Supplementary materials

The COCOS-IPF Core Outcome Set for IPF/PPF Care: A Mixed-Method Multi-Perspective Approach

COCOS-IPF Consortium:

University of Leuven, University Hospitals Leuven, Belgium:
Fabienne Dobbels, Wim Wuyts, Sofie Breuls, Anouk Delameillieure, Liesbet Van Bulck

Mainz Lung Center, Mainz, Germany:
Michael Kreuter, Vivien Somogyi

Psychologische Hochschule Berlin, Germany:
Nikola Stenzel, Silja Schenk

Ege University, Türkiye:
Nesrin Mogulkoç, Zehra Nur Töreyin, Ömer Faruk Dadaş

European Pulmonary Fibrosis Federation:
Steve Jones, Liam Galvin

European Lung Foundation:
Jeanette Boyd

University of Bern:
Thomy Tonia

Documents related to the best-worst scaling exercise (conducted in the third Delphi round), documents related to the consortium's discussion meetings analysing the Delphi results, documents on sensitivity analyses or other documents are available upon reasonable request.

Please contact Fabienne Dobbels for inquiries: fabienne.dobbels@kuleuven.be

TABLE OF CONTENT

THE COCOS-IPF CORE OUTCOME SET FOR IPF/PPF CARE: A MIXED-METHOD MULTI-PERSPECTIVE APPROACH 1

SUPPLEMENT A: DEVELOPMENT OF LIST WITH DELPHI SURVEY OUTCOMES 3

SUPPLEMENT B: OUTCOMES AND CORRESPONDING DEFINITIONS 10

SUPPLEMENT C: LIST OF PATIENT AND PROFESSIONAL ORGANIZATIONS CONTACTED 14

SUPPLEMENT D: DESCRIPTIVES OF PARTICIPANTS IN ALL ROUNDS 15

SUPPLEMENT E: SUGGESTED ITEMS IN ROUND 1 20

SUPPLEMENT F: PROPORTION OF PARTICIPANTS THAT CONSIDER THE OUTCOME AS CRITICALLY IMPORTANT FOR INCLUSION. 21

SUPPLEMENT G: RESULTS OF BEST-WORST SCALING EXERCISE 25

SUPPLEMENT H: ARGUMENTS FOR INCLUSION OR EXCLUSION OF THE OUTCOMES WITHOUT CONSENSUS (CONSENSUS WORKSHOP). 26

SUPPLEMENT I: VOTING OF OUTCOMES 'WITHOUT CONSENSUS YET' DURING CONSENSUS WORKSHOP 28

SUPPLEMENT J: TIPS AND CONSIDERATIONS FOR FUTURE COS DEVELOPMENTS 29

REFERENCES 31

Supplement A: Development of list with Delphi survey outcomes

Compiling the list of 56 outcomes

A list of outcomes related to IPF/PPF care was compiled based on three information sources: 1) a scoping review on outcomes mentioned in primary quantitative and qualitative research papers on IPF/PPF [1]; 2) a European survey with 149 healthcare professionals experienced in IPF/PPF, to understand which outcomes are currently addressed in routine care or research, and which they deem important to consider [2]; and c) patient-led focus groups with patients in five European countries (Belgium, Greece, Norway, Türkiye and UK) to understand what matters most to patients in terms of health outcomes when living and dealing with IPF or PPF (paper in preparation).

This resulted in a list of 97 outcomes to send out in a Delphi survey. However, to increase the retention rate of participants, it is recommended to have fewer items in a Delphi survey [3]. Therefore, the list was shortened to 56 outcomes, based on guidance of previous core outcome set developments, three criteria defined by the consortium, five discussion rounds within the consortium, and final round of feedback and endorsement of the consortium on the final version of the list [4, 5]. The three criteria that the consortium compiled were 1) “Is the outcome relevant for the majority of patients with IPF/PFF?”; 2) “Is the outcome relevant across the cycle of care, from diagnosis until end-of-life or transplantation?” and 3) “Is the outcome patient-centred enough?”.

The table shows the outcomes retrieved from each source (first and second column), categorized according the COMET CORE Areas [6]. The third column describes the discussion points of each outcome, resulting in keeping or deleting the outcome for the Delphi list (fourth column). Green cells indicate included outcomes, blue cells indicate outcomes that were merged with a green outcome and red cells indicate outcomes that were not included in the final list for the Delphi survey. * Refers to comorbidities that were extensively discussed in the consortium and finally decided to include only the most important or frequent comorbidities in the Delphi list.

Outcome	Source	Discussion	Final
COMET Core Area: Death			
1. Survival	Focus groups		**Survival**
2. All-cause mortality	Review, Survey	Merge into outcome 'survival' as this is what matters most to patients.	
3. Disease-related mortality	Review, Survey		
4. Transplant free survival	Review	Not relevant for all patients and in all countries.	/
COMET Core Area: Adverse events/complications			
5. Burden of side effects	Review, Survey, Focus groups	Keep outcome.	**Burden of side effects**
6. Adverse events/complications	Review, Survey, Focus groups	Rename, as this outcome refers to the side effects of treatment or care, and not due to the disease. Keep outcome.	**Complications and side effects due to treatment**
COMET Core Area: Physiological/clinical			
7. Acute exacerbation	Review, Survey	Keep outcome.	**Acute exacerbation**
8. Bone problems	Review	Rename and keep outcome.	**Bone fragility**
9. Breathlessness	Review, Survey, Focus groups	Keep outcome.	**Breathlessness**
10. Oxygenation	Review, Survey	This refers to e.g. hypoxia, which is captured by breathlessness from patient perspective. Merge with breathlessness.	
11. Cough	Review, Survey, Focus groups	Keep outcome.	**Cough**
12. Sputum	Review, Survey	Merge with cough.	
13. Chest problems	Review, Survey, Focus groups	Rename and keep outcome.	**Chest tightness**
14. Disease severity	Review, Survey	Keep outcome.	**Disease severity**
15. Exercise capacity	Review, Survey	Keep outcome.	**Exercise capacity**
16. Fatigue	Review, Survey, Focus groups	Keep outcome. Clear definition needed with a distinction between fatigue and level of energy.	**Fatigue**
17. Frailty	Review	Gives a profile to a person. Keep	**Frailty**

		outcome.	
18. Oesophageal disorder	Review	Rename and keep outcome.	**Gastro-oesophageal reflux disease (GERD)**
19. Airway infection	Review, Survey, Focus groups	Rename to infections to broaden domain. Keep outcome.	**Infections**
20. Level of Energy	Review, Focus groups	Keep outcome.	**Level of energy**
21. Loss of appetite	Review, Focus groups	Rename & keep outcome. Renaming the outcome happened based on cognitive debriefings with patient representatives.	**Loss or change of appetite**
22. Lung function	Review, Survey	Keep outcome.	**Lung function**
23. Muscle mass and strength	Review, Survey	Keep outcome.	**Muscle mass and strength**
24. Nutritional Status	Review, Survey	Gives a profile to a person. Keep outcome.	**Nutritional status**
25. Signs of disease on lung imaging	Review, Survey	Rename and keep outcome.	**Pattern of disease on lung imaging**
26. Physical activity	Review, Survey, Focus groups	Keep outcome.	**Physical activity**
27. Sleep problems	Review, Survey, Focus groups	Rename and keep outcome.	**Quality of sleep**
28. Respiratory muscle strength	Review, Survey	Keep outcome.	**Respiratory muscle strength**
29. Weight Loss	Review	Keep outcome.	**Weight loss**
30. Pulmonary hypertension*	Review	Keep outcome.	**Pulmonary Hypertension**
31. Obstructive sleep apnoea*	Review	Keep outcome.	**Obstructive sleep apnoea (OSA)**
32. Body Composition	Review	Covered by other domains.	/
33. Comorbidities*	Review	Most important comorbidities are selected and included in the list.*	/
34. Diaphragm dysfunction	Review	Too specific, and not relevant for majority of patients.	/
35. Disease progression	Review, Survey	This domain implies multiple time points. Keep outcome individual outcomes that can assess disease progression over time.	/

36. Dizziness	Review	Not relevant for most of the persons with IPF/PPF. Mainly related to medications or certain comorbidities.	/
37. Fever	Review	Not relevant for most of the persons with IPF/PPF.	/
38. Heart function	Review, Survey	Dysfunction covered by comorbidities.	/
39. Nail Clubbing	Review	Not used in clinical practice as assessment of care/treatment	/
40. Nausea	Review	Not relevant for most of the persons with IPF/PPF. Mainly related to medications or certain comorbidities.	/
41. Pain	Review, Survey	Not relevant for most of the persons with IPF/PPF.	/
42. Physical examination outcomes	Survey	Too vague and overlap with other variables.	/
43. Respiratory sounds on auscultation	Review, Survey	Mainly important during diagnostic phase, and not during the entire cycle of care.	/
44. Throat problems	Review	Not relevant for most of the persons with IPF/PPF.	/
45. Vital signs	Survey	Too vague and overlap with other variables.	/
46. Weakness	Review	Covered by other domains (e.g. muscle strength).	/
COMET Core Area: Life Impact			
47. Ability to work	Review, Focus groups	It should focus on impact on volunteering, community work, paid work. Rename and keep outcome.	**Ability to work or do volunteering roles**
48. Activities of daily living (ADLs)	Review, Survey, Focus groups	Keep outcome.	**Activities of daily living (ADLs)**

49. Medication adherence	Review, Survey	Merge into new outcome 'Adherence to treatment' as all domains refer to patient behaviour towards treatment recommendations.	**Adherence to treatment**
50. Adherence to other treatment components	Review		
51. Consuming too much alcohol	Review (subdomain PROMs analyses)		
52. Being knowledgeable and informed about disease and treatment	Review, Focus groups	Rename, because 'informed' refers to a process of care, and keep outcome.	**Being knowledgeable about disease and treatment**
53. Limitations in daily activities you enjoy	Review, Focus groups	Rename and keep outcome.	**Capability to do activities you enjoy**
54. Cognitive problems	Review	Rename and keep outcome.	**Cognitive functioning**
55. Coping with the disease	Review, Survey, Focus groups	Keep outcome.	**Coping with the disease**
56. Dealing with disease progression	Review, Focus groups	Merge with 'coping with the disease'	
57. Depressive feelings	Review, Survey, Focus groups	Rename and keep outcome.	**Depressive feelings and symptoms**
58. Depressive disorder	Review	Merge with 'depressive feelings and symptoms'.	
59. Feeling in control	Review, Focus groups	Keep outcome.	**Feeling in control**
60. Feeling like a burden	Review, Focus groups	Keep outcome.	**Feeling like a burden**
61. Feeling respected and understood	Focus groups	Keep outcome.	**Feeling respected and understood**
62. Feelings of anger	Review	Keep outcome.	**Feelings of anger**
63. Feelings of frustration	Review, Focus groups	Merge with 'feelings of anger'.	
64. Feelings of anxiety, worry, fear	Review, Survey, Focus groups	Rename and keep outcome.	**Feelings of anxiety, worry, fears related to the disease**
65. Anxiety disorder	Review	Merge with 'feelings of anxiety, worry, fears related to the disease'	
66. Feelings of guilt	Review	Keep outcome.	**Feelings of guilt**
67. Feelings of loneliness or social isolation	Review, Focus groups	Keep outcome.	**Feelings of loneliness**
68. Feelings of shame	Review, Focus groups	Keep outcome.	**Feelings of shame**

69. Stress/overwhelm	Review, Survey, Focus groups	Rename and keep outcome.	**Feelings of stress and overwhelming feelings**
70. Financial concerns	Review	Rename and keep outcome.	**Financial implications due to progressive pulmonary fibrosis**
71. Changes in the role within relationships	Review, Focus groups	Rename with focus on impact and keep outcome.	**Impact on relationships with friends and family**
72. Life satisfaction	Focus groups	Keep outcome.	**Life satisfaction**
73. Loss of independence	Review, Survey, Focus groups	Keep outcome.	**Loss of independence**
74. Change in sense of self	Review, Focus groups	Rename and keep outcome.	**Perception of self**
75. Quality of death	Review, Focus groups	Rename and keep outcome.	**Quality of dying**
76. Religious and spiritual wellbeing	Review (subdomain PROMs analyses)	Keep outcome.	**Religious and spiritual wellbeing**
77. Attitudes towards treatment/care	Review, Focus groups	Rename and keep outcome.	**Satisfaction with care**
78. Sense of hope	Review, Focus groups	Keep outcome.	**Sense of hope**
79. Difficulties with sexual intimacy	Review, Focus groups	Rename and keep outcome.	**Sexual intimacy**
80. Life participation (or burden on social life)	Review, Survey, Focus groups	Rename and keep outcome.	**Social functioning**
81. Wellbeing	Survey	It is too vague and can better be merged in other domains such as psychological wellbeing or religious/spiritual wellbeing.	
82. Feeling emotionally weak	Review	Too vague and overlap with other variables.	/
83. Health-related quality of life	Review, Survey, Focus groups	An umbrella term that is covered by several domains in the list, e.g. life satisfaction. If this outcome is selected, we will not know which aspect of someone's health-related quality of life should be targeted for improvement in clinical care.	/

84. Needs in palliative care	Survey	Focusses only on end of life. COS should be used over the different phases in life. Also overlap with other domains.	/
85. Psychological wellbeing	Review, Survey, Focus groups	Captured by other domains.	/
86. Psychosocial disabilities	Review	Captured by other domains and negatively phrased.	/
87. Selfcare	Focus groups	Overlap with other variables, e.g. activities of daily living.	/
COMET Core Area: Resource use			
88. Emergency department visit	Review	Keep outcome.	**Emergency department visit**
89. Hospitalization	Review, Survey	Keep outcome.	**Hospitalization**
90. Intensive care visit	Review	Merge with hospitalization.	
91. Outpatient visit	Review	Process of care, remove outcome.	/
92. Disease specific costs	Review	Costs are important when assessing the care. However, it is not within the scope as our COS should focus on aspects of a patient's health and wellbeing that should be considered in the care.	/
93. End of life related costs	Review		/
94. Hospitalization related costs	Review		/
95. Outpatient treatment costs	Review		/
96. Overall healthcare costs	Review		/
97. Treatment related costs	Review		/

Supplement B: Outcomes and corresponding definitions

Outcome	Definition
Ability to work or do volunteering roles	The ability to work or do volunteering roles refers to an individual's capacity to engage in formal employment or volunteer activities due to IPF/PPF.
Activities of daily living	Activities of daily living refer to daily, necessary activities for which a person with IPF/PPF may need help or support. These include: bathing, toileting, getting dressed, walking, eating meals and personal hygiene. This may also include other basic activities such as cooking, cleaning, transportation, laundry and managing finances.
Acute exacerbation	An acute exacerbation is a sudden and significant worsening or flare-up of pulmonary fibrosis. It is a period when the symptoms of the disease become more severe or intense, often requiring immediate or intensified medical attention and treatment.
Adherence to treatment	People with IPF/PPF receive treatment and care for the disease. Adherence to treatment means sticking to and following the recommended plan or instructions for the treatment and care of IPF/PPF. It involves consistently and correctly taking prescribed medications, following advised therapies, and making suggested lifestyle changes (such as being physically active, reducing alcohol use or quitting smoking).
Being knowledgeable about the disease and treatment	This refers to the knowledge a person with IPF/PPF has or should have about the disease and treatment. This may be impacted by difficulties in understanding, receiving, assessing and interpreting (medical) information.
Bone fragility	Bone fragility refers to bones that are more vulnerable to breaking or fracturing than usual. Bone fragility is often associated with conditions such as osteoporosis.
Breathlessness	Breathlessness or shortness of breath is the uncomfortable sensation of not getting enough air to breathe. In patients with IPF/PPF, this may occur in a variety of situations, for example when walking, climbing stairs, or even when sitting still.
Burden of side effects	Burden of side effects captures the extent to which a person with IPF/PPF may be concerned physically or emotionally by the side effects of a treatment. An example is not feeling free to go where one wants, because of diarrhea.
Capability to do activities you enjoy	Capability to do activities you enjoy refers to the effect of IPF/PPF on a person's capacity to engage in individual interests or tasks that bring pleasure.
Chest tightness	Chest tightness includes pressure tightness, or other discomfort originating in or extending to the chest.
Cognitive functioning	Cognitive functioning refers to how well a person's brain performs mental processes such as thinking, learning, remembering, or planning. It addresses a person's ability to process information. For example, issues with cognitive functioning can lead to disorientation and memory- or concentration problems.
Complications and side effects due to treatment	Side effects or complications of treatment refer to reactions that occur as a result of using a particular medication or treatment for IPF/PPF. Examples are diarrhea, skin rash and nausea.
Coping with the disease	Coping means finding ways to deal with and manage the challenges that come with the disease. It involves different approaches or behaviors to manage the stress and/or emotional problems that may arise due to the disease. Examples of coping strategies can include seeking support from others, learning to deal with different emotions or looking for activities and goals that still gives one joy in life.
Cough	Cough is the body's way of responding when something irritates the throat or airways. Cough for people with IPF/PPF can be severe and/or prolonged with or without sputum.
Depressive feelings and symptoms	People having IPF/PPF might experience depressive feelings or symptoms. Examples of depressive symptoms are feeling sad, hopeless or losing interest in activities that used to be enjoyable. Above that, other symptoms may occur such as lack of energy, sleep problems, difficulty concentrating, increased or decreased appetite or even having

	suicidal thoughts. These feelings and symptoms may be temporary, but they can also persist over time and significantly interfere with day-to-day activities.
Disease severity	Disease severity refers to how serious an illness is, and is classified in several severity categories, such as mild, moderate and severe.
Emergency department visit	An Emergency Department (ED) visit refers to going to the hospital or other medical department for immediate medical attention when a person with IPF/PPF has a health problem that needs urgent care. The Emergency Department is where people go when they have a sudden illness, injury, or a health issue that can't wait for a regular doctor's appointment.
Exercise capacity	Exercise capacity is the maximum amount of physical exertion that a person can tolerate and reflects a person's overall fitness.
Fatigue	Fatigue is a feeling of extreme tiredness, weakness, and lack of energy. Fatigue can be sensed physically, mentally, or both. When someone is fatigued, simple tasks may feel difficult and there is less capacity to perform usual activities.
Feeling in control	Having a sense of control when dealing with IPF/PPF means feeling empowered and capable of taking certain actions to manage and cope withthe challenges of the illness. Having a sense of control might involve making informed decisions about treatment options, adopting healthy lifestyle changes, and actively participating in one's care. It's the feeling that one is not entirely powerless in the face of the disease and that has the ability to take steps to enhance their well-being.
Feeling like a burden	A person with IPF/PPF might experience feelings of being a burden. This refers to a sense that a person with fibrosis has that the health condition is causing inconvenience, stress, or added responsibilities for those who care about him/her, such as loved ones or caregivers. These feelings can lead to feelings of sadness, isolation, and a reluctance to ask for support, as individuals may fear being a source of trouble for others.
Feeling respected and understood	A person with IPF/PPF might feel respected and understood when he/she senses that others acknowledge the challenges he/she faces due to the disease. It involves having people around that recognize the impact of the illness on daily life, showing empathy, and making an effort to understand their unique needs and experiences.
Feelings of anger	People with IPF/PPF might experience feelings of anger. Angry feelings can vary in intensity from mild irritation or annoyance to fury and rage.
Feelings of anxiety, worry, fears related to the disease	People having IPF/PPF might experience feelings of anxiety, nervousness or worried thoughts. Anxiety is a feeling associated with the anticipation of a future concern (such as how the disease will progress, or whether someone will need oxygen therapy, etc). When a person feels anxious, they typically experience physical symptoms, such as restlessness, increased breathlessness, difficulty concentrating, muscle tension, or sleeping problems. In addition, patients with IPF/PPF might develop fears and anxious beliefs that are closely related to the specific nature of the disease. Examples include fear of running out of breath, fear of disease progression, and fear and avoidance of physical activity. These feelings and symptoms may be temporary, but they can also persist over time and significantly interfere with day-to-day activities.
Feelings of guilt	Guilt is an emotion that can be experienced when there is a feeling of blame for something we did or did not do. Some people with IPF/PPF for instance might feel guilty that their partner is taking over the chores due to the disease.
Feelings of loneliness	Loneliness refers to the feeling of not belonging or no longer being needed and means that someone feels socially isolated and misses meaningful contact with family, friends, colleagues or people living in the community.
Feelings of shame	Shame is an emotion that is linked to the internal believe that we are somehow flawed or inadequate. It may arise in situations where we feel embarrassed or humiliated. Shame is often linked to concerns about social acceptance and belonging. For instance, a person with IPF/PPF might feel shame when coughing during public events.

Feelings of stress and overwhelming feelings	People with IPF/PPF might experience feelings of stress or other overwhelming feelings. Stress can occur when someone finds it hard to cope with demands in their everyday life. These demands include elements of unpredictability, uncontrollability and feeling overloaded. Feeling overwhelmed means feeling completely overcome or overpowered by thoughts or feelings (e.g. desperation, feeling powerless) without having an effective response or solution available.
Financial implications due to IPF/PPF	Financial implications might include worries or fears of a person with IPF/PPF related to their financial situation or the financial impact of the disease.
Frailty	Frailty is a condition that consists of a combination of weakness, slow walking speed, low physical activity, self-reported exhaustion and unintentional weight loss.
Gastro-oesophageal reflux disease (GERD)	Gastro-oesophageal reflux disease (GERD) is a condition where the stomach acid frequently flows back in the tube connecting the oesophagus (gullet). This may cause irritation and inflammation, leading to symptoms such as heartburn.
Hospitalization	Hospitalization means being admitted to a hospital for medical care and treatment. It can be due to IPF/PPF or due to other causes.
Impact on relationships with friends and family	Impact on relationships with friends and family refers to the effect that IPF/PPF might have on a person's interactions and connections with friends and family members. For instance, if the disease does not allow a patient to play with grandchildren, this might impact their role and relationship with their grandchildren.
Infections	Infections are caused by microorganisms, such as viruses and bacteria. These microorganisms can make a person sick. Symptoms of infection may include fever and pain. Examples of an infection is a respiratory tract infection or lung inflammation.
Level of energy	Level of energy refers to the amount of vitality or alertness a person has. A low level of energy can be associated with feeling tired or less motivated to participate in activities.
Life satisfaction	Life satisfaction refers to how content and happy a person with IPF/PPF feels with his/her life overall. It takes into account various aspects such as personal relationships, work, health, and other factors that contribute to one's well-being. If someone has a high level of life satisfaction, it generally means they feel fulfilled, pleased, and content with the way their life is going, despite having IPF/PPF.
Loss of independence	Loss of independence means that someone with IPF/PPF is unable to continue with their daily life and tasks without the help of others. Examples can be losing physical independence to take a bath or shower or to get dressed, or becoming unable to take their share of chores in and around the house.
Loss or change of appetite	In patients with IPF/PPF, a change in appetite may occur. Typically, this presents as a reduced desire to eat, but it may also be a change in preferences regarding food choices. These changes happen unintentionally, because of the disease, and are not the result of following a diet.
Lung function	Lung function describes how well the lungs work. Lung function tests help to measure lung volume, capacity, rates of flow, and gas exchange. Examples for lung function outcomes are forced vital capacity (FVC) or the diffusing capacity for carbon monoxide (DLCO).
Muscle mass and strength	Muscle mass is the amount of muscle tissue in the body, and muscle strength is the ability of a muscle to apply force against resistance. People with IPF/PPF might experience a progressive and generalized loss of muscle mass and strength.
Nutritional status	Nutritional status refers to the condition of the body as a result of the intake, absorption and use of nutrition as well as the influence of disease-related factors. To maintain good health, an appropriate level of nutrition is necessary. Nutritional risks might include weight loss, being overweight or having a vitamin deficiency.
Obstructive sleep apnea (OSA)	Obstructive Sleep Apnea (OSA) is a sleep disorder that happens when a person's breathing is repeatedly interrupted during sleep. The term "obstructive" refers to the cause of the interruption, which is the blockage or obstruction of the airway.

Pattern of disease on lung imaging	Contains all outcomes or aspects measured using lung imaging techniques, such as CT-scan or X-ray, to detect signs of inflammation, the extent of fibrosis, or signs of an acute flare-up of the disease.
Perception of self	A person with IPF/PPF might experience changes in the ways they see themselves due to the disease. For instance, there can be a shift in how someone defines him/herself because of the demands of the disease. Another example is a change in how someone perceives his/her body due to physical changes or limitations due to the disease. There can also be a change in life goals due to the disease as someone might experience a reassessment of what is truly important for him/her.
Physical activity	Physical activity is any movement that requires the body to use energy. This can include walking, doing sports, or simple activities and moving in general.
Pulmonary hypertension	Pulmonary hypertension is high blood pressure in the blood vessels that supply the lungs (pulmonary arteries). This condition can damage the right side of the heart, as the walls of the pulmonary arteries become thick and stiff, and cannot expand as well to allow blood through.
Quality of dying	Quality of dying refers to the overall experience and conditions surrounding the death of a person with IPF/PPF. It encompasses various factors aiming to ensure that the individual passes away with dignity, comfort, and in a manner that aligns with their values and preferences. Examples of factors are comfort management, emotional support, communication and decision making, and family- and social support.
Quality of sleep	Quality of sleep refers to how well someone sleeps and how restorative that sleep is. Poor quality of sleep may involve frequent awakenings, difficulties falling asleep or waking up tired.
Religious and spiritual wellbeing	Religious and spiritual wellbeing refers to the needs and expectations someone has to find meaning, purpose, and value in life. It can also refer to having a sense of inner peace, connecting to one's values, beliefs, or faith.
Respiratory muscle strength	Respiratory muscle strength refers to the power and ability of the muscles involved in breathing to do their job effectively. When we breathe, various muscles in the chest, belly and diaphragm work together to help pull air into our lungs and push it out. The strength of these muscles determines how well we can take in air. Strong respiratory muscles make breathing easier and more efficient.
Satisfaction with care	Satisfaction with care refers to how content or pleased a person with IPF/PPF is with the professional healthcare they receive. It reflects feelings about the treatment, attention and support they receive from healthcare professionals.
Sense of hope	Having a sense of hope when dealing with IPF/PPF is the feeling that, even though there may be difficulties and uncertainties, there is the belief or expectation that things could get better, or, despite the disease, that one can live a full and good life. This hope can come from support of loved ones, advancements in medical treatments or personal coping strategies. Sense of hope can provide resilience and emotional strength during tough times.
Sexual intimacy	Sexual intimacy experiences refer to the challenges a person with IPF/PPF, or a couple, experience during any stage of sexual activity or intimacy. This might also include the loss of sexually intimate contact.
Social functioning	Social functioning refers to the ability a person with IPF/PPF has to engage in and manage social activities and relationships. It refers to how much IPF/PPF affects their ability to do so.
Survival	The length of time a person with IPF/PPF lives.
Weight loss	Weight loss is a measurable decline in body weight either from illness or malnutrition (a serious condition when the diet does not contain the right amount of nutrients) or intentionally.

Supplement C: List of patient and professional organizations contacted

We contacted the following patient and healthcare professional organizations to help recruit participants for the Delphi study.

	Organisation	Region
1.	Action for Pulmonary Fibrosis	UK
2.	ARIR: Italian association for physiotherapists	Italy
3.	Asociacion de familias y enfermos de fibrosis	Spain
4.	Asociatia pacientilor cu fibroza pulmonara idiopática	Romania
5.	Asthma & Lung UK	UK
6.	Association Belge Francophone contra la Fibrose Pulmonaire	Belgium
7.	Association Fibroses Pulmonaires France	France
8.	Association of Respiratory Nurse Specialists	UK
9.	Belgische Vereniging voor Longfibrose	Belgium
10.	Central & Eastern European Interstitial Lung Diseases Patient Network	Europe
11.	Český občanský spolek proti plicním nemocem	Czech Republic
12.	EU-PFF	Europe
13.	ERS: call to assembly 9	Europe
14.	Fimarp: Federazione Italiana IPF e Malattie Rare Polmonari	Italy
15.	ILD-IN: Interstitial Lung Disease Interdisciplinary Network	UK
16.	IPF Polish Society	Poland
17.	Irish Lung Fibrosis Association	Ireland
18.	Longfibrose patiëntenvereniging	The Netherlands
19.	Lungenfibrose e.V.	Germany
20.	Lungenfibrose Forum Austria	Austria
21.	National Organisation For Heart and Lung	Norway
22.	Pulmonary Fibrosis Trust	England
23.	Pulmoner Hipertansiyon ve Skleroderma Hasta Derneği	Turkiye
24.	RESPIRA	Portugal
25.	Tüdőfibrózis Egyesület	Hungary
26.	Unione Trapiantati Polmone Di Padova	Italy

Supplement D: Descriptives of participants in all rounds

	Patients	***Caregivers***	***Pulmonologists***	***Nurses***	***Other HCPs***
Round 1 N participants	28	14	25	21	- 16 physiotherapists - 3 psychologists - 2 occupational therapists - 1 social worker
Age, median (Q1-Q3)	68.5 (61-74.5)	64 (50-65)	47 (40-55)	49 (37-51)	39 (35-45)
Sex N M/F/Prefer not to say	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
United Kingdom	1	4	3	5	1
Unknown	0	0	0	1	0
Living situation					
With partner	22	11	N.A.	N.A.	N.A.
Without partner	5	2	N.A.	N.A.	N.A.
Other	0	1	N.A.	N.A.	N.A.
Missing	1	0	N.A.	N.A.	N.A.
Employed/unemployed, N	7 / 21	5 / 9	N.A.	N.A.	N.A.
Relation to patient:	N.A.	9 / 3 / 2	N.A.	N.A.	N.A.

partner/parent/other					
Disease of patient					
IPF	22	13	N.A.	N.A.	N.A.
CHP	2	0	N.A.	N.A.	N.A.
CTD-ILD	1	1	N.A.	N.A.	N.A.
Sarcoidosis	1	0	N.A.	N.A.	N.A.
Don't know	1	0	N.A.	N.A.	N.A.
Missing	1	0	N.A.	N.A.	N.A.
Disease severity of patient					
No symptoms	2	0	N.A.	N.A.	N.A.
Mild	3	1	N.A.	N.A.	N.A.
Moderate	11	6	N.A.	N.A.	N.A.
Severe	12	7	N.A.	N.A.	N.A.
Years of experience with IPF/PPF	N.A.	N.A.	14.5 (9.5-20)	13 (6-18)	10 (7-12)
Working in and ILD centre of expertise	N.A.	N.A.	23 / 1	19 / 2	12 / 10
Percentage of time spent on clinical work	N.A.	N.A.	72.5 (50-80)	70 (50-100)	50 (35-70)
Round 2 N participants	22	7	20	13	- 15 physiotherapists - 1 social worker
Age, median (Q1-Q3)	68.5 (64-74)	64.5 (49-70)	48 (41-55)	49 (41-51)	40.5 (35-45.5)
Sex N M/F/Prefer not to say	15 / 7 / 0	1 / 6 / 0	8 / 11 / 1	2 / 11 / 0	5 / 11 / 0
Country					
Belgium	2	3	2	4	2
Czech Republic	0	0	0	0	1
Denmark	0	0	3	0	0
Germany	9	1	1	0	1
Hungary	0	0	2	0	0
Ireland	0	1	0	1	0
Italy	0	0	2	0	1
Netherlands	7	1	0	2	3
Poland	1	0	1	0	0

Portugal	0	0	0	0	2
Spain	0	0	3	1	1
Switzerland	0	0	1	2	1
Türkiye	3	0	2	0	4
United Kingdom	0	1	0	2	0
Living situation					
With partner	17	6	N.A.	N.A.	N.A.
Without partner	4	1	N.A.	N.A.	N.A.
Missing	1	0	N.A.	N.A.	N.A.
Employed/unemployed, N	5/17	3/4	N.A.	N.A.	N.A.
Relation to patient: partner/parent	N.A.	5 / 2	N.A.	N.A.	N.A.
Disease of patient					
IPF	17	7	N.A.	N.A.	N.A.
CHP	1	0	N.A.	N.A.	N.A.
Sarcoidosis	1	0	N.A.	N.A.	N.A.
Don't know	1	0	N.A.	N.A.	N.A.
Disease severity of patient					
No symptoms	2	0	N.A.	N.A.	N.A.
Mild	2	1	N.A.	N.A.	N.A.
Moderate	9	3	N.A.	N.A.	N.A.
Severe	9	3	N.A.	N.A.	N.A.
Years of experience with IPF/PPF	N.A.	N.A.	15 (10-20)	14.5 (8-18.5)	10 (7.5-15)
Working in and ILD centre of expertise	N.A.	N.A.	19 / 1	12 / 1	7 / 9
Percentage of time spent on clinical work	N.A.	N.A.	75 (50-80)	50 (45-90)	50 (20-70)
Round 3 N participants	18	6	17	12	- 12 physiotherapists - 1 social worker
Age, median (Q1-Q3)	67.5 (61-76)	65 (64-70)	47 (41-56)	49 (39-53)	41 (35-45)
Sex N M/F/Prefer not to say	11 / 7 / 0	1 / 5 / 0	7 / 9 / 1	2 / 10 / 0	5 / 8 / 0
Country					

Belgium	2	3	2	3	2
Czech Republic	0	0	0	0	1
Denmark	0	0	2	0	0
Germany	8	1	1	0	0
Hungary	0	0	2	0	0
Ireland	0	0	0	1	0
Italy	0	0	2	0	1
Netherlands	4	1	0	2	3
Poland	1	0	0	0	0
Portugal	0	0	0	0	2
Spain	0	0	3	1	1
Switzerland	0	0	0	2	1
Türkiye	3	0	2	0	2
United Kingdom	0	1	0	2	0
Living situation					
With partner	14	6	N.A.	N.A.	N.A.
Without partner	3	0	N.A.	N.A.	N.A.
Missing	1	0	N.A.	N.A.	N.A.
Employed/unemployed, N	4 / 14	2 / 4	N.A.	N.A.	N.A.
Relation to patient: partner/parent	N.A.	5 / 1	N.A.	N.A.	N.A.
Disease of patient					
IPF	13	6	N.A.	N.A.	N.A.
CHP	1	0	N.A.	N.A.	N.A.
Sarcoidosis	1	0	N.A.	N.A.	N.A.
Other	1	0	N.A.	N.A.	N.A.
Don’t know	1	0	N.A.	N.A.	N.A.
Disease severity of patient					
No symptoms	2	0	N.A.	N.A.	N.A.
Mild	2	1	N.A.	N.A.	N.A.
Moderate	5	3	N.A.	N.A.	N.A.
Severe	9	2	N.A.	N.A.	N.A.

Years of experience with IPF/PPF	N.A.	N.A.	14.5 (10.5-18)	16 (6-20)	10 (10-15)
Working in and ILD centre of expertise	N.A.	N.A.	16 / 1	11 / 1	7 / 6
Percentage of time spent on clinical work	N.A.	N.A.	75 (50-85)	50 (40-100)	50 (20-70)

Disease severity is self-reported. CHP: Chronic hypersensitivity pneumonitis; CTD-ILD: Connective tissue disease associated ILDs; HCPs: healthcare professionals.

Supplement E: Suggested items in round 1

The following items were suggested to include as outcomes, but none of them were suggested by at least 10% of the 110 participants and some referred to interventions or treatment (and not outcomes).

Suggested outcome	Number of participants
Discuss the needs for oxygen therapy	7
Discuss importance and access to respiratory rehabilitation	4
Referral to support groups	2
Self-management of symptoms	2
Advanced care planning	1
Comorbidities	1
Coping caregivers	1
Disease interference	1
Expectations	1
Family worries	1
Fear of suffocation	1
Heredity	1
Informal care availability	1
Learn expectoration techniques	1
Medication interference	1
Motivation/control physical activity	1
Other disciplines	1
Other medical occurrences	1
Palliative care	1
Prevention	1
Scientific research participation	1
Social support needs	1
Treatment adherence barriers	1
Treatment experience	1
Transplantation	1

Supplement F: Proportion of participants that consider the outcome as critically important for inclusion.

	Round 1					Round 2					Round 3					Consensus workshop
	Patients	CG	Pulm.	Nurses	HCP	Patients	CG	Pulm.	Nurses	HCP	Patients	CG	Pulm.	Nurses	HCP	
COMET Core Area: Death																
Survival	71	71	80	70	68	73	57	55	69	56						
COMET Core Area: Adverse events/complications																
Complications & side effects of treatment	67	71	100	100	95	73	43	80	77	75	100	67	100	100	92	Included
Burden of side effects	61	71	92	100	91	59	43	70	77	38						
COMET Core Area: Physiological/clinical																
Acute exacerbation	82	93	72	90	91	73	86	65	46	81	83	100	94	92	92	Included
Breathlessness	86	93	96	95	95	91	86	100	100	100	100	83	100	100	100	Included
Cough	79	93	96	95	91	82	71	95	92	69	94	100	100	100	92	Included
Exercise capacity	75	100	96	95	82	82	71	80	92	94	94	100	94	100	100	Included
Fatigue	71	100	84	86	73	73	71	30	77	50	72	100	82	92	77	
Infections	71	93	76	90	82	73	86	50	85	44	89	83	82	100	69	
Lung function	93	86	68	76	77	77	71	65	31	56	94	83	71	42	77	Included
Nutritional status	82	100	88	90	91	68	71	70	77	69	89	100	94	92	100	Included
Pattern of disease on lung imaging	86	79	56	45	64	86	71	30	8	19	100	83	59	8	31	
Physical activity	96	100	92	100	91	86	86	80	100	94	94	100	100	100	100	Included
Quality of sleep	82	86	52	86	82	77	29	25	31	56	94	83	59	92	85	
Chest tightness	50	86	20	67	45	50	29	10	31	13						
Disease severity	71	86	88	76	77	64	57	70	62	63						
Gastro-oesophageal reflux disease (GERD)	44	71	52	76	45	45	43	30	46	19						
Muscle mass and strength	82	86	48	81	68	73	57	15	38	56						

Respiratory muscle strength	89	86	48	76	73	82	71	20	54	56						
Frailty	57	93	84	95	77	45	71	40	54	69						
Level of energy	89	79	60	86	86	59	57	15	38	38						
Weight loss	57	93	76	81	82	36	57	75	69	31						
Loss or change of appetite	68	86	80	90	64	32	71	45	62	50						
Pulmonary hypertension	79	93	60	76	73	73	71	25	23	34						
Obstructive sleep apnea (OSA)	61	85	32	71	55	41	14	15	8	25						
Bone fragility	50	57	32	57	45											
COMET Core Area: Life impact – functioning																
Activities of daily living	64	86	88	95	95	59	43	65	77	81	83	83	88	92	92	Included
Capabilities to do activities you enjoy	79	79	80	81	86	64	71	40	85	63	89	83	76	83	85	Included
Coping with the disease	86	100	88	100	95	77	100	75	100	75	94	100	94	100	100	Included
Feelings of anxiety, worry, fears related to the disease	75	100	88	100	91	50	57	40	77	56	72	100	82	100	85	Included
Loss of independence	79	93	76	76	82	55	71	65	69	63	89	83	82	83	92	Included
Cognitive functioning	71	64	52	71	55	59	14	25	23	38						
Depressive feelings and symptoms	68	86	76	100	82	50	71	35	62	56						
Feeling in control	93	71	64	90	50	68	57	25	69	19						
Feeling like a burden	50	71	48	86	59	41	29	10	31	19						
Feeling respected and understood	75	71	60	90	64	68	57	30	69	44						

Feelings of stress and overwhelming feelings	61	86	64	95	77	41	14	15	38	25						
Feelings of loneliness	61	64	52	76	77	23	14	20	54	31						
Impact on relationships	75	77	76	81	68	45	57	25	62	44						
Perception of self	75	79	36	71	59	45	14	5	23	19						
Sense of hope	79	93	56	81	73	86	43	40	62	44						
Social functioning	64	79	72	95	73	23	14	15	38	31						
Ability to work or do volunteering roles	54	29	40	48	55											
Feelings of anger	36	57	28	67	45											
Feelings of guilt	39	50	24	67	41											
Feelings of shame	32	54	48	67	45											
Religious and spiritual wellbeing	29	43	32	57	36											
Sexual intimacy	25	33	36	52	55											
COMET Core Area: Life impact – QoL/health status																
Life satisfaction	79	93	84	86	82	77	43	65	62	75	94	100	88	83	85	Included
COMET Core Area: Life impact – delivery of care																
Adherence to treatment	96	100	88	86	91	91	100	80	54	75	100	100	100	92	100	Included
Quality of dying	89	86	88	95	73	86	57	60	77	50	89	83	100	92	77	
Being knowledgeable about the disease and treatment	93	100	72	90	82	86	86	70	85	69	100	100	82	92	100	Included
Satisfaction with care	96	93	76	86	64	82	14	45	100	63	89	100	88	100	77	Included
COMET Core Area: Life impact – personal circumstances																

Financial implications due to IPF/PPF	54	43	40	62	27											
COMET Core Area: Resource use																
Hospitalization	64	64	84	76	73	50	29	50	38	38						
Emergency department visit	64	79	56	67	50	55	57	20	31	25						

The proportion of participants in the panel, expressed as percentage, that considered the outcome as *critical for inclusion in the core outcome set* (round 1: score ≥7; round 2: score ≥8; round 3: score ≥7). **For round 1 and 2**: Green cells: based on predefined criteria, this stakeholder group considers the outcome important to include in the next round. White cells: based on the predefined criteria, this stakeholder group considers the outcome not important to include in the next round. Blue cells: discussed within the COCOS-IPF consortium to include the outcome in next round. Red cells: discussed within the COCOS-IPF consortium not to include the outcome in the next round. **For round 3**: Green cells: considered as *consensus in*. White cells: considered as *no consensus yet*. No outcome fulfilled the criterium to be considered *consensus out*. **For consensus workshop**: Green cells: outcomes included in the core outcome set. White cells: outcomes not included in the core outcome set. Discussions of the COCOS-IPF consortium on reasons to include/exclude certain outcomes (indicated with blue and red cells) are available upon reasonable request. CG: caregivers; Pulm.: pulmonologists; HCP: healthcare professionals

Supplement G: Results of best-worst scaling exercise

The following list is the result of the best-worst scaling exercise, where the outcome on the first place is considered as the most important outcome to include in the COS.

1. Breathlessness
2. Acute Exacerbation
3. Life satisfaction
4. Activities of daily living
4. Coping with the disease (shared 4th place)
6. Physical activity
7. Complications of side effects
8. Cough
9. Capability to do activities you enjoy
10. Feelings of anxiety
11. Being knowledgeable about the disease
12. Loss of independence
13. Exercise capacity
14. Quality of dying
15. Treatment adherence
15. Infections (shared 15th place)
17. Lung function
18. Fatigue
19. Quality of sleep
20. Nutritional status
21. HRCT

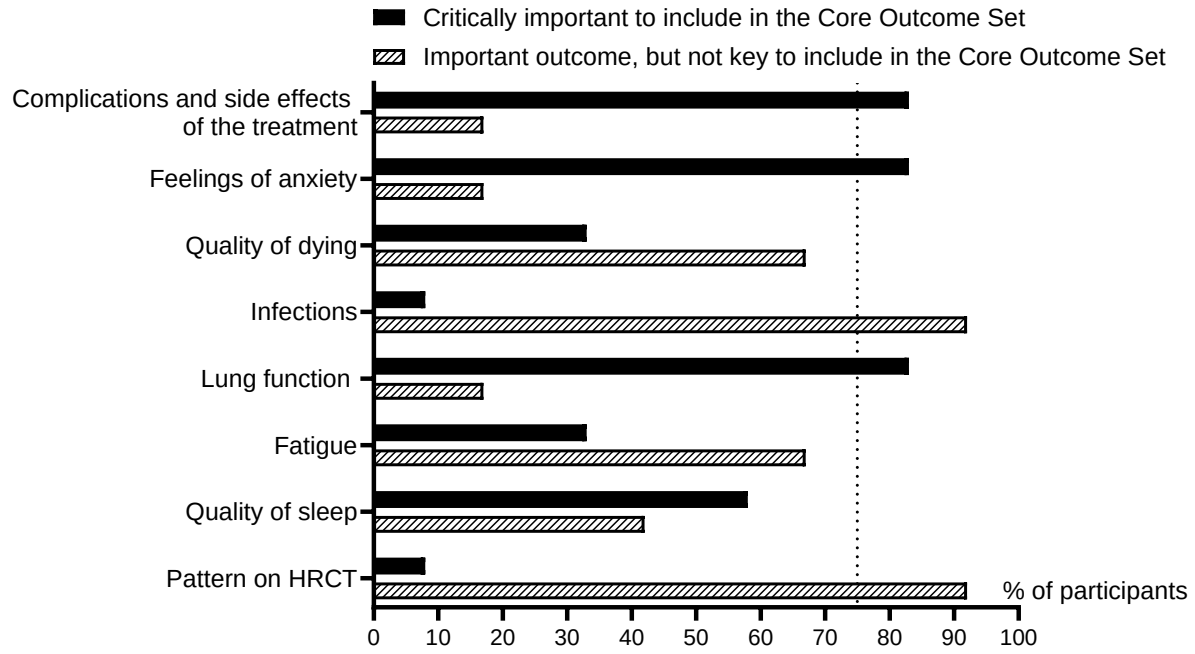
Supplement H: Arguments for inclusion or exclusion of the outcomes without consensus (consensus workshop).

	Arguments to **include** this outcome in the COS	Arguments **against including** this outcome in the COS
Complications and side effects of the treatment	- It can lead to a decline in quality of life. - It is important for clinicians to know if they are on the safe side with the treatment. - It might interact with other drugs, e.g. from comorbidities. - It is a protective parameter to avoid non-adherence to the treatment. - It is related to treatment adherence, but they differ in a way, e.g. there can be many reasons for treatment non-adherence. - It can have a huge impact on other outcomes, e.g. physical activity.	- No arguments discussed
Fatigue	- Present in a lot of patients. - It is also one of the primary symptoms.	- It is closely related to other aspects, e.g. physical activity and exercise capacity. - It is difficult to treat.
Feelings of anxiety	- Mental health is not being covered in the included outcomes. - Anxiety about different topics is present in many patients, e.g. the disease progression, the prospect of dying, what they can do, the impact on their family lives. - It is critical throughout the different disease stages. - Mental health should be addressed more with physical health, as they are interlinked. - It is also one of the primary symptoms.	- No arguments discussed
Infections	- They are treatable.	- It is already covered by acute exacerbations. - It will be picked up if a patient is having an infection. - It is only important in the later stages of the disease.
Lung function	- To have the possibility for an early intervention. - The trajectory and possible decline should be carefully monitored to intervene and to help the patient. - From the patient perspective, it is also very important to know about lung function. - Already part of standard care.	- It is an objective measure, but it does not always capture how the patient feels.
Pattern on HRCT	- It is important for the diagnosis. - It is done already regularly.	- It is a very specific measure. - It is very heterogeneous. - It is difficult to interpret, especially for non-pulmonologists. - Not in the guidelines how it should be monitored.
Quality of dying	- It is in the head of many people. - It can help to reassure patients to learn what could happen and what could be done to make	- It is a difficult situation that people do not want to talk about. - It is very much related to the personal perspective.

	it a high quality of dying.	- It may not be important to all patients at all stages of the disease. - It is hard to capture
Quality of sleep	- Poor quality of sleep is present in a lot of patients. - It can be related to the amount and intensity of symptoms. - It can be related to people's mental health: the night is the time when people can become anxious and worried about their life and future. - It is an indication of the day to day quality of life. - Interventions exist that can improve the sleep quality. - Patients are beginning to talk more about this topic, which can come up quite a lot in the future.	- It may not be of the highest interest regarding the whole spectrum of the disease. - It might be a challenge to measure, as the objective sleep parameters can differ a lot from the subjective perspective. - It is related to symptoms, which are already included in the core outcome set.

Arguments presented by participants in the consensus workshop, both for and against the inclusion of outcomes in the core outcome set, for which no consensus was reached in the Delphi study. COS: core outcome set.

Supplement I: voting of outcomes 'without consensus yet' during consensus workshop



Results of the anonymous voting on 'the outcomes without consensus yet' in the consensus workshop. The vertical dashed line marks the threshold for including an outcome in the core outcome set. An outcome is included in the set if the black bar, representing the percentage of participants who rated it as *critically important to include*, reaches this line.

Supplement J: Tips and considerations for future COS developments

Below, you can find a list of all challenges we faced during the development of our COS. We ordered them according to the phase of the development process.

Phase	Challenge	Advice on how this challenge can be avoided or minimised
1. Preparatory phase		
- Scoping Review	Challenging to extract concepts or outcomes from questionnaires and qualitative papers.	Have a multidisciplinary group that can focus on this aspect.
- Survey with healthcare professionals	To the question 'Which outcomes are currently being measured in your clinical practice?' we received both outcomes, but also measurement methods of outcomes and processes of care.	Give a definition and example of what an outcome and outcome measure is, so that participants know the difference between both. However, we provided definitions, so there might be a need for more awareness around terminology use.
- Focus groups with patients	It is challenging to know what ethical approvals are needed when involving and inviting patients in/to focus groups, that are led by patient advocates. Challenging to explain the difference between outcomes, outcome domains, measurement methods to patients.	
2. Delphi study	Providing the survey in different languages to engage patients from different countries, makes it more time and cost consuming. Including healthcare professionals and patients makes it difficult to use scientific language. A variety of consensus criteria are suggested in literature, making it difficult to choose which criteria you will use. Cultural differences and variations in healthcare systems can make it challenging to engage participants from diverse backgrounds.	Think ahead which languages most of your participants will speak. This will depend on your network and which patient organisations you can help in recruiting patients. Use lay definitions, with a formal tone, and let it check by two or more patient representatives.
	Recruiting patients through hospitals requires additional ethical approvals.	You can choose to recruit via patient organisations only.
	Recruiting via patient organisations can result in a low response rate.	Try to connect with patient organisations in person or recruit via persons of your network to contact patient organisations.
	Lengthy surveys can result in a high drop out rate	Prevent drop outs by short but clear messages.
	Some panels can be overrepresented while others can be	Use the panels in total in consensus criteria, not the amount

	underrepresented. Also, n**o recommendations** exist on **how many patients** and caregivers should be included relative to the other stakeholder groups [7].	of participants.
3. Consensus workshop	There's a risk that the voices of patients may be overshadowed by those of the more powerful or experienced professionals.	creating a supportive environment for discussion and use for example NGT

References

1 Delameillieure A, Somogyi V, Schenk S, *et al.* Identifying outcome domains to establish a core outcome set for progressive pulmonary fibrosis: a scoping review. .

2 Somogyi V, Delameillieure A, Schenk S, *et al.* Person-centred health outcomes in the routine care for people with progressive pulmonary fibrosis: the COCOS-IPF project's European survey on healthcare professionals' views and practices. *Respir Res* 2025; 26: 81.

3 Gargon E, Crew R, Burnside G, *et al.* Higher number of items associated with significantly lower response rates in COS Delphi surveys. *Journal of Clinical Epidemiology* 2019; 108: 110–120.

4 Fackrell K, Smith H, Colley V, *et al.* Core Outcome Domains for early phase clinical trials of sound-, psychology-, and pharmacology-based interventions to manage chronic subjective tinnitus in adults: the COMIT'ID study protocol for using a Delphi process and face-to-face meetings to establish consensus. *Trials* 2017; 18: 388.

5 Smith H, Horobin A, Fackrell K, *et al.* Defining and evaluating novel procedures for involving patients in Core Outcome Set research: creating a meaningful long list of candidate outcome domains. *Research involvement and engagement* [Internet] Res Involv Engagem; 2018 [cited 2025 Feb 20]; 4. Available from: https://pubmed.ncbi.nlm.nih.gov/29507772/.

6 Dodd S, Clarke M, Becker L, *et al.* A taxonomy has been developed for outcomes in medical research to help improve knowledge discovery. *Journal of Clinical Epidemiology* 2018; 96: 84–92.

7 Young B, Bagley H. Including patients in core outcome set development: issues to consider based on three workshops with around 100 international delegates. *Res Involv Engagem* 2016; 2: 25.