BTS UK ILD Registry –Data Collection Sheet February 2023

Patient Demographics: Part A

Patient ID	

Please do not complete questions which are greyed out – these are calculated automatically on the Registry site.

1.1a	Has the patient consent form been completed? ☐ Yes ☐ No		
1.1b	Has the patient agreed that they can be contacted by the clinical staff within their hospital about any future research study (question 4 on the consent form)? ☐ Yes ☐ No		
1.1c	Consent obtained prior to 21st February 2023 **is still valid**. Consent obtained after this date makes data linkage easier, but you do not need to renew consent. If consent was obtained prior to 21st February 2023 please let us know if you have also obtained renewed consent. ☐ Yes ☐ N/A		
1.2 1.3 1.4 1.5 1.6a	Forename: Surname: NHS (CHI/H&C) number: Date of birth: DD/ MM / YYYY Sex: ☐ Male ☐ Female	1.6b 1.7 1.8a 1.8b	Gender identity: ☐ Male ☐ Female ☐ Other ☐ None ☐ Not known ☐ Not disclosed Home postcode: Date of first presentation to your chest clinic: If diagnosis was historic, year of original diagnosis:
1.9	Age at presentation to your chest clinic (calculated field). *Do not complete.*		
1.10	Date of referral* from GP or other specialist: DD/ MM / YYYY * *Please enter the date the GP/ specialist letter was received into the treating clinician's centre.*		
1.11a	Category of ILD: ☐ IPF ☐ Exposure-related: asbestosis ☐ Exposure-related: drug reaction ☐ Exposure-related: hypersensitivity pneumonitis ☐ Exposure-related: pneumoconiosis ☐ Exposure-related: silicosis ☐ Connective tissue: lupus (SLE) ☐ Connective tissue: MCTD ☐ Connective tissue: myositis (PM/DM) ☐ Connective tissue: rheumatoid arthritis ☐ Connective tissue: scleroderma ☐ Connective tissue: Sjorgens ☐ Connective tissue: UCTD ☐ Interstitial pneumonia with autoimmune features (IPAF) ☐ NSIP – nonspecific interstitial pneumonia ☐ Sarcoidosis ☐ Unclassifiable ☐ Other specified ILD		
1.11b	If other interstitial lung disease ☐ IIPs: AIP – acute interstitial pneumonia ☐ IIPs: DIP – desquamative interstitial pneumonia ☐ IIPs: COP– cryptogenic organising pneumonia ☐ IIPs: LIP –Lymphocytic interstitial pneumonia ☐ IIPs: RB-ILD – respiratory bronchiolitis ILD ☐ Misc.: eosinophilic pneumonias ☐ Misc.: inherited disorders ☐ Misc.: LAM – lymphagioleiomyomatosis ☐ Misc.: LCH – Langerhans cell histiocytosis ☐ Misc.: lipoid pneumonias ☐ Misc.: mycobacterial or fungal infection ☐ Misc.: neurofibromatosis ☐ Misc.: PAP – pulmonary alveolar proteinosis ☐ Misc.: vasculitis/diffuse alveolar haemorrhage (DAH) ☐ Other		
1.11c	If 'Other' please specify:		

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Patient Demographics: Part A

1.12	Ethnic Group: ☐ White English, Welsh, Scottish, Northern Irish or British ☐ White Irish ☐ Gypsy or Irish Traveller ☐ Roma ☐ Any other white background ☐ White and Black Caribbean ☐ White and Black African ☐ White and Asian ☐ Any other mixed or multiple ethnic background ☐ Indian ☐ Pakistani ☐ Bangladeshi ☐ Chinese ☐ Any other Asian background ☐ Black Caribbean ☐ Black African ☐ Any Other Black, Black British or Caribbean background ☐ Arab ☐ Any other ethnic group ☐ Not stated
1.13	Close relative(s) also have ILD? *First-degree relatives are parents, siblings or offspring. Second degree relatives include uncles/aunts, nephews/nieces, grandparents, grandchildren, half-siblings, and cousins, etc.* ☐ No - none ☐ First degree ☐ Second degree ☐ Not known
1.14a	Date of death: DD / MM / YYYY
1.14b	To the best of your knowledge, what was the main underlying cause of death? ☐ ILD ☐ ILD/ Pneumonia/ respiratory tract infection ☐ Lung cancer ☐ Acute cardiac event ☐ PE ☐ Other ☐ Unknown
1.14c	I have seen or am aware of what was on the patient's death certificate *This includes if you have had a discussion with the patient's GP or consultant team, who will know what the content of the death certificate was.* ☐ Yes ☐ No
1.14d	Place of death: *The option of Other has been included to encompass death abroad, in a hotel, outdoors, etc.* ☐ Hospital ☐ Hospice ☐ Home address (if residential or nursing home select the option below) ☐ Residential or nursing home ☐ Other ☐ Not known

BTS UK ILD Registry –Data Collection Sheet September 2023

Clinical Features: Part B

Patient ID	

Please do not complete questions which are greyed out – these are calculated automatically on the Registry site.

Core dataset – to be completed for all cases unless otherwise stated

2.1a	At the time of this clinic visit does the patient have idiopathic pulmonary fibrosis (IPF) or progressive pulmonary fibrosis (PPF)? ☐ Yes ☐ No ☐ Not known
2.1b	Characteristics of IPF/PPF? *(Please select all that apply)* ☐ IPF ☐ PPF – Clinical progression ☐ PPF- Lung function progression ☐ PPF -Radiological progression
2.2	Duration of chest symptoms prior to presentation to your chest clinic: ☐ Less than 6 months ☐ 12-24 months ☐ Not known ☐ 6-12 months ☐ More than 24 months ☐ No known symptoms
2.3	MRC dyspnoea grade (at clinic today): ☐ Grade 1: not troubled by breathlessness except on strenuous exercise ☐ Grade 2: short of breath when hurrying or walking up a slight hill ☐ Grade 3: walks slower than contemporaries on level ground because of breathlessness, or has to stop for breath when walking at own pace ☐ Grade 4: stops for breath after walking about 100m or after a few minutes on level ground ☐ Grade 5: too breathless to leave the house, or breathless when dressing or undressing ☐ Not recorded
2.4	Smoker at first presentation at this clinic? ☐ No never smoked/negligible (less than 5 pack years) ☐ Ex-smoker (quit more than 3 months ago) ☐ Current smoker ☐ Not known
2.5	Comorbidities (past and present): ☐ No – none ☐ Ischaemic heart disease ☐ TB ☐ Atrial arrhythmias ☐ Lung cancer ☐ Symptoms of gastro-oesophageal reflux disease ☐ COPD ☐ Other current malignancy ☐ Diabetes ☐ Major depressive disorder ☐ Known hiatus hernia ☐ Hypertension ☐ Moderate/severe left ventricular failure ☐ Valvular heart disease
2.6a	For which of the following is there a clinically relevant exposure history? *Please select all that apply* ☐ Asbestos ☐ Silica ☐ None ☐ Bird allergens ☐ Other ☐ Not known ☐ Coal dust
2.6b	Please select all clinically relevant drug reactions and exposures: ☐ Amiodarone ☐ Other cancer-related medications ☐ Other ☐ Nitrofurantoin ☐ Methotrexate ☐ None ☐ Chemotherapy ☐ Other immunosuppressants ☐ Not known
2.6c	If other, please specify
2.7a	Is your patient in paid employment? ☐ Yes ☐ No ☐ Unknown
2.7b	If no, please select which of the following apply to your patient: ☐ Unable to work due to their ILD ☐ Retired ☐ In full/part time education ☐ Other ☐ Providing full time care (e.g. for child or dependent adult)
2.8	At this clinic visit have you referred the patient to any other services or informed them of any other form of non-clinical support? (This could be official or unofficial) ☐ Mental health support ☐ Helplines ☐ No - none ☐ Patient support groups ☐ Other ☐ Not known ☐ Charities

British Thoracic Society

BTS UK ILD Registry –Data Collection Sheet September 2023

Clinical Features: Part B

2.9a	Height (in metres):	2.9c	BMI (calculated): *Do not complete*
2.9b	Weight (in kgs):		
2.10	Date of most recent spirometry tests: DD/ MM / YYYY		
2.11a	FEV1 - absolute value in litres:	2.11c	FEV1 % predicted (calculated): *Do not complete*
2.11b	FEV1 - predicted value in litres:		
2.12a	FVC - absolute value in litres:	2.12c	FVC % predicted (calculated): *Do not complete*
2.12b	FVC - predicted value in litres:	2.12d	Ratio of FEV1:FVC (calculated): *Do not complete*
2.13	Date of most recent gas transfer tests: DD/ MM / YYYY		
2.14	TLC litres at current investigation if available		
2.15a	TLCO/DLCO in mmol/min/kPa at first clinic visit - absolute value: *Please give response in mmol/min/kPa. The response should fall within 0.00 - 15.To convert units given in ml/min/mmHg to mmol/min/kPa please multiply by 0.33*		
2.15b	TLCO/DLCO (mmol/min/kPa) – predicted value:		
2.15c	TLCO/DLCO (mmol/min/kPa) % predicted (calculated): *Do not complete*		
2.16a	KCO mmol/min/kPa/l - absolute value:	2.16c	KCO % predicted (calculated): *Do not complete*
2.16b	KCO mmol/min/kPa/l - predicted value:		
2.17	Blood tests (most recent): *(Tick all that apply)* ☐ Lymphopenia ☐ Abnormal liver function ☐ Raised IgG ☐ Raised eosinophil ☐ Abnormal renal function ☐ Any other antibodies ☐ Raised ESR ☐ Raised Ca2++ ☐ Other abnormality ☐ Raised CRP ☐ Raised ACE level ☐ Not recorded ☐ Positive ANA ☐ Raised BNP/NTproBNP ☐ Raised anti-CCP ☐ Positive ANCA		
2.18a	Date of most recent HRCT scan: DD/ MM / YYYY		
2.18b	HRCT features *Please select all that apply*: ☐ Nodules ☐ Cysts ☐ Emphysema (>25% lung volume) ☐ Ground glass density ☐ Traction bronchiectasis ☐ Normal ☐ Consolidation ☐ Honeycombing ☐ Other ☐ Reticulation		
2.18c	What was the HRCT pattern on the scan that was used to make a diagnosis? *For IPF the choices follow ATS/ERS 2018 IPF Guideline* ☐ Definite UIP ☐ Probable UIP ☐ Indeterminate for UIP ☐ Alternative diagnosis ☐ Not recorded		
2.19	Broncho-alveolar lavage with differential cell count? ☐ Lymphocytic ☐ Neutrophilic ☐ Eosinophilic ☐ Other ☐ Not done ☐ Not known		
2.20a	Was a lung biopsy obtained during diagnosis? ☐ Yes – biopsy aided diagnosis ☐ Yes – biopsy did not contribute to diagnosis ☐ No ☐ Unknown		
2.20b	**IPF only:** Surgical biopsy results (please select one only at discretion of physician / pathologist). *Choices follow ATS/ERS 2018 IPF Guideline:* ☐ Surgical biopsy not done ☐ Definite UIP ☐ Probable UIP ☐ Indeterminate for UIP		
2.21a	Was an MDT held as part of the diagnosis? ☐ Yes ☐ Awaiting MDT ☐ No ☐ Not known		
2.21b	Date of MDT		
2.21c	**IPF only:** What was the outcome of the multi-disciplinary team meeting (MDT)? ☐ Definite diagnosis of IPF ☐ Likely diagnosis of IPF ☐ Working diagnosis of IPF		
2.22a	Extra pulmonary organ needs assessment and input given as required from: ☐ Cardiology ☐ Ophthalmology ☐ Neurology ☐ Dermatology ☐ Rheumatology ☐ Other ☐ None		
2.22b	☐ If other, please specify		

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Clinical Features: Part B

2.23	**Sarcoidosis only:** Current clinical features: (*Tick all that apply)*			
	☐ None	☐ Lupus pernio	☐ Musculoskeletal pain	☐ Cardiac symptoms/palpitations
	☐ Cough	☐ Erythema nodosum/ other skin rash	☐ Eye symptoms	☐ Other
	☐ Fever		☐ Fatigue	☐ Not known
	☐ Breathlessness	☐ Subcutaneous nodules	☐ Neurological symptoms	
2.24	If the diagnosis is historic, what year was the patient initially diagnosed: YYYY			

Drug treatment questions – to be completed for all cases unless otherwise stated

3.1a	Has the patient received any of the following systemic immunomodulatory drugs in the last 3 months (including drugs started at this clinic visit)? ☐ Oral prednisolone – low dose (≤10mg) ☐ Oral prednisolone – high dose (>10mg) ☐ Azathioprine ☐ Methotrexate ☐ Mycophenolate mofetil ☐ IV methyl prednisolone ☐ IV cyclophosphamide ☐ Hydroxychloroquine ☐ Infliximab ☐ Rituximab ☐ Other ☐ None ☐ Not recorded
3.2a	Has the patient received any of the following other drugs in the last 3 months (including drugs started at this clinic visit)? *This excludes immunomodulatory and antifibrotic drugs* ☐ Anticoagulants ☐ Inhaled steroids ☐ Lorazepam or other anxiolytic ☐ Mucolytic ☐ Oral morphine ☐ Proton pump inhibitor ☐ Other drugs specifically for lung disease ☐ None ☐ Not recorded
3.2b	If other drugs for lung disease given, please specify:
3.3	Has the patient received any of the following antifibrotic drugs in the last 3 months (including drugs started at this clinic visit)? ☐ Nintedanib ☐ Pirfenidone ☐ None ☐ Not recorded
3.4	If this patient was not started today on an anti-fibrotic drug please tell us why not (*select all that apply*): ☐ Hospital is not a prescribing centre ☐ Does not meet NICE criteria ☐ Patient has sarcoidosis which is non-fibrotic ☐ Patient choice (declined drugs) ☐ Significant CKD e.g. Cr Cl <30mls/min ☐ Deranged liver function tests at baseline ☐ Patient wants time to consider options ☐ Patient has previously had adverse events to antifibrotic medication ☐ Other
3.5	If this patient has been receiving an anti-fibrotic drug please tell us (*select all that apply*): ☐ Continuous for the last 12 months without adverse effects ☐ Continuous for last 12 months with adverse effects ☐ Intermittent or at submaximal dose due to adverse effects ☐ Switched from pirfenidone to nintedanib ☐ Switched from nintedanib to pirfenidone ☐ Stopped permanently during the last 12 months due to adverse effects ☐ Stopped permanently during the last 12 months due to lack of efficacy ☐ Stopped permanently as for end of life care only ☐ Other ☐ Not known
3.6	If adverse effects, please describe ☐ Diarrhoea ☐ Nausea or vomiting ☐ Abdominal pain ☐ Rash ☐ Decreased appetite ☐ Headache ☐ Weight loss ☐ Hypertension ☐ Liver function tests abnormalities ☐ Other blood abnormality ☐ Other ☐ Not known

BTS UK ILD Registry –Data Collection Sheet September 2023

Clinical Features: Part B

Extended dataset – for progressive cases only unless otherwise stated

4.1	**Including non-progressive sarcoidosis:** Has the patient ever been confirmed to have pulmonary hypertension or right heart strain, secondary to their lung disease, from any hospital? Confirmed by: *Pulmonary hypertension is defined as a resting mean pulmonary artery pressure greater than 25 mmHg.* ☐ Echo or right hand catheter ☐ Raised NTproBNP or BNP ☐ Clinical ☐ None of the above ☐ Not known
4.2a	Oxygen saturation at rest at this clinic visit (%):
4.2b	Was the oxygen saturation taken on room air? ☐ Yes ☐ No ☐ Not known
4.2c	If the oxygen saturation was not measured at room air what was the fraction of inspired oxygen?
4.3a	Has the patient undergone a 6 minute walk test (6MWT) or equivalent in the last 12 months? ☐ Yes ☐ Not attempted (virtual clinic visit) ☐ Not attempted (other) ☐ Patient not able ☐ Not known
4.3b	Lowest oxygen saturation during walk (%):
4.4a	**All cases – NHSE ILD QD item:** Have you assessed the oxygen needs of this patient at this clinic visit? ☐ Yes – assessed and referred (or already on oxygen) ☐ Yes – assessed but patient DOES NOT REQUIRE oxygen therapy at this time ☐ Yes – assessed but PATIENT DECLINED (does not wish it, etc.) ☐ Yes – assessed but NOT SUITABLE (e.g. home environment unsafe for oxygen use) ☐ No – not assessed ☐ Unknown
4.4b	Is the patient on oxygen (including oxygen started at this clinic visit)? *Please select all that apply.* ☐ No ☐ Yes - ambulatory ☐ Yes – palliative O2 ☐ Yes – short burst ☐ Yes – LTOT ☐ Not known
4.5	**All cases – NHSE ILD QD item:** At this clinic visit have you assessed if this patient is suitable to be referred to a pulmonary rehabilitation programme and referred them if appropriate? ☐ Yes – assessed and referred ☐ Yes – assessed but PATIENT DECLINED (does not wish it, no transport, etc.) ☐ Yes – assessed but has completed PR in the last 12 months ☐ Yes – assessed but NOT SUITABLE (e.g. very poor mobility/very good fitness level already) ☐ No – not assessed ☐ Not known
4.6a	**All cases – NHSE ILD QD item:** Have you assessed and managed the palliative care needs of this patient at this clinic visit? ☐ Yes ☐ No ☐ Not known
4.6b	If yes, please select all that apply: ☐ Referral to specialist palliative care services ☐ Referral to non-specialist palliative care services (e.g. within the ILD team) ☐ Advance care planning conversation/documentation including ReSPECT or DNACPR ☐ Provided pharmacological interventions for cough and breathlessness ☐ Provided non-pharmacological interventions for cough and breathlessness ☐ Enquired about other physical symptoms including fatigue ☐ Enquired about and addressed psychosocial and spiritual needs ☐ Symptoms appeared controlled ☐ Patient did not volunteer any specific needs ☐ Other ☐ Not known
4.7	**All cases – NHSE ILD QD item:** At the time of diagnosis, was the patient offered an interaction with an ILD specialist nurse? ☐ Yes ☐ No ☐ Not known
4.8a	Has the patient been referred for lung transplantation? ☐ Yes ☐ Not applicable at this time ☐ Not applicable at any time ☐ Not known
4.8b	Referral date for lung transplantation: DD/ MM / YYYY
4.8c	Has the patient been placed on the active transplant list? ☐ Yes ☐ Pending ☐ No – declined ☐ Not known
4.9	Has the patient been offered involvement in a clinical trial? ☐ Yes – offered ☐ Yes – in contact with research team ☐ Yes - recruited ☐ No ☐ Not known

British Thoracic Society

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Follow Up: Part C

Patient ID	

Please do not complete questions which are greyed out – these are calculated automatically on the Registry site.

Core dataset – To be completed for all cases unless otherwise stated

5.1	Date of annual review: *Please add the date of the follow up review* DD/ MM / YYYY
5.2a	Has the patient's diagnosis changed since their previous clinic visit? ☐ Yes ☐ No ☐ Not known
5.2b	If yes, what is the current category of ILD? ☐ IPF ☐ Exposure-related: asbestosis ☐ Exposure-related: drug reaction ☐ Exposure-related: hypersensitivity pneumonitis ☐ Exposure-related: pneumoconiosis ☐ Exposure-related: silicosis ☐ Connective tissue: lupus (SLE) ☐ Connective tissue: MCTD ☐ Connective tissue: myositis (PM/DM) ☐ Connective tissue: rheumatoid arthritis ☐ Connective tissue: scleroderma ☐ Connective tissue: Sjorgens ☐ Connective tissue: UCTD ☐ Interstitial pneumonia with autoimmune features (IPAF) ☐ NSIP – nonspecific interstitial pneumonia ☐ Sarcoidosis ☐ Unclassifiable ☐ Other specified ILD
5.2c	If other interstitial lung disease ☐ IIPs: AIP – acute interstitial pneumonia ☐ IIPs: DIP – desquamative interstitial pneumonia ☐ IIPs: COP– cryptogenic organising pneumonia ☐ IIPs: LIP –Lymphocytic interstitial pneumonia ☐ IIPs: RB-ILD – respiratory bronchiolitis ILD ☐ Misc.: eosinophilic pneumonias ☐ Misc.: inherited disorders ☐ Misc.: LAM – lymphagioleiomyomatosis ☐ Misc.: LCH – Langerhans cell histiocytosis ☐ Misc.: lipoid pneumonias ☐ Misc.: mycobacterial or fungal infection ☐ Misc.: neurofibromatosis ☐ Misc.: PAP – pulmonary alveolar proteinosis ☐ Misc.: vasculitis/diffuse alveolar haemorrhage (DAH) ☐ Other
5.2d	If 'Other' please specify:
5.3a	At the time of this clinic visit does the patient have idiopathic pulmonary fibrosis (IPF) or progressive pulmonary fibrosis (PPF)? ☐ Yes ☐ No ☐ Not known
5.3b	Characteristics of IPF/PPF? *(Please select all that apply)* ☐ IPF ☐ PPF – Clinical progression ☐ PPF- Lung function progression ☐ PPF -Radiological progression
5.4	MRC dyspnoea grade (at annual review): ☐ Grade 1: not troubled by breathlessness except on strenuous exercise ☐ Grade 2: short of breath when hurrying or walking up a slight hill ☐ Grade 3: walks slower than contemporaries on level ground because of breathlessness, or has to stop for breath when walking at own pace ☐ Grade 4: stops for breath after walking about 100m or after a few minutes on level ground ☐ Grade 5: too breathless to leave the house, or breathless when dressing or undressing ☐ Not recorded
5.5a	Is your patient in paid employment? ☐ Yes ☐ No ☐ Unknown
5.5b	If no, please select which of the following apply to your patient: ☐ Unable to work due to their ILD ☐ In full/part time education ☐ Providing full time care (e.g. for child or dependent adult) ☐ Retired ☐ Other

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Follow Up: Part C

5.6	At this clinic visit have you referred the patient to any other services or informed them of any other form of non-clinical support? (This could be official or unofficial) ☐ Mental health support ☐ Helplines ☐ No - none ☐ Patient support groups ☐ Other ☐ Not known ☐ Charities		
5.7a	Height (in metres):	5.7c	BMI (calculated): *Do not complete*
5.7b	Weight (in kgs):		
5.8	Date of most recent spirometry tests: DD/ MM / YYYY		
5.9a	FEV1 - absolute value in litres:	5.9c	FEV1 % predicted (calculated): *Do not complete*
5.9b	FEV1 - predicted value in litres:		
5.10a	FVC - absolute value in litres:	5.10c	FVC % predicted (calculated): *Do not complete*
5.10b	FVC - predicted value in litres:	5.10d	Ratio of FEV1:FVC (calculated): *Do not complete*
5.11	Date of most recent gas transfer tests: DD/ MM / YYYY		
5.12	TLC litres at current investigation if available		
5.13a	TLCO/DLCO in mmol/min/kPa - absolute value: *Please give response in mmol/min/kPa. The response should fall within 0.00 - 15.To convert units given in ml/min/mmHg to mmol/min/kPa please multiply by 0.33*		
5.13b	TLCO/DLCO (mmol/min/kPa) – predicted value:		
5.13c	TLCO/DLCO (mmol/min/kPa) % predicted (calculated): *Do not complete*		
5.14a	KCO mmol/min/kPa/l - absolute value:	5.14c	KCO % predicted (calculated): *Do not complete*
5.14b	KCO mmol/min/kPa/l - predicted value:		
5.15a	Has there been a CT scan in the last 12 months? ☐ Yes ☐ No ☐ Not known		
5.15b	If yes, date of most recent HRCT scan: DD/ MM / YYYY		
5.15c	HRCT features *Please select all that apply*: ☐ Nodules ☐ Cysts ☐ Emphysema (>25% lung volume) ☐ Ground glass density ☐ Traction bronchiectasis ☐ Normal ☐ Consolidation ☐ Honeycombing ☐ Other ☐ Reticulation		
5.16	**Sarcoidosis only:** Clinical features at annual review?: (*Tick all that apply)* ☐ None ☐ Lupus pernio ☐ Musculoskeletal pain ☐ Cardiac symptoms/palpitations ☐ Cough ☐ Erythema nodosum/ other skin rash ☐ Eye symptoms ☐ Other ☐ Fever ☐ Fatigue ☐ Not known ☐ Breathlessness ☐ Subcutaneous nodules ☐ Neurological symptoms		

Drug treatment questions – to be completed for all cases unless otherwise stated

6.1	Has the patient received any of the following systemic immunomodulatory drugs in the last 3 months (including drugs started at this clinic visit)? ☐ Oral prednisolone – low dose (≤10mg) ☐ Oral prednisolone – high dose (>10mg) ☐ Azathioprine ☐ Methotrexate ☐ Mycophenolate mofetil ☐ IV methyl prednisolone ☐ IV cyclophosphamide	☐ Hydroxychloroquine ☐ Infliximab ☐ Rituximab ☐ Other ☐ None ☐ Not recorded

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Follow Up: Part C

6.2a	Has the patient received any of the following other drugs in the last 3 months (including drugs started at this clinic visit)? ☐ Anticoagulants ☐ Inhaled steroids ☐ Lorazepam or other anxiolytic ☐ Mucolytic ☐ Oral morphine ☐ Proton pump inhibitor ☐ Other drugs specifically for lung disease ☐ None ☐ Not recorded
6.2b	If other drugs for lung disease given, please specify:
6.3	Has the patient received any of the following antifibrotic drugs in the last 3 months (including drugs started at this clinic visit)? ☐ Nintedanib ☐ Pirfenidone ☐ None ☐ Not recorded
6.4	**Progressive cases only (including all IPF):** If this patient was not started today on an anti-fibrotic drug please tell us why not (*select all that apply*): ☐ Hospital is not a prescribing centre ☐ Does not meet NICE criteria ☐ Patient choice (declined drugs) ☐ Significant CKD e.g. Cr Cl <30mls/min ☐ Deranged liver function tests at baseline ☐ Patient wants time to consider options ☐ Patient has previously had adverse events to antifibrotic medication ☐ Other
6.5	If this patient has been receiving an anti-fibrotic drug please tell us (*select all that apply*): ☐ Continuous for the last 12 months without adverse effects ☐ Continuous for last 12 months with adverse effects ☐ Intermittent or at submaximal dose due to adverse effects ☐ Switched from pirfenidone to nintedanib ☐ Switched from nintedanib to pirfenidone ☐ Stopped permanently during the last 12 months due to adverse effects ☐ Stopped permanently during the last 12 months due to lack of efficacy ☐ Stopped permanently as for end of life care only ☐ Other ☐ Not known
6.6	If adverse effects**,** please describe ☐ Diarrhoea ☐ Nausea or vomiting ☐ Abdominal pain ☐ Rash ☐ Decreased appetite ☐ Headache ☐ Weight loss ☐ Hypertension ☐ Liver function tests abnormalities ☐ Other blood abnormality ☐ Other ☐ Not known

Questions for progressive fibrosing cases only (unless otherwise stated)

7.1	How many times has the patient been hospitalised for their chest disease in the last 12 months? *Please enter '0' into box if none. Hospitalised refers to patients admitted for a minimum of 24 hours*
7.2	Has this patient been diagnosed with any of the following co morbidities '*de novo*' in last 12 months? ☐ Stroke (infarct or haemorrhage) ☐ DVT ☐ None ☐ Myocardial infarction ☐ Pulmonary embolism ☐ Not known ☐ Lung cancer ☐ Other
7.3a	Oxygen saturation at rest at this clinic visit (%):
7.3b	Was the oxygen saturation taken on room air? ☐ Yes ☐ No ☐ Not known
7.3c	If the oxygen saturation was not measured at room air what was the fraction of inspired oxygen?

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Follow Up: Part C

7.4a	Has the patient undergone a 6 minute walk test (6MWT) or equivalent in the last 12 months? ☐ Yes ☐ Not attempted (virtual clinic visit) ☐ Not attempted (other) ☐ Patient not able ☐ Not known
7.4b	Lowest oxygen saturation during walk (%):
7.5	Have you assessed the oxygen needs of this patient at this clinic visit? ☐ Yes – assessed and referred (or already on oxygen) ☐ Yes – assessed but patient DOES NOT REQUIRE oxygen therapy at this time ☐ Yes – assessed but PATIENT DECLINED (does not wish it, etc.) ☐ Yes – assessed but NOT SUITABLE (e.g. home environment unsafe for oxygen use) ☐ No – not assessed ☐ Unknown
7.6	Is the patient on oxygen (including oxygen started at this clinic visit)? *Please select all that apply.* ☐ No ☐ Yes - ambulatory ☐ Yes – palliative O2 ☐ Yes – short burst ☐ Yes – LTOT ☐ Not known
7.7a	Have you assessed and managed the palliative care needs of this patient at this clinic visit? ☐ Yes ☐ No ☐ Not known
7.7b	If yes, please select all that apply: ☐ Referral to specialist palliative care services ☐ Referral to non-specialist palliative care services (e.g. within the ILD team) ☐ Advance care planning conversation/documentation including ReSPECT or DNACPR ☐ Provided pharmacological interventions for cough and breathlessness ☐ Provided non-pharmacological interventions for cough and breathlessness ☐ Enquired about other physical symptoms including fatigue ☐ Enquired about and addressed psychosocial and spiritual needs ☐ Symptoms appeared controlled ☐ Patient did not volunteer any specific needs ☐ Other ☐ Not known
7.8	Has the patient been given today or do they already have contact details for ILD specialist nurse, or have they seen ILD specialist nurse today? ☐ Yes ☐ No ☐ Not known
7.9a	Has the patient been referred for lung transplantation? ☐ Yes ☐ Not applicable at any time ☐ Not applicable at this time ☐ Not known
7.9b	Referral date for lung transplantation: DD/ MM / YYYY
7.9c	Has the patient been placed on the active list? ☐ Yes ☐ Pending ☐ No – declined ☐ Not known
7.9d	Transplanted date: DD/ MM / YYYY
7.10	Has the patient been offered involvement in a clinical trial? ☐ Yes – offered ☐ Yes – in contact with research team ☐ Yes - recruited ☐ No ☐ Not known