

Supplement 4. Outcome measures used in studies reporting quantitative results

Outcome measure		Number of studies (total, n=83) N (%)
Exercise capacity		
Clinical exercise tests	6-minute walk test	50 (60)
	Cardiopulmonary exercise test using treadmill/arm ergometry/cycle ergometry	
	- Peak oxygen consumption	8 (10)
	- Maximal workload	8 (10)
	Muscle strength and endurance test	
	- Quadriceps	7 (8)
	- Handgrip	4 (5)
	Shuttle walk test	
	- Incremental	6 (7)
	- Endurance	1 (1)
	6-minute stepper test	3 (4)
	30s chair-stand test	3 (4)
	Test of 10 chair stands	1 (1)
	Chair sit-and-reach test	1 (1)
	Timed 'up and go' test	1 (1)
	Short Physical Performance Battery	1 (1)
Patient self-reported measures	Barthel index	1 (1)
	Nagasaki University Respiratory Activities of Daily Living Questionnaire	1 (1)
	Manchester Respiratory Activities of Daily Living Questionnaire	1 (1)
	University of Alabama at Birmingham Study of Aging Life-Space Assessment	1 (1)
Health-related quality of life		
Patient self-reported measures	St George's Respiratory Questionnaire	31 (37)
	Short Form Survey	
	- 12-item	1 (1)
	- 36-item	15 (18)
	Chronic Respiratory Disease Questionnaire	12 (14)
	King's Brief Interstitial Lung Disease Questionnaire	5 (6)
	EQ-5L-5D Questionnaire	2 (2)
	Visual Simplified Respiratory Questionnaire	2 (2)
	Maugeri Respiratory Questionnaire	1 (1)
	A Tool to Assess Quality of Life in IPF	1 (1)
	Clinical COPD Questionnaire	1 (1)
Symptom burden		
Patient self-reported measures	Medical Research Council Dyspnoea Scale	28 (34)
	Borg Dyspnoea Scale	16 (19)
	Baseline/transit dyspnoea index	6 (7)

	University of California San Diego Shortness of Breath Questionnaire	5 (6)
	Visual Analog Scale (for cough, dyspnoea, fatigue)	4 (5)
	Fatigue Assessment Scale	3 (4)
	Fatigue Severity Scale	2 (2)
	D-12 Dyspnoea Scale	2 (2)
	COPD Assessment Test	2 (2)
	Cough and Sputum Assessment Questionnaire	1 (1)
	Measure Yourself Medical Outcome Profile	1 (1)
	Patient-Reported Outcomes Measurement Information System-29	1 (1)
	Pittsburgh Sleep Quality Index	1 (1)
Psychological wellbeing		
Patient self-reported measures	Hospital Anxiety and Depression Scale	20 (24)
	Patient Health Questionnaire	3 (4)
	Centre for Epidemiologic Studies-Depression Scale	3 (4)
	Perceived Stress Scale	3 (4)
	General Anxiety Disorder-7 Scale	2 (2)
	Geriatric Depression Scale	2 (2)
	Beck Anxiety/Depression Inventory	1 (1)
	Psychological General Wellbeing Index	1 (1)
	Profile of Mood State	1 (1)
	4-item Patient-Reported Outcomes Measurement Information System Anxiety	1 (1)
	Rosenberg Self-esteem Scale	1 (1)
	COVID-19 Fears Questionnaire	1 (1)
	Multidimensional State Boredom Scale	1 (1)
	University of California Los Angeles Loneliness Scale	1 (1)
Use of PF-related treatments and medication adherence		
Review of medical records/ patient self-reported	Medication adherence (including maintenance and discontinuation rate, time to discontinuation)	4 (5)
	Use of opioids	3 (4)
	Use of antibiotics	2 (2)
	Medication adjustments	2 (2)
	Use of antifibrotic therapy	1 (1)
	Use of prednisone	1 (1)
	Use of short-acting bronchodilator inhalers	1 (1)
Physical activity		
Objective measures	Steps/day (using Sensewear armband)	4 (5)
	Total daily energy expenditure	2 (2)
	Time spent in moderate physical activity (>2.5 - 3 METs)	3 (4)
	Time spent in sedentary	1 (1)
	7-day pedometer	1 (1)

	7-day vector magnitude counts/min	1 (1)
Patient self-reported measures	International Physical Activity Questionnaire	3 (4)
	Rapid Assessment of Physical Activity Questionnaire	1 (1)
Disease knowledge and self-efficacy in disease management		
Patient self-reported measures	Self-efficacy for Managing Chronic Disease 6-item Scale	2 (2)
	Rating of control/confidence/preparedness in managing disease	2 (2)
	Disease knowledge assessment	2 (2)
	COPD Self-efficacy Scale	1 (1)
Healthcare utilisation		
Review of medical records	Hospital admission	8 (10)
	Number of outpatient/physician/GP visits	4 (5)
	Number of emergency department visits	3 (4)
	Time spent in intensive care unit	1 (1)
	Referral to allied healthcare support	1 (1)
	Pulmonary rehabilitation enrolment	1 (1)
	Long term care enrolment	1 (1)
	End-of-life associated costs	1 (1)
End-of-life planning		
Review of medical records	Discussion of advance care plan	4 (5)
	Completion of advance directives (including POLST, DNR orders)	2 (2)

IPF: idiopathic pulmonary fibrosis; COPD: chronic obstructive pulmonary disease; MET: metabolic equivalents of task; GP: general practitioner; POLST: Physician Orders for Life Sustaining Treatment; DNR order: do not resuscitate order