NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Idiopathic pulmonary fibrosis

Date of Quality Standards Advisory Committee post-consultation meeting:
20 October 2014

2 Introduction

The draft quality standard for idiopathic pulmonary fibrosis was made available on the NICE website for a 4-week public consultation period between 26 August and 23 September 2014. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 16 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the Quality Standards Advisory Committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the Committee as part of the final meeting where the Committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the Committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically

not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the Committee should read this summary alongside the full set of consultation comments, which are provided in appendix 1.

3 Questions for consultation

Stakeholders were invited to respond to the following general questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?

2. If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures?

3. For each quality statement what do you think could be done to support improvement and help overcome barriers?

4 General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

- There was general support for the quality standard though one stakeholder commented that the statements are ‘soft’ and simple in scope compared to other quality standards, reflecting the lack of therapeutic opportunity in the field.
- There is confusion between ILD and IPF often used interchangeably.
- The statement that two-thirds of people with IPF smoke on page 1 is incorrect as many will be ex-smokers.

Consultation comments on the key areas for quality improvement (question 1)

- The quality standard was generally welcomed and will contribute to improving positive outcomes for people with idiopathic pulmonary fibrosis.
- There are no statements relating to medication particularly pirfenidone, and TA282 should be added to the development sources.
- Consideration of patients for lung transplantation is not included in the standard.

Comments on data collection (Consultation question 2)

Few general comments on data collection were received however the following were noted:

- Comments received that it would be possible to collect the data.
- Support for the use of a national data collection register for people with IPF (The British Thoracic Society's IPF Registry) and NHS England could promote this.

Comments on supporting improvement and overcoming barriers (Consultation question 3)

- For each quality statement improved awareness of the condition in primary and secondary care would support improvement and overcome barriers.

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

People with suspected idiopathic pulmonary fibrosis are diagnosed only with the consensus of a multidisciplinary team with expertise in interstitial lung disease.

Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

- Diagnosis by a specialist MDT was supported.
- Agreement that the presence of a CNS in the MDT should be stipulated.
- Statement unclear regarding whether patients will be expected to attend the MDT or whether there is MDT discussion and the outcome fed back locally.
- There may be occasions when MDT isn't possible. (Diagnosis made on severely ill patient.)
- Prompt referral to specialist MDT and referral for appropriate treatment is needed.
- Slight change of the rationale wording to 'delay of referral to a specialist multidisciplinary team and/or misdiagnosis can be serious….'
- Stipulate the experience/number of patients seen for the physician, radiologist and pathologist.
- A specialist pharmacist should form part of the MDT.
- Changes to the service providers and patients sections for equity of service quality (See comment 15).
- Statement should cover diagnosis and management/treatment of IPF.

Additional points to discuss

- Remove 'only'. Should it be with or by the consensus of or just "diagnosed by an MDT"?

Comments on data collection (consultation question 2)

Stakeholders made the following comments in relation to consultation question 2:

- Discrepancy between the numerator and denominator which refer only to patients subsequently diagnosed with IPF and the standard which refers to the bigger population of patients with initially “suspected IPF”.
- Quality measures will be difficult to obtain as there is no mechanism for identifying patients diagnosed with IPF unless they are reviewed in the MDT and registered.
- There is no standardised tool for collecting quality of life data in an IPF population.

Comments on supporting improvement and overcoming barriers (Consultation question 3)

Stakeholders made the following comments in relation to consultation question 3:

- Comments on who should ensure access to, arrange and fund transport.
- Including pharmacists as a named member of the MDT in the quality standard could help ensure this is costed as part of service development.
- A national standardised rapid referral pathway needs to be established to enable robust evaluation.
- Virtual MDTs could potentially improve speed of diagnosis and referral.
- More specialist training in diagnosis in primary and secondary care would improve speed of diagnosis and referral.

5.2 Draft statement 2

People with idiopathic pulmonary fibrosis have an interstitial lung disease specialist nurse available to them and if they wish their families and carers.

Consultation comments

Stakeholders made the following comments in relation to draft statement 2:

- Agreement that access to a specialist nurse is appropriate.
- Specialist nurses meeting the definition in the QS will be very rare therefore the definition of competence should be withdrawn.
- There is not currently a six monthly course of specialised training.
- The training/workload of the ILD specialist nurse should be considered.
- A nurse working in ILD speciality must be highly trained and working towards a masters level of education or equivalent.
- The role of the nurse should be more specific. Suggested addition to the statement: “to coordinate care and provide information and support.”
- Clarity is needed on what is meant by “access to an ILD nurse”. Does this include out of hours/access to helplines such as the BLF?
- Suggest adding ‘treatments, side effect management’ to the last sentence of the rationale to support patients to make the most effective use of medication.
- QS should reflect that in a number of areas of the UK networks exist to provide ILD support to general specialist respiratory nurses.

Additional points to discuss

- What is meant by ‘available’? Concern raised there may not be many ILD specialist nurses, though they do form part of the MDT.
- ‘And if they wish their families and carers’ should be removed and referred to in the rationale/descriptor.

Comments on data collection (consultation question 2)

No comments were received in relation to this consultation question.

Comments on supporting improvement and overcoming barriers (Consultation question 3)

Stakeholders made the following comments in relation to consultation question 3:

- The community respiratory nurse could provide a level of support. Additional training or support is needed to assist in the clinical decision making.
- Nurses must be supported in accessing specialist training in ILD, specifically in IPF.
- Senior nurses who can be trained in clinical decision making and be able to provide nurse led clinics need to be developed.

5.3 Draft statement 3

People with idiopathic pulmonary fibrosis are assessed for oxygen therapy if they are breathless at rest or on exertion, or have been admitted to hospital because of idiopathic pulmonary fibrosis.

Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

- Parts of the QS are incongruous with new draft home oxygen guidelines (BTS) which state the evidence for exertional oxygen use is poor and it should not be routinely offered.
- IPF experienced staff should assess patients with breathlessness on exertion for ambulatory oxygen with an exercise test (eg 6 minute walk test).
- Consider mentioning the assessment of both ambulatory and resting oxygen requirement.
- Personalisation of oxygen services specifically for IPF patients is crucial and users must be thoroughly trained.
- Ambulatory oxygen should be an early consideration and continuous monitoring and titration.
- IPF patients require reassessment of their oxygen requirements particularly post exacerbation.
- Oxygen needs in end of life need attention so that lack of access to appropriate oxygen supplies does not hasten death.
- Patients find the transition to oxygen therapy distressing therefore access to psychological support should be offered.

Additional points to discuss

- It should be clear this is for home oxygen (add this into the first line). Should ‘at rest or on exertion’ be removed?

Comments on data collection (consultation question 2)

No comments were received in relation to this consultation question.

Comments on supporting improvement and overcoming barriers (Consultation question 3)

Stakeholders made the following comment in relation to consultation question 3:

- Community respiratory nurses need to receive training / be offered guidance on how to meet the oxygen needs of patients with IPF.

5.4 Draft statement 4

People with idiopathic pulmonary fibrosis who are suitable are offered pulmonary rehabilitation that includes exercise and educational components tailored to their needs.

Consultation comments

Stakeholders made the following comments in relation to draft statement 4:

- Agreement that pulmonary rehabilitation tailored to IPF should be offered.
- Pulmonary rehabilitation should be available for all people with IPF and everyone with IPF should be offered assessment.
- There is no evidence of what should be included to provide the most benefit to IPF patients and research in this area is needed.
- There is no definition of suitability.
- Patients should have access to oxygen at the centre offering pulmonary rehabilitation to conserve their own supplies for travel.

Additional points to discuss

Should this be a service statement rather than a person-centred statement?

Comments on data collection (consultation question 2)

Stakeholders made the following comment in relation to consultation question 2:

- The denominator is very vague and is not possible to determine as there is no clear evidence based guidance on who to select for referral for rehabilitation.

Comments on supporting improvement and overcoming barriers (Consultation question 3)

No comments were received in relation to this consultation question.

5.5 Draft statement 5

People with idiopathic pulmonary fibrosis, and their families and carers, have access to the full range of services offered by palliative care teams.

Consultation comments

Stakeholders made the following comments in relation to draft statement 5:

- Statement should require units to demonstrate they have systems in place for the provision of symptom based management with defined links and pathways in place with palliative care, without mandating all patients are seen by palliative care specialists.
- Amend the patient audience descriptor to highlight signposting to palliative care at the earliest opportunity.
- Consider reflux management as part of symptomatic control with provision for gastric manometry in selected patients and availability of corrective procedures.
- Mandate the use of a palliative care screening tool in ILD clinics to better determine the needs of patients.
- Include symptom control, social support and end of life care to ensure palliative care services are not only used for end of life issues.
- Physiotherapists are also often good at breathing control and cough.
- Palliation should be initiated in the moderate stages of the disease with a community healthcare professional acting as a continuing link to respiratory services locally and palliative care provision.

Additional points to discuss

- Change statement to ‘People with idiopathic pulmonary fibrosis, and their families and carers, have access to a palliative care service’.

Comments on data collection (consultation question 2)

No comments were received in relation to this consultation question.

Comments on supporting improvement and overcoming barriers (Consultation question 3)

No comments were received in relation to this consultation question.

6 Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements.

- NICE approved disease modifying therapies for IPF and careful monitoring.
- The option of taking part in a clinical trial should be available for patients with IPF.
- Access to IPF or pulmonary fibrosis specific patient support groups.
- The role, benefits and availability of psychology support to patients with interstitial lung disease (particularly IPF).
- Pre-operative targeting, in relation to undertaking surgical lung biopsy of diseased, but not end-stage, lung.
- High quality lung function testing with diffusion and relevant investigations HRCT, bloods etc.
- Measuring of FVC (forced vital capacity) for prognosis.
- Proforma development.
- Keeping of a data base or joining BTS data base.
- Use of patient heath status tools.

Appendix 1: Quality standard consultation comments table

ID	*Stakeholder*	*Statement No*	**Comment on**	**Comments** Please insert each new comment in a new row.
1	Action for Pulmonary Fibrosis		General	We note that consideration of patients for lung transplantation is not included in the standard.
2	UK Clinical Pharmacy Association (UKCPA) – Respiratory Group		General	It is surprising that there are no quality statements addressing access to medication, such as pirfenidone.
3	UK Clinical Pharmacy Association (UKCPA) – Respiratory Group		Introduction	The statement that two-thirds of people with idiopathic pulmonary fibrosis smoke on page 1 of draft is incorrect. It probably true that there is a history of smoking in 2/3 or so of patients with IPF but many are ex-smokers. I think that would be true for most patients in this age range. Without going into the evidence in too much detail; ASCEND – 61% (placebo) vs. 66% (pirfenidone) former smoker INPULSIS – Former smoker ~70%, current smoker ~5%, never smoker ~30% CAPACITY – Former smoker ~65%, current smoker ~5%, never smoker ~35%
4	British Thoracic Society		General	The document is very straightforward, general and based around the delivery of 'best supportive care'. We note that the document does not refer to access to anti-fibrotic therapies e.g. pirfenidone - ie all patients with FVC 50-80% should be considered for the suitability of pirfenidone (whether locally or in a specialist centre) etc. We are concerned that in the omission of this important area there is a suggestion that IPF can be managed in a non-expert setting, and reinforces the nihilistic view of many generalist centres toward IPF or the additional value of specialist care. It is difficult to establish the denominator in each case as there is limited data to on the number of people who actually have IPF and most current databases rely on patients as specialist centres and so miss community based patients with the disease.

ID	*Stakeholder*	*Statement No*	Comment on	Comments Please insert each new comment in a new row.
5	NHS England		General	The quality standards cover the main areas of care that could be improved in IPF. They are very simple in scope compared to more specific QS statements in other respiratory disease areas. This reflects the lack of therapeutic opportunity in the field and the minimal evidence for benefit for most interventions. However, it is good to make a start somewhere.
6	Primary Care Respiratory Society UK		P5 list of quality statements	The only issue we have picked up on this is that there is nothing about pharmacotherapy in the Quality standard. This is a rapidly changing field, and there are many new products in the pipeline.
7	Digital Assessment Service, NHS Choices		General	We welcome the quality standard and have no comments on its content as part of the consultation.
8	Boehringer Ingelheim Ltd		General	For each quality statement we believe improved awareness of the condition in primary and secondary care would support improvement and overcome barriers.
9	InterMune		General	InterMune welcomes the development of this quality standard and the opportunity to comment on it. We believe it will contribute to improving positive outcomes for people with idiopathic pulmonary fibrosis.
10	InterMune		Page 25: Development Sources	Under this section we welcome the acknowledgement of the relationships with the various NICE guidance development programmes to ensure that recommendations in clinical guidelines, public health and social care guidance can be used to form the basis of quality statements being clear, specific, sufficiently detailed and measurable. However, we feel it is important that links to the NICE Technology Appraisal Programme are also made clear and in this instance specifically NICE TA282: Pirfenidone for treating idiopathic pulmonary fibrosis. Pirfenidone represents a first-in-class treatment, which has been shown to be effective in IPF by reducing decline in lung function and slowing disease progression (Noble, 2011). Pirfenidone is the only drug to have been granted a licence by the European Medicines Agency (EMA) for the treatment of adults with mild to moderate IPF and to have received a positive NICE technology appraisal. InterMune believes that NICE TA282 should be referenced under “Evidence Sources” as organisations will need to demonstrate that they have implemented NICE guidance.
11	Royal College of Nursing		General	Overall. Whilst NICE is to be welcomed for producing ILD / IPF Guidelines we think there are some points that need considering. We felt there was a confusion between ILD and IPF often used

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				interchangeably but IPF is one form of ILD The RCN feels that these statements seemed rather 'soft'.
12	Association of Respiratory Nurse Specialists		General	**Q1:** Does this draft quality standard accurately reflect the key areas for quality improvement? Mostly see comments **Q2:** If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures? YES **Q3:** For each quality statement what do you think could be done to support improvement and help overcome barriers?
13	Royal College of Pathologists	1	Page 9	In relation to the MD team, the pathologist should have requisite expertise in ILD if participating. This is difficult to govern/assess but, as a minimum, the pathologist should participate fully at the required level within the national pulmonary EQA (External Quality Assessment) Scheme. Even within this group, the volume of cases is low (there will likely only be one surgical lung biopsy for every 10-20 patients (if that) undergoing CT), making it difficult for pathologists to maintain the subspecialist level of expertise, so (as in the briefing document for imaging), recommendation for structured or informal access to ILD-specific second opinion should be considered as routine for the biopsy. Evidence from gatekeeping international trials has shown over 20% of cases submitted as UIP/IPF are rejected by "experts" (abstract only).
14	Action for Pulmonary Fibrosis	1		The Quality Standard should mandate the experience and number of patients seen (as it does for ILD specialist nurse) for physician, radiologist and pathologist as otherwise anyone can call themselves a specialist, given that there is a delay in naming ILD specialist centres.
15	British Lung Foundation	1		The British Lung Foundation (BLF) welcomes the draft quality standard for which we feel there is an urgent need. We are pleased that NICE has highlighted the crucial importance of an accurate diagnosis; the central role of an ILD nurse; the benefits of personalised oxygen and pulmonary rehabilitation; and the importance of palliative care teams to improving quality of life. Respondents to our online survey and members of the IPF focus groups that we have consulted showed unanimous support for the draft quality statements. Over 90% agreed with each of the five statements. The BLF is therefore happy to endorse the IPF Quality Standard, and we have made some suggestions below which we believe may strengthen some of the language in the draft

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				document. <u>Description of BLF methodology:</u> Over 300 people answered our online survey between 28 August and 5 September 2014. More than half of the respondents were IPF patients - the remainder comprised family members and carers of patients, or health care staff. The BLF also held focus groups on 2 September and 10 September 2014 with IPF patients, their family members and carers, and a specialist nurse. Due to the large number of responses – including from an estimated 1% of the country's IPF patient population - we are submitting an additional document listing some of our respondents' experiences of IPF which we hope that you will find of interest. This will be cross-published at: **www.blf.org.uk/IPF** We welcome this statement in acknowledging the complexities around IPF diagnosis and recognition of the need to increase consistency in diagnostic practice. Awareness of the disease is very low, even amongst health care professionals, and it has a high rate of misdiagnosis resulting in patients given incorrect treatments. Respondents told us of missed opportunities to correctly diagnose their condition, and some patients underwent multiple, staggered tests before an IPF diagnosis was finally confirmed. Symptoms of IPF are frequently confused with other respiratory conditions - recent BLF research found that often a final IPF diagnosis is delayed by an initial misdiagnosis of asthma or COPD, and sometimes symptoms are dismissed altogether. One health care professional commented: *"Diagnosis is difficult, the condition is rare and presentation individualistic. Rapid recognition of a potential diagnosis and onward referral to a specialist MDT is crucial for appropriate and timely intervention and treatment."*

ID	***Stakeholder***	***Statement No***	**Comment on**	**Comments** Please insert each new comment in a new row.
				A prompt referral to a specialist MDT can have a significant impact on patient health outcomes, as dedicated ILD specialists would be able to outline and offer the full range of treatment options, including assessment for lung transplantation, at the earliest possible opportunity. However, many patients and health care professionals are unsure where local ILD specialists are to be found - no timescales or details of the process of allocating ILD specialist centres across the country have been published, and NHS England has yet to indicate how it intends to ensure that patients can be guaranteed equity of service quality. Recommended new wording: i) What the quality statement means for service providers and commissioners: *"…suspected idiopathic pulmonary fibrosis**, initiate appropriate treatment (including assessment for lung transplantation), and provide clear referral pathways to and from primary and secondary care."*** ii) What the quality statement means for patients: *"People who have symptoms of idiopathic pulmonary fibrosis are offered diagnosis **at the earliest opportunity** by a specialist team of healthcare professionals who are skilled and experienced in diagnosing and treating **interstitial** lung diseases."*
16	The Royal College of Radiologists (RCR & the British Society of Thoracic Imaging (BSTI)	1		The RCR and BSTI agree fully with this statement.
17	UK Clinical Pharmacy Association (UKCPA) – Respiratory Group	1	Introduction (p9-10)	It would be useful to elaborate on the comment about providing transport and/or organising appointments closer to home. This is quite tricky in the many areas of England, particularly with regards to access to specialist centres Who should be responsible for ensuring access via transport to a specialist centre or to clinics closer to home, and how will these services be funded?

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				This should also provide provision for patient attendance for transplant assessment and follow up (the ILD centre and transplant centre may be some distance apart).
18	UK Clinical Pharmacy Association (UKCPA) – Respiratory Group	1		As part of the multidisciplinary team, we would recommend that patients should have access to a specialist pharmacist to provide support to patients with respect to expertise on education about treatments, monitoring and support with side effects. - A named pharmacist is included in draft ILD service specification, and including pharmacists as a named member of the MDT in the quality standards could help ensure this is costed as part of service development.
19	British Thoracic Society	1		Statement 1 (MDT team diagnosis) Statement 1 does not make it clear whether patients will be expected to attend centres running a specialist MDT or whether it will be sufficient that their cases are discussed at MDT and the outcomes then feedback locally. There is a discrepancy between the numerator and denominator which refer only to patients subsequently diagnosed with IPF and the standard which refers to the bigger population of patients with initially “suspected IPF”. A reasonable proportion of these patients will not have IPF but it is important that their cases are nonetheless discussed at MDT. Thought needs to be given to the best way of capturing the whole population of individuals with suspected IPF in the outcome measure.
20	NHS England	1		I think this is worded badly. In reality MDT panels are review committees who do not physically see the patient. Most reviews will be conducted remotely with the help of clinical notes, imaging and physiology. A preliminary diagnosis is usually made by a referring respiratory specialist. The purpose of the MDT is to review and confirm the diagnosis and to distinguish IPF from other types of interstitial lung disease. In many cases, the information is simply passed back to the referring physician with advice about management. It is not practical or necessary for every patient to physically attend a centre for review. I would suggest that the wording is changed to “ all patients with suspected IPF have their diagnosis reviewed by the multidisciplinary team” Quality measures will also be difficult to obtain here. There is no mechanism for identifying patients who have been diagnosed with IPF unless they are reviewed in the MDT and registered.
21	Boehringer Ingelheim Ltd	1		We support the statement that people with suspected idiopathic pulmonary fibrosis should be

ID	***Stakeholder***	***Statement No***	**Comment on**	**Comments** Please insert each new comment in a new row.
				diagnosed with the consensus of a multi-disciplinary team (MDT) but we suggest there should be more emphasis on a prompt diagnosis and referral for appropriate treatment. For example, the MDT should decide on the person's appropriateness for targeted IPF treatments at this point.
22	Boehringer Ingelheim Ltd	1		Rapid referral pathways would support improvement and overcome barriers to better patient outcomes.
23	Boehringer Ingelheim Ltd	1		Virtual MDTs could potentially improve speed of diagnosis and referral and therefore support improvement and overcome barriers to better patient outcomes More specialist training in diagnosis would improve speed of diagnosis and referral and therefore support improvement and overcome barriers to better patient outcomes.
24	InterMune	1		"People with suspected idiopathic pulmonary fibrosis are diagnosed only with the consensus of a multidisciplinary team with expertise in interstitial lung disease." InterMune wonders if the Quality statement 1 should be more encompassing to cover diagnosis and management of IPF and that the statement should be: "People with suspected idiopathic pulmonary fibrosis are diagnosed **and treated** only with the consensus of a multidisciplinary team with expertise in interstitial lung disease." (Rationale) As recognised in the final sentence of the rationale, "early and accurate diagnosis can improve the person's quality of life and, in many cases, extend their life". Delayed referral to a specialist centre decreases the survival time (Lamas 2011) and we therefore believe it important to stress the importance of early diagnosis and suggest including the following words 'delay of referral to a specialist multidisciplinary team' in the penultimate sentence so that it reads "….. **delay of referral to a specialist multidisciplinary team and/or** misdiagnosis can be serious…." Lamas D et al. Am J Respir Crit Care Med 2011; 184:842–847 (Structure) "Evidence of local arrangements to ensure the availability of a specialist multidisciplinary team with expertise in interstitial lung disease to diagnose people with suspected idiopathic pulmonary fibrosis." InterMune wonders if the Quality statement 1 should be more encompassing to cover diagnosis and

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				management of IPF under structure so that it should state “Evidence of local arrangements to ensure the availability of a specialist multidisciplinary team with expertise in interstitial lung disease to diagnose **and treat** people with suspected idiopathic pulmonary fibrosis.”
25	Royal College of Nursing	1		The RCN feel the idea of all suspected cases of IPF coming before a consensus MDT is laudable although there may be occasions when this isn’t possible. i.e diagnosis made on severely ill patient. It will be necessary for the discussion and instigation of high cost therapies.
26	Association of Respiratory Nurse Specialists	1		Comment about quality statement 1:**Diagnosis** People with suspected idiopathic pulmonary fibrosis are diagnosed only with the consensus of a multidisciplinary team with expertise in interstitial lung disease.Early and accurate diagnosis is essential but this gives rise to training needs in the general practice setting – this perhaps links in with the need to establish quality standards for spirometry in primary care – We are aware that there is a piece of work ongoing on a competency framework by NHS England. – some cross referencing may be necessary. Referral pathways need to be established and well defined to ensure that patients are referred to the appropriate specialist centre. A national standardised pathway needs to be established. This will enable robust evaluation.
27	Association of Respiratory Nurse Specialists	1		With regard to early diagnosis – the existence of BASAL crackles needs to be stipulated – it is essential that GPs auscultate the full chest wall – bases can be missed The importance of taking a detailed history is essential – familial IPF can occasionally present in those aged under 45 years and in someone in this age group id is essential that early access to a specialist centre is facilitated We agree that the presence of a clinical nurse specialist in the MDT should be stipulated With regard to quality of life – there is currently no standardised tool that is used for collecting HRQoL in an IPF population – this is challenging given the need to validate existing tools longitudinally. My own NIHR funded work is producing a patient PROM measure specifically for IPF that will be available in autumn 2015. Further discussion in this regard is needed With regard to facilitating transport for patients to attend a specialist centre – this is often a source of stress – there does need to be clear guidance on where the initial request for transport comes from – usually the GP – and that this is initiated in a timely fashion.

ID	***Stakeholder***	***Statement No***	**Comment on**	**Comments** Please insert each new comment in a new row.
28	Action for Pulmonary Fibrosis	2		To become an ILD specialist nurse, and not just a respiratory nurse who has been allocated ILD patients, nurses need to have evidence of training such as the ILD MSc module at Respiratory Education UK or equivalent, as well as standards already described.
29	British Lung Foundation	2		The BLF welcomes this statement regarding access to interstitial lung disease specialist nurses, but wishes to make their role more explicit (see 'Recommended new wording' below). ILD specialist nurses are essential in coordinating care, informing decision-making and providing support for patients, their families and carers at every stage of the care pathway, including transitions between the different stages. Many respondents argued that personal access to an ILD specialist nurse is a necessity in order to better manage their condition as it develops. Specialist nurses are also best placed to identify and alleviate developing symptoms arising from comorbidities, such as from chronic obstructive pulmonary disease and obstructive sleep apnoea, improving health outcomes for a number of IPF patients. Some patients worry that they are seldom provided with information about their condition and potential treatments. Knowing that an ILD nurse is available to them significantly improves well-being, and ensures there is no break between treatment in specialist centres and locally commissioned services. One patient told us: *"Because I only go for check-ups on a six-monthly basis, if I have an exacerbation in between these visits I feel very isolated and alone. However, I can contact a nurse at the Brompton and she advises me and points me in the right direction."* However, provision of ILD nurses across the country is patchy, and some patients who do have access have raised concerns about out-of-hours availability. With a full understanding of available treatments and the ability to appropriately tailor care to each individual case, ILD specialist nurses can offer credible information about disease progression, and provide social support not only to patients, but also their families and carers. One family member

ID	***Stakeholder***	***Statement No***	**Comment on**	**Comments** Please insert each new comment in a new row.
				commented: "*[Access to a specialist nurse] is fundamental. Patients and carers need a point of contact who understands their condition and the effect it has on them and their families*." Recommended new wording: i) Quality statement: *"People with idiopathic pulmonary fibrosis have an interstitial lung disease specialist nurse available to them and if they wish their families and carers* ***, to coordinate care and provide information and support.****"* ii) Rationale: *"An interstitial lung disease specialist nurse can* ***coordinate care, and*** *ensure that people with idiopathic pulmonary fibrosis, and if they wish their families and carers, receive all necessary information and support, including information about investigations, diagnosis and management."* iii) Outcome: *"****Improved quality of life for*** *people with idiopathic pulmonary fibrosis and if they wish their families and* ***carers.****"* iv) What the quality statement means for patients: "*People who have idiopathic pulmonary fibrosis and, if they wish, their families and carers have a specialist nurse with training and experience in* ***interstitial*** *lung disease available to them at all stages of their care."*
30	UK Clinical Pharmacy Association (UKCPA) – Respiratory Group	2		The Quality Statements outlines the level of experience for this nurse but not the workload. We wonder whether a patient caseload level be specified to ensure sufficient availability and support funding for access to specialist nurses?
31	British Thoracic Society	2		Statement 2 (access to ILD nurse) – Further clarity is required on what is meant by "access to an ILD nurse". This could be done by defining maximum caseload for an individual nurse. Otherwise, every patient with IPF being managed in a centre with and ILD nurse could be said to have access to that nurse, irrespective of the time available for that individual to interact with all patients. Additionally, following diagnosis at a specialist unit, many patients are likely to remain under follow up with their local respiratory physician. In such circumstances patients may have access to a Specialist

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				Respiratory Nurse but not necessarily a nurse with a dedicated ILD practice. In a number of areas of the UK networks exist to provide ILD support to general specialist respiratory nurses. This should be reflected in the quality standards so as to ensure that not all aspects of care are driven, by necessity, towards dedicated specialist centres.
32	NHS England	2		Whilst the involvement of a specialist nurse is a good thing, the definition of such is arbitrary. Individual nurses who work in centres with more than 500 patients per year or who have more than six months specific training will be very rare. A centre size qualification of this nature would mean that patients (or nurses) would have to travel large distances. This is not practical in the foreseeable future and the arbitrary definition of competence should be withdrawn.
33	InterMune	2		(Rationale) It is likely that patients may need support to help them make the most effective use of their medicines (NICE CG76). Lack of support may lead to non-adherence which may limit the benefits of medicines, resulting in lack of improvement or deterioration in health and increased costs; medicines wastage and costs arising from increased demands for healthcare if health deteriorates. A recent study demonstrated that adherence and compliance can be achieved by specialist nurse and clinician review, support and education of the patient (Chaudhuri). We therefore believe it important to add "treatments and side effect management" to the final sentence of the rationale so that it reads "Interstitial lung disease specialist nurses can sensitively discuss prognosis, disease severity and progression, **treatments, side effect management** and life expectancy." Chaudhuri, N et al. Respir Med. 2014 Jan;108(1):224-6
34	Royal College of Nursing	2		Is this for all ILD patients seen at a centre not 500 IPF in one centre and definitely not 500 IPF seen by one nurse? There is not currently 6/12 of specialised training.
35	Association of Respiratory Nurse Specialists	2		Comment about quality statement 2:**Access to a specialist Nurse** People with idiopathic pulmonary fibrosis have an interstitial lung disease specialist nurse available to them and if they wish their families and carers. IPF is a complex disease – any nurse working in ILD speciality must be highly trained and working towards a masters level of education Ideally nurses should be supported in undertaking training in non-medical prescribing or work to

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				agreed group directives to be able to prescribe in order to be able to streamline care for their patients and be able to manage exacerbations which are more complex that those exacerbations experienced in COPD Often the needs of patients and their families are greater out of hours when they feel isolated and find that disease expertise is not available to them – though needs to be given with regard to out of hours service provision / access to telephone helplines such as those provided by the BLF The role of the community respiratory nurse / matron could further incorporate a level of support but such nurses require either additional training of support from the specialist centre to assist in the clinical decision making It is difficult for nurse to access specialist training in ILD specifically in IPF – they must be supported in being able to access this Senior nurses who can be trained in clinical decision making and be able to provide nurse led clinics need to be developed – given the rising incidence and prevalence of IPF and the increasing burden on medics at specialist centres.
36	Wigan Borough CCG	3		Parts of this statement are incongruous with the new draft home oxygen guidelines (consultation period recently closed) due for publication early 2015. It was cited in those draft guidelines that the evidence for exertional oxygen use to be poor and that it should not be routinely offered. This quality standard implies benefit that may not be present. It does not mention any difference between LTOT or ambulatory which may be confusing or misleading to patients and clinicians.
37	Action for Pulmonary Fibrosis	3		Our concern is that Oxygen assessment services have been set-up to assess patients with COPD whose oxygen needs differ considerably from those patients with IPF. It should be made specific in the IPF Quality standard that those patients describing breathlessness on exertion are assessed for ambulatory oxygen with an exercise test such as 6 minute walk test to measure degree of oxygen de-saturations. They should be assessed by staff experienced in IPF, rather than as often currently happens, that they are assessed by staff who have no such experience and who do not understand the needs of patients with IPF.
38	British Lung Foundation	3		We welcome this statement on assessment for oxygen therapy. Oxygen therapy tailored to a patient's needs can help maintain lung function, relieve breathlessness and play a crucial role in increasing their day-to-day independence. One member of an IPF support group we visited in Worthing simply

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				said: *"It keeps me alive."* Having been accurately assessed by ILD specialists for suitability, people with IPF should be provided with information on the value of oxygen therapy and the different types of oxygen equipment available to them. One woman who uses oxygen told us that she was not offered an oxygen assessment for some time: *"I became a prisoner. I could barely walk around the house or go out before I asked for an assessment for oxygen. If I hadn't been pro-active, I wouldn't have got it. I wonder what happens to people who don't know you can access these services?"* Personalisation of oxygen services specifically for IPF patients is crucial, and users must be thoroughly trained to avoid incorrect oxygen technique. A number of people told us that their own oxygen services were inadequate, in some cases having been designed for patients with COPD. At one IPF focus group, we heard stories of patients buying oxygen canisters online, or even borrowing from family members with different respiratory conditions. Due to the progressive nature of the condition, it would be appropriate for IPF patients to be re-assessed for oxygen more frequently than COPD patients, for whom an annual assessment is the norm. Recommended new wording: i) Rationale: "…are able to exercise. **Oxygen therapy is often tailored to chronic obstructive pulmonary disease (COPD) and not to idiopathic pulmonary fibrosis. It is more effective at improving health-related quality of life and exercise capacity if it is tailored to the needs of a person with idiopathic pulmonary fibrosis."**
39	British Thoracic Society	3		Statement 3 (oxygen assessment) Whilst recognising that there is a lack of robust evidence in this area we support the statement that patients who get breathless on exertion should be assessed for oxygen. Consideration should be given to mentioning the assessment of both ambulatory and resting oxygen requirement.
40	NHS England	3		No Comments

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41	Royal College of Nursing	3		Ambulatory oxygen should be an early consideration and continuous monitoring and titration.
42	Association of Respiratory Nurse Specialists	3		Comment about quality statement 3:**Oxygen Assessment** People with idiopathic pulmonary fibrosis are assessed for oxygen therapy if they are breathless at rest or on exertion, or have been admitted to hospital because of idiopathic pulmonary fibrosis. Community respiratory nurses need to receives training / be offered guidance in how to meet the oxygen needs of patients with IPF in order to be able to support patients at home, specifically those with progressive disease Patients diagnosed with IPF require reassessment of their oxygen requirements particularly post exacerbation Oxygen needs in end of life needs particular attention so that lack of access to appropriate oxygen supplies does not hasten death Patients find the transition to oxygen therapy distressing – access to psychological support to enable a smoother transition should be offered Many nurses feel that a caseload of 500 in this disease group is too large to enable the provision of quality care – given the complexity of the disease processes and high mortality
43	Papworth Hospital NHSFT and CUHNHSFT/ Addenbrooke's Hospital	4	Pulmonary Rehabilitation	There is no good quality evidence to support the use of pulmonary rehabilitation in patients with IPF. Research is needed in this area to tailor a pulmonary rehabilitation programme specific for the needs of individuals with IPF.
44	Action for Pulmonary Fibrosis	4		Fully agree that tailored pulmonary rehab is essential for IPF patients and separate courses are needed, not linked with COPD patients. However, there is no evidence of what should be included to provide the most benefit to IPF patients and research in this area is needed.
45	British Lung Foundation	4		The BLF welcomes this statement, but would like pulmonary rehabilitation to be available for all people with IPF. In most cases, patients find pulmonary rehabilitation programmes beneficial to them, improving their general health and quality of life. Both the education and exercise components of pulmonary rehabilitation play a crucial role for patients in successfully managing their condition and better understanding their physical abilities. One respondent commented: *"I have completed an eight week exercise course in Norwich run by excellent nurses – their help and support has been*

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				invaluable." We are pleased that NICE recognises that pulmonary rehabilitation designed for COPD patients is unsuitable for people with IPF, and would like to see more IPF-specific programmes commissioned locally. A number of our respondents mentioned that the pulmonary rehabilitation programmes available to them largely catered for people with COPD. One commented: *"Some of the talks do not relate to us. It would be good for nurses with experience of IPF to give relevant talks."* Some people told us that they were not informed of the programmes that they could attend, or that appropriate services were often not locally accessible. *"Some GPs don't seem to be aware of what is available"* said one respondent, whilst another told us that they only attended pulmonary rehabilitation because they had *"heard about it through 'Breathe Easy'"*, a BLF patient support group. Recommended new wording: i) Quality statement: *"People with idiopathic pulmonary fibrosis are **assessed for and** offered pulmonary rehabilitation that includes exercise and educational components tailored to their needs."* ii) What the quality statement means for patients: *"People who have idiopathic pulmonary fibrosis are **assessed for and** offered pulmonary rehabilitation programmes that include exercise and educational elements tailored to their needs.*
46	British Thoracic Society	4		Statement 4 (rehab) - denominator "number of patients with IPF suitable for rehab" – this is very vague and is not be possible to determine as there is no clear evidence based guidance on who to select for referral for rehab. This will result in inconsistent data collection across regions. The denominator could either be defined according to physiological criteria or could simply remain the whole IPF population.
47	NHS England	4		There is no definition of suitability. Does this mean that patients can be too fit to benefit or too frail to participate? The evidence base here is not very strong and there is a suggestion that once respiratory failure develops that rehabilitation may do more harm than good.

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48	Royal College of Nursing	4		There is currently no evidence which parts of PR work for IPF.
49	Association of Respiratory Nurse Specialists	4		Comment about quality statement 4: **Pulmonary Rehabilitation** People with idiopathic pulmonary fibrosis who are suitable are offered pulmonary rehabilitation that includes exercise and educational components tailored to their needs. Patients should be able to have access to oxygen at the centre offering PR to enable them to conserve their own supplies for travel.
50	Action for Pulmonary Fibrosis	5		No further comments on this standard.
51	British Lung Foundation	5		We welcome this statement regarding palliative care, which plays a key role in symptom management and improving quality of life. Palliative care services should be signposted at the earliest possible opportunity. A number of respondents told us that they were unaware of the range of services offered by palliative care teams until the final stages of IPF development. Whilst one carer believed that *"To discuss palliative care too early can cause unnecessary stress"*, a health care professional argued: *"[Palliative care] should be available from diagnosis if wanted by patient and family, rather than just end of life care."* We are pleased that NICE has emphasised giving patients, their carers and families access to the full range of services offered by palliative care teams. IPF often leads to sudden and considerable changes in the lifestyles and financial situations of patients, their families and carers. It is important that health care professionals are able either to provide or to signpost information on issues such as welfare benefits, professional counselling, social care, lifestyle adaptations and emotional support for families and carers. Patient experience suggests that this is less likely to be provided than medical information. Recommended new wording: i) What the quality statement means for patients: *"People who have idiopathic pulmonary fibrosis, and their families and carers, **are signposted** to palliative care teams who can offer help and support to*

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				manage symptoms, psychological support and information about their condition ***at the earliest opportunity****."*
52	UK Clinical Pharmacy Association (UKCPA) – Respiratory Group	5		It may be appropriate to consider reflux management as part of symptomatic control. Ideally there should be provision for gastric manometry in selected patients and availability of corrective procedures (i.e. fundoplication) in patients who may benefit.
53	British Thoracic Society	5		Statement 5 (palliative care) – We strongly endorse the principle of palliative or symptom based therapies in the management of IPF especially for those individuals with end stage disease. Whilst in some areas these services will be delivered directly by palliative care teams in other regions different solutions currently exist including provision of access to respiratory physiotherapists, clinical psychologists and ILD nurses who are generally very skilled at offering breathless control advice/pacing advice/detailed advice on the use of lorazepam and oramoroph/oxygen etc. In many areas there is a seamless transition between hospital based symptom based management (ILD specialist nurse) and community/home based ILD nursing care for patients with severe disease - and at all parts of the pathway there is the option to interact with palliative care (for hospice etc), interaction with community matrons etc, adding to gold standards framework etc. The statement, as currently drafted, risks swamping palliative care with patients who already receive excellent end-of-life and symptom based care through well-established pathways of care. We would favour a statement which requires all units to demonstrate that they have systems in place for the provision of symptom based management with defined links and pathways in place with palliative care. This should ensure that all patients with IPF have access to appropriate services without mandating that all patients necessarily be seen by palliative care specialists per se Consideration could be given to mandating the use of a palliative care screening tool in ILD clinics so that the needs of patients is better determined. Such tools can be applied by any of the multiple health care professionals who interact with ILD/IPF patients.
54	NHS England	5		No Comments
55	Boehringer Ingelheim Ltd	5		This could be more specific and mention symptom control, social support and end of life care. Otherwise the temptation could be to only call on palliative care services for end of life issues.

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56	Royal College of Nursing	5		Palliative care services is important for symptom control but physiotherapists are also often good at breathing control and cough
57	Association of Respiratory Nurse Specialists	5		Comment about quality statement 5: **Palliative Care** People with idiopathic pulmonary fibrosis, and their families and carers, have access to the full range of services offered by palliative care teams. Patients should have continued access to the professionals who have provided care from diagnosis – given the rapidity with which some patients decline it is unrealistic that a completely new team of health care professionals can come in and build rapport It is essential that palliation is initiated in the moderate stages of the disease and that a community healthcare profession either GP or community nurse is a continuing link to respiratory services locally and palliative care provision Again access to psychological support from a professional with an understanding of IPF is essential Again access to oxygen must be planned for and thought through to enable the patient to remain at home or within the hospice setting – up to 15L of oxygen may be needed.
58	Papworth Hospital NHSFT and CUHNHSFT/ Addenbrooke's Hospital	Additional statement	Introduction – Why is this quality standard needed section	Comment about Page 2 section that begins " This quality standard is expected to contribute to improvements in the following outcomes " The second bullet point states " preventing premature mortality among people with idiopathic pulmonary fibrosis" which is highlighted in Table 2 NHS Outcomes Framework 2014-15 as domain 1 and Table 3 Public Health Outcomes Framework for England 2013-2016, domain 4. Since publication of NICE IPF Clinical Guidelines (CG163), NICE have undertaken technical appraisal and approved Pirfenidone for treatment of IPF in patients with FVC 50-80%. This was based upon CAPACITY clinical trials. Subsequent ASCEND study has been published (King TE et al NEJM 2014; 370:2083-92) which confirms findings from CAPACITY and demonstrates improvement in progression free survival. Pooled analysis from CAPACITY and ASCEND showed Pirfenidone reduced risk of IPF related death. This is the highest grade of evidence to support this treatment for patients with IPF. Similarly another therapy Nintedanib has RCT evidence to supports its efficacy in slowing decline in

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				FVC in patients with IPF compared to placebo arm based (Richeldi L et al NEJM 2014; 370:2071). Given the positive outcomes from these clinical trials we recommend that the quality standards include a statement pertaining to disease modifying therapies for IPF. Such as all patients with IPF must be assessed for their suitability for disease modifying therapies. This would include NICE approved therapies in particular. However a number of novel therapies are being assessed in clinical trials and the option of taking part in a clinical trial should also be available for patients with IPF.
59	Papworth Hospital NHSFT and CUHNHSFT/ Addenbrooke's Hospital	Additional statement	Introduction, section "How this quality standard supports delivery of outcome frameworks"	Comment on Table 2 NHS Outcomes Framework 2014-15, domain 2 We recommend that there is a quality statement about access to IPF or pulmonary fibrosis specific patient support groups to help support patients as well as their families and carers. Based upon our own experience of pulmonary fibrosis support group, this helps to enhance quality of life for carers and ensure people feel supported to manage their condition.
60	Action for Pulmonary Fibrosis	Additional statement	General	We recommend that a statement is included which requires all IPF patients to be assessed as to their suitability for NICE approved disease modifying therapies and to have the option of taking part in appropriate clinical trials.
61	British Lung Foundation	Additional statement		The BLF believes that at the earliest opportunity and having been presented with the full range of treatment options, people with IPF should be able to dictate the direction of their care. Health care professionals can act accordingly - placing people with IPF at the heart of decision-making about their future care, providing up-to-date information and support, and respecting the wishes of patients and their families. In 2013, the BLF published the IPF Patient Charter (http://www.blf.org.uk/Page/IPF-patient-charter) and we have supported the subsequent development of a European IPF Patient Charter. We believe that an additional quality statement concerning patient-centred care adopted by NICE may play a role in improving the quality of care for IPF patients across the country.

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				Recommended wording: i) Quality statement: *"**People with IPF are actively involved in planning and decision-making regarding their care at all stages, and supported by health care professionals to make informed choices about self-management and treatment options.**"* The BLF believes that it is possible to collect data for the proposed quality measures, and we support the use of a national data collection register for people with IPF. The British Thoracic Society's IPF Registry provides clear guidelines as to how this could operate, benefiting clinical researchers, health care professionals, patients and their families. We believe that NHS England can play a role in promoting the use of the registry, and the up-to-date and accurate collection of local data.
62	Royal College of Pathologists	Additional statement	Definitions (statement 1)	In relation to undertaking surgical lung biopsy, some form of recommendation for pre-operative targeting, ideally of more than one site, of diseased but not end-stage, lung would be beneficial, as there remain a minority for patients who undergo surgery only for the tissue to be non-diagnostic due to sampling of the wrong areas.
63	UK Clinical Pharmacy Association (UKCPA) – Respiratory Group	Additional statement	General	It is surprising that there are no quality statements addressing access to medication, such as pirfenidone. There should be a quality standard to state that patients are offered the appropriate medication, given medicine education and monitored carefully. It is important to ensure the availability of lung function testing, including validated measurement of DLCO & lung volumes because this is required prior to commencing pirfenidone.
64	Primary Care Respiratory Society UK	Additional statement	P5 list of quality statements	The only issue we have picked up on this is that there is nothing about pharmacotherapy in the Quality standard. This is a rapidly changing field, and there are many new products in the pipeline. We would like to see a statement such as 'People with IPF should have access to/ be offered evidence based pharmacotherapy'.
65	Boehringer Ingelheim Ltd	Additional		As well as assessing for oxygen therapy we believe the standard should include a statement on

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		statement		access to potentially disease modifying therapies
66	Royal College of Nursing	Additional statement	General	The RCN feels that these statements seemed rather 'soft' and we think there should be others: i.e. high quality lung function testing with diffusion relevant investigations HRCT Lung biopsy bloods etc i.e. Proforma development i.e. keeping of a data base or joining BTS data base i.e. measuring of FVC for prognosis i.e. use of patient heath status tools i.e. support for a patient group and patient information
67	North Bristol NHS Trust (Interstitial Lung Disease Service)	Additional statement	Psychosocial support is referred to in the sections on both pulmonary rehabilitation and palliative care (Quality Statement 5)	There needs to be an elaboration on the role, benefits & availability of psychology support to patients with interstitial lung disease (particularly IPF). This is particularly pressing as the majority of 'generic' services are unfamiliar with the difficulties and challenges of assisting patients dealing with a diagnosis of an interstitial lung disease. There is inconsistent availability of, and access to, support. In some areas this may be; attached to services managing other patients with chronic conditions, dependent on volunteer organised support groups, or entirely absent. The benefits of psychology within an ILD service are geared towards self-management strategies to improve quality of life by: reducing emotional distress, helping individuals adjust to the diagnosis, maximising daily functioning at home and work (e.g., by learning to pace activities), reducing reliance on medical services, and improving medication adherence. Interventions utilise evidence-based approaches in the management of long-term conditions. The importance, and benefit, of a psychologist within, or available to an ILD service is distinct from the provision of support delivered by palliative care services (although often complementary) and should be included as a separate consideration with advice/recommendations on commissioning psychology support for specialist services.

Stakeholders who submitted comments at consultation

- Action for Pulmonary Fibrosis
- Association of Respiratory Nurse Specialists
- Boehringer Ingelheim Ltd
- British Lung Foundation
- British Thoracic Society
- Digital Assessment Service, NHS Choices
- InterMune
- NHS England
- North Bristol NHS Trust (Interstitial Lung Disease Service)
- Papworth Hospital NHSFT and CUHNHSFT/Addenbrooke's Hospital
- Primary Care Respiratory Society UK
- Royal College of Nursing
- Royal College of Pathologists
- Royal College of Radiologists (RCR & the British Society of Thoracic Imaging (BSTI)
- UK Clinical Pharmacy Association (UKCPA) – Respiratory Group
- Wigan Borough CCG