

BTS IPF Sarcoidosis Data Collection Sheet 2018 – Patient Demographics: Part A

Has the patient consent form been completed? <input type="checkbox"/> Yes <input type="checkbox"/> No	
1.1	Title:
1.2	Forename:
1.3	Surname:
1.4	NHS number:
1.5	Date of birth: DD / MM / YYYY
1.6	Gender:
1.7	Date first seen in this clinic: DD / MM / YYYY
1.8	Age when first seen in this clinic (calculated)
1.9	Home postcode:
1.10	How did the patient come to this clinic? <input type="checkbox"/> Not recorded <input type="checkbox"/> Secondary care (non-respiratory specialist) <input type="checkbox"/> Secondary care (respiratory specialist) <input type="checkbox"/> Other tertiary care specialist <input type="checkbox"/> General practitioner
1.11	GP postcode:
1.12	Consultant name (for this clinic):
1.13	Ethnic Group: <input type="checkbox"/> White British <input type="checkbox"/> Bangladeshi <input type="checkbox"/> White Irish <input type="checkbox"/> Any other Asian background <input type="checkbox"/> White - any other background <input type="checkbox"/> Caribbean <input type="checkbox"/> Mixed (White and Caribbean) <input type="checkbox"/> African <input type="checkbox"/> Mixed (White and Black African) <input type="checkbox"/> Any other Black background <input type="checkbox"/> Mixed (White and Asian) <input type="checkbox"/> Chinese <input type="checkbox"/> Any other mixed background <input type="checkbox"/> Any other ethnic group <input type="checkbox"/> Indian <input type="checkbox"/> Not stated <input type="checkbox"/> Pakistani
1.14	First degree relative(s) with sarcoidosis (tick all that apply): <input type="checkbox"/> No – none <input type="checkbox"/> Yes - Sister <input type="checkbox"/> Yes - Mother <input type="checkbox"/> Not known <input type="checkbox"/> Yes - Father <input type="checkbox"/> Not recorded <input type="checkbox"/> Yes - Brother
1.15	Current occupation (<i>Brief details of current job</i>):
1.16	When was the initial diagnosis of sarcoidosis made? <input type="checkbox"/> Less than 12 months ago <input type="checkbox"/> More than 12 months ago? <i>If the diagnosis of sarcoidosis was made more than 12 months ago, you will be asked to enter data about the initial diagnosis (part B) and data about current investigations at the time of this clinic visit (part C). If the diagnosis of sarcoidosis was made less than 12 months ago (from the date of this clinic visit) you will be asked to complete questions in part C only.</i>

BTS Sarcoidosis Registry Data Collection Sheet 2018 – Clinical Features: Part B

2.1	Date of initial diagnosis of sarcoidosis: DD / MM / YYYY <i>If the precise date is not known, enter the year of diagnosis in the format dd/mm/yyyy</i>
2.2	Diagnosis made at time of initial diagnosis: <input type="checkbox"/> CT <input type="checkbox"/> Clinically <input type="checkbox"/> Biopsy <input type="checkbox"/> Not recorded
2.3	Smoker at initial diagnosis? <input type="checkbox"/> No (never/negligible) <input type="checkbox"/> Ex-smoker (quit >3 months before diagnosis) <input type="checkbox"/> Current smoker <input type="checkbox"/> Unknown
2.4	Co-morbidities at the time of diagnosis (<i>Tick all that apply</i>): <input type="checkbox"/> No - none <input type="checkbox"/> Lung cancer <input type="checkbox"/> Ischaemic heart disease <input type="checkbox"/> Asthma <input type="checkbox"/> Diabetes <input type="checkbox"/> Arrythmia <input type="checkbox"/> TB <input type="checkbox"/> Obesity <input type="checkbox"/> Other <input type="checkbox"/> COPD <input type="checkbox"/> Hypertension
2.5	Sarcoidosis confirmed on histology? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not recorded
2.6	Endobronchial biopsy? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not recorded
2.7	Transbronchial biopsy? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not recorded
2.8	EBUS? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not known
2.9	Mediastinoscopy? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not recorded
2.10a	Lung biopsy? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not recorded
2.10b	Other biopsy site? <input type="checkbox"/> No <input type="checkbox"/> Yes – Extra-thoracic lymph node <input type="checkbox"/> Yes - Kidney <input type="checkbox"/> Yes – Liver <input type="checkbox"/> Yes – Brain <input type="checkbox"/> Yes – Other <input type="checkbox"/> Yes - Skin <input type="checkbox"/> Yes - Heart
2.11	Bronchoscopy (if done as part of investigations at initial diagnosis)? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
2.12	Bronchoalveolar lavage (if done as part of investigations at initial diagnosis)? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
2.12a	If bronchoalveolar lavage done, please give % lymphocytes:
2.13	Symptoms at initial diagnosis: (<i>Tick all that apply</i>) <input type="checkbox"/> None <input type="checkbox"/> Erythema nodosum <input type="checkbox"/> Neurological symptoms <input type="checkbox"/> Cough <input type="checkbox"/> Subcutaneous nodules <input type="checkbox"/> Joint pain <input type="checkbox"/> Fever <input type="checkbox"/> Other skin rash <input type="checkbox"/> Other <input type="checkbox"/> Breathlessness <input type="checkbox"/> Eye symptoms <input type="checkbox"/> Not known <input type="checkbox"/> Lupus pernio <input type="checkbox"/> Fatigue
2.14	MRC dyspnoea grade (at initial diagnosis): <input type="checkbox"/> Grade 1: not troubled by breathlessness except on strenuous exercise <input type="checkbox"/> Grade 2: short of breath when hurrying or walking up a slight hill <input type="checkbox"/> Grade 3: walks slower than peers on level ground, or has to stop for breath when walking at own pace <input type="checkbox"/> Grade 4: stops for breath after walking about 100m or after a few minutes on level ground <input type="checkbox"/> Grade 5: too breathless to leave the house, or breathless when dressing or undressing <input type="checkbox"/> Not recorded <input type="checkbox"/> Patient not breathless
2.15	Was the diagnosis of sarcoidosis incidental (i.e. made during the course of investigations for other conditions)? <input type="checkbox"/> No <input type="checkbox"/> Yes - abnormal blood tests <input type="checkbox"/> Yes - other <input type="checkbox"/> Yes - abnormal radiology <input type="checkbox"/> Yes - skin biopsy <input type="checkbox"/> Not recorded
2.16	Chest radiograph at initial diagnosis: <input type="checkbox"/> Stage 0 <input type="checkbox"/> Stage II BHL + infiltrates <input type="checkbox"/> Stage IV fibrosis <input type="checkbox"/> Stage I BHL <input type="checkbox"/> Stage III infiltrates alone <input type="checkbox"/> Not recorded
2.17	Blood tests at initial diagnosis: (<i>Tick all that apply</i>) <input type="checkbox"/> Lymphopenia <input type="checkbox"/> Abnormal liver function <input type="checkbox"/> Not recorded <input type="checkbox"/> Raised ESR <input type="checkbox"/> Raised Ca²⁺⁺ <input type="checkbox"/> Raised CRP <input type="checkbox"/> Other abnormality

BTS Sarcoidosis Registry Data Collection Sheet 2018 – Clinical Features: Part B

2.18a	ACE level (decimal):	
2.18b	Immunoglobulin G (IgG) g/l (decimal):	
2.19a	FEV1 - absolute value in litres at diagnosis:	c) FEV1 % Predicted (auto calculated on Registry site):
2.19b	FEV1 - predicted value in litres:	
2.20a	FVC - absolute value in litres at diagnosis:	c) FVC % Predicted (auto calculated on Registry site):
2.20b	FVC - predicted value in litres (decimal):	
2.21	TLC litres at initial diagnosis if available:	
2.22a	TLCO mmol/min/kPa at diagnosis - absolute:	c) TLCO % Predicted (auto calculated on Registry site):
2.22b	TLCO (mmol/min/kPa) - predicted value:	
2.23a	KCO mmol/min/kPa/l at diagnosis - absolute:	c) KCO % predicted (auto calculated on Registry site):
2.23b	KCO (mmol/min/kPa/l) - predicted value:	
2.24	Oxygen saturation at initial diagnosis if available:	
2.25	Treatment record at initial diagnosis: <i>(Tick all that apply)</i> <input type="checkbox"/> None <input type="checkbox"/> Azathioprine <input type="checkbox"/> Transplantation <input type="checkbox"/> Oral pred <input type="checkbox"/> Hydroxychloroquine <input type="checkbox"/> LTOT or ambulatory oxygen <input type="checkbox"/> IV methyl pred <input type="checkbox"/> Topical therapy <input type="checkbox"/> Other <input type="checkbox"/> Inhaled steroids <input type="checkbox"/> Mycophenolate mofetil <input type="checkbox"/> Not recorded <input type="checkbox"/> Methotrexate <input type="checkbox"/> Infliximab	
2.26	HRCT (at initial diagnosis) <i>Please select all that apply:</i> <input type="checkbox"/> Nodules <input type="checkbox"/> Cysts <input type="checkbox"/> Sarcoid-related pleural disease <input type="checkbox"/> Ground glass density <input type="checkbox"/> Fibrosis <input type="checkbox"/> Normal <input type="checkbox"/> Consolidation <input type="checkbox"/> Intrathoracic lymphadenopathy	

BTS Sarcoidosis Registry Data Collection Sheet 2018 – Clinical Features: Part C

3.1	Date of investigations recorded in this section (use latest date): DD / MM / YYYY		
3.2	Diagnosis made: <input type="checkbox"/> CT <input type="checkbox"/> Clinically <input type="checkbox"/> Biopsy <input type="checkbox"/> Not recorded		
3.3	Smoker at this visit? <input type="checkbox"/> No (never/negligible) <input type="checkbox"/> Ex-smoker (quit >3 months before diagnosis) <input type="checkbox"/> Current smoker <input type="checkbox"/> Unknown		
3.4	Co-morbidities (<i>Tick all that apply</i>): <input type="checkbox"/> No - none <input type="checkbox"/> Lung cancer <input type="checkbox"/> Ischaemic heart disease <input type="checkbox"/> Asthma <input type="checkbox"/> Diabetes <input type="checkbox"/> Arrhythmia <input type="checkbox"/> TB <input type="checkbox"/> Obesity <input type="checkbox"/> Other <input type="checkbox"/> COPD <input type="checkbox"/> Hypertension		
3.5	Sarcoidosis confirmed on histology? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not recorded		
3.6	Endobronchial biopsy? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not recorded		
3.7	Transbronchial biopsy? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not recorded		
3.8	EBUS? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not known		
3.9	Mediastinoscopy? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not recorded		
3.10a	Lung biopsy? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not recorded		
3.10b	Other biopsy site? <input type="checkbox"/> No <input type="checkbox"/> Yes – Extra-thoracic lymph node <input type="checkbox"/> Yes - Kidney <input type="checkbox"/> Yes – Liver <input type="checkbox"/> Yes – Brain <input type="checkbox"/> Yes – Other <input type="checkbox"/> Yes - Skin <input type="checkbox"/> Yes - Heart		
3.11	Bronchoscopy (if done as part of current investigations)? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		
3.12	Bronchoalveolar lavage (if done as part of current investigations)? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		
3.12a	If bronchoalveolar lavage done, please give % lymphocytes:		
3.13	Symptoms at current investigation: (<i>Tick all that apply</i>) <input type="checkbox"/> None <input type="checkbox"/> Erythema nodosum <input type="checkbox"/> Neurological symptoms <input type="checkbox"/> Cough <input type="checkbox"/> Subcutaneous nodules <input type="checkbox"/> Joint pain <input type="checkbox"/> Fever <input type="checkbox"/> Other skin rash <input type="checkbox"/> Other <input type="checkbox"/> Breathlessness <input type="checkbox"/> Eye symptoms <input type="checkbox"/> Not known <input type="checkbox"/> Lupus pernio <input type="checkbox"/> Fatigue		
3.14	MRC dyspnoea grade (at current investigation): <input type="checkbox"/> Grade 1: not troubled by breathlessness except on strenuous exercise <input type="checkbox"/> Grade 2: short of breath when hurrying or walking up a slight hill <input type="checkbox"/> Grade 3: walks slower than peers on level ground, or has to stop for breath when walking at own pace <input type="checkbox"/> Grade 4: stops for breath after walking about 100m or after a few minutes on level ground <input type="checkbox"/> Grade 5: too breathless to leave the house, or breathless when dressing or undressing <input type="checkbox"/> Not recorded <input type="checkbox"/> Patient not breathless		
3.15	Was the diagnosis of sarcoidosis incidental (i.e. made during the course of investigations for other conditions)? <input type="checkbox"/> No <input type="checkbox"/> Yes - abnormal blood tests <input type="checkbox"/> Yes - other <input type="checkbox"/> Yes - abnormal radiology <input type="checkbox"/> Yes - skin biopsy <input type="checkbox"/> Not recorded		
3.16	Chest radiograph at current investigation: <input type="checkbox"/> Stage 0 <input type="checkbox"/> Stage II BHL + infiltrates <input type="checkbox"/> Stage IV fibrosis <input type="checkbox"/> Stage I BHL <input type="checkbox"/> Stage III infiltrates alone <input type="checkbox"/> Not recorded		

BTS Sarcoidosis Registry Data Collection Sheet 2018 – Clinical Features: Part C

3.17	Blood tests (most recent): <i>(Tick all that apply)</i>		
	<input type="checkbox"/> Lymphopenia	<input type="checkbox"/> Abnormal liver function	<input type="checkbox"/> Not recorded
	<input type="checkbox"/> Raised ESR	<input type="checkbox"/> Raised Ca ²⁺⁺	
	<input type="checkbox"/> Raised CRP	<input type="checkbox"/> Other abnormality	
3.18a	ACE level Decimal IU/l:		
3.18b	Immunoglobulin G (IgG) g/l:		
3.19a	FEV1 - absolute value in litres (latest):	c) FEV1 % Predicted (auto calculated on Registry site):	
3.19b	FEV1 - predicted value in litres:		
3.20a	FVC - absolute value in litres (latest)s:	c) FVC % Predicted (auto calculated on Registry site):	
3.20b	FVC - predicted value in litres (decimal):		
3.21	TLC litres at current investigation if available:		
3.22a	TLCO mmol/min/kPa (latest) - absolute:	c) TLCO % Predicted (auto calculated on Registry site):	
3.22b	TLCO (mmol/min/kPa) - predicted value:		
3.23a	KCO mmol/min/kPa/l (latest) - absolute:	c) KCO % predicted (auto calculated on Registry site):	
3.23b	KCO (mmol/min/kPa/l) - predicted value:		
3.24	Oxygen saturation at current investigation if available:		
3.25	Treatment record at current investigation: <i>(Tick all that apply)</i>		
	<input type="checkbox"/> None	<input type="checkbox"/> Azathioprine	<input type="checkbox"/> Transplantation
	<input type="checkbox"/> Oral pred	<input type="checkbox"/> Hydroxychloroquine	<input type="checkbox"/> LTOT or ambulatory oxygen
	<input type="checkbox"/> IV methyl pred	<input type="checkbox"/> Topical therapy	<input type="checkbox"/> Other
	<input type="checkbox"/> Inhaled steroids	<input type="checkbox"/> Mycophenolate mofetil	<input type="checkbox"/> Not recorded
	<input type="checkbox"/> Methotrexate	<input type="checkbox"/> Infliximab	
3.26	HRCT (latest) <i>Please select all that apply:</i>		
	<input type="checkbox"/> Nodules	<input type="checkbox"/> Cysts	<input type="checkbox"/> Sarcoid-related pleural disease
	<input type="checkbox"/> Ground glass density	<input type="checkbox"/> Fibrosis	<input type="checkbox"/> Normal
	<input type="checkbox"/> Consolidation	<input type="checkbox"/> Intrathoracic lymphadenopathy	
3.27	Is the patient recruited to a clinical trial? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not known		
3.27a	Name of trial:		
3.27b	Date enrolled: DD / MM / YYYY		
3.27c	Date trial ended: DD / MM / YYYY		
3.28	Would you consider this patient for recruitment to a clinical trial in sarcoidosis pending detailed inclusion/exclusion criteria? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Do not know		
3.29	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)? <input type="checkbox"/> Yes <input type="checkbox"/> No		

BTS Sarcoidosis Registry Data Collection Sheet 2018 – Follow Up

1	Date of annual review: DD / MM / YYYY	
2	Symptoms at annual review?: <i>(Tick all that apply)</i>	
	<input type="checkbox"/> None <input type="checkbox"/> Cough <input type="checkbox"/> Fever <input type="checkbox"/> Breathlessness <input type="checkbox"/> Lupus pernio	<input type="checkbox"/> Erythema nodosum <input type="checkbox"/> Subcutaneous nodules <input type="checkbox"/> Other skin rash <input type="checkbox"/> Eye symptoms <input type="checkbox"/> Fatigue
	<input type="checkbox"/> Neurological symptoms <input type="checkbox"/> Joint pain <input type="checkbox"/> Other <input type="checkbox"/> Not known	
3	MRC dyspnoea grade (at annual review):	
	<input type="checkbox"/> Grade 1: not troubled by breathlessness except on strenuous exercise <input type="checkbox"/> Grade 2: short of breath when hurrying or walking up a slight hill <input type="checkbox"/> Grade 3: walks slower than peers on level ground, or has to stop for breath when walking at own pace <input type="checkbox"/> Grade 4: stops for breath after walking about 100m or after a few minutes on level ground <input type="checkbox"/> Grade 5: too breathless to leave the house, or breathless when dressing or undressing <input type="checkbox"/> Not recorded <input type="checkbox"/> Patient not breathless	
4	Chest radiograph (most recent):	
	<input type="checkbox"/> Stage 0 <input type="checkbox"/> Stage I BHL	<input type="checkbox"/> Stage II BHL + infiltrates <input type="checkbox"/> Stage III infiltrates alone <input type="checkbox"/> Stage IV fibrosis <input type="checkbox"/> Not recorded
5	Blood tests (most recent): <i>(Tick all that apply)</i>	
	<input type="checkbox"/> Lymphopenia <input type="checkbox"/> Raised ESR <input type="checkbox"/> Raised CRP	<input type="checkbox"/> Abnormal liver function <input type="checkbox"/> Raised Ca ²⁺⁺ <input type="checkbox"/> Other abnormality <input type="checkbox"/> Not recorded
6a	ACE level <i>(Decimal)</i> :	
6b	Immunoglobulin G (IgG) g/l <i>(decimal)</i> :	
7	Height (most recent) <i>(metres)</i> :	
8	Weight (most recent) <i>(kilograms)</i> :	
9	Body Mass Index (BMI) (auto calculated on Registry site):	
10a	FEV1 - absolute value in litres (latest):	c) FEV1 % Predicted (auto calculated on Registry site):
10b	FEV1 - predicted value in litres:	
11a	FVC - absolute value in litres (latest):	c) FVC % Predicted (auto calculated on Registry site):
11b	FVC - predicted value in litres (decimal):	
12	TLC litres at current investigation if available <i>(Decimal)</i>	
13a	TLCO mmol/min/kPa (latest) - absolute:	c) TLCO % Predicted (auto calculated on Registry site):
13b	TLCO (mmol/min/kPa) - predicted value:	
14a	KCO mmol/min/kPa/l (latest) - absolute:	c) KCO % predicted (auto calculated on Registry site):
14b	KCO (mmol/min/kPa/l) - predicted value:	
15	Oxygen saturation at current investigation if available <i>(Decimal)</i>	
16	Treatment record at annual review: <i>(Tick all that apply)</i>	
	<input type="checkbox"/> None <input type="checkbox"/> Oral pred <input type="checkbox"/> IV methyl pred <input type="checkbox"/> Inhaled steroids <input type="checkbox"/> Methotrexate	<input type="checkbox"/> Azathioprine <input type="checkbox"/> Hydroxychloroquine <input type="checkbox"/> Topical therapy <input type="checkbox"/> Mycophenolate mofetil <input type="checkbox"/> Infliximab <input type="checkbox"/> Transplantation <input type="checkbox"/> LTOT or ambulatory oxygen <input type="checkbox"/> Other <input type="checkbox"/> Not recorded
17	HRCT (latest) <i>Please select all that apply:</i>	
	<input type="checkbox"/> Nodules <input type="checkbox"/> Ground glass density <input type="checkbox"/> Consolidation	<input type="checkbox"/> Cysts <input type="checkbox"/> Fibrosis <input type="checkbox"/> Intrathoracic lymphadenopathy <input type="checkbox"/> Sarcoid-related pleural disease <input type="checkbox"/> Normal

BTS Sarcoidosis Registry Data Collection Sheet 2018 – Follow Up

18	Is the patient enrolled in a clinical trial? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not known
18a	Name of trial:
18b	Date enrolled: DD / MM / YYYY
18c	Date trial ended: DD / MM / YYYY
19.	Would you consider this patient for recruitment to a clinical trial in sarcoidosis pending detailed inclusion/ exclusion criteria? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Do not know
19a	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)? <input type="checkbox"/> Yes <input type="checkbox"/> No
20.	If the patient died during the period since the last review please give date of death: DD / MM / YYYY
21.	If the patient died in the period since the last review please give cause of death: