Supplementary material

Supplementary material S1

Acronyms

ACE-IPF	Anti-Coagulant Effectiveness in Idiopathic Pulmonary Fibrosis
ATAQ-IPF	An Tool to Assess Quality of life in IPF
ATS/ERS	American Thoracic Society/ European Respiratory Society
ATS/ERS/JRS/ALAT	American Thoracic Society/ European Respiratory Society/ Japanese Respiratory Society /Latin American Thoracic Society
BP	Bodily Pain
BUILD	Bosentan Use in Interstitial Lung Disease
CEA	Cost-Effectiveness Analysis Registry
CI	Confidence Interval
CQLQ	The Cough Quality of Life Questionnaire
COPD	Chronic Obstructive Pulmonary Disease
CRD	Centre for Reviews and Dissemination
CTS	Chinese Thoracis Society
DARE	Database of Abstracts of Reviews of Effects
EQ5D	EuroQol assessment instrument five dimensions
FVC	Forced Vital Capacity
GH	General Health
HRQL	Health Related Quality of Life
HUI2	Health Utilities Index Mark 2
ICD	International Classification of Diseases
ILD	Interstitial Lung Disease
IPF	Idiopathic Pulmonary Fibrosis
K-BILD	King's Brief Interstitial Lung Disease
LCQ	Leicester Cough Questionnaire
MCS	Mental Health Component Summary
MH	Mental Health
NHSEED	National Health Service Economic Evaluation Database
NR	Not reported
PANTHER	Prednisone, Azathioprine, and N-acetylcysteine in Participants With IPF
PCS	Physical Health Component Summary
PF	Physical function
PGWBI	The Psychological general Well-Being Index
PR	Physical Role
PRISMA-P	Preferred Reporting Items for Systematic Reviews and Meta-Analysis Protocols
PROMIS	Patient Reported Outcomes Measurement Information System
PROM	Patient reported outcome measures (PROM)
PROSPERO	International Prospective Register of Systematic Reviews
QoL	Quality of Life
RAND36	Research and Development 36 item health survey
RCT	Randomised Controlled Trial
RE	Emotional Role
SF	Social Functioning
SF12	Short Form-12
SF36	Short Form-36
SGRQ	St. George`s Respiratory Questionnaire
SGRQ-I	IPF-specific version of the SGRQ
STEP-IPF	Sildenafil Trial of Exercise Performance In Idiopathic Pulmonary Fibrosis
UK	United Kingdom
USA	United States of America
VAS	Visual Analogue Scale
VSRQ	Visual Simplified Respiratory Questionnaire
VT	Vitality
WHO-QoL	World Health Organization Quality of Life Assessment
WRAP-IPF	Treatment of IPF With Laparoscopic Anti-Reflux Surgery

Supplementary material S2

Inclusion and exclusion criteria

Inclusion Criteria	Exclusion criteria
• Clinical trials,Observation or intervention studies • Involve human subjects only • Diagnosis of IPF • Studies available in full text or abstract form • English, French, German or Spanish articles/studies • Studies reporting quality of life indicators on IPF • Studies reporting instruments used for measuring QoL/HRQL	• Case reports, letters, commentaries, editorials, expert opinions, article reviews • Conference abstracts • Studies which report IPF data inexorably combined with other non-IPF data i.e. data is not disaggregated so that data related only to IPF patients cannot be used • Studies solely describing pathophysiology, physiology and aetiology of IPF • Animal trials • Clinical trials, intervention studies quality of life indicators related to IPF • Systematic reviews or metanalysis • Non-English/-Spanish/-French/-German studies

Supplementary material S3

Search Strategies for Main Databases

Medline via Ovid

1. idiopathic pulmonary fibrosis/

2. ("idiopathic pulmonary fibrosis" or "cryptogenic fibrosing alveolitis" or "usual interstitial pneumonitis" or "usual interstitial pneumonia"or "fibrosing alveolitis").ab,ti,ot.

3. (ipf or uip).ab,ti,ot.

4. 1 or 2 or 3

5. "quality of life"/

6. quality adjusted life years/

7. health status indicators/

8. Sickness Impact Profile/

9. health status/

10. "activities of daily living"/

11. "surveys and questionnaires"/

12. health surveys/

13. (qol* or hql* or hqol* or HRQL* or hrql*).ab,ot,ti.

14. quality of life*.ab,ot,ti.

15. (qal* or qtime* or daly*).ab,ti,ot.

16. disability adjusted life*.ab,ot,ti.

17. sickness impact profile.ab,ti,ot.

18. (euroqol* or eq5d* or eq-5d* or eq6d* or eq-6d* or eqvas* or eq-vas*).ab,ti,ot.

19. (health utility* or utility score* or utilit* or disutilit*).ab,ot,ti.

20. (hui or hui or hui2 or hui3).ab,ot,ti.

21. health* year* equivalent*.ab,ti,ot.

22. hye*.ab,ot,ti.

23. health stat*.ab,ti,ot.

24. world health organization quality of life*.ab,ti,ot.

25. whoqol*.ab,ti,ot.

26. george* questionnaire*.ab,ti,ot.

27. activit* of daily living*.ab,ti,ot.

28. functional assessment*.ab,ti,ot.
29. self-questionnaire.ab,ti,ot.

30. respiratory questionnaire*.ab,ti,ot.

31. (quality adj2 (wellbeing or well being or well-being)).ab,ti,ot.

32. rosser*.ab,ti,ot.

33. (sf36* or sf-36* or short-form 36* or shortform 36* or shortform36*).ab,ti,ot.

34. (sf12* or sf-12* or short-form 12* or shortform 12* or shortform12*).ab,ti,ot.

35. (sf20* or sf-20* or short-form 20* or shortform 20* or shortform20*).ab,ti,ot.

36. (sf8* or sf-8* or short-form 8* or shortform 8* or shortform8*).ab,ti,ot.

37. (sf6* or sf-6* or short-form 6* or shortform 6* or shortform6*).ab,ti,ot.

38. 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37

39. 4 and 38

Embase via Ovid

1. fibrosing alveolitis/

2. ("idiopathic pulmonary fibrosis" or "cryptogenic fibrosing alveolitis" or "usual interstitial pneumonitis" or "usual interstitial pneumonia" or "fibrosing alveolitis").ab,ti,ot.

3. (ipf or uip).ab,ti,ot.

4. 1 or 2 or 3

5. "quality of life"/

6. quality adjusted life years/

7. health status indicators/

8. Sickness Impact Profile/

9. health status/

10. "activities of daily living"/

11. health surveys/

12. "surveys and questionnaires"/

13. (qol* or hql* or hqol* or hrqol*or hrql*).ab,ot,ti.

14. quality of life*.ab,ot,ti.

15. (qal* or qtime* or daly*).ab,ti,ot.

16. disability adjusted life*.ab,ot,ti.

17. sickness impact profile.ab,ti,ot.

18. (euroqol* or eq5d* or eq-5d* or eq6d* or eq-6d* or eqvas* or eq-vas*).ab,ti,ot.

19. (health utility* or utility score* or utilit* or disutilit*).ab,ot,ti.

20. (hui or hui1 or hui2 or hui3).ab,ot,ti.

21. health* year* equivalent*.ab,ti,ot.

22. hye*.ab,ot,ti.

23. health stat*.ab,ti,ot.

24. world health organization quality of life*.ab,ti,ot.

25. whoqol*.ab,ti,ot.

26. george* questionnaire*.ab,ti,ot.

27. activit* of daily living*.ab,ti,ot.

28. sgrq*.ab,ti,ot.

29. functional assessment*.ab,ti,ot.

30. respiratory questionnaire*.ab,ti,ot.

31. self-questionnaire.ab,ti,ot.

32. (quality adj2 (wellbeing or well being or well-being)).ab,ti,ot.

33. rosser*.ab,ti,ot.

34. (sf36* or sf-36* or short-form 36* or shortform 36* or shortform36*).ab,ti,ot.

35. (sf6* or sf-6* or short-form 6* or shortform 6* or shortform6*).ab,ti,ot.

36. (sf12* or sf-12* or short-form 12* or shortform 12* or shortform12*).ab,ti,ot.

37. (sf20* or sf-20* or short-form 20* or shortform 20* or shortform20*).ab,ti,ot.

38. (sf8* or sf-8* or short-form 8* or shortform 8* or shortform8*).ab,ti,ot.

39. "willingness to pay".ab,ti,ot.

40. "standard gamble".ab,ot,ti.

41. ("Time trade off" or tto).ab,ti,ot.

42. 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41

43. 4 and 42

Psychinfo via Ovid

1. Idiopathic Pulmonary Fibrosis/

2. ("idiopathic pulmonary fibrosis" or "cryptogenic fibrosing alveolitis" or "usual interstitial pneumonitis" or "usual interstitial pneumonia" or "fibrosing alveolitis").ab,ti,ot.

3. (ipf or uip).ab,ti,ot.

4. 1 or 2 or 3

5. health status indicators/ or sickness impact profile/

6. Health Status/

7. "Activities of Daily Living"/

8. "Surveys and Questionnaires"/

9. Health Surveys/

10. (qol* or hql* or hqol* or hrqol* or h qol* or hr qol* or hrql*).ab,ot,ti.

11. quality of life*.ab,ot,ti.

12. (qal* or qtime* or daly*).ab,ti,ot.

13. disability adjusted life*.ab,ot,ti.

14. sickness impact profile.ab,ti,ot.

15. (euroqol* or eq5d* or eq 5d*).ab,ti,ot.

16. (health utility* or utility score* or utilit* or disutilit*).ab,ot,ti.

17. (hui or hui1 or hui2 or hui3).ab,ot,ti.

18. health* year* equivalent*.ab,ti,ot.

19. health stat*.ab,ti,ot.

20. world health organization quality of life*.ab,ti,ot.

21. whoqol*.ab,ti,ot.

22. activities of daily living*.ab,ti,ot.

23. george* questionnaire*.ab,ti,ot.

24. sgrq*.ab,ti,ot.

25. functional assessment*.ab,ti,ot.

26. respiratory questionnaire*.ab,ti,ot.

27. self* questionnaire.ab,ti,ot.

28. (quality adj2 (wellbeing or well being or well-being)).ab,ti,ot.

29. rosser*.ab,ti,ot.

30. (willingness to pay or time trade off or tto or standard gamble*).ot,ab,ti.

31. (sf36* or sf 36* or short form 36* or shortform 36* or shortform36*).ab,ti,ot.

32. (sf6* or sf 6* or short form 6* or shortform 6* or shortform6*).ab,ti,ot.

33. (sf20* or sf 20* or short form 20* or shortform 20* or shortform20*).ab,ti,ot.

34. (sf12* or sf 12* or short form 12* or shortform 12* or shortform12*).ab,ti,ot.

35. (sf8* or sf 8* or short form 8* or shortform 8* or shortform8*).ab,ti,ot.

36. (sf8* or sf 8* or short form 8* or shortform 8* or shortform8*).ab,ti,ot.

37. 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36

38. 4 and 37

SCOPUS

((TITLE-ABS ("idiopathic pulmonary fibrosis")) OR (TITLE-ABS ("cryptogenic fibrosing alveolitis")) OR (TITLE-ABS ("fibrosing alveolitis")) OR (TITLE-ABS ("usual interstitial pneumonitis") or (TITLE-ABS ("usual interstitial pneumonia")) OR (TITLE-ABS (ipf)) OR (TITLE-ABS (uip))) AND (TITLE-ABS ("quality of life" OR "quality of living") OR TITLE-ABS ("quality adjusted life years" OR "quality adjusted life year") OR TITLE-ABS ("Health status" OR "health status indicator" OR "health status indicators") OR TITLE-ABS ("Health state" OR "health states") OR TITLE-ABS ("activities of daily living" OR "activities of daily life") OR TITLE-ABS ("sickness impact profile") OR TITLE-ABS ("health survey" OR "health surveys") OR TITLE-ABS ("surveys and questionnaires") OR TITLE-ABS (qol OR hql OR hqol OR hrqol OR hrql) OR TITLE-ABS (qal* OR daly* OR qtime*) OR TITLE-ABS ("disability adjusted life years" OR "disability adjusted life year") OR TITLE-ABS (euroqol* OR eq5* OR eq-5* OR eq6* OR eq-6* OR eqvas* OR eq-vas) OR TITLE-ABS ("health utility" OR "utility score" OR utilit* OR disutilit*) OR TITLE-ABS ("health year equivalent" OR hye*) OR TITLE-ABS (hui OR hui1 OR hui2 OR hui3) OR TITLE-ABS ("world health organization quality of life" OR whoqol*) OR TITLE-ABS ("st georges questionnaire" OR sgrq*) OR TITLE-ABS ("functional assessment") OR TITLE-ABS ("respiratory questionnaire") OR TITLE-ABS ("quality of wellbeing" OR "quality of well being" OR "quality of well-being") OR TITLE-ABS (rosser) OR TITLE-ABS ("willingness to pay") OR TITLE-ABS ("time trade off" OR tto) OR TITLE-ABS ("standard gamble") OR TITLE-ABS (sf36* OR short-form AND 36* OR shortform36*) OR TITLE-ABS (sf6* OR short-form AND 6* OR shortform6*) OR TITLE-ABS (sf8* OR short-form AND 8* OR shortform8*) OR TITLE-ABS (sf20* OR short-form AND 20* OR shortform20*) OR TITLE-ABS (sf12* OR short-form AND 12* OR shortform12*))

Supplementary material S4

Quality assessment

The quality assessment will be based on adequacy of the following criteria, which will also take into consideration both internal and external validity:

1. Clinical characteristics of the IPF participants
2. Criteria for case definition of IPF(1-4)
3. Criteria for evaluating QoL studies (5)

Table S4-1 Quality Assessment Criteria

Element	Quality Assessment Criteria	Question code
Characteristics of IPF Participants		
Age Distribution	Does the article report age distribution for the IPF participants?	S1
Sex distribution	Does the article report sex distribution for the IPF participants?	S2
Race/Ethnicity	Is the race/ethnicity distribution reported for the IPF participants?	S3
Criteria for case definition of IPF		
Exclusion of other causes of ILD	Have other potential causes of ILD or pulmonary fibrosis been excluded in the participants? (environmental/domestic/occupational exposures, connective tissue disease, drug toxicity, radiation,)	CS1
Clinical	Was the diagnosis made on the basis of the classic signs, symptoms and physical examination characteristics of IPF as per international standards at the time of the study?	CS2
	Is there an FVC done for the participants?	CS3
	Does the study document disease severity of the participants?	CS4
	Are there any other respiratory physiology tests mentioned if an FVC was not done that can serve as a proxy for disease severity? (Spirometry, TLC, DL_{CO}, FEV, SPO_2 , PaO_2 ,etc)	CS5
High-resolution computerised tomography (HRCT)	Was the diagnosis in participants made on the basis of HRCT?	CS6
	Was the pattern consistent with the international standards/ guidelines at the time of the study?	CS7
Histopathological confirmation	If diagnosis was not made by HRCT in participants, was there mention of histopathological confirmation?	CS8
	Was the pattern consistent with the international standards/ guidelines at the time of the study?	CS9
Criteria for quality of life studies		
Sample size	Was the sample size >50?	QL1
Measurement instrument used	Was mention made of the rationale used for the choice of instrument?	QL2
	Was the instrument used specific to IPF?	QL3

Element	Quality Assessment Criteria	Question code
	If the study was not one to validate the instrument, was mention made of previous studies that have validated the tool for IPF participants?	QL4
	If the study was not one to validate the instrument, did the authors document evidence of the reliability of the tool for IPF participants?	QL5
	Did the authors mention the timing or frequency of the administration of the instrument of measurement?	QL6
	Did the authors explain the instrument scoring?	QL7
	Did the authors explain interpretation of the scoring?	QL8
Comorbidities	Were comorbidities relevant to quality of life discussed?	QL9
	Were HRQL scores reported for comorbidities?	QL10
Utility values	Were the utility values calculated?	QL11
	Was the method of estimation of the utility values described?	QL12
	Were the utility values calculated using an appropriate methodology?	QL13
	Were correct value sets used	QL14
	Were utility values mentioned for comorbidities?	QL15
Data and analysis	Were the results of the HRQL adequately represented to support the conclusions of the study? (Means, standard deviations etc)	QL16
	Was there reporting on missing data?	QL17
	Did the authors mention how missing data was treated?	QL18
	Did the authors mention and explain any outlier results?	QL19
	Were statistical methods used to conduct the analysis detailed enough to be replicated by other researchers?	QL20
	Were confidence intervals or p-values reported for the results?	QL21
	Were any limitations of the study reported?	QL22

Figure S4-1 Summary of performance of studies against quality assessment criteria

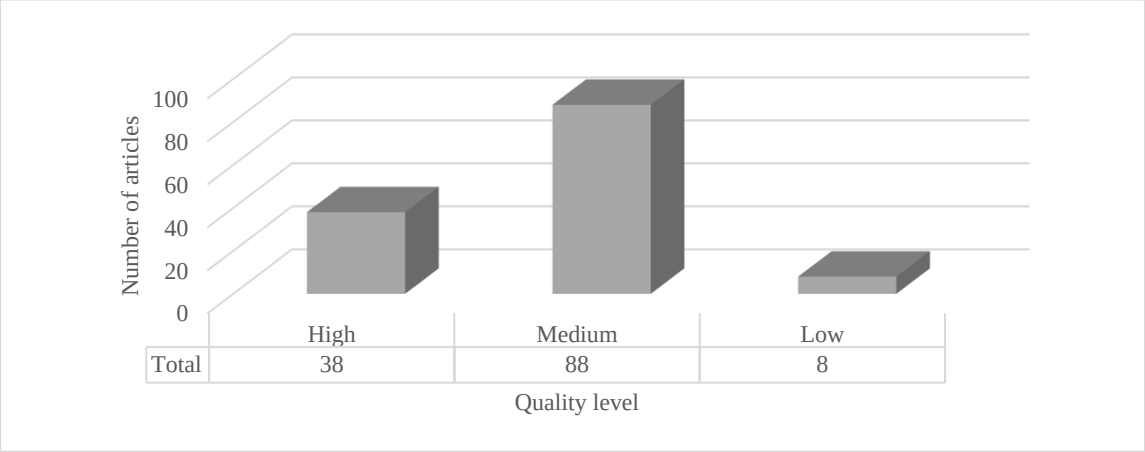


Figure S4-2 Performance of studies against assessment criteria related to IPF participants

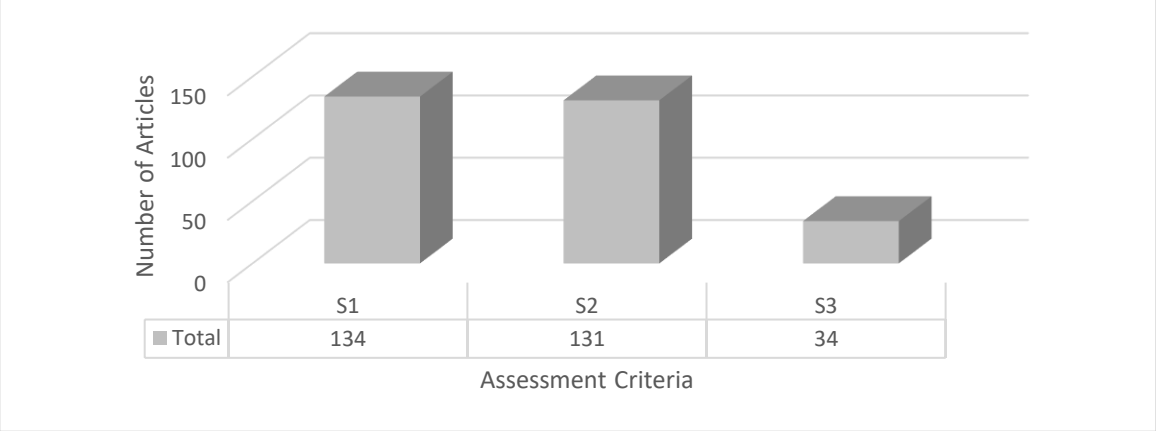


Figure S4-3 Performance of studies against assessment criteria related to case definition

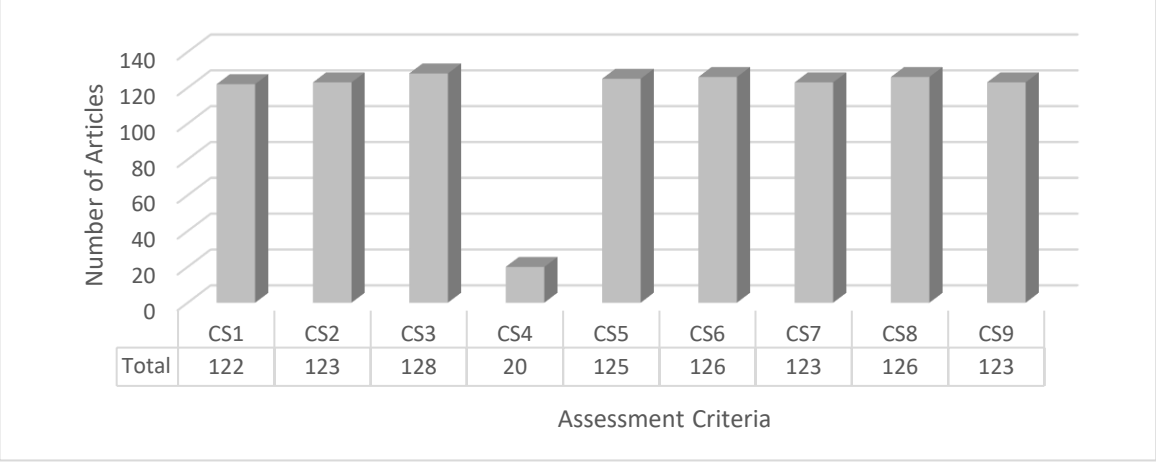
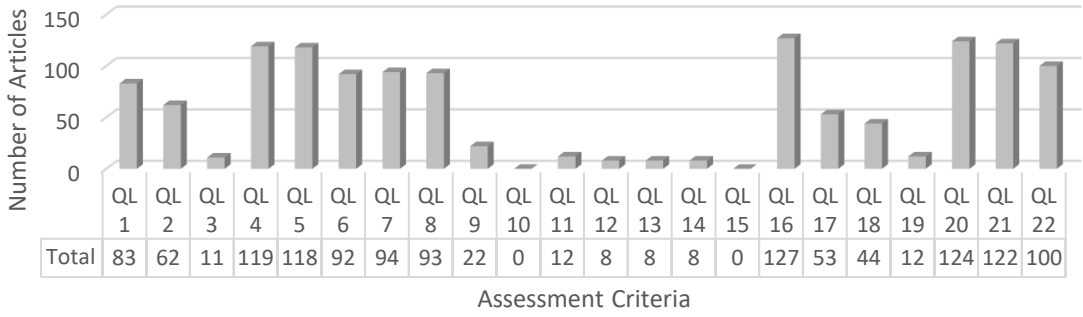


Figure S4-4 Performance of studies against assessment criteria related to quality of life



	QL 1	QL 2	QL 3	QL 4	QL 5	QL 6	QL 7	QL 8	QL 9	QL 10	QL 11	QL 12	QL 13	QL 14	QL 15	QL 16	QL 17	QL 18	QL 19	QL 20	QL 21	QL 22
Total	83	62	11	119	118	92	94	93	22	0	12	8	8	8	0	127	53	44	12	124	122	100

Supplementary material S5

Table S5-1 Categories for age groupings

Age Group	Category	Number of studies
1	<50	1
2	50-59	8
3	60-69	67
4	70-79	21
5	>80	0
NR	Not reported	4

Table S5-2 Categories for Disease severity

Disease Severity	Category	Number of studies
Mild	>75	40
Moderate	50-75	64
Severe	50>	5
NR	Not reported	13

The categories for disease severity are based on percent FVC predicted (6-8)

Supplementary material S6

Reasons for exclusions of full text

227 Abstracts from conferences and journals
29 Studies with IPF data combined with non IPF data (data is not disaggregated)
36 Duplicates
27 Article review, editorial, letter
12 Clinical trials, intervention studies that do not report quality of life indicators related to IPF
16 Qualitative studies
10 Article comparing measurement instruments but not specifically reporting quality of life indicators for IPF
6 Studies solely describing pathophysiology, physiology and aetiology of IPF
5 Inappropriate language

Supplementary material S7

Studies included in Metanalysis

KBILD

1. Atkins CP, Gilbert D, Brockwell C, Robinson S, Wilson AM. Fatigue in sarcoidosis and idiopathic pulmonary fibrosis: differences in character and severity between diseases. Sarcoidosis Vasc Diffuse Lung Dis. 2016;33 (2):130-8.
2. Atkins C, Baxter M, Jones A, Wilson A. Measuring sedentary behaviors in patients with idiopathic pulmonary fibrosis using wrist-worn accelerometers. Clinical Respiratory Journal. 2018;12(2):746-53.
3. Birring SS, Wijsenbeek MS, Agrawal S, van den Berg JWK, Stone H, Maher TM, et al. A novel formulation of inhaled sodium cromoglicate (PA101) in idiopathic pulmonary fibrosis and chronic cough: a randomised, double-blind, proof-of-concept, phase 2 trial. The Lancet Respiratory medicine. 2017;5(10):806-15.
4. Nolan CM, Maddocks M, Maher TM, Canavan JL, Jones SE, Barker RE, et al. Phenotypic characteristics associated with slow gait speed in idiopathic pulmonary fibrosis. Respirology. 2018;23(5):498-506.
5. Nolan CM, Birring SS, Maddocks M, Maher TM, Patel S, Barker RE, et al. Kings Brief Interstitial Lung Disease questionnaire: Responsiveness and minimum clinically important difference. European Respiratory Journal. 2019;20:20.
6. Sinha A, Patel AS, Siegert RJ, Bajwah S, Maher TM, Renzoni EA, et al. The King's Brief Interstitial Lung Disease (KBILD) questionnaire: An updated minimal clinically important difference. BMJ Open Respiratory Research. 2019;6 (1) (e000363).
7. Szentes BL, Kreuter M, Bahmer T, Birring SS, Claussen M, Waelscher J, et al. Quality of life assessment in interstitial lung diseases: A comparison of the disease-specific K-BILD with the generic EQ-5D-5L. Respiratory Research. 2018;19 (1).
8. Wapenaar M, Patel AS, Birring SS, Domburg RTV, Bakker EW, Vindigni V, et al. Translation and validation of the King's Brief Interstitial Lung Disease (K-BILD) questionnaire in French, Italian, Swedish, and Dutch. Chronic Respiratory Disease. 2017;14 (2):140-50.
9. Moor CC, Mostard RLM, Grutters JC, Bresser P, Aerts JGJV, Chavannes NH, et al. Home Monitoring in Patients with Idiopathic Pulmonary Fibrosis: A Randomized Controlled Trial. American journal of respiratory and critical care medicine. 2020;23.
10. Prior TS, Hoyer N, Hilberg O, Shaker SB, Davidsen JR, Bendstrup E. Responsiveness and minimal clinically important difference of SGRQ-I and K-BILD in idiopathic pulmonary fibrosis. Respiratory Research. 2020;21(1):91.
11. Tzouvelekis A, Karampitsakos T, Kourtidou S, Bouros E, Tzilas V, Katsaras M, et al. Impact of Depression on Patients With Idiopathic Pulmonary Fibrosis. Frontiers in medicine. 2020;7:29.
12. Kalafatis D, Gao J, Pesonen I, Carlson L, Sköld CM, Ferrara G. Gender differences at presentation of idiopathic pulmonary fibrosis in Sweden. BMC Pulmonary Medicine. 2019;19(1).

EQ5D

1. Idiopathic Pulmonary Fibrosis Clinical Research N, Zisman DA, Schwarz M, Anstrom KJ, Collard HR, Flaherty KR, et al. A controlled trial of sildenafil in advanced idiopathic pulmonary fibrosis. New England Journal of Medicine. 2010;363 (7):620-8.
2. Idiopathic Pulmonary Fibrosis Clinical Research N, Martinez FJ, de Andrade JA, Anstrom KJ, King TE, Jr., Raghu G. Randomized trial of acetylcysteine in idiopathic pulmonary fibrosis. The New England journal of medicine. 2014;370 (22):2093-101.
3. King TE, Jr., Brown KK, Raghu G, du Bois RM, Lynch DA, Martinez F, et al. BUILD-3: a randomized, controlled trial of bosentan in idiopathic pulmonary fibrosis. American Journal of Respiratory & Critical Care Medicine. 2011;184 (1):92-9.
4. Kolb M, Raghu G, Wells AU, Behr J, Richeldi L, Schinzel B, et al. Nintedanib plus Sildenafil in Patients with Idiopathic Pulmonary Fibrosis. New England Journal of Medicine. 2018;15:15.
5. Kreuter M, Swigris J, Pittrow D, Geier S, Klotsche J, Prasse A, et al. Health related quality of life in patients with idiopathic pulmonary fibrosis in clinical practice: Insights-IPF registry. Respiratory Research. 2017;18 (1) (139).

6. Noth I, Anstrom KJ, Calvert SB, De Andrade J, Flaherty KR, Glazer C, et al. A placebo-controlled randomized trial of warfarin in idiopathic pulmonary fibrosis. American Journal of Respiratory and Critical Care Medicine. 2012;186 (1):88-95.
7. Szentes BL, Kreuter M, Bahmer T, Birring SS, Claussen M, Waelscher J, et al. Quality of life assessment in interstitial lung diseases: A comparison of the disease-specific K-BILD with the generic EQ-5D-5L. Respiratory Research. 2018;19 (1).
8. Wapenaar M, Patel AS, Birring SS, Domburg RTV, Bakker EW, Vindigni V, et al. Translation and validation of the King's Brief Interstitial Lung Disease (K-BILD) questionnaire in French, Italian, Swedish, and Dutch. Chronic Respiratory Disease. 2017;14 (2):140-50.
9. Wuyts WA, Dahlqvist C, Slabbynck H, Schlesser M, Gusbin N, Compere C, et al. Baseline clinical characteristics, comorbidities and prescribed medication in a real-world population of patients with idiopathic pulmonary fibrosis: The PROOF registry. BMJ Open Respiratory Research. 2018;5 (1) (e000331).
10. Bloem AEM, Mostard RLM, Stoot N, Vercoulen JH, Peters JB, Janssen DJA, et al. Severe Fatigue is Highly Prevalent in Patients with IPF or Sarcoidosis. Journal of Clinical Medicine. 2020;9(4):20.
11. O'Brien EC, Hellkamp AS, Neely ML, Swaminathan A, Bender S, Snyder LD, et al. Disease Severity and Quality of Life in Patients With Idiopathic Pulmonary Fibrosis: A Cross-Sectional Analysis of the IPF-PRO Registry. Chest. 2020;157(5):1188-98.
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SF36

1. Alhamad E. Pirfenidone treatment in idiopathic pulmonary fibrosis: A Saudi experience. Annals of Thoracic Medicine. 2015;10 (1):38-43.
2. Baddini Martinez JA, Martinez TY, Lovetro Galhardo FP, de Castro Pereira CA. Dyspnea scales as a measure of health-related quality of life in patients with idiopathic pulmonary fibrosis. Medical Science Monitor. 2002;8 (6):CR405-10.
3. Bors M, Tomic R, Perlman DM, Kim HJ, Whelan TP. Cognitive function in idiopathic pulmonary fibrosis. Chronic Respiratory Disease. 2015;12(4):365-72.
4. Chehere B, Bougault V, Chenivesse C, Grosbois JM, Wallaert B. Cardiorespiratory adaptation during 6-Minute Walk Test in fibrotic idiopathic interstitial pneumonia patients who did or did not respond to pulmonary rehabilitation. European journal of physical and rehabilitation medicine. 2019;55 (1):103-12.
5. da Fontoura FF, Berton DC, Watte G, Florian J, Schio SM, Camargo JJP, et al. Pulmonary Rehabilitation in Patients With Advanced Idiopathic Pulmonary Fibrosis Referred for Lung Transplantation. J Mol Signal. 2018;38 (2):131-4.
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7. Idiopathic Pulmonary Fibrosis Clinical Research N, Zisman DA, Schwarz M, Anstrom KJ, Collard HR, Flaherty KR, et al. A controlled trial of sildenafil in advanced idiopathic pulmonary fibrosis. New England Journal of Medicine. 2010;363 (7):620-8.
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Supplementary material S8

Study and patient characteristics

Figure S8-1 Regional distribution of studies included in the review

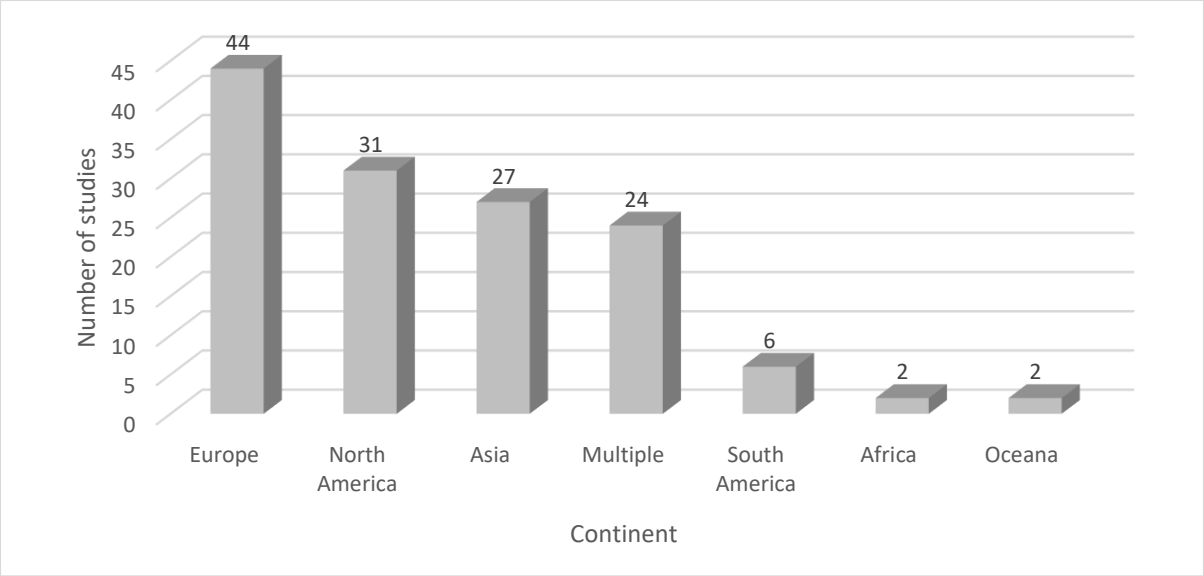


Figure S8-2 Distribution of studies included in the review by country

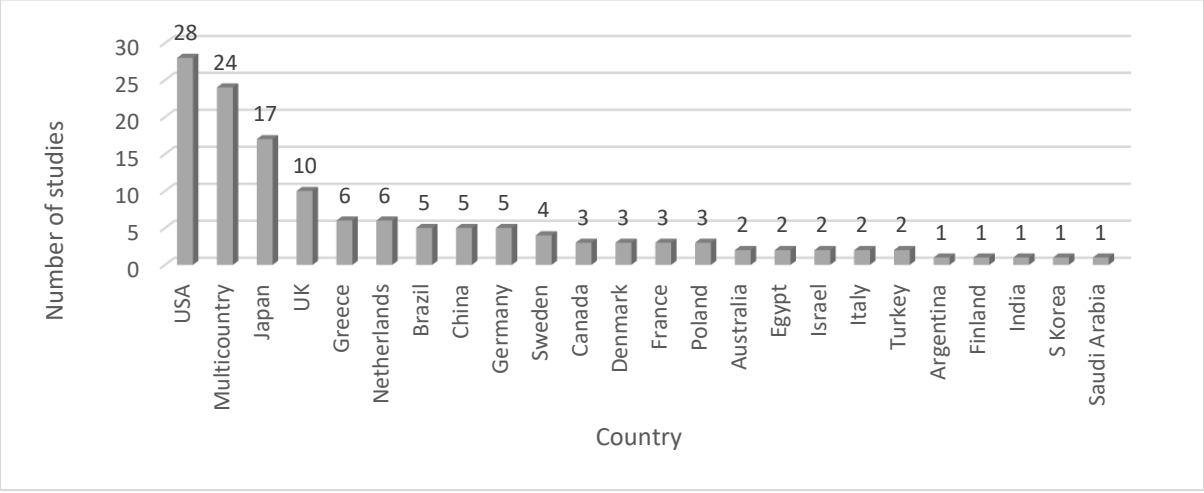


Figure S8-3 Distribution of studies included in the review by age group

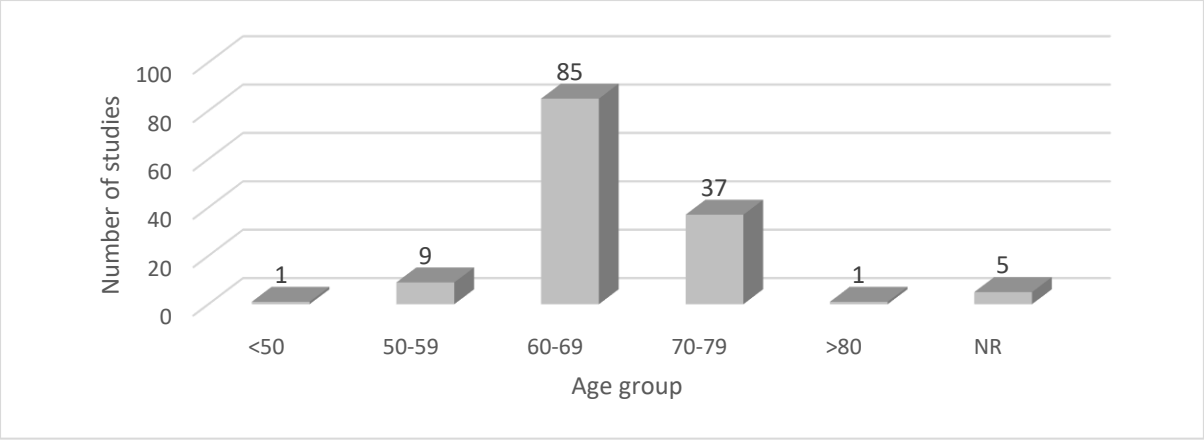


Figure S8-4 Distribution of studies included in the review by disease severity

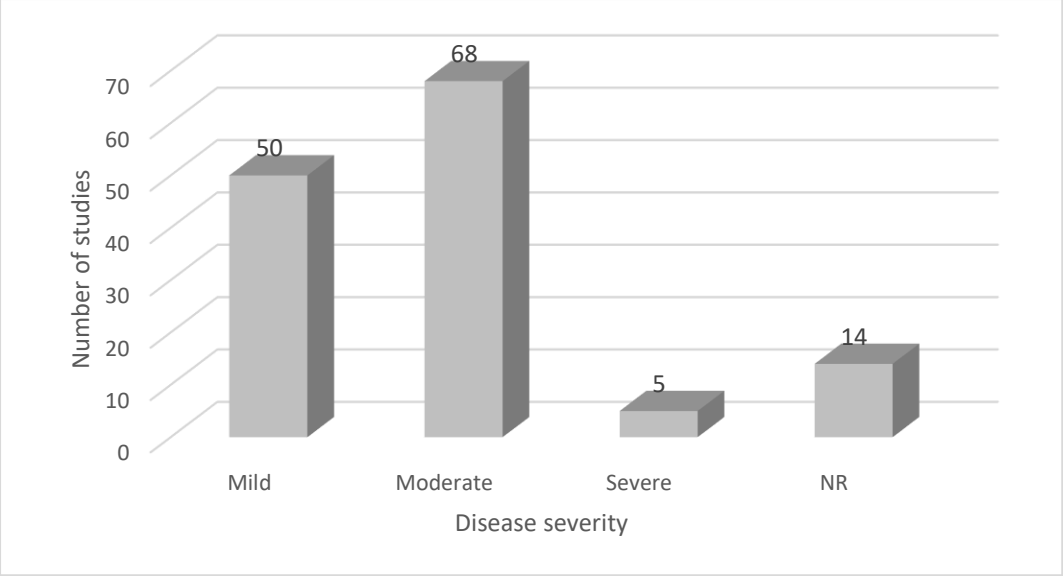


Figure S8-5 Summary of quality of life instruments used in studies

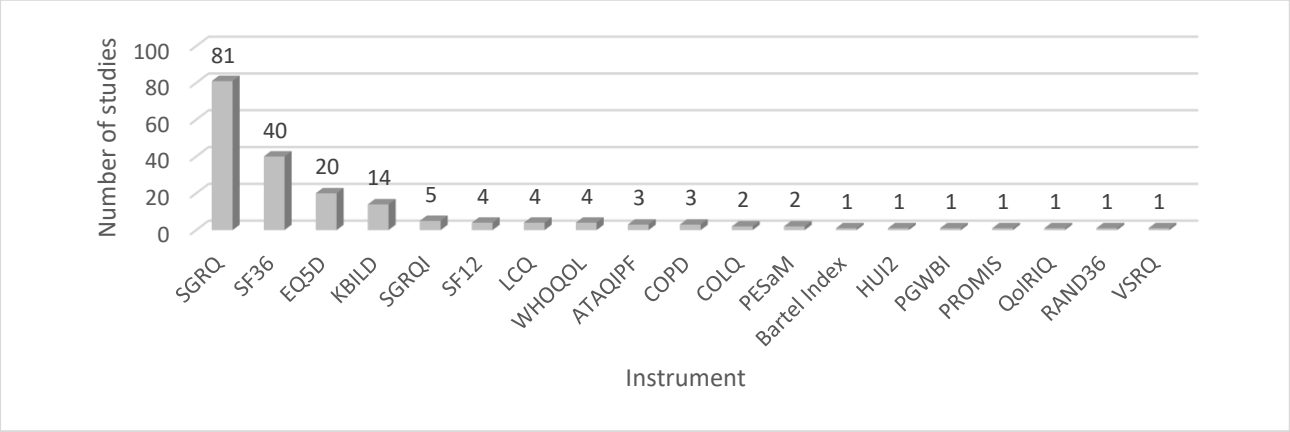


Figure S8-6 Summary of quality of life instruments used in studies by combinations

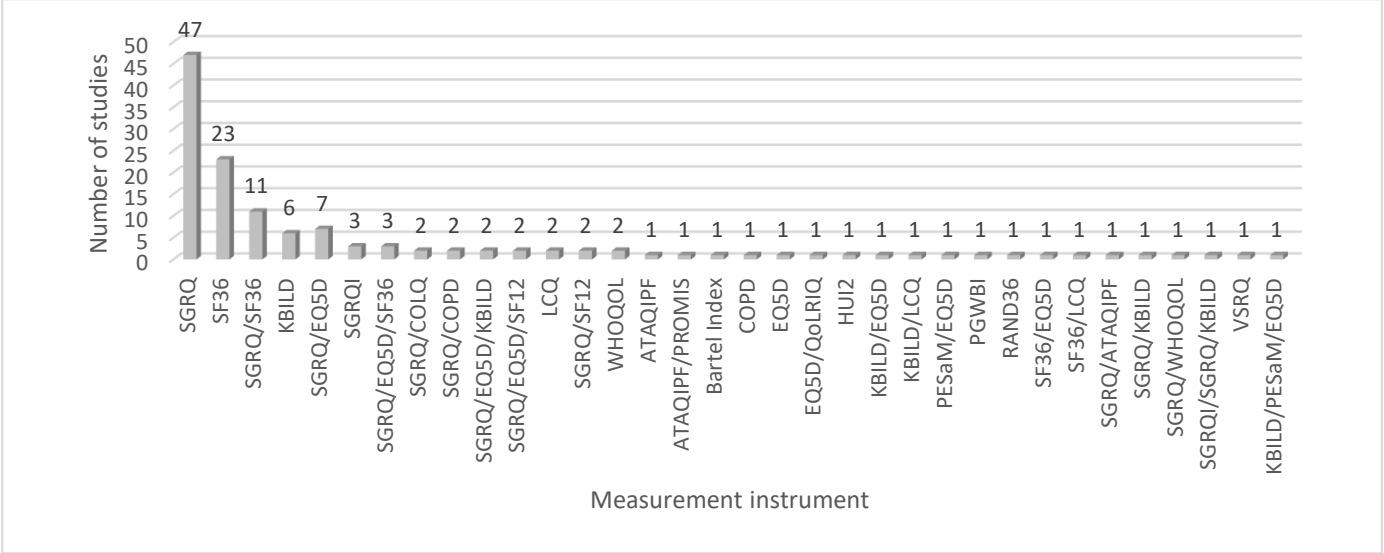


Figure S8-7 Summary of clinical guidelines used for diagnosing IPF

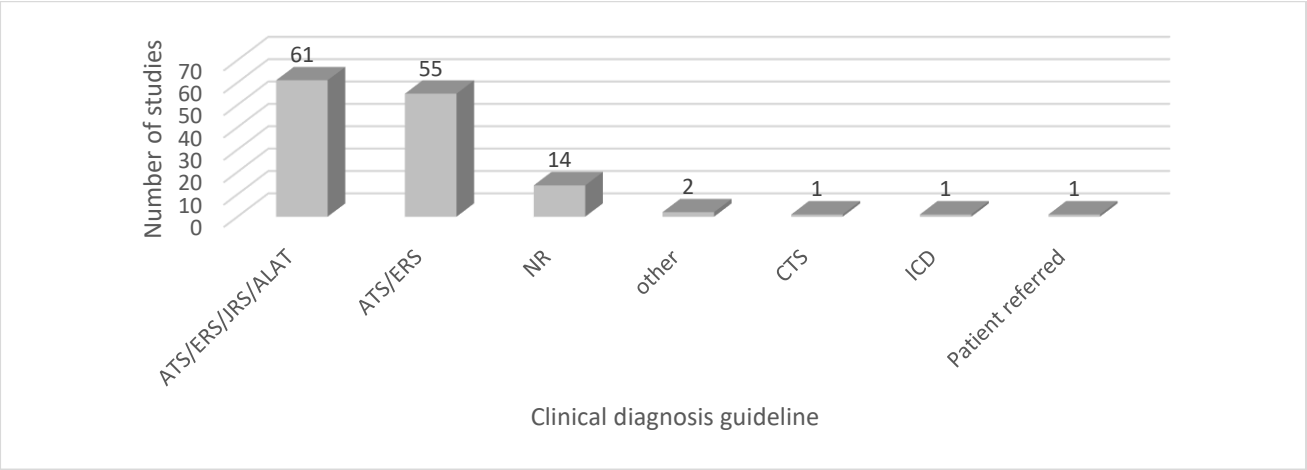
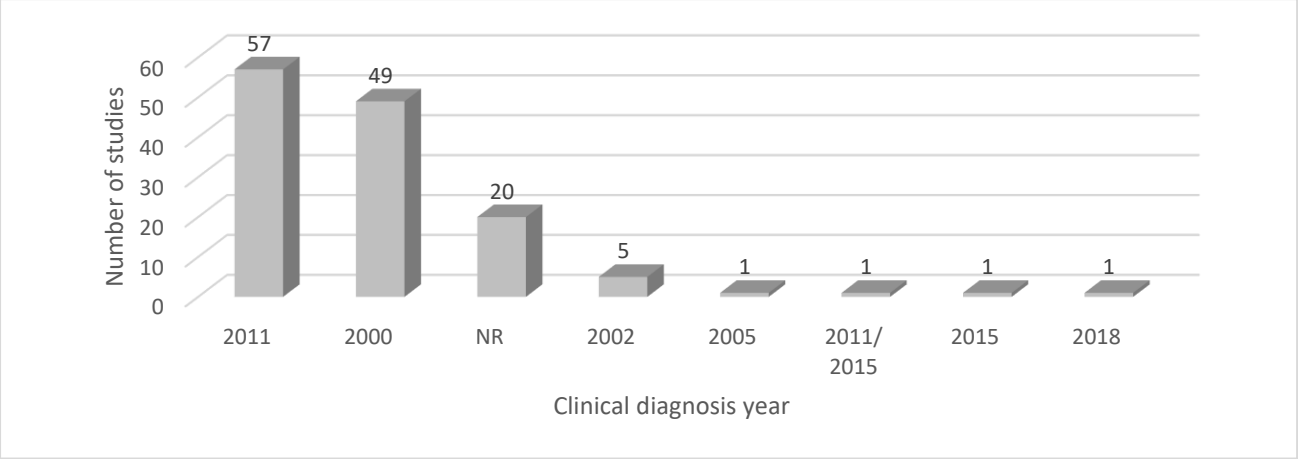


Figure S8-7 Summary of clinical guidelines year used for diagnosing IPF



Supplementary material S9

Metanalysis results

Table S9-1 Summary of meta-analysis results for SGRQ

	ACTIVITY	SYMPTOMS	IMPACT	TOTAL
MAIN ANALYSIS	57.13(48.4,65.87)	50.82(48.32,53.32)	37(34.31,39.68)	44.72(42.21,47.22)
AGE GROUP				
50-59	78.28(71.55,85.01)	62.40(59.51,65.29)	62.36(54.15,70.57)	63.68(59.43,67.92)
60-69	52.58(41.44, 63.72)	49.57(46.59, 52.55)	33.65(30.92, 36.39)	41.94(38.91, 44.96)
70-79	56.54(52.56,60.52)	46.31(43.16,49.45)	29.56(24.84,34.27)	42.99(38.75,47.22)
DISEASE SEVERITY				
Mild	50.36(45.87, 54.86	44.50(42.43, 46.57)	29.06(25.91, 32.20)	39.59(37.07,42.1)
Moderate	56.66(42.47,70.85)	51.96(48.57,55.34)	35.99(31.89,40.09)	45.17(41.3,49.04)
Severe	68.11(57.68, 78.53)	59.99(54.92, 65.07)	54.27(29.68, 78.86)	59.00(42.67,75.33)
QUALITY LEVEL				
Low	73.03(54.15,91.91)	60.40(45.60,75.20)	59.85(43.75,75.96)	57.94(47.06,68.82)
Medium	55.68(41.97,69.39)	52.11(48.33,55.89)	38.06(32.98,43.13)	44.53(39.95,49.12)
High	56.2(53.07,59.34)	47.49(44.54,50.43)	31.59(28.82,34.36)	42.75(40.29,45.22)

All p values were <0.001

Table S9-2 Summary of meta-analysis results for EQ5D

	UTILITY	VAS
MAIN ANALYSIS	0.73(0.68,0.79)	65.66(61.75,69.58)
AGE GROUP		
60-69	0.73 (0.68, 0.78)	66.54 (61.87, 71.21)
70-79	0.75(0.63,0.87)	63.81(54.53,73.08)
DISEASE SEVERITY		
Mild	0.70(0.62,0.77)	61.45(59.93,62.97)
Moderate	0.75(0.69,0.80)	67.44(62.38,72.50)
QUALITY LEVEL		
Medium	0.75(0.73,0.76)	67.10(62.23,71.97)
High	0.73(0.66,0.80)	64.97(59.43,70.51)

All p values were <0.001

Table S9-3 Summary of meta-analysis results for SF36

	PF	RP	BP	GH	VT
MAIN ANALYSIS	38.66(34.26, 43.05)	38.09(33.38, 42.80)	62.19(56.00, 68.38)	42.87 (39.38, 46.36)	46.46(44.20, 48.73)
AGE GROUP					
50-59	26.71(16.58, 36.83)	33.69(26.26, 41.12)	68.04 (62.63, 73.46)	43.83 (36.65, 51.01)	45.45 (41.23, 49.67)
60-69	42.65(36.80, 48.51)	37.77(30.05, 45.48)	61.45 (55.48, 67.42)	43.00 (38.59, 47.41)	45.54 (41.87, 49.22)
70-79	53.42(28.46, 78.38)	55.98(33.40, 78.55)	62.48 (39.42, 85.55)	45.14 (35.97, 4.31)	54.44 (45.33,63.54)
DISEASE SEVERITY					
Moderate	40.85(36.39, 45.30)	37.71(32.26, 43.17)	63.42(55.91, 70.93)	43.28(39.14, 47.41)	45.54(43.03, 48.05)
Severe	21.79(17.01, 26.58)	23.21(16.78, 29.65)	55.44(32.63, 78.26)	36.92(19.79, 54.04)	45.13(32.09, 58.18)
QUALITY LEVEL					
Low	23.01(-2.63,48.66)	30.87(11.71,50.03)	61.16(39.33,82.99)	42.7(25.62,59.77)	43.24(33.98,52.5)
Medium	42.11(35.88,48.35)	40.25(33.78,46.71)	63.9(55.69,72.11)	44.36(39.73,48.98)	48.46(45.61,51.32)
High	37.28(33,41.56)	35.18(30.04,40.31)	56.28(48.3,64.25)	38.06(35.5,40.62)	41.7(37.04,46.35)
	SF	**RE**	**MH**	**PCS**	**MCS**
MAIN ANALYSIS	56.57(50.26, 62.88)	52.01(44.69, 59.33)	58.72(55.12, 62.32)	37.00(34.74, 39.26)	50.18(48.41, 51.95)
AGE GROUP					
50-59	56.76 (51.35, 62.16)	61.32 (54.79, 67.86)	63.38 (58.65, 68.11)	29.80 (25.75,33.84)	44.50 (38.06, 50.95)
60-69	56.41 (47.19, 65.64)	47.04 (35.75, 58.33)	57.02 (50.42, 63.61)	38.10(35.82, 40.39)	50.92(48.71, 53.13)
70-79	65.25 (40.33, 90.18)	60.45 (43.39, 77.52)	59.24 (49.71, 68.77)	41.54(33.30, 49.79)	53.16(48.64, 57.69)
DISEASE SEVERITY					
Moderate	57.03(49.56, 64.50)	51.44(42.69, 60.19)	58.41(54.17, 62.66)	36.79(34.64, 38.95)	50.52(48.75, 52.28)
Severe	48.50(18.47, 78.54)	46.08(34.57, 57.58)	61.23(37.93, 84.53)	29.97(22.02, 37.92)	41.61(34.60, 48.63)
QUALITY LEVEL					
Low	50.84(29.99,71.68)	55.04(39.71,70.37)	59.06(49.71,68.4)	-	-
Medium	59.63(50.58,68.67)	53.05(43.1,62.99)	60.6(55.23,65.97)	37.7(34.73,40.66)	51.04(48.98,53.09)
High	49.22(42.55,55.88)	45.76(41.48,50.03)	51.93(46.04,57.83)	37.53(34.34,40.71)	49.37(45.97,52.77)

All p values were <0.001. PF, Physical function; PR, Physical role; GH, General health; VT, Vitality; RE, Emotional role; SF, Social Function; MH, Mental health; BP, Body pain; PCS, Physical component summary; MCS, Mental component summary

Table S9-4 Summary of meta-analysis results for KBILD

MAIN ANALYSIS	58.38(55.26,61.51)
AGE GROUP	
60-69	54.11(52.08,56.15)
70-79	59.53(54.49,64.57)
DISEASE SEVERITY	
Mild	63.28(58.27,68.28)
Moderate	52.23(48.73,55.73)
QUALITY LEVEL	
Medium	61.15(56.14,66.16)
High	55.72(51.12,60.32)

All p values were <0.001.

Supplementary material S10

Sensitivity analysis

Table S10-1 Summary of sensitivity analysis results for the summary measures of all measurement instruments using method 1

Instrument	Domain	Variable	Main analysis	Minimum	Maximum
EQ5D	VAS	Results (95% CI)	65.66 (61.75, 69.58)	64.53 (60.91, 68.15)	66.38 (62.44, 70.32)
		Statistics	(n=12, Q=504.82, p<0.001, I^2=97.8%)	(n=11, Q=350.24, p<0.001, I^2=97.1%)	(n=11, Q=427.57, p<0.001, I^2=97.7%)
	Utility	Results (95% CI)	0.73 (0.68, 0.79)	0.72 (0.68, 0.77)	0.74 (0.69, 0.8)
		Statistics	(n=9, Q=372.11, p<0.001, I^2=97.9%)	(n=8, Q=181.48 p<0.001, I2=96.1%)	(n=8, Q=287.38, p<0.001, I^2=97.6%)
SF36	Summary Mental	Results (95% CI)	50.18 (48.41, 51.95)	49.61 (47.87, 51.36)	50.67 (48.93, 52.4)
		Statistics	(n=21, Q=319.4, p<0.001, I^2=93.7%)	(n=20, Q=294.22, p<0.001, I^2=93.5%)	(n=20, Q=290.69, p<0.001, I^2=93.5%)
	Summary Physical	Results (95% CI)	37 (34.74, 39.26)	35.86 (33.82, 37.9)	37.56 (35.31, 39.82)
		Statistics	(n=20, Q=581.04, p= p<0.001, I^2=96.7%)	(n=19, Q=439.65, p<0.001, I^2=95.9%)	(n=19, Q=532.81, p<0.001, I^2=96.6%)
SGRQ	Total	Results (95% CI)	44.72 (42.21, 47.22)	44.3 (41.82, 46.78)	45.16 (42.83, 47.5)
		Statistics	(n=58, Q=2406.25, p=0, I^2=97.6%)	(n=57, Q=2299.64, p=0, I^2=97.6%)	(n=57, Q=1981.65, p=0, I^2=97.2%)
KBILD	Total	Results (95% CI)	58.38 (55.26, 61.51)	57.09 (54.22, 59.95)	60.02 (57.09, 62.94)
		Statistics	(n=12, Q=230.09, p<0.001, I2=95.2%)	(n=11, Q=169.79, p<0.001, I2=94.1%)	(n=11, Q=180.57, p<0.001, I2=94.5%)

Table S10-2 Summary of sensitivity analysis results for the summary measures of all measurement instruments using method 2

Instrument	Domain	Variable	Main analysis	Minimum	Maximum
EQ5D	VAS	Results (95% CI)	65.66 (61.75, 69.58)	63.79 (59.02, 68.57)	67.79 (59.98, 75.59)
		Statistics	(n=12, Q=504.82, p<0.001, I2=97.8%)	(n=7, Q=318.7, p<0.001, I2=98.1%)	(n=3, Q=176.19, p<0.001, I2=98.9%)
	Utility	Results (95% CI)	0.73 (0.68, 0.79)	0.73 (0.64, 0.82)	0.75 (0.65, 0.85)
		Statistics	(n=9, Q=372.11, p<0.001, I2=97.9%)	(n=4, Q=306.64, p<0.001, I2=99%)	(n=3, Q=229.15, p<0.001, I2=99.1%)
SF36	Summary Mental	Results (95% CI)	50.18 (48.41, 51.95)	51.11 (48.80, 53.43)	49.48 (47.49, 51.47)
		Statistics	(n=21, Q=319.4, p<0.001, I^2=93.7%)	(n=11, Q=176.79, p<0.001, I^2=94.3%)	(n=17, Q=224.99, p<0.001, I^2=92.9%)
	Summary Physical	Results (95% CI)	37.00 (34.74, 39.26)	38.86 (34.81, 42.92)	35.93 (33.67, 38.21)
		Statistics	(n=20, Q=581.04, p<0.001, I^2=96.7%)	(n=17, Q=61.75, p<0.001, I^2=96.76%)	(n=18, Q=531.44, p<0.001, I^2=96.8%)
SGRQ	Total	Results (95% CI)	44.72 (42.21, 47.22)	40.29 (38.8, 41.79)	45.66 (42.88, 48.44)
		Statistics	(n=58, Q=2406.25, p=0, I2=97.6%)	(n=3, Q=8.68, p<0.001, I2=77%)	(n=19, Q=644.57, p<0.001, I2=97.2%)
KBILD	Total	Results (95% CI)	58.38 (55.26, 61.51)	52.5 (49.5, 55.49)	58.58 (55.27, 61.89)
		Statistics	(n=12, Q=230.09 p<0.001, I2=95.2%)	(n=5, Q=59.36, p<0.001, I2=93.3%)	(n=11, Q=230.03, p<0.001, I2=95.7%)