The COCOS-IPF core outcome set for idiopathic pulmonary fibrosis/progressive pulmonary fibrosis care: a mixed-method multi-perspective approach

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Shareable abstract (@ERSpublications)
A core outcome set for IPF/PPF routine care has been developed, involving patients and healthcare professionals across Europe. This set includes 17 key outcomes, aiming to enhance patient-centred treatment, to standardise care and to guide future research. https://bit.ly/4gAQsHv

Cite this article as: Breuls S, Somogyi V, Schenk S, *et al*. The COCOS-IPF core outcome set for idiopathic pulmonary fibrosis/progressive pulmonary fibrosis care: a mixed-method multi-perspective approach. *ERJ Open Res* 2026; 12: 00872-2025 [DOI: 10.1183/23120541.00872-2025].

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Received: 3 July 2025
Accepted: 15 Sept 2025

Abstract

Background It is unclear which outcomes are essential for the care of individuals with idiopathic pulmonary fibrosis or progressive pulmonary fibrosis (IPF/PPF). We aimed to develop a core outcome set (COS) together with patients with IPF/PPF for standard care across Europe.

Methods A modified three-round Delphi study in five languages involved patients, caregivers, pulmonologists, nurses and other healthcare professionals. The initial survey consisted of 56 outcomes potentially relevant for IPF/PFF care that were identified through a scoping review, a survey with healthcare professionals and patient-led focus groups with patients and caregivers. The importance of each outcome for IPF/PPF care was scored on a 9-point Likert scale. After each round, outcomes were removed if not deemed critically important by all stakeholder groups, using predefined criteria. Afterwards, a multi-stakeholder consensus workshop was held to endorse the included outcomes and discuss and vote on those without consensus.

Results The three rounds involved 110, 78 and 66 participants from 14 European countries (one third being patients and caregivers). 14 stakeholders contributed to the consensus workshop. The final COS consists of 17 outcomes: acute exacerbation, breathlessness, complications and side-effects of the treatment, cough, exercise capacity, lung function, nutritional status, physical activity, activities of daily living, being knowledgeable about the disease, capability to do activities you enjoy, coping with the disease, feelings of anxiety, life satisfaction, loss of independence, satisfaction with care and treatment adherence.

Conclusions This COS is recommended for use in clinical IPF/PPF care, but will also guide future intervention research.

Introduction

Progressive pulmonary fibrosis (PPF) refers to a worsening fibrotic phenotype that can develop in various fibrotic interstitial lung diseases (fILD) other than idiopathic pulmonary fibrosis (IPF), which is the most

common fILD [1]. Both IPF or PPF have a poor prognosis, a challenging diagnostic process and a complex therapeutic management for which patients are often treated in specialised interdisciplinary expert centres [2–4]. Evidence-based guidelines for IPF/PPF treatment focus on the pharmacological and medical dimension of care, but may overlook the broader patient needs [4].

The European IPF charter highlighted holistic care as a key need for people with IPF [5]. When developing a care model, it is therefore recommended to incorporate patients' holistic needs alongside the medical dimension of care to further improve value-based care and quality of life [6–10]. This could be achieved by developing a core outcome set (COS) with input from multiple stakeholders, including patients [11]. According to the Core Outcome Measures in Effectiveness Trials (COMET), a COS is defined as "an agreed standardised set of outcomes that should be measured and reported, as a minimum, in all clinical trials in specific areas of health or healthcare" [12]. In 2013, a COS for IPF was developed, primarily through physicians' input with the focus to establish outcomes for clinical trials [13]. Unfortunately, the majority of COSs for many disease populations are primarily developed to standardise research outcomes and data reporting and are less suitable to standardise clinical practice [14]. Moreover, although most COS projects included patients, half of them included patients from one country only or overlooked sociodemographic or clinical characteristics [15]. As for many other chronic diseases, there is no consensus on which outcomes patients and healthcare professionals (HCPs) deem essential within IPF/PPF care. Therefore, we aimed to co-design a core outcome set for routine care in Europe with and for patients with IPF/PPF (COCOS-IPF). To enhance implementation of the COS, we developed the mnemonic "standard IPF/PPF care", summarising the key outcomes and promoting standardised IPF/PPF care across Europe.

Methods

The COS was developed by the COCOS-IPF international consortium, consisting of pulmonologists, European patient representatives, researchers with a background in pulmonology, psychology and physiotherapy, and the European Respiratory Society. Below, we report the steps conducted to define the final COS. This involved a multi-step preparatory phase, a three-round Delphi study including a best–worst scaling exercise, followed by an online consensus workshop with relevant stakeholders. Patients or their representatives were involved as active partners in all steps.

Multi-step preparatory phase: information sources

First, we created a comprehensive list of outcomes with potential relevance for IPF/PPF care, based on: 1) a scoping review on outcomes mentioned in primary quantitative and qualitative research papers on IPF/PPF [16]; 2) a European survey with 149 HCPs experienced in IPF/PPF, to understand which outcomes are currently addressed or considered important to address in routine care or research [17]; and 3) patient-led focus groups with patients and caregivers, conducted in five European countries, to understand what matters most to patients in terms of health outcomes. This resulted in a list of 97 outcomes, which was subsequently shortened to decrease participant burden based on strategies used in previous COS development initiatives, discussion rounds within the consortium and a final endorsement round (supplementary material A) [18–20].

Next, lay definitions were prepared with patient representatives through iterative discussions. Two other patient representatives checked the comprehensiveness and clarity of the outcomes and definitions during cognitive debriefings. No domains needed to be added or deleted. Feedback on domain labelling was incorporated (supplementary material A).

Afterwards, the outcomes and definitions were translated from English into German, Hungarian, Spanish and Turkish to facilitate broad European participation. The translations were performed using machine translators (DeepL, https://www.deepl.com/ and ChatGPT, https://chatgpt.com/) in line with the methodology for culturally sensitive translations of questionnaires [20]. Native speaking HCPs of each respective language validated the merged translation, followed by a back translation to English to identify any discrepancies with the English source document [21]. HCPs and patients provided feedback to ensure clarity and comprehensibility [21]. The obtained list with 56 outcomes and definitions is provided in supplementary material B.

Three-round Delphi study

To obtain consensus on the key outcomes to be embedded in IPF/PPF routine care, a modified three-round Delphi study was conducted, the prevailing method for consensus building on COSs [22]. Three Delphi surveys were sent out on 26 August, 14 October and 3 December 2024, each remaining open for 4 weeks.

Participants

We composed five stakeholder groups for the Delphi study: patients with IPF/PPF, informal caregivers living with a person with IPF/PPF, pulmonologists, nurses specialising in interstitial lung diseases and other HCPs with IPF/PPF expertise. Participants were eligible if they were currently living in Europe. Lung transplant recipients and their caregivers were excluded, as they were deemed not being actively involved anymore in the IPF/PPF cycle of care. Patients and informal caregivers acted as experts, expressing the views of the wider IPF/PPF patient population. Pulmonologists, nurses and other HCPs were required to have knowledge and experience regarding the holistic needs of IPF/PFF patients throughout the entire cycle of care. Members of the COCOS-IPF consortium were not eligible to participate.

Patients and caregivers were recruited by local patient organisations (supplementary material C). Pulmonologists, nurses and other HCPs were recruited through the consortium's network, by the European Respiratory Society who invited HPCs in the field and by identifying authors of relevant publications in IPF/PPF from our scoping review [16]. Individuals who expressed interest in participating were screened against the eligibility criteria and, if eligible, received an invitation to the first Delphi round. Eligibility was reassessed using background questionnaire data. To prevent over-representation and ensure balanced geographic and stakeholder input, the number of participants invited per country per panel was limited, with additional attention to sex and age diversity. While there are no definitive recommendations for Delphi study sample sizes, a minimum of 10 participants per panel is commonly suggested [23]. Additionally, a systematic review reported a median number of 100 participants across Delphi studies [24].

Before participating, all participants gave informed consent to complete three rounds of online surveys (eDelphi, version 1.1; Metodix Ltd, Espoo, Finland, www.edelphi.org). Participation was possible in English, German, Hungarian, Spanish and Turkish, based on geographical location and preference.

Consensus process

The Delphi survey was pilot tested with an HCP and native English-speaking patient for feedback on survey length and structure and to ensure the functioning of technical aspects.

The Delphi survey invitation was e-mailed to potential participants, directing them to the eDelphi website. The survey started with a background questionnaire covering age, sex, country, disease subtype, self-reported disease severity, professional experience and years of experience in the IPF/PPF field. This was followed by the 56 outcomes, shown in randomised order (SAS statistical software) "to reduce order effect and scoring fatigue", as recommended by COMET [25]. Each outcome was accompanied with its definition and the following question: "On a scale from 1 (not important) to 9 (extremely important), how important is it to address this health aspect routinely in the clinical care for people with a progressive form of pulmonary fibrosis (IPF/PPF)?". The scoring system was chosen according to the GRADE criteria (Grading of Recommendations Assessment and Evaluation): 1–3 (not important for the current COS), 4–6 (important, but not critical for the current COS) and 7–9 (critical for inclusion in the current COS) [26]. Participants could suggest missing outcomes in round 1 and provide comments on each outcome in all rounds.

Individuals invited for round 1 were also invited for round 2. For round 3, individuals who participated in at least one round were invited. After each round, some outcomes were retained for the next round based on predefined criteria (table 1). In rounds 2 and 3, each outcome and definition were accompanied by: 1) a graph showing the previous round's score distribution (for all stakeholder groups separately and the total group); 2) the participant's previous round score; and 3) the same question as in round 1. Participants could change their previous score based on the responses of the other participants.

Round 3 also included a "case 1 best–worst scaling exercise", using a balanced incomplete block design: participants were asked to indicate which outcome they consider the most and least important in 21 blocks of five outcomes [27]. The resulting ranking was used to guide the consensus workshop discussions.

Consensus workshop

Following the three-round Delphi study, an online consensus workshop was held on 18 February 2025 to endorse the outcomes that would be included in the COS and to discuss outcomes where uncertainty remained.

Participants

We aimed for two to three representatives per stakeholder group to attend the workshop. The recruitment strategy mirrored that of the Delphi study. Members of the COCOS-IPF consortium were not eligible to

TABLE 1 Consensus criteria of the Delphi study and consensus workshop

	Classification of outcome	Description	Criteria
Round 1	Include in round 2	The outcome is considered important	At least in one panel: ⩾75% scored 7–9 AND ⩽15% scored 1–3
Round 2	Include in round 3	The outcome is considered important	At least in one panel: ⩾75% scored 8–9 AND ⩽15% scored 1–3
Round 3	Consensus in	Consensus that outcome should be included in the COS	All panels: ⩾75% scored 7–9
	Consensus out	Consensus that outcome should be excluded from the COS	All panels: ⩽75% scored 7–9
	No consensus yet	No consensus if outcome should be included or excluded from COS. Will be discussed in consensus workshop	At least one panel, but not all: ⩾75% scored 7–9
Consensus workshop	Include in COS	Consensus that outcome should be included in the COS	⩾75% votes for inclusion

Classification of outcomes in Delphi rounds and consensus workshop, based on predefined criteria. COS: core outcome set.

participate in the discussions or voting. Before participating, all participants gave informed consent to represent the voice of their stakeholder group in an online English meeting.

Consensus process

A week before the workshop, participants received an e-mail containing: 1) a written and video introduction to the project; 2) the workshop programme and objectives; 3) an overview of the Delphi results; and 4) the option to schedule a call to clarify any questions [28].

The consensus workshop was conducted online *via* Zoom (Zoom Communications, Inc. 2025) and the Delphi study results were presented first. In phase one, participants could provide remarks on the outcomes included in the COS (table 1). In phase two, small mixed-stakeholder groups, led by a consortium member, discussed the outcomes without consensus using a modified nominal group technique [29]. First, participants wrote down reasons to include or exclude these outcomes. The Delphi scoring results and the best–worst exercise results were shown to support data-driven decisions. Next, each participant expressed their thoughts, followed by a small group discussion. Then, participants reconvened and the group leaders summarised their group discussion to all participants. In phase three, participants anonymously voted on whether to include outcomes without consensus in the COS, requiring 75% of votes for inclusion. In the final phase, participants reviewed the final COS and shared remaining feedback.

Following the consensus workshop, we derived the mnemonic "standard IPF/PPF care" *post hoc* to support dissemination and clinical implementation, by aligning the initial letters of each outcome.

Statistics

Participants who completed ⩾90% of the outcomes were included in the Delphi analyses. Analyses of round 2 and 3 were restricted to those who completed the preceding rounds. Consensus criteria for the Delphi study and workshop were predefined (table 1).

Newly suggested outcomes from at least 10% of participants in round 1 were considered for the next round. Stability of consensus was measured by calculating the difference between the coefficients of variance (CV) for each outcome between consecutive rounds, where a difference of 0 to 0.2 in CV difference indicated stable consensus [27]. Best–worst scaling results were analysed using R (version 4.4.1, support.bws). Other analyses were performed using SAS (V.9.4; SAS Institute Inc., Cary, NC, USA).

Ethics and registry

Approval of the Ethics Committee Research UZ/KU Leuven was obtained in June 2024 for the Delphi study (G-2023-7460-R2(MIN)) and in January 2025 for the consensus workshop (G-2024-8932). This study has been registered in the COMET initiative database (www.comet-initiative.org/Studies/Details/2472). The COMET handbook, COS-STAndards and COS-STAR were used as guidelines for the COS development and reporting [22, 30, 31].

Results

Results of the preparatory phase are provided in the supplementary material or previously published [16, 17].

Delphi study

Participants

Out of the 206 individuals invited, 121 participated, of which 110 met the eligibility criteria and scored ⩾90% of the outcomes in round 1. 14 countries were represented, with the highest response rate from Germany (n=20), Belgium (n=17), the Netherlands (n=14), the UK (n=14) and Türkiye (n=13). Of the 110 participants, 78 and 66 completed rounds 2 and 3, respectively. In all rounds, patients and caregivers represented one third of the participants, with characteristics representative of the overall disease population (table 2, supplementary material D).

Outcomes

In round 1, none of the additional items suggested met the criteria to be included in round 2 (supplementary material E). Supplementary material F shows the proportion of stakeholder representatives who considered an outcome critically important for inclusion, for each Delphi round.

The first Delphi survey included 56 outcomes, with 48 retained in round 2 and 22 in round 3 (figures 1 and 2). Based on the results of round 3, a consensus to include 14 outcomes was reached and eight outcomes needed more discussion (figure 2). According to the best–worst scaling exercise, the five top-rated outcomes were breathlessness, acute exacerbation, life satisfaction, activities of daily living and coping with the disease (supplementary material G).

Concerning the stability of scoring, the absolute differences in CVs between outcomes across two consecutive rounds ranged from 0.0005 to 0.089 (results not shown).

Consensus workshop

Participants

We invited 49 stakeholder representatives to participate in the consensus workshop. 16 accepted the invitation to participate and 14 attended the meeting: five patients, two caregivers, four pulmonologists, two physiotherapists and one psychologist. The workshop was led by two consortium members. Three smaller break-out groups were formed, with patients being represented in all groups.

TABLE 2 Baseline characteristics of the Delphi survey participants

	Patients	Caregivers	Pulmonologists	Nurses	Other HCPs
Participants	28	14	25	21	22
Age years	68.5 (61–74.5)	64 (50–65)	47 (40–55)	49 (37–51)	39 (35–45)
Sex (male/female/not completed)	19/9/0	2/12/0	10/14/1	4/17/0	7/15/0
Country					
Belgium	3	3	2	5	4
Czech Republic	0	0	0	0	1
Denmark	0	0	3	1	0
Germany	10	3	4	0	3
Hungary	0	0	2	1	0
Ireland	1	2	0	2	0
Italy	0	0	2	0	1
Netherlands	7	1	1	2	3
Poland	1	0	1	0	0
Portugal	0	0	0	0	2
Spain	0	0	4	2	1
Switzerland	0	0	1	2	1
Türkiye	5	1	2	0	5
UK	1	4	3	5	1
Missing	0	0	0	1	0
Self-reported patient's disease severity (no symptoms/mild/moderate/severe)	2/3/11/12	0/1/6/7	NA	NA	NA
Years of experience with IPF/PPF	NA	NA	14.5 (9.5–20)	13 (6–18)	10 (7–12)
Working in an ILD centre of expertise, Yes/No	NA	NA	23/1	19/2	12/10
Clinical work, % of time	NA	NA	72.5 (50–80)	70 (50–100)	50 (35–70)

Characteristics of Delphi participants in round 1. Results are shown as median (Q1–Q3) and n. HCPs: healthcare professionals; IPF: idiopathic pulmonary fibrosis; PPF: progressive pulmonary fibrosis; ILD: interstitial lung disease.

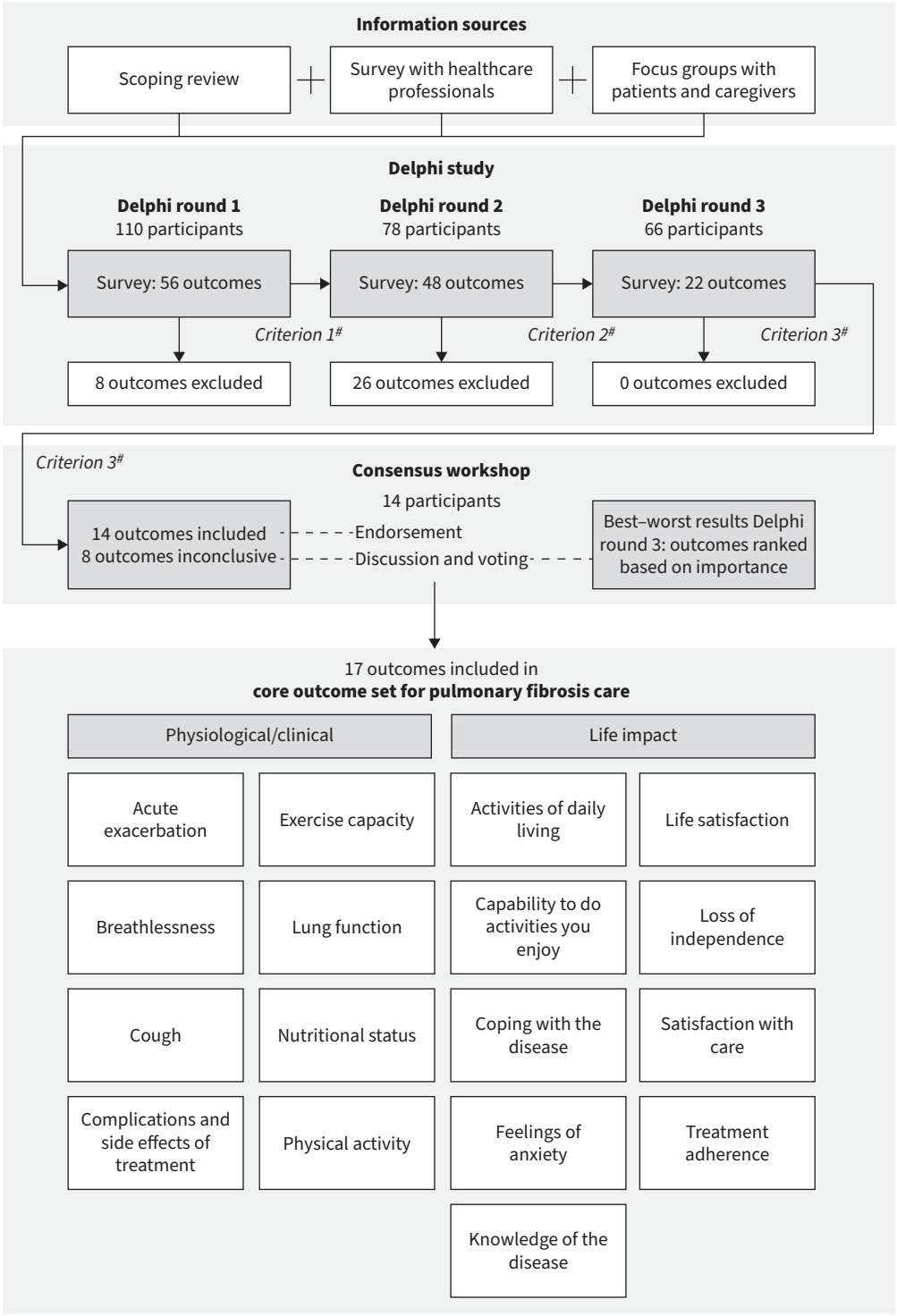


FIGURE 1 Overview of the core outcome set development process: the information sources used to create the list with outcomes for the Delphi survey (box 1), the reduction process of the list in the Delphi rounds (box 2) and finalising the core outcome set during the consensus workshop (box 3). The final core outcome set for usual care in patients with idiopathic pulmonary fibrosis or progressive pulmonary fibrosis is shown in box 4. #: criteria are described in table 1.

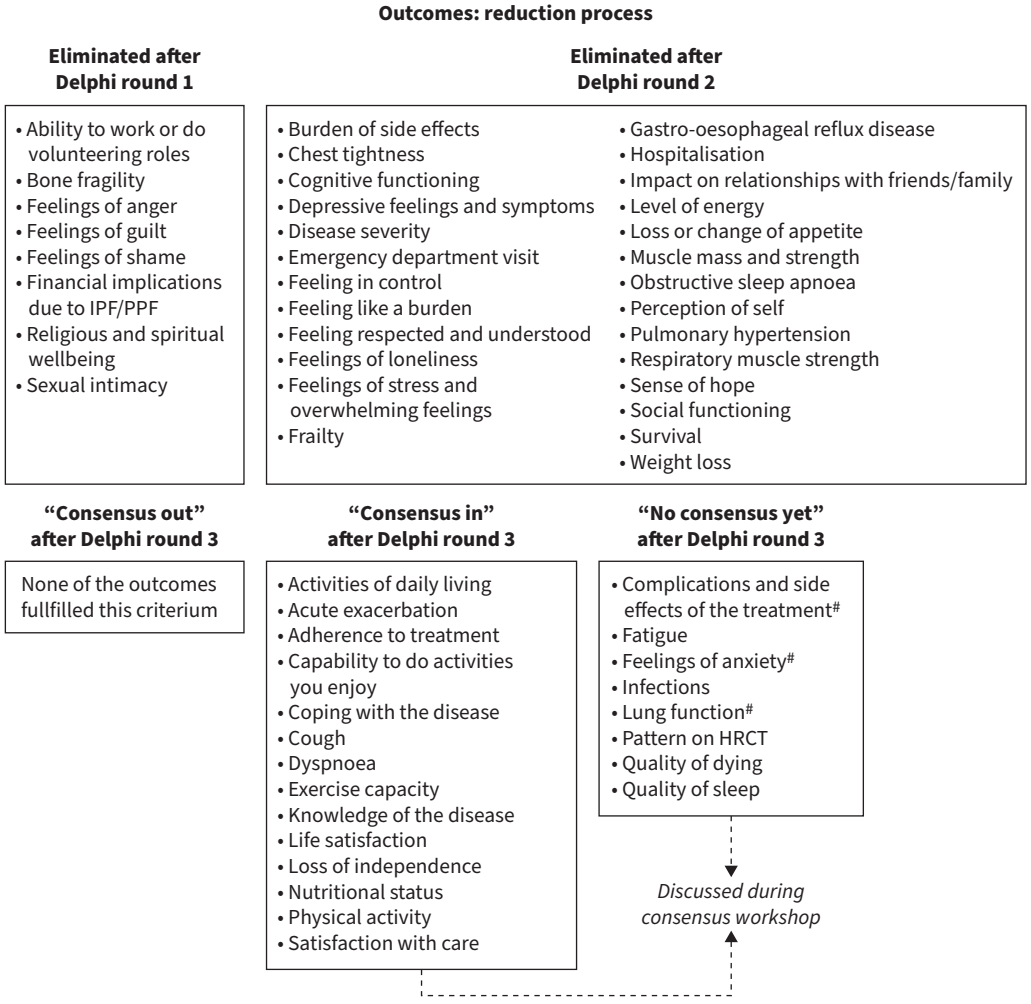


FIGURE 2 Overview of the reduction process of the outcomes during the Delphi rounds. IPF: idiopathic pulmonary fibrosis; PPF: progressive pulmonary fibrosis; HRCT: high-resolution computed tomography. #: outcomes that were decided to be included in the final core outcome set, based on discussion and voting in the consensus workshop.

Outcomes

The 14 outcomes considered "consensus in" were presented and endorsed for inclusion by the participants (figure 2). After the small group discussions, the group leaders summarised the arguments for or against inclusion of the discussed outcomes "without consensus yet" (supplementary material H). In the anonymous voting, the majority of participants voted in favour of adding the following three outcomes into the COS: complications and side-effects of the treatment, feelings of anxiety and lung function (supplementary material I). The final COS consists of 17 outcomes (figure 1) and is summarised by the mnemonic "standard IPF/PPF care" (figure 3).

Discussion

Based on a rigorous mixed-method approach and the COMET initiative recommendations, the COCOS-IPF consortium developed a COS for clinical IPF/PPF care in collaboration with patients, caregivers and HCPs. The final COS includes 17 outcomes deemed critically important by all stakeholders, featuring a balanced mix of clinical and life impact outcomes. Many of these outcomes are not specific to IPF/PPF (*e.g.* physical activity, feelings of anxiety, coping with the disease), but are recommended to address in other chronic diseases (*e.g.* heart failure, COPD) and often receive insufficient focus in IPF/PPF care [5, 32, 33]. Patient contributions were crucial in identifying our key outcomes: of the 13 outcomes considered important by patients in all three Delphi rounds, 10 were included in the final COS, highlighting the integration of patients' voices. This extensive patient input resulted in a patient-centred COS, which could

S - Satisfaction with life and care#
T - Treatment adherence#
A - Ability to do activities you enjoy#
N - Nutritional status
D - Disease and treatment knowledge#
A - Activities of daily living#
R - Resilience/coping#
D - Dyspnoea

I/P - Independence#/physical activity
P - Pulmonary function
F - Feelings of anxiety#

C - Cough
A - Acute exacerbation
R - Reaction to treatment (complications and side effects)
E - Exercise capacity

FIGURE 3 The mnemonic "standard IPF/PPF care" summarises the key outcomes included in the core outcome set for IPF/PPF care. Each letter corresponds to one outcome, except for "S", which represents two outcomes. The mnemonic was developed *post hoc* to improve dissemination and clinical implementation of the core outcome set (COS) across Europe. IPF: idiopathic pulmonary fibrosis; PPF: progressive pulmonary fibrosis. #: outcomes categorised as life impact outcomes. Outcomes without # represent clinical or physiological outcomes.

serve as a foundation to improve the care for other chronic diseases too. Moreover, our rigorous step-wise methodological approach, alongside the supporting documents, which also includes an overview of challenges and possible solutions, might serve as a guide for future COS development initiatives (supplementary material J).

By implementing this COS throughout Europe, we aim to standardise and improve individual patient care and drive the shift towards value-based healthcare [10, 34]. It can also guide clinical research by improving comparability across centres or studies and expand the focus of drug or other intervention trials, addressing meaningful outcomes that go beyond traditionally used outcomes (*e.g.* survival, lung function, *etc.*) [34].

Some remarkable differences across stakeholder groups were observed during the Delphi process. Lung function and pattern of disease on HRCT were deemed critically important by patients and caregivers, but not by all professionals. Both outcomes were retained for discussion in the consensus workshop, where clinicians noted that these tests do not capture how patients feel, while patients expressed the need for tangible information to understand disease progression. The workshop voting resulted in including lung function into the final COS. Second, while professionals viewed outcomes related to side-effects as critically important, not all patients and caregivers shared this perspective. Some patients in the Delphi study indicated that some side-effects can be managed with medication and others reported not experiencing any. The voting process in the workshop resulted in including complications and side-effects of the treatment in the COS.

Compared to the previously developed COS for IPF clinical trials, our COS covers breathlessness, cough and lung function, but not pattern on HRCT and survival [13]. This shift highlights differing priorities between research and clinical practice. Pattern on HRCT was excluded due to its complexity and heterogeneity for clinical care, as noted by participants. Regarding survival, the difficulty to predict an individual patient's prognosis, combined with the view that "a longer life has limited value if the quality of life is compromised" may explain why participants did not consider this outcome key for the COS. Lastly, health-related quality of life was included in the COS for clinical trials, but was not included in the Delphi survey, as it was encompassed by several initial outcomes [13]. Additionally, our approach focused on patient involvement and participation, as recommended when aiming to improve care [11]. As this was not the focus of Saketkoo's COS, it may explain why our COS included several patient-reported outcomes [13].

The mixed-method approach used to develop this COS ensured a comprehensive, evidence and experience-based input in the preparatory phase and included relevant stakeholders in all phases [22, 30, 31]. Patients were involved and participated in all stages of the project, ensuring their needs were acknowledged [35]. The availability of the Delphi study in five languages facilitated widespread participation from patients and

HCPs, supporting the COS's implementation as a standardised framework across European healthcare settings. However, as input was limited to European stakeholders, its applicability to non-Europeans requires further validation in international settings, due to potential differences in healthcare delivery, access and cultural context. Caregivers were slightly under-represented in the Delphi study, and no nurse attended the workshop. However, using panels in the Delphi rounds' cut-off criteria ensured equal weighting of each stakeholder group's voice, avoiding bias from unevenly distributed groups [36]. Besides, although patients with PPF were less represented than patients with IPF in the Delphi rounds, a balanced representation of both groups in the consensus workshop helped to ensure that PPF perspectives were meaningfully considered in the development of the final COS. Lastly, not defining a maximum number of outcomes for the final COS resulted in including all critically important outcomes, strengthening the COS's comprehensiveness.

To summarise, this study developed a COS for IPF/PFF routine care, recommended for use to improve value-based healthcare. The mnemonic "standard IPF/PPF care" may support clinicians in integrating the COS into routine care, with future work focused on defining corresponding outcome measures and their recommended assessment frequency.

Acknowledgements: We would like to thank the individuals who contributed to the translation of the documents used in the Delphi study: Prof. Ana Laura Solano López (Universidad de Costa Rica, Costa Rica), Dr Laura Delgado Ortiz (IS Global, Spain), Dr Mariela Acuña Mora (University of Borås, Sweden) and Lara Andreoli (KU Leuven, Belgium) for Spanish; Prof. Şirin Özkan (Uludağ Üniversitesi, Türkiye, and KU Leuven, Belgium) and Eda Şen (Association for Social Development and Aid Mobilization, Ankara, Türkiye) for Turkish; David Nothdurfter (Psychologische Hochschule Berlin) for German; and Lévai Eszter (Semmelweis University, Hungary) and László Loibl (patient) for Hungarian translations. We extend our thanks to all the participants of the Delphi study for their valuable contributions. We also sincerely thank the participants of the consensus workshop: Eleni Stamouli (patient), Chantal Vandendungenen (patient advocate and caregiver), Christina Bache (caregiver), Jacobo Sellares (pulmonologist), Jaume Bordas-Martinez (pulmonologist), Saher Shaker (pulmonologist), Veronika Müller (pulmonologist), Iris Coosemans (physiotherapist), Thomas Riegler (physiotherapist) and Markus Hayden (psychologist). Additionally, we are grateful to the five patient representatives who took part in the workshop and prefer to remain anonymous. Without all their efforts, this project would not have been possible and their input was key to developing this COS. We hereby declare that artificial intelligence has been used to ensure grammatical accuracy (DeepL, version 24).

Data availability: The COCOS-IPF consortium is committed to transparency and collaboration. Methodologies and study protocols used in this research are available to qualified researchers upon reasonable request, to support further validation studies in diverse populations.

Provenance: Submitted article, peer reviewed.

COCOS-IPF consortium: Fabienne Dobbels, Wim Wuyts, Sofie Breuls, Anouk Delameillieure, Liesbet Van Bulck (all University of Leuven, University Hospitals Leuven, Belgium), Michael Kreuter, Vivien Somogyi (both Mainz Lung Center, Mainz, Germany), Nikola Stenzel, Silja Schenk (both Psychologische Hochschule Berlin, Germany), Nesrin Mogulkoç, Zehra Nur Töreyin, Ömer Faruk Dadas (all Ege University, Türkiye), Steve Jones, Liam Galvin (both European Pulmonary Fibrosis Federation), Jeanette Boyd (European Lung Foundation) and Thomy Tonia (University of Bern).

Ethics statement: The approval of the Ethics Committee Research UZ/KU Leuven was obtained in June 2024 for the Delphi study (G-2023-7460-R2(MIN)) and in January 2025 for the consensus workshop (G-2024-8932).

Conflict of interest: L. Galvin reports grants from Boehringer Ingelheim, Roche Group, Trevi Therapeutics, Chiesi Pharmaceuticals, Bristol Meyer Squibb, Vicore Pharma, CSL Behring, Ferrer, Agomab and Avalyn; support for attending meetings from European Pulmonary Fibrosis Federation, European Reference Network for Rare Lung Diseases, European Respiratory Society and European Lung Health Group; and leadership roles with European Pulmonary Fibrosis Federation, European Lung Foundation, Irish Lung Fibrosis Association, European Reference Network for Rare Lung Diseases and Irish Rare Disease Clinical Trial Network. J. Boyd is employed by the European Lung Foundation, founded by European Respiratory Society (ERS). T. Tonia is an ERS Methodologist. M. Kreuter reports consultancy fees from GSK, Boehringer, AstraZeneca, Pliant and BMS; and a leadership role with the ERS. W. Wuyts reports grants from Roche, Sanofi, Boehringer Ingelheim and Alentis; consultancy fees from Boehringer Ingelheim, Alentis, Endeavor, Sanofi, Pliant, Agomab, Quotient and Insilico; and payment or honoraria for lectures, presentations, manuscript writing or educational events from Boehringer Ingelheim, Alentis, Endeavor,

Sanofi, Pliant, Agomab, Quotient and Insilico. A. Delameillieure, F. Dobbels, L. Van Bulck, N. Toreyin, N. Mogulkoc, N. Stenzel, S. Breuls, S. Schenk, Ö.F. Dadaş, V. Somogyi and S. Jones confirm no conflicts of interest to report.

Support statement: This project is funded by the European Joint Programme on Rare Disease (EJPRD21–045). Funding information for this article has been deposited with the Open Funder Registry.

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