Table S1. Search strategy

1.	Care adj1 need$.mp. or patient$ adj1 need$.mp. or need$ adj1 assess$.mp. or support$ adj1 care adj1 need$.mp. or healthcare need$.mp.
2.	(Qualitative Research).mp
3.	(Patient Education).mp
4.	(Quality of life).mp
5.	or/1-4
6.	exp Lung Diseases, Interstitial/
7.	(interstitial$ adj lung$ adj disease$).mp.
8.	(interstitial$ adj (fibros$ or pneumonitis or pneumonia or pneumopathy)).mp.
9.	alveolitis.mp.
10.	exp Bronchiolitis Obliterans/ or (bronchiolitis adj obliterans).mp.
11.	(goodpasture$ adj syndrome$).mp.
12.	granulomatosis.mp.
13.	exp Histiocytosis/ or histiocytosis$.mp.
14.	exp Pneumoconiosis/ or pneumoconiosis.mp. or pneumokoniosis.mp. or pneumonoconiosis.mp.
15.	bagassosis.mp.
16.	(pulmonary$ adj sarcoid$).mp.
17.	(pulmonary$ adj fibros$).mp.
18.	(wegener$ adj granuloma$).mp.
19.	(lung$ adj purpura).mp. (6)
20.	((bird$ or farmer$ or pigeon$ or avian$ or budgerigar$) adj (lung$ or disease$)).mp.
21.	(asbestosis or byssinosis or siderosis or silicosis or berylliosis or anthracosilicosis or silicotuberculosis).mp.
22.	or/6-21
23.	5 and 22
24.	Limit 23 to English language

Databases were searched from inception (EMBASE 1947, CINAHL 1937, MEDLINE 1946 and PsychINFO 1967) to 10 July 2019.

Table S2. Characteristics of included studies

Study	Reference type	Sample size	Participant	Age years[#]	Disease characteristics[¶]	Baseline pulmonary function Mean % (range)	Intervention	Study design	Country	Recruitment context	Time of study
Albright 2016 (1)	Journal article	471 responses to blog entries/ forum strings	Freely available to the public	Unclear	Unclear	Unclear	Unclear	Qualitative Narrative	United States	Unclear	2013 - 2014
Bajwah 2012 (2)	Journal article	18	Patients (n=8); IC's (n=4); HCP's (n=6)	Age range, Patient: 56-81; IC: 41-63	Patients: IPF (n=7), NSIP (n=1) IC's: of patients with IPF (n=4)	*TLCO* % pred: range 30-39	Unclear	Qualitative Semi-structured in-depth interview	United Kingdom	Purposive sampling Royal Brompton Hospital & King's College Hospital	2010 - 2011
Bajwah 2013 (3)	Journal article	18	Patients (n=8); IC's (n=4; 3 spouse, 1 daughter); HCP's (n=6)	Age range, Patient: 56-81; IC: 41-63; HCP: 31-59	IPF (n=7), NSIP (n=1) IC's: of patients with IPF (n=4)	*TLCO* % pred: range 30-39	Unclear	Qualitative Semi-structured interview	United Kingdom	Purposive sampling Royal Brompton Hospital & King's College Hospital	2010 - 2011
Belkin 2014 (4)	Journal article	14	IC's	Mean age, IC: 67 ± 7 (55-76); Patient: 69 ± 7 (57-78)	IPF Mean time since diagnosis: 4 ± 3 years (6 months-8 years)	Mean FVC % : 66 ± 16 (47-99); Mean *D*LCO %: 33 ± 19 (13-76)	24/7 O_2 therapy (n=10)	Qualitative Semi-structured focus group	United States	Convenience sampling National Jewish Health ILD Clinic	2012 - 2013

Belz 2018 (5)	Conference abstract	40	Patients	Median age: 72	IPF GAP index stage 1 (n=31) GAP index stage 2 (n=9)	Unclear	Unclear	Quantitative Survey to choose 3 most important issues out of 15; SF-36	Poland	Unclear Patients qualified for treatment were recruited	Unclear
Bonella 2016 (6)	Journal article	12 PGs interviewed 16 attended Working Group meeting	PGs: Patients (n=4); Spouse/child (n=3); Unspecified participants (n=5) Working Group meeting participants: Patients (n=4); Spouse/child (n=3); Unspecified participants (n=4) IPF specialist (n=5; 4 physicians, 1 specialist nurse)	Unclear	IPF (n=6), non-IPF lung fibrosis (n=1)	Unclear	Lung transplant (n=2)	Qualitative Individual telephone interview using questionnaire developed by patient advocacy groups and external healthcare consultancy	Europe: Austria, Belgium, France, Germany, Ireland, Italy, Spain, UK, Netherlands	Patient advocacy groups	2014

Bridges 2014 (7)	Journal article	20	Patients, IC's (spouses/adult children), and advocates (n=7); Providers and clinical researchers (n=8); Industry/policy experts (n=5)	Unclear	IPF	Unclear	Unclear	Qualitative Semi-structure interview (in person and telephone)	United States	Purposive and snowball sampling Partnership with national advocacy organization	Unclear
Burnett 2019 (8)	Journal article	100	Patients	Age range: 57-90	IPF	Median FVC % pred: 77 (46-106); Median *D*LCO % pred: 54 (21-95)	Anti-fibrotic therapy (n=46); Had ceased anti-fibrotic therapy (n=7); Never been offered anti-fibrotic therapy (n=39); Could not report (n=8)	Qualitative Semi-structured interview (telephone) Grounded theory	Australia	The Australian IPF Registry	Unclear
Collard 2007 (9)	Journal article	1448 (79.0% respond rate to survey)	Patients (n=1251); IC's responding on behalf of patients (n=197)	Median age: 65	IPF Year diagnosed: Prior to 2000 (23.9%); 2000 - 2001 (24.8%); 2002 - 2003 (39.9%); In 2004 (10.2%)	Unclear	Unclear	Quantitative Survey - 52 defined-choice and open-ended questions regarding PF diagnosis and management	United States	The coalition for PF website, sponsored seminars and institutional partners	2003 - 2004

Conoscenti 2013 (10)	Conference abstract	61	Patients	Unclear	IPF	Unclear	Unclear	Qualitative In person interview Grounded theory	United States	Unclear	Unclear
Duck 2015 (11)	Journal article	823 follow-up phone calls (representing 239 patients); 44 completed surveys	Patients	Unclear	IPF Patients diagnosed in the previous 12 months of study	Unclear	Pirfenidone IPF Care Patient Support Program	Quantitative Posted evaluation questionnaire	United Kingdom Austria	IPF Care Patient Support Program	2013 - 2014
Duck 2015 (12)	Journal article	23	Patients (n=17); IC's (n=6, 5 spouses; 1 daughter)	Median age: 67	IPF; Moderate to advanced	Mean FVC % pred: 68 (44-104; n=17); Mean *D*LCO % pred: 43 (23-67; n=13)	Long-term O_2 therapy and ambulatory O_2 (n=10); Ambulatory O_2 only (n=2); Not using O_2 (n=5); Lung transplant waiting list (n=3); Clinical trial (n=3)	Qualitative Individual or joint semi-structured interview (in person)	United Kingdom	Regional respiratory and lung transplant centre	2007 - 2012

Gillon 2016 (13)	Conference abstract	Unclear	Patients; ILD staff	Unclear	IPF	Unclear	Specialist palliative care	Mixed method Staff confidence scales; Patient's unmet needs	United Kingdom	Unclear	Unclear
Giot 2013 (14)	Journal article	63	Patients (n=45); IC's (n=18)	Median age: 67	IPF - progressive (16%) Year diagnosed: Since 2000 (16%); 2006 - 2010 (60%)	Unclear	Continuous O_2 therapy (40%)	Qualitative Individual or joint in-depth structured interview (in person); Pilot test online forum	Europe: Germany, France, Italy, Spain, UK	Unclear	2010
Graney 2017 (15)	Journal article	20	IC's (16 spouses , 4 children)	Mean age: 62.2 ± 9.7 (44–76)	PF	Unclear	O_2 therapy for > 8 months; Mean duration of O_2 use: 3.9 years ± 3.0	Qualitative Semi-structured telephone interview Grounded theory	United States	Convenience sampling National Jewish Health ILD Clinic/ Participation Program for PF website	Unclear

Graney 2017 (16)	Journal article	5	Patients	Mean age: 64.6 ± 9.4 (53–76)	IPF (n=4), chronic HP (n=1) Median time since diagnosis: 2 years (2-15)	Mean FVC % pred: 52.2 ± 14.8 (40-77)	O_2 therapy (0%)	Mixed method Longitudinal (at 4 time points from enrolment to 9-12 months after initiation of O_2 therapy) Qualitative Serial structured telephone interviews	United States	Unclear	2013 - 2015
Holland 2015 (17)	Journal article	32	Patients (n=18); Clinicians (n=14; 5 nurses, 4 physicians, 3 physiotherapists, 1 respiratory therapist, 1 exercise physiologist)	Age range, Patient: 49-81	IPF (n=9), NSIP (n=3), pulmonary lymphangio-myomatosis (n=1), HP (n=3), sarcoidosis (n=1), unclassifiable ILD (n=1)	FVC % pred, range: 31-100; *T*LCO % pred, range: 28-94; 6MWD (m), range: 270-663	Previous PR program (50%)	Qualitative Semi-structured interview	Australia	Purposive sampling Tertiary hospital with a specialist ILD clinic	Unclear
Killin 2010 (18)	Conference abstract	24	Patients IC's	Unclear	IPF; A range of severity	Unclear	Unclear	Quantitative Cross sectional Structured interview with questionnaires: WHOQOL 100 (others unclear)	United Kingdom	Consecutive patients from ILD clinic	Unclear

Lindell 2017 (19)	Journal article	13	Patients (n=5); IC's of current patients (n=5); IC's of decedent patients (n=3; 75% spouses, 25% daughters)	Mean age, Patient: 71.4 ± 7.2	IPF Time since diagnosis: range 1-11 years	Most recent FVC % pred, range: 65-125; Most recent *D*LCO % pred, range: 26-70	O_2 therapy, Yes (n=3); No (n=2)	Qualitative Focus group	United States	Convenience sampling IPF clinic and support group at the Dorothy P. & Richard P. Simmons Center for ILD (University of Pittsburgh Medical Center)	2014 - 2015
Maher 2018 (20)	Journal article	347 completed survey 129 participated interview	Survey: Patients (n=60); Pulmonologists (n=287) Interview: Patients (n=68) IC's were allowed for interview participation but number is unclear); Pulmonologists (n=61)	Mean age: 64.6 ± 9.0	IPF	Unclear	Pirfenidone (73%, n=44/60); Nintedanib (18%, n=11/60); Both treatments sequentially (Pirfenidone then Nintedanib; 8%, n=5/60) At the time of survey completion, patients receiving treatment (77%, n=(46/60); stopped treatment (22%, n=13/60	Mixed method Interview (in person and telephone) Online survey	Canada, France, Germany, Italy, Spain, United Kingdom	Patients recruited via physician referrals, patient groups, or market research panels . HCPs recruited from market research panels.	2016

McLean 2018 (21)	Conference abstract	38	Patients	Mean age: 66 ± 13	IPF (n=12, 31.6%), CTD-ILD (n=7, 18.4%), uncertain of ILD diagnosis (n=14, 37%)	Unclear	Unclear	Mixed method Survey collecting both quantitative and qualitative data	Australia	Sub-specialist multidisciplinary ILD clinic within the Royal Prince Alfred Hospital (NSW)	Unclear
Morisset 2016 (22)	Journal article	34	Patients (n=24) ILD HCP's (n=10)	Mean age, Patient: 67 ± 9	IPF (n=12), HP (n=4), CTD-ILD (n=5), others (n=3)	Mean FVC % pred: 70 ± 20; Mean *D*LCO % pred: 52 ± 10	Long-term O_2 therapy (n=10); Previous participation in PR (n=14); Previous participation in support group (n=15); Current drug therapy: Prednisone (n=2), Azathioprine (n=1), Mycophenolate mofetil (n=5), Nintedanib (n=2), Pirfenidone (n=8)	Qualitative Focus group (with patients) Semi-structured individual interviews (with HCP's) Grounded theory	United States; Canada	Purposive sampling ILD clinics (University of California San Francisco/ Centre Hospitalier de l'Universit´e de Montr´eal)	2015

Overgaard 2016 (23)	Journal article	49	Patients (n=25); IC's (n=24)	Mean age, Patient: 71.1 (50-91)	IPF	Mean FEV_1 % pred: 85.5 (30-123); Mean FVC % pred: 83.1 (31-120); Mean *D*LCO % pred: 50.5 (23-76)	Long-term O_2 therapy (n=7); Pirfenidone (n=15)	Qualitative In person interview	Denmark	Convenience sampling Specialist clinics at two University hospitals	2014
Pooler 2018 (24)	Journal article	8	Bereaved IC's of > 3 months	Patients in their, 50's (n=2); 60's (n=3); 70's (n=2); 80's (n=1)	IPF	Unclear	Unclear	Qualitative Open-ended interview (in person and telephone)	Canada	Purposive sampling Multidisciplinary ILD clinic via intermediary and third person contact	2016
Ramadurai 2019 (25)	Journal article	345	Patients (n=160) IC's (n=29) HCP's (n=156)	Unclear	IPF	Unclear	Unclear	Mixed method Online survey collecting both quantitative and qualitative data	United States	Convenience and purposive sampling Research contact registry, targeted social media outreach, IPF support groups, and National Jewish Health HCP education program database	2017

Ramadurai 2018 (26)	Journal article	17	Patients (n=13) IC's (n=4)	Mean age, Patient: 68.1 ± 7.2; Caregiver: 63.3 ± 7.7	IPF Mean disease duration: 5.7 ± 4.4 years	Unclear	Not using supplemental O_2 (n=1); Use on exertion only (n=5); Continuous use (n=7)	Qualitative Focus group	United States	National Jewish Health ILD Programme	2016
Russell 2016 (27)	Journal article	45	Patients	Mean age: 68.5	IPF Mean time since diagnosis: 3.5 years	Unclear	Pirfenidone (100%); O_2 therapy as needed (55%); Continual O_2 therapy (35%)	Qualitative Semi-structured interview (in person)	United Kingdom; Germany; Italy	Patient support groups (UK), specialist centres (Italy), advocacy group (Germany)	2012
Sampson 2015 (28)	Journal article	48	Patients (n=27) IC's (n=21)	Mean age, Extensive progressive group: 69.5 (56-77); Limited progressive group: 72.6 (59-81); Extensive stable group: 71 (69-82); Limited stable group: 75.1 (66-87)	IPF Extensive progressive (n=3); Limited progressive (n=5); Extensive stable (n=6); Limited stable (n=9)	Limited: FVC > 50 %; and *T*LCO > 40 %; Extensive: FVC < 50 %, or *T*LCO < 40 %; Stable: decline of < 10 % in FVC, or < 15 % in *T*LCO in last 12 months; Progressive: decline of > 10 % in FVC, or > 15 % in *T*LCO in last 12 months	Pirfenidone (0%); Lung transplant (n=2); O_2 therapy (n=5)	Mixed method Cross-sectional Qualitative Semi-structured interview	United Kingdom	Two UK specialist ILD clinics	2012 - 2014

Senanayake 2018 (29)	Journal article	10	Patients (2 spouses accompanied patient at interview)	Mean age: 70.5 ± 10.4 Age range: 53-81	IPF Disease onset range: 7 months–10 years Onset > 1 year (n=5); Onset 3–5 years (n=2); Onset 8–10 years (n=3)	Unclear	O_2 use during interview (n=1); O_2 use during strenuous activities (n=2)	Qualitative Semi-structured interview (in person) Grounded theory	United Kingdom	Purposive sampling Patients support group	Unclear
Schoenheit 2011 (30)	Journal article	45	Patients (25% from each country); IC's participated in 40% of the 45 interviews	Median age: 67	IPF Median time since diagnosis: 1.5 years (< 1 week-12 years)	Unclear	O_2 therapy, None (44%); Continuous (40%); Non-continuous (16%)	Qualitative In-depth interview (in person)	Europe: Germany, France, Italy, Spain, UK	Unclear	Unclear
Shah 2018 (31)	Journal article	37 completed survey 15 participated focus group	IC's	Mean age: 66 ± 13	Non specific interstitial pneumonitis (6%, n=2), sarcoidosis (3%, n=1), other (9%, n=3) Median duration of disease (IQR): 1 year (0,4)	Unclear	Not requiring supplemental O_2 (30%); Using supplemental O_2 with exertion (27%); Using supplemental O_2 all the time (43%)	Mixed method Focus group Grounded theory Paper form and online surveys including SF-36, a revised Zarit Burden Interview questionnaire and the Connor-Davidson resilience scale	United States	Convenience sampling University of California, San Francisco ILD clinic	Unclear

Swigris 2005 (32)	Journal article	20	Patients	Median age: 67 (44-82)	IPF Median time since diagnosis: 1.8 years (0.67-11 years)	Unclear	Medication for IPF (n=19); O_2 therapy, None (n=6); Use with exertion and sleep (n=4); Continuous (n=10)	Qualitative Focus group Interview	United States	The general pulmonary and ILD Clinics (Stanford University)	2003 - 2004
van Manen 2017 (33)	Journal article	329	Netherlands (n=278; 134 patients, 144 partners); Germany (n=51; 27 patients, 24 partners)	Unclear	Netherlands, IPF (70%, n=88), CTD-PF (11%, n=14), exposure related (11%, n=14), unknown (8%, n=10); Germany, IPF (80%, n=20), CTD-PF (8%, n=2), exposure related (12%, n=3), unknown (0%, n=0)	Unclear	Unclear	Quantitative Interactive voting system (Netherlands) Questionnaire (Germany): GAD-SI	Netherlands ; Germany	PF information meetings at two tertiary ILD centres (the Erasmus University Medical Center & the Thoraxklinik, Heidelberg University Hospital)	2013 - 2015
Wall 2013 (34)	Conference abstract	97	Patients	Median age: 69 (47-86)	IPF (81%, n=79), NSIP (19%, n=18), severe lung function defects (TLCO <40%; 39%, n=38)	Unclear	Unclear	Quantitative Cross-sectional Questionnaire: SPARC	United Kingdom	Specialist clinics	Unclear

Wright 2016 (35)	Conference abstract	57	Patients (n=27) Family members (n=25)	Unclear	IPF	Unclear	Workshop led by clinical psychologist and palliative care clinical nurse specialist	Qualitative Semi-structured questionnaire	United Kingdom	ILD clinics	Unclear

HCP: healthcare professional; IC: informal caregiver; PG: patient advocacy group representative; IPF: idiopathic pulmonary fibrosis; NSIP: non-specific interstitial pneumonitis; ILD: interstitial lung disease; HP: hypersensitivity pneumonitis; CTD-ILD: connective tissue disease related interstitial lung disease; CTD-PF: connective tissue disease related pulmonary fibrosis; GAP: Gender-Age-Physiology; T_{LCO}: transfer factor for carbon monoxide; FVC: forced vital capacity; D_{LCO}: diffusing capacity of the lung for carbon monoxide; FEV_1: forced expiratory volume in 1 s; PR: pulmonary rehabilitation; SF-36: 36-Item Short Form Health Survey; WHOQOL 100: The World Health Organization Quality of Life 100-item questionnaire; GAD-SI: the Generalised Anxiety Disorder-single item questionnaire; SPARC: the Sheffield Profile for Assessment and Referral to Care questionnaire; [#]: data is presented as mean ± standard deviation (range), median and/or range, whichever available; [¶]: data includes diagnosis, disease severity, disease stage, time of/since diagnosis, or duration of symptoms [mean year ± standard deviation (range)].

Table S3. Quality assessment of included qualitative studies

Study	QualSyst criteria for qualitative studies 2 = Yes; 1 = Partial; 0 = No										Summary score
	1. Question / objective sufficiently described?	2. Study design evident and appropriate?	3. Context for the study clear?	4. Connection to a theoretical framework / wider body of knowledge?	5. Sampling strategy described, relevant and justified?	6. Data collection methods clearly described and systematic?	7. Data analysis clearly described and systematic?	8. Use of verification procedure(s) to establish credibility?	9. Conclusions supported by the results?	10. Reflexivity of the account?	
Albright, 2016 (1)	2	2	2	1	1	2	2	2	2	1	85%
Bajwah, 2012 (2)	2	2	2	1	2	2	2	2	2	0	85%
Bajwah, 2013 (3)	2	2	2	1	2	2	2	2	2	2	95%
Belkin, 2014 (4)	2	2	2	1	1	1	2	2	2	1	80%
Bonella, 2016 (6)	2	2	2	0	1	2	2	2	2	0	75%
Bridges, 2014 (7)	2	2	2	1	2	2	2	0	2	0	75%
Burnett, 2019 (8)	2	2	2	2	2	2	2	2	2	1	95%
Conoscenti, 2013 (10)	2	2	1	2	0	1	1	0	2	0	55%
Duck, 2015 (12)	2	2	2	2	2	2	2	2	2	0	90%

Gillon, 2016 (13)	1	0	0	0	0	1	0	0	0	0	10%
Giot , 2013 (14)	2	2	2	1	1	2	2	0	2	0	70%
Graney, 2017 (15)	2	2	2	2	1	2	2	2	2	0	85%
Graney, 2017 (16)	2	2	2	2	2	2	2	2	2	0	90%
Holland, 2015 (17)	2	2	2	2	2	2	2	2	2	0	90%
Lindell, 2017 (19)	2	2	2	1	1	2	2	2	2	1	85%
Morisset, 2016 (22)	2	2	2	2	2	2	2	2	2	1	95%
Overgaard, 2016 (23)	2	2	2	2	1	2	2	2	2	1	90%
Pooler, 2018 (24)	2	2	2	1	2	2	2	0	2	1	80%
Ramadurai, 2018 (26)	2	2	2	1	1	1	2	2	2	0	75%
Russell, 2016 (27)	2	2	2	1	2	2	1	0	2	0	70%
Sampson, 2015 (28)	2	2	2	2	2	2	2	2	2	0	90%
Senanayake, 2018 (29)	2	2	2	2	2	2	2	2	2	2	100%
Schoenheit, 2011 (30)	2	2	1	1	1	2	2	2	2	0	75%
Shah, 2018 (31)	2	2	2	2	1	2	2	2	2	0	85%
Swigris, 2005 (32)	2	2	2	2	1	2	2	0	2	0	75%
Wright, 2016 (35)	2	2	1	1	1	1	1	0	2	0	55%

Table S4. Quality assessment of quantitative studies

Study	QualSyst criteria for quantitative studies 2 = Yes; 1 = Partial; 0 = No; N/A=not applicable for this study design														Summary score
	1. Question / objective sufficiently described?	2. Study design evident and appropriate?	3. Method of subject/comparison group selection or source of information/input variables described and appropriate?	4. Subject (and comparison group, if applicable) characteristics sufficiently described?	5. If interventional and random allocation was possible, was it described?	6. If interventional and blinding of investigators was possible, was it reported?	7. If interventional and blinding of subjects was possible, was it reported?	8. Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported?	9. Sample size appropriate?	10. Analytic methods described/justified and appropriate?	11. Some estimate of variance is reported for the main results?	12. Controlled for confounding?	13. Results reported in sufficient detail?	14. Conclusions supported by the results?	
Belz, 2018 (5)	2	2	1	2	N/A	N/A	N/A	1	0	1	0	0	2	2	59%
Collard, 2007 (9)	2	2	1	2	N/A	N/A	N/A	2	2	2	N/A	N/A	2	2	94%
Duck, 2015 (11)	2	2	1	0	N/A	N/A	N/A	2	1	1	1	N/A	2	2	70%
Killin, 2010 (18)	2	1	2	0	N/A	N/A	N/A	1	N/A	1	0	N/A	0	1	44%

Maher, 2018 (20)	2	2	2	2	N/A	N/A	N/A	2	2	2	N/A	N/A	2	2	100%
McLean, 2018 (21)	2	2	1	1	N/A	N/A	N/A	1	N/A	1	N/A	N/A	2	2	75%
van Manen, 2017 (33)	2	1	1	1	N/A	N/A	N/A	2	N/A	N/A	N/A	N/A	2	2	79%
Ramadurai, 2019 (25)	2	2	2	1	N/A	N/A	N/A	2	N/A	2	N/A	N/A	2	2	94%
Wall, 2013 (34)	2	2	1	1	N/A	N/A	N/A	2	N/A	N/A	N/A	N/A	2	2	86%

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