UDRIS E M, UMAN J, et al. The effect of end-of-life discussions on perceived quality of care and health status among patients with COPD [J]. Chest, 2012, 142(1): 128-133. DOI: 10.1378/chest.11-2222.
- [8] MIRAVITLLES M, MONTERO-CABALLERO J, RICHARD F, et al. A cross-sectional study to assess inhalation device handling and patient satisfaction in COPD [J]. Int J Chron Obstruct Pulmon Dis, 2016, 11: 407-415. DOI: 10.2147/COPD.S91118.
- [9] MOUSING C A, SØRENSEN D. Living with the risk of being infected: COPD patients' experiences during the coronavirus pandemic [J]. J Clin Nurs, 2021, 30(11/12): 1719-1729. DOI: 10.1111/jocn.15727.
- [10] MARX G, NASSE M, STANZE H, et al. Meaning of living with severe chronic obstructive lung disease: a qualitative study [J]. BMJ Open, 2016, 6(11): e011555. DOI: 10.1136/bmjopen-2016-011555.

- [11] MCDONALD V M, SIMPSON J L, MCEL DUFF P, et al. Older peoples' perception of tests used in the assessment and management of COPD and asthma [J]. *Clin Respir J*, 2013, 7(4): 367-374. DOI: 10.1111/crj.12017.
- [12] LUHR K, HOLMEFUR M, THEANDER K, et al. Patient participation during and after a self-management programme in primary healthcare - The experience of patients with chronic obstructive pulmonary disease or chronic heart failure [J]. *Patient Educ Couns*, 2018, 101(6): 1137-1142. DOI: 10.1016/j.pec.2017.12.020.
- [13] MESHE O F, BUNGAY H, CLAYDON L S. Participants' experiences of the benefits, barriers and facilitators of attending a community-based exercise programme for people with chronic obstructive pulmonary disease [J]. *Health Soc Care Community*, 2020, 28(3): 969-978. DOI: 10.1111/hsc.12929.
- [14] MAN K N, TIAN Z P, LAM D C L, et al. Satisfaction, preference and error occurrence of three dry powder inhalers as assessed by a cohort naïve to inhaler operation [J]. *Int J Chron Obstruct Pulmon Dis*, 2018, 13: 1949-1963. DOI: 10.2147/COPD.S152285.
- [15] LINDE P, HANKE G, VOLTZ R, et al. Unpredictable episodic breathlessness in patients with advanced chronic obstructive pulmonary disease and lung cancer: a qualitative study [J]. *Support Care Cancer*, 2018, 26(4): 1097-1104. DOI: 10.1007/s00520-017-3928-9.
- [16] WU Yangjing, DU Xiaojun, WANG Mengna. Effect of motivational interviewing on oxygen therapy adherence in COPD patients [J]. *Chinese Journal of Clinical Health Care*, 2012, 15(5): 548-549. DOI: 10.3969/J.issn.1672-6790.2012.05.042.
- [17] MAHMUDAH R L, IKAWATI Z, WAHYONO D. A qualitative study of perspectives, expectations and needs of education in chronic obstructive pulmonary disease (COPD) [J]. *Int J Curr Pharm Sci*, 2016, 9(1): 32. DOI: 10.22159/ijcpr.2017v9i1.16601.
- [18] LI Dan, ZHU Sucui. Qualitative study on influencing factors of COPD patients refusing pulmonary rehabilitation therapy [J]. *Journal of Nursing Science*, 2017, 32(13): 6-9. DOI: 10.3870/j.issn.1001-4152.2017.13.006.
- [19] VAN HARLINGEN A O W, VAN DE VEN L G, HASSELAAR J, et al. Developing a toolkit for patients with COPD or chronic heart failure and their informal caregivers to improve person-centredness in conversations with healthcare professionals: a Design Thinking approach [J]. *Patient Educ Couns*, 2022, 105(11): 3324-3330. DOI: 10.1016/j.pec.2022.07.002.
- [20] CHERREZ OJEDA I, CALDERON J C, JOVE O L, et al. What kind of information and communication technologies do patients with COPD prefer to use? A cross-sectional study in Latin America [J]. *Chron Respir Dis*, 2018, 15(3): 286-295. DOI: 10.1177/1479972317741895.

- [21] BUNNAG C, FUANGTONG R, POTHIRAT C, et al. A comparative study of patients' preferences and sensory perceptions of three forms of inhalers among Thai asthma and COPD patients [J]. *Asian Pac J Allergy Immunol*, 2007, 25(2/3): 99-109.
- [22] APPS L D, HARRISON S L, MITCHELL K E, et al. A qualitative study of patients' experiences of participating in SPACE for COPD: a Self-management Programme of Activity, Coping and Education [J]. *ERJ Open Res*, 2017, 3(4): 00017-02017. DOI: 10.1183/23120541.00017-2017.
- [23] BALZANO G, BATTILORO R, BIRAGHI M, et al. Effectiveness and acceptability of a domiciliary multidrug inhalation treatment in elderly patients with chronic airflow obstruction: metered dose inhaler versus jet nebulizer [J]. *J Aerosol Med*, 2000, 13(1): 25-33. DOI: 10.1089/jam.2000.13.25.
- [24] MOLIMARD M, COLTHORPE P. Inhaler devices for chronic obstructive pulmonary disease: insights from patients and healthcare practitioners [J]. *J Aerosol Med Pulm Drug Deliv*, 2015, 28(3): 219-228. DOI: 10.1089/jamp.2014.1142.
- [25] CAHALAN R, GREEN J, MEADE C, et al. "SingStrong" : singing for better lung health in COPD - A pilot study [J]. *Physiother Theory Pract*, 2022, 38(12): 1978-1986. DOI: 10.1080/09593985.2021.1907825.
- [26] CHAPMAN K R, FOGARTY C M, PECKITT C, et al. Delivery characteristics and patients' handling of two single-dose dry-powder inhalers used in COPD [J]. *Int J Chron Obstruct Pulmon Dis*, 2011, 6: 353-363. DOI: 10.2147/COPD.S18529.
- [27] OHNO T, WADA S, HANADA S, et al. Efficacy of indacaterol on quality of life and pulmonary function in patients with COPD and inhaler device preferences [J]. *Int J Chron Obstruct Pulmon Dis*, 2014, 9: 107-114. DOI: 10.2147/COPD.S56777.
- [28] KERWIN E M, SPANGENTHAL S, ZVARICH M, et al. ELLIPTA Versus DISKUS plus HandiHaler in COPD: a Randomized, Open-Label, Crossover Study in a Clinical Trial Setting [J]. *Chronic Obstr Pulm Dis*, 2020, 7(2): 118-129. DOI: 10.15326/jcopdf.7.2.2019.0153.
- [29] UTENS C M A, GOOSSENS L M A, VAN SCHAYCK O C P, et al. Patient preference and satisfaction in hospital-at-home and usual hospital care for COPD exacerbations: results of a randomised controlled trial [J]. *Int J Nurs Stud*, 2013, 50(11): 1537-1549. DOI: 10.1016/j.ijnurstu.2013.03.006.
- [30] ZWAKMAN M, WELDAM S W M, VERVOORT S C J M, et al. Patients' perspectives on the COPD-GRIP intervention, a new nursing care intervention for COPD [J]. *BMC Fam Pract*, 2019, 20(1): 78. DOI: 10.1186/s12875-019-0957-0.
- [31] BOURNE C, HOUCHEWOLLOFF L, PATEL P, et al. Self-management programme of activity coping and education-SPACE for COPD (C)-in primary

- care: a pragmatic randomised trial [J]. *BMJ Open Respir Res*, 2022, 9(1): e001443. DOI: 10.1136/bmjresp-2022-001443.
- [32] APPS L D, MITCHELL K E, HARRISON S L, et al. The development and pilot testing of the self-management programme of activity, coping and education for chronic obstructive pulmonary disease (SPACE for COPD) [J]. *Int J Chron Obstruct Pulmon Dis*, 2013, 8: 317-327. DOI: 10.2147/COPD.S40414.
- [33] KARDOS P, HAGEDORN-PEINZ I. The impact of indacaterol/glycopyrronium fixed-dose combination versus tiotropium monotherapy on lung function and treatment preference: a randomized crossover study - the FAVOR study [J]. *Int J Chron Obstruct Pulmon Dis*, 2017, 13: 69-77. DOI: 10.2147/COPD.S146189.
- [34] PATALANO F, GUTZWILLER F S, SHAH B, et al. Gathering structured patient insight to drive the PRO strategy in COPD: patient-centric drug development from theory to practice [J]. *Adv Ther*, 2020, 37(1): 17-26. DOI: 10.1007/s12325-019-01134-x.
- [35] PAAP M C S, BODE C, LENFERINK L I M, et al. Identifying key domains of health-related quality of life for patients with chronic obstructive pulmonary disease: the patient perspective [J]. *Health Qual Life Outcomes*, 2014, 12: 106. DOI: 10.1186/s12955-014-0106-3.
- [36] ALTMAN P, BERGNA M A, GARCIA G R, et al. Patient perception of Breezhaler® and Ellipta® device feedback mechanisms in COPD: the PREFER study [J]. *Curr Med Res Opin*, 2019, 35(2): 221-227. DOI: 10.1080/03007995.2018.1464437.
- [37] DUMAIS K M, DIAS N, KHURANA L, et al. Preferences for use and design of electronic patient-reported outcomes in patients with chronic obstructive pulmonary disease [J]. *Patient*, 2019, 12(6): 621-629. DOI: 10.1007/s40271-019-00376-9.
- [38] CARON-FLINTERMAN J F, BROERSE J E W, TEERLING J, et al. Patients' priorities concerning health research: the case of asthma and COPD research in the Netherlands [J]. *Health Expect*, 2005, 8(3): 253-263. DOI: 10.1111/j.1369-7625.2005.00337.x.
- [39] GRIGOLETTO I, DE LIMA F F, ETO D A, et al. Satisfaction and adherence of COPD patients to a conventional training associated with functional exercises and to a conventional training isolated: a qualitative study [J]. *Patient Prefer Adherence*, 2022, 16: 2759-2772. DOI: 10.2147/PPA.S367088.
- [40] FLINK M, BRANDBERG C, EKSTEDT M. Why patients decline participation in an intervention to reduce re-hospitalization through patient activation: whom are we missing? [J]. *Trials*, 2019, 20(1): 82. DOI: 10.1186/s13063-019-3187-9.
- [41] NILSEN E S, MYRHAUG H T, JOHANSEN M, et al. Methods of consumer involvement in developing healthcare policy and research, clinical practice guide-

lines and patient information material [J]. *Cochrane Database Syst Rev*, 2006, 2006(3): CD004563. DOI: 10.1002/14651858.CD004563.pub2.

[42] Global Strategy for Prevention, Diagnosis and Management of COPD: 2024 Report [EB/OL]. [2024-04-01]. <https://goldcopd.org/>.

[43] GALLEFOSS F, BAKKE P S. Impact of patient education and self-management on morbidity in asthmatics and patients with chronic obstructive pulmonary disease [J]. *Respir Med*, 2000, 94(3): 279-287. DOI: 10.1053/rmed.1999.0749.

### Author Contributions

Chen Yahong identified the clinical question and research need, and discussed with Chu Hongling to propose the research concept—analyzing the current status of patient involvement in healthcare quality improvement in the COPD field to provide references for developing implementation strategies for Chinese COPD patients. Chu Hongling was responsible for overall planning and literature search of the scoping review. Li Shurun and Li Xinlin were responsible for literature screening, data extraction, and data analysis. Chu Hongling and Li Shurun drafted the manuscript, with Li Xinlin participating in manuscript revision. Chen Yahong was responsible for final version revision and takes responsibility for the manuscript. All authors confirmed the final manuscript.

### Conflict of Interest

The authors declare no conflict of interest.

*Note: Figure translations are in progress. See original paper for figures.*

*Source: ChinaXiv –Machine translation. Verify with original.*