

# Idiopathic pulmonary fibrosis in adults

Quality standard

Published: 29 January 2015

[www.nice.org.uk/guidance/qs79](https://www.nice.org.uk/guidance/qs79)

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This standard is based on CG163.

This standard should be read in conjunction with QS15, QS43 and QS13.

## Introduction

This quality standard covers the diagnosis and management of idiopathic pulmonary fibrosis in adults, from the initial suspicion of the disease to referral, supportive care and treatment. For more information see the topic [overview](#).

## Why this quality standard is needed

Idiopathic pulmonary fibrosis is a serious and progressive disease in which the alveoli (the tiny air sacs of the lungs) and the lung tissue next to the alveoli become damaged and scarred. The cause of the disease is unknown. Although it is associated with characteristic clinical, radiological and histological features, it is difficult to diagnose. Confirmation of diagnosis often requires the collaborative expertise of a consultant respiratory physician, a thoracic radiologist and a thoracic histopathologist. Most people with idiopathic pulmonary fibrosis have symptoms of breathlessness, which may at first occur only on exertion, and cough, with or without sputum. Over time, these symptoms are associated with a decline in lung function, reduced quality of life and ultimately death.

Idiopathic pulmonary fibrosis is rare in people younger than 45 years and in the UK the median age of presentation is 70 years. The prevalence is around 15 to 25 cases per 100,000 people and increases with age. Most people with idiopathic pulmonary fibrosis smoke or have a history of smoking, and idiopathic pulmonary fibrosis often coexists with chronic obstructive pulmonary disease.

The median survival for people with idiopathic pulmonary fibrosis in the UK is approximately 3 years from the time of diagnosis. However, about 20% of people with the disease survive for more than 5 years. The rate of disease progression varies. A person's prognosis is difficult to estimate at the time of diagnosis and may only become apparent after a period of careful follow-up.

This quality standard is expected to contribute to improvements in the following outcomes:

- quality of life of people with idiopathic pulmonary fibrosis

- premature mortality
- experience of care
- emergency admissions or attendances at emergency departments

## How this quality standard supports delivery of outcome frameworks

NICE quality standards are a concise set of prioritised statements designed to drive measurable quality improvements within a particular area of health or care. They are derived from high-quality guidance, such as that from NICE or other sources accredited by NICE. This quality standard, in conjunction with the guidance on which it is based, should contribute to the improvements outlined in the following 3 outcomes frameworks published by the Department of Health:

- [NHS Outcomes Framework 2014–15](#)
- [The Adult Social Care Outcomes Framework 2014–15](#) (Department of Health, November 2012)
- Improving outcomes and supporting transparency: a public health outcomes framework for England 2013–2016, [Parts 1 and 1A](#).

Tables 1–3 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

### Table 1 [The Adult Social Care Outcomes Framework 2014–15](#)

Domain	Overarching and outcome measures
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<p>1 Enhancing quality of life for people with care and support needs</p>	<p><b>Overarching measure</b></p> <p>1A Social care-related quality of life*</p> <p><b>Outcome measures</b></p> <p>People manage their own support as much as they wish, so that are in control of what, how and when support is delivered to match their needs.</p> <p>1B Proportion of people who use services who have control over their daily life</p> <p>Carers can balance their caring roles and maintain their desired quality of life.</p> <p>1D Carer-reported quality of life*</p>
<p>3 Ensuring that people have a positive experience of care and support</p>	<p><b>Overarching measure</b></p> <p>People who use social care and their carers are satisfied with their experience of care and support services.</p> <p>3A Overall satisfaction of people who use services with their care and support</p> <p>3B Overall satisfaction of carers with social services</p>
<p><b>Aligning across the health and care system</b></p> <p>* Indicator complementary with the NHS Outcomes Framework</p>	

**Table 2 NHS Outcomes Framework 2014–15**

Domain	Overarching indicators and improvement areas
<p>1 Preventing people from dying prematurely</p>	<p><b>Overarching indicator</b></p> <p>1a Potential Years of Life Lost (PYLL) from causes considered amenable to healthcare</p> <p>i Adults</p> <p>1b Life expectancy at 75</p> <p>i Males ii Females</p> <p><b>Improvement area</b></p> <p>1.2 Under 75 mortality rate from respiratory disease*</p>

<p>2 Enhancing quality of life for people with long-term conditions</p>	<p><b>Overarching indicator</b></p> <p>2 Health-related quality of life for people with long-term conditions**</p> <p><b>Improvement areas</b></p> <p><b>Ensuring people feel supported to manage their condition</b></p> <p>2.1 Proportion of people feeling supported to manage their condition</p> <p><b>Reducing time spent in hospital by people with long-term conditions</b></p> <p>2.3 i Unplanned hospitalisation for chronic ambulatory care sensitive conditions</p> <p><b>Enhancing quality of life for carers</b></p> <p>2.4 Health-related quality of life for carers**</p>
<p>4 Ensuring that people have a positive experience of care</p>	<p><b>Overarching indicator</b></p> <p>4a Patient experience of primary care</p> <p>i GP services</p> <p>ii GP out-of-hours services</p> <p>4b Patient experience of hospital care</p> <p><b>Improvement areas</b></p> <p><b>Improving hospitals' responsiveness to personal needs</b></p> <p>4.2 Responsiveness to in-patients' personal needs</p> <p><b>Improving people's experience of accident and emergency services</b></p> <p>4.3 Patient experience of A&amp;E services</p>
<p><b>Alignment across the health and social care system</b></p> <p>* Indicator shared with Public Health Outcomes Framework (PHOF)</p> <p>** Indicator complementary with Adult Social Care Outcomes Framework (ASCOF)</p>	



**Table 3 Public health outcomes framework for England, 2013–2016**

Domain	Objectives and indicators
4 Healthcare public health and preventing premature mortality	<p><b>Objective</b></p> <p>Reduced numbers of people living with preventable ill-health and people dying prematurely, while reducing the gap between communities</p> <p><b>Indicators</b></p> <p>4.7 Under 75 mortality rate from respiratory diseases*</p>
<p><b>Aligning across the health and care system</b></p> <p>* Indicator shared with the NHS Outcomes Framework</p>	

## Patient experience and safety issues

Ensuring that care is safe and that people have a positive experience of care is vital in a high-quality service. It is important to consider these factors when planning and delivering services relevant to idiopathic pulmonary fibrosis.

NICE has developed guidance and an associated quality standard on patient experience in adult NHS services (see the NICE pathway on [patient experience in adult NHS services](#)), which should be considered alongside this quality standard. They specify that people receiving care should be treated with dignity, have opportunities to discuss their preferences, and be supported to understand their options and make fully informed decisions. They also cover the provision of information to patients. Quality statements on these aspects of patient experience are not usually included in topic-specific quality standards. However, recommendations in the development source(s) for quality standards that impact on patient experience and are specific to the topic are considered during quality statement development.

## Coordinated services

Between 2000 and 4000 new cases of interstitial lung disease are diagnosed in England each year, and most of these are either sarcoidosis or idiopathic pulmonary fibrosis. Care for people with idiopathic pulmonary fibrosis is subject to specialised commissioning arrangements through NHS England and its area teams. In 2014 there were 11 hospitals providing specialised care. Disease-specific management plans are drawn up after multidisciplinary team assessment at

regional specialist centres.

The quality standard for idiopathic pulmonary fibrosis specifies that services should be commissioned from and coordinated across all relevant agencies encompassing the whole idiopathic pulmonary fibrosis care pathway. A person-centred, integrated approach to providing services is fundamental to delivering high-quality care to adults with idiopathic pulmonary fibrosis.

The Health and Social Care Act 2012 sets out a clear expectation that the care system should consider NICE quality standards in planning and delivering services, as part of a general duty to secure continuous improvement in quality. Commissioners and providers of health and social care should refer to the library of NICE quality standards when designing high-quality services. Other quality standards that should also be considered when choosing, commissioning or providing a high-quality idiopathic pulmonary fibrosis service are listed in [related quality standards](#).

## Training and competencies

The quality standard should be read in the context of national and local guidelines on training and competencies. All healthcare professionals involved in assessing, caring for and treating adults with idiopathic pulmonary fibrosis should have sufficient and appropriate training and competencies to deliver the actions and interventions described in the quality standard. Quality statements on staff training and competency are not usually included in quality standards. However, recommendations in the development source(s) on specific types of training for the topic that exceed standard professional training are considered during quality statement development.

## Role of families and carers

Quality standards recognise the important role families and carers have in supporting people with idiopathic pulmonary fibrosis. If appropriate, healthcare professionals should ensure that family members and carers are involved in the decision-making process about investigations, treatment and care.

## List of quality statements

Statement 1. People are diagnosed with idiopathic pulmonary fibrosis only with the consensus of a multidisciplinary team with expertise in interstitial lung disease.

Statement 2. People with idiopathic pulmonary fibrosis have an interstitial lung disease specialist nurse available to them.

Statement 3. People with idiopathic pulmonary fibrosis have an assessment for home and ambulatory oxygen therapy at each follow up appointment and before they leave hospital following an exacerbation of the disease.

Statement 4. Pulmonary rehabilitation programmes provide services that are designed specifically for idiopathic pulmonary fibrosis.

Statement 5. People with idiopathic pulmonary fibrosis and their families and carers have access to services that meet their palliative care needs.

# Quality statement 1: Diagnosis of idiopathic pulmonary fibrosis

## Quality statement

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

## Rationale

Idiopathic pulmonary fibrosis is difficult to diagnose. The main symptom is shortness of breath that gradually becomes worse. It can only be diagnosed with confidence by a specialist multidisciplinary team with expertise in interstitial lung disease. Diagnosis is based on clinical features, lung function, radiological findings and pathology if indicated. Because of the severity of idiopathic pulmonary fibrosis and its poor prognosis, being incorrectly diagnosed with this disease can cause unnecessary distress for the person and their families or carers.

## Quality measures

### Structure

Evidence of local arrangements to ensure the availability of a multidisciplinary team with expertise in interstitial lung disease to diagnose idiopathic pulmonary fibrosis.

*Data source:* Local data collection.

### Process

Proportion of people diagnosed with idiopathic pulmonary fibrosis by a multidisciplinary team with expertise in interstitial lung disease.

Numerator – the number in the denominator whose condition was diagnosed with the consensus of a multidisciplinary team with expertise in interstitial lung disease.

Denominator – the number of people diagnosed with idiopathic pulmonary fibrosis.

**Data sources:** British Thoracic Society's [BTS Lung Disease Registry Programme for idiopathic pulmonary fibrosis](#) and [NICE guideline CG163 clinical audit tool](#).

## What the quality statement means for service providers, healthcare professionals and commissioners

**Service providers** (hospitals and regional specialist centres) collaborate to ensure that a multidisciplinary team comprising healthcare professionals with expertise in interstitial lung disease is available to diagnose people who have suspected idiopathic pulmonary fibrosis.

**Healthcare professionals** who suspect idiopathic pulmonary fibrosis refer people to a multidisciplinary team with expertise in interstitial lung disease for confirmation of the diagnosis. Healthcare professionals within the multidisciplinary team collaborate to diagnose idiopathic pulmonary fibrosis by consensus based on clinical features, lung function, radiological findings and pathology if indicated.

**Commissioners** (NHS England through specialised services area teams collaborating with clinical commissioning groups) commission services from regional specialist centres that have a multidisciplinary team consisting of healthcare professionals with expertise in interstitial lung disease.

## What the quality statement means for patients, service users and carers

People who might have idiopathic pulmonary fibrosis receive a diagnosis only after their symptoms and any test results have been discussed by a team of healthcare professionals who specialise in diagnosing and treating lung diseases. This will help to make sure that people are given the correct diagnosis. They do not need to attend this discussion.

## Source guidance

- [Idiopathic pulmonary fibrosis \(2013\) NICE guideline CG163](#), recommendations 1.2.2 (key priority for implementation) and 1.2.3.

## Definitions of terms used in this quality statement

### Suspected idiopathic pulmonary fibrosis

The presence of clinical features of idiopathic pulmonary fibrosis. These are:

- age over 45 years
- persistent breathlessness on exertion
- persistent cough
- bilateral inspiratory crackles in the chest
- clubbing of the fingers
- normal or impaired spirometry, usually with a restrictive pattern but sometimes with an obstructive pattern.

[Adapted from [idiopathic pulmonary fibrosis](#) (NICE guideline CG163), recommendation 1.1.1]

### Multidisciplinary team with expertise in interstitial lung disease

A multidisciplinary team that includes a consultant respiratory physician, a consultant thoracic radiologist, an interstitial lung disease specialist nurse and a multidisciplinary team coordinator. The multidisciplinary team is based in a regional specialist centre.

[[Idiopathic pulmonary fibrosis](#) (NICE guideline CG163), recommendation 1.2.3 and expert opinion]

In addition, the following healthcare professionals join the multidisciplinary team at these stages of diagnosis and treatment.

- When considering bronchoalveolar lavage, transbronchial biopsy or surgical lung biopsy: a consultant histopathologist and a thoracic surgeon (as appropriate).
- When considering the results of bronchoalveolar lavage, transbronchial biopsy or surgical biopsy: a consultant histopathologist.

[[Idiopathic pulmonary fibrosis](#) (NICE guideline CG163), recommendations 1.2.2 (key priority for implementation), 1.2.3 and 1.2.4]

For more information on the expertise of the multidisciplinary team see section 6.1.4 of the [full guideline on idiopathic pulmonary fibrosis](#).

## Interstitial lung disease

A group of lung diseases of known and unknown cause that are characterised by varying degrees of inflammation and fibrosis of the lung tissue.

[\[Full guideline on idiopathic pulmonary fibrosis\]](#)

## Equality and diversity considerations

People with suspected idiopathic pulmonary fibrosis are likely to need hospital tests and investigations. Some services may not be available in local hospitals and people may need to go to specialist centres. To ensure equality of access to care, measures should be put in place to help people attend local hospitals and specialist centres, for example by providing transport and offering appointments in centres as near to the person's home as possible.

## Quality statement 2: Access to a specialist nurse

### Quality statement

People with idiopathic pulmonary fibrosis have an interstitial lung disease specialist nurse available to them.

### Rationale

An interstitial lung disease specialist nurse can ensure that people with idiopathic pulmonary fibrosis, and their families and carers, receive all the information and support they need throughout the care pathway. This includes information about investigations, diagnosis and management. Interstitial lung disease specialist nurses can sensitively discuss prognosis, disease severity and progression, and life expectancy.

### Quality measures

#### Structure

Evidence of local arrangements to ensure that an interstitial lung disease specialist nurse is available to people with idiopathic pulmonary fibrosis at all stages of the care pathway.

*Data source:* Local data collection.

#### Process

Proportion of people with idiopathic pulmonary fibrosis with an allocated interstitial lung disease specialist nurse.

Numerator – the number in the denominator with an allocated interstitial lung disease specialist nurse.

Denominator – the number of people with idiopathic pulmonary fibrosis.

*Data source:* Local data collection.



## Outcome

Satisfaction of people with idiopathic pulmonary fibrosis, and their families and carers, with the support they receive.

*Data source:* Local data collection.

## What the quality statement means for service providers, healthcare professionals and commissioners

**Service providers** (regional specialist centres) ensure that an interstitial lung disease specialist nurse is available to people with idiopathic pulmonary fibrosis, and their families and carers, at all stages of their care.

**Healthcare professionals** ensure that a referral is made to an interstitial lung disease specialist nurse who is available to people with idiopathic pulmonary fibrosis, and their families and carers, to support them throughout their care pathway.

**Commissioners** (NHS England specialised services area teams) ensure that they commission services from regional specialist centres that employ interstitial lung disease specialist nurses as part of their multidisciplinary teams.

## What the quality statement means for patients, service users and carers

People who have idiopathic pulmonary fibrosis have a specialist nurse with training and experience in lung disease to provide information and support to them, and their families and carers, throughout all stages of their care. They can discuss tests, treatment options and any other concerns they have about their condition with the specialist nurse.

## Source guidance

- [Idiopathic pulmonary fibrosis \(2013\) NICE guideline CG163, recommendations 1.3.1 and 1.3.3](#) (key priorities for implementation).

## Definitions of terms used in this quality statement

### Interstitial lung disease specialist nurse

An interstitial lung disease specialist nurse is involved in a service that sees at least 500 people with interstitial lung disease a year or has completed at least 6 months of specialist training in interstitial lung disease. The interstitial lung specialist nurse is readily contactable by people with idiopathic pulmonary fibrosis (and if they wish their families and carers) at all stages of the care pathway.

[[Full guideline on idiopathic pulmonary fibrosis](#) and expert opinion]

### Equality and diversity considerations

Some people with idiopathic pulmonary fibrosis may have an interstitial lung disease specialist nurse who is located a considerable distance from them, because of the specialist nature of these nurses' role. To ensure equality of access to care, measures should be put in place to support access to interstitial lung disease specialist nurses, for example by providing telephone and email contact details and, if needed, transport, and offering appointments in centres as near to the person's home as possible.

## Quality statement 3: Assessment for oxygen therapy

### Quality statement

People with idiopathic pulmonary fibrosis have an assessment for home and ambulatory oxygen therapy at each follow-up appointment and before they leave hospital following an exacerbation of the disease.

### Rationale

Oxygen therapy relieves symptoms of breathlessness. Exercise can cause a greater reduction in levels of oxygen in the blood in people with idiopathic pulmonary fibrosis than in people with other lung diseases, and higher flow rates of oxygen can be needed to correct this. Therefore oxygen therapy can help people to take part in pulmonary rehabilitation exercises to improve their quality of life and maintain their lung function. Assessment of a person's need for home and ambulatory oxygen therapy before they leave hospital after admission for treatment of an exacerbation of idiopathic pulmonary fibrosis will help to identify changes in their oxygen needs and may prevent a further exacerbation. Repeating the assessment at regular intervals will ensure that people with idiopathic pulmonary fibrosis receive oxygen therapy when they need it.

### Quality measures

#### Structure

a) Evidence of local arrangements to ensure that people with idiopathic pulmonary fibrosis have an assessment for home and ambulatory oxygen therapy considered at each follow-up appointment.

*Data source:* Local data collection.

b) Evidence of local arrangements to ensure that people with idiopathic pulmonary fibrosis are assessed for home and ambulatory oxygen therapy before discharge if they have been admitted to hospital because of an exacerbation of the disease.

*Data source:* Local data collection.

## Process

a) Proportion of idiopathic pulmonary fibrosis follow-up appointments at which an assessment for home and ambulatory oxygen therapy was made.

Numerator – the number in the denominator at which assessment for home and ambulatory oxygen therapy was carried out.

Denominator – the number of follow-up appointments for people with idiopathic pulmonary fibrosis.

*Data source:* Local data collection.

b) Proportion of hospital stays because of an exacerbation of idiopathic pulmonary fibrosis during which an assessment for home and ambulatory oxygen therapy was made.

Numerator – the number in the denominator during which an assessment for home and ambulatory oxygen therapy was carried out before discharge.

Denominator – the number of hospital stays because of an exacerbation of idiopathic pulmonary fibrosis.

*Data source:* Local data collection.

## Outcomes

a) Quality of life and wellbeing of people with idiopathic pulmonary fibrosis.

*Data source:* Local data collection.

## What the quality statement means for service providers, healthcare professionals and commissioners

Service providers (hospitals and regional specialist centres) ensure that home and ambulatory oxygen therapy is available for people with idiopathic pulmonary fibrosis. They ensure that arrangements are in place for an assessment for home and ambulatory oxygen therapy to be made before discharge for people who are admitted to hospital because of an exacerbation of idiopathic pulmonary and at every follow-up appointment for idiopathic pulmonary fibrosis.

**Healthcare professionals** ensure that they assess people's need for home and ambulatory oxygen therapy at follow-up appointments and before discharge if they have been admitted to hospital because of an exacerbation of idiopathic pulmonary fibrosis.

**Commissioners** (NHS England through specialised services and clinical commissioning groups) ensure that the services they commission for people with idiopathic pulmonary fibrosis include assessment for home and ambulatory oxygen therapy at follow-up appointments and before they are discharged if they are admitted to hospital because of an exacerbation of idiopathic pulmonary fibrosis.

## What the quality statement means for patients, service users and carers

People with idiopathic pulmonary fibrosis will have an assessment to find out whether oxygen therapy (extra oxygen) to use at home would help to ease their symptoms. This assessment will be done at every check-up and, if they are in hospital because of a flare-up of their condition, before they leave hospital.

## Source guidance

- [Idiopathic pulmonary fibrosis](#) (2013) NICE guideline CG163, recommendations 1.5.8 and 1.6.1(key priority for implementation).

## Definitions of terms used in this quality statement

### Assessment for oxygen therapy

Assessment for oxygen therapy is the process of deciding whether to prescribe oxygen to a person and how much to give them. This assessment may take account of whether the person with idiopathic pulmonary fibrosis is experiencing breathlessness and, based on clinical judgement, may involve blood gas tests and specific local protocols.

[Expert opinion]

### Oxygen therapy

Oxygen therapy involves breathing air with a higher concentration of oxygen. In someone with impaired lung function resulting in reduced oxygen levels, oxygen therapy can help to overcome

breathlessness by increasing the level of oxygen. Oxygen therapy is prescribed for use at home or during exercise and activities of daily living (ambulatory oxygen therapy).

[Expert opinion]

## Follow-up appointments

Appointments that are considered for people with idiopathic pulmonary fibrosis:

- every 3 months or sooner if they are showing rapid disease progression or rapid deterioration of symptoms or
- every 6 months or sooner if they have steadily progressing disease or
- initially every 6 months if they have stable disease and then annually if they have stable disease after 1 year.

[[Idiopathic pulmonary fibrosis](#) (NICE guideline CG163), recommendation 1.6.2]

# Quality statement 4: Pulmonary rehabilitation

## Quality statement

Pulmonary rehabilitation programmes provide services that are designed specifically for idiopathic pulmonary fibrosis.

## Rationale

Pulmonary rehabilitation is often tailored to chronic obstructive pulmonary disease and not to idiopathic pulmonary fibrosis. For people with idiopathic pulmonary fibrosis, pulmonary rehabilitation is more likely to contribute to improved health-related quality of life and exercise capacity if it is tailored to their condition.

## Quality measures

### Structure

Evidence of local arrangements to ensure that pulmonary rehabilitation programmes are tailored to the needs of people with idiopathic pulmonary fibrosis.

*Data source:* Local data collection.

### Process

Proportion of people with idiopathic pulmonary fibrosis who are offered pulmonary rehabilitation tailored to idiopathic pulmonary fibrosis.

Numerator – the number in the denominator whose pulmonary rehabilitation is tailored to idiopathic pulmonary fibrosis.

Denominator – the number of people with idiopathic pulmonary fibrosis who start pulmonary rehabilitation.

*Data source:* Local data collection.

## Outcomes

a) Quality of life and wellbeing of people with idiopathic pulmonary fibrosis.

*Data source:* Local data collection.

b) Hospital admissions, inpatient hospital days and readmissions for people with idiopathic pulmonary fibrosis.

*Data source:* Local data collection.

## What the quality statement means for service providers, healthcare professionals and commissioners

**Service providers** (hospitals and regional specialist centres) ensure that pulmonary rehabilitation programmes provide services designed specifically for idiopathic pulmonary fibrosis.

**Healthcare professionals** ensure that people with idiopathic pulmonary fibrosis receive pulmonary rehabilitation designed specifically for idiopathic pulmonary fibrosis.

**Commissioners** (NHS England through specialised services area teams and clinical commissioning groups) use collaborative commissioning to ensure that the services they commission provide pulmonary rehabilitation programmes that are designed specifically for idiopathic pulmonary fibrosis.

## What the quality statement means for patients, service users and carers

**People with idiopathic pulmonary fibrosis who could benefit from pulmonary rehabilitation** (sessions that teach people about how their lungs work and how to cope with symptoms such as breathlessness) are offered a programme that is specially designed for idiopathic pulmonary fibrosis.

## Source guidance

- [Idiopathic pulmonary fibrosis \(2013\) NICE guideline CG163, recommendation 1.5.3.](#)



## Definitions of terms used in this quality statement

### Pulmonary rehabilitation

A multidisciplinary programme of care for people with a chronic respiratory condition. It is tailored and designed to optimise each person's physical performance and their independence. Pulmonary rehabilitation includes education, exercise training, psychosocial support and advice on nutrition.

[Adapted from [full guideline on idiopathic pulmonary fibrosis](#)]

### Equality and diversity considerations

Pulmonary rehabilitation should be available to everyone with idiopathic pulmonary fibrosis who can benefit from it. To ensure equality of access to pulmonary rehabilitation, measures such as providing transport for people to attend rehabilitation sessions and providing the sessions in different locations should be considered. Pulmonary rehabilitation should be held in centres that have access for disabled people.

Healthcare professionals should take into consideration the communication needs of people with idiopathic pulmonary fibrosis when delivering pulmonary rehabilitation. All information should be in a format that the person receiving it can understand. If the person's first language is not English, an interpreter should be available.

## Quality statement 5: Palliative care

### Quality statement

People with idiopathic pulmonary fibrosis and their families and carers have access to services that meet their palliative care needs.

### Rationale

Symptoms of idiopathic pulmonary fibrosis, such as debilitating cough, can be difficult to manage and have a negative effect on a person's quality of life. There is no cure for idiopathic pulmonary fibrosis except lung transplantation, which may not be possible. Medication to treat the symptoms of idiopathic pulmonary fibrosis may be ineffective. People with idiopathic pulmonary fibrosis at any stage (not just at the end of life), and their families and carers, can benefit from palliative care services for symptom management and control, psychological care and the provision of information. Access to services to meet palliative care needs will depend on people with idiopathic pulmonary fibrosis and their families and carers having an effective assessment of their needs.

### Quality measures

#### Structure

Evidence of local arrangements to ensure that people with idiopathic pulmonary fibrosis and their families and carers have access to services that meet their palliative care needs.

*Data source:* Local data collection.

#### Process

a) Proportion of follow-up appointments for people with idiopathic pulmonary fibrosis with a recorded assessment of their current palliative care needs (including the needs of families and carers, if appropriate).

Numerator – the number in the denominator at which the current palliative care needs (including the needs of families and carers, if appropriate) have been assessed.

Denominator – the number of follow-up appointments for people with idiopathic pulmonary

fibrosis.

**Data source:** Local data collection.

b) Proportion of people with idiopathic pulmonary fibrosis whose current recorded palliative care needs (including the needs of families and carers, if appropriate) are met.

Numerator – the number in the denominator whose current palliative care needs (including the needs of families and carers, if appropriate) are met.

Denominator – the number of people with idiopathic pulmonary fibrosis whose palliative care needs have been assessed.

**Data source:** Local data collection.

## Outcome

Satisfaction of people with idiopathic pulmonary fibrosis, and their families and carers, with the support they receive to manage their condition.

**Data source:** Local data collection.

## What the quality statement means for service providers, healthcare professionals and commissioners

**Service providers** (GPs, community nursing teams, hospitals and regional specialist centres) ensure the availability of services that meet the palliative care needs of people with idiopathic pulmonary fibrosis and, if appropriate, their families and carers.

**Health and social care practitioners** ensure that the palliative care needs of people with idiopathic pulmonary fibrosis (and their families and carers, if appropriate) are identified and are met by referral to the appropriate services. If specialist input is needed to ensure that these needs are met, the palliative care team can be involved.

**Commissioners** (NHS England through specialised services area teams and clinical commissioning groups) use collaborative commissioning to ensure that services offer people with idiopathic pulmonary fibrosis (and their families and carers, if appropriate) palliative care needs assessment and access to services that meet their palliative care needs.

## What the quality statement means for patients, service users and carers

People who have idiopathic pulmonary fibrosis, and if they wish their families and carers, are offered services that help them manage and control the symptoms of idiopathic pulmonary fibrosis and provide psychological support and information about the condition.

### Source guidance

- [Idiopathic pulmonary fibrosis \(2013\) NICE guideline CG163, recommendation 1.5.10.](#)

## Definitions of terms used in this quality statement

### Palliative care needs

Palliative care is not only end of life care. It is an approach that improves the quality of life of patients and their families facing problems associated with serious illness. It is given as it is needed, including during the early stage of an illness, to identify, assess and treat pain and other problems. Palliative care services include (but are not limited to) self-help and support, patient and carer involvement, information giving, psychological support, symptom management and control, social support, rehabilitation and spiritual support.

Palliative care may be needed at all stages of idiopathic pulmonary fibrosis from diagnosis. Palliation of symptoms relies on a multidisciplinary approach that includes input from primary care, the interstitial lung disease specialist nurse and, if needed, specialists in palliative care. People with idiopathic pulmonary fibrosis do not need to be referred to specialists in palliative care unless their needs cannot be managed by other healthcare professionals.

[Adapted from [full guideline on idiopathic pulmonary fibrosis](#) and expert opinion]

# Using the quality standard

## Quality measures

The quality measures accompanying the quality statements aim to improve the structure, process and outcomes of care in areas identified as needing quality improvement. They are not a new set of targets or mandatory indicators for performance management.

We have indicated if current national indicators exist that could be used to measure the quality statements. These include indicators developed by the Health and Social Care Information Centre through its [Indicators for Quality Improvement Programme](#). If there is no national indicator that could be used to measure a quality statement, the quality measure should form the basis for audit criteria developed and used locally.

See NICE's [what makes up a NICE quality standard?](#) for further information, including advice on using quality measures.

## Levels of achievement

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, NICE recognises that this may not always be appropriate in practice, taking account of safety, choice and professional judgement, and therefore desired levels of achievement should be defined locally.

## Using other national guidance and policy documents

Other national guidance and current policy documents have been referenced during the development of this quality standard. It is important that the quality standard is considered alongside the documents listed in [development sources](#).

## Information for the public

NICE has produced [information for the public](#) about this quality standard. Patients, service users and carers can use it to find out about the quality of care they should expect to receive; as a basis for asking questions about their care, and to help make choices between providers of social care

services.

## Diversity, equality and language

During the development of this quality standard, equality issues have been considered and [equality assessments](#) are available.

Good communication between health, public health and social care practitioners and people with idiopathic pulmonary fibrosis is essential. Treatment, care and support, and the information given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English. People with idiopathic pulmonary fibrosis should have access to an interpreter or advocate if needed.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

## Development sources

Further explanation of the methodology used can be found in the [quality standards process guide](#) on the NICE website.

## Evidence sources

The documents below contain recommendations from NICE guidance or other NICE-accredited recommendations that were used by the Quality Standards Advisory Committee to develop the quality standard statements and measures.

- [BTS guideline on pulmonary rehabilitation in adults \(2013\)](#) British Thoracic Society.
- [Idiopathic pulmonary fibrosis \(2013\)](#) NICE guideline CG163.

## Policy context

It is important that the quality standard is considered alongside current policy documents, including:

- British Thoracic Society (2014) [BTS quality standards for pulmonary rehabilitation in adults](#).
- Department of Health (2013) [Improving quality of life for people with long term conditions](#).
- NHS England (2013) [NHS standard contract for respiratory: interstitial lung disease \(adult\)](#).
- NHS Lung Improvement (2013) [Improving the quality and safety of home oxygen services: the case for spread](#).

## Definitions and data sources for the quality measures

- British Thoracic Society [BTS Lung Disease Registry Programme – idiopathic pulmonary fibrosis \(ongoing audit\)](#).
- [Idiopathic pulmonary fibrosis: clinical audit tool \(2013\)](#) NICE guideline CG163.



## Related NICE quality standards

### Published

- [Smoking cessation: supporting people to stop smoking \(2013\)](#) NICE quality standard 43.
- [Lung cancer \(2012\)](#) NICE quality standard 17.
- [Patient experience in adult NHS services \(2012\)](#) NICE quality standard 15.
- [End of life care for adults \(2011\)](#) NICE quality standard 13.
- [Chronic obstructive pulmonary disease \(2011\)](#) NICE quality standard 10.

# Quality Standards Advisory Committee and NICE project team

## Quality Standards Advisory Committee

This quality standard has been developed by Quality Standards Advisory Committee 4. Membership of this committee is as follows:

**Miss Alison Allam**

Lay member

**Dr Harry Allen**

Consultant Old Age Psychiatrist, Manchester Mental Health and Social Care Trust

**Mrs Claire Beynon (until June 2014)**

Head of Threshold Management and Individual Funding Requests, NHS South West Commissioning Support Unit

**Dr Jo Bibby**

Director of Strategy, The Health Foundation

**Mrs Jane Bradshaw**

Lead Nurse Specialist in Neurology, Norfolk Community Health and Care

**Dr Allison Duggal**

Consultant in Public Health, Public Health England

**Mr Tim Fielding**

Consultant in Public Health, North Lincolnshire Council

**Mrs Frances Garraghan**

Lead Pharmacist for Women's Health, Central Manchester Foundation Trust

**Mrs Zoe Goodacre**

Network Manager, South Wales Critical Care Network

**Mr Malcolm Griffiths**

Consultant Obstetrician and Gynaecologist, Luton & Dunstable University Hospital NHS Foundation Trust

**Dr Jane Hanson**

Head of Cancer National Specialist Advisory Group Core Team, Cancer National Specialist Advisory Group, NHS Wales

**Ms Nicola Hobbs**

Assistant Director of Quality and Contracting, Northamptonshire County Council, Northampton

**Mr Roger Hughes**

Lay member

**Mr John Jolly**

Chief Executive Officer, Blenheim Community Drug Project, London

**Dr Damien Longson (Chair)**

Consultant Liaison Psychiatrist, Manchester Mental Health and Social Care Trust

**Dr Rubin Minhas**

GP Principal, Oakfield Health Centre, Kent

**Mrs Julie Rigby**

Quality Improvement Programme Lead, Strategic Clinical Networks, NHS England

**Mr Alaster Rutherford**

Primary Care Pharmacist, NHS Bath and North East Somerset

**Mr Michael Varrow**

Information and Intelligence Business Partner, Essex County Council

**Mr John Walker**

Head of Operations, Greater Manchester West Mental Health NHS Foundation Trust

## Specialist committee members

The following specialist members joined the committee to develop this quality standard:

**Dr Sanjay Agrawal**

Consultant respiratory consultant, Glenfield Hospital, University Hospitals of Leicester NHS Trust

**Dr Sabrina Bajwah**

Consultant in palliative medicine and honorary senior lecturer, King's College Hospital NHS Foundation Trust (member from July 2014)

**Dr Sujal Desai**

Consultant radiologist and honorary senior lecturer, King's College Hospital NHS Foundation Trust

**Dr Nick Screatton**

Consultant radiologist, Papworth Hospital NHS Foundation Trust

**Mr Malcolm Weallans**

Lay member

## **NICE project team**

**Dylan Jones**

Associate Director

**Shirley Crawshaw**

Consultant Clinical Adviser

**Tony Smith**

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**Rachel Neary-Jones**

Programme Manger

**Anthony Gildea**

Project Manager

**Nicola Cunliffe**

Coordinator

## About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

The methods and processes for developing NICE quality standards are described in the [quality standards process guide](#).

This quality standard has been incorporated into the NICE pathway on [idiopathic pulmonary fibrosis](#).

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ISBN: 978-1-4731-0976-6

## Endorsing organisation

This quality standard has been endorsed by NHS England, as required by the Health and Social Care Act (2012)

## Supporting organisations

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- [Action for Pulmonary Fibrosis](#)
- [Association of Respiratory Nurse Specialists](#)
- [British Lung Foundation](#)
- [British Thoracic Society](#)
- [Pulmonary Fibrosis Trust](#)
- [Royal College of Nursing \(RCN\)](#)
- [Royal College of Pathologists](#)
- [UK Clinical Pharmacy Association \(UKCPA\)](#)