

Idiopathic pulmonary fibrosis

NICE quality standard

Draft for consultation

August 2014

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 idiopathic pulmonary fibrosis [overview](#).

Why this quality standard is needed

Idiopathic pulmonary fibrosis is a chronic, progressive fibrotic interstitial lung disease of unknown origin. It is a serious disease in which the alveoli (the tiny air sacs of the lungs) and the lung tissue next to the alveoli become damaged and scarred. It is a difficult disease to diagnose and often requires the collaborative expertise of a consultant respiratory physician, thoracic radiologist and, if lung biopsy has been undertaken, a thoracic histopathologist to reach a consensus diagnosis. Most people with idiopathic pulmonary fibrosis have symptoms of breathlessness, which may initially be 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. Around two-thirds of people with idiopathic pulmonary fibrosis smoke, 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:

- enhancing the quality of life for people with idiopathic pulmonary fibrosis
- preventing premature mortality among people with idiopathic pulmonary fibrosis
- ensuring people have a positive experience of care
- reducing 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:

- [The Adult Social Care Outcomes Framework 2014–15](#) (Department of Health, November 2012)
- [NHS Outcomes Framework 2014–15](#)
- Improving outcomes and supporting transparency: a public health outcomes framework for England 2013–2016, [Part 1 and Part 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
1 Enhancing quality of life for people with care and support needs	<p>Overarching measure</p> <p>1A Social care-related quality of life*</p> <p>Outcome measures</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>
3 Ensuring that people have a positive experience of care and support	<p>Overarching measure</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>
Aligning across the health and care system	
* Indicator complementary with the NHS Outcomes Framework	

Table 2 [NHS Outcomes Framework 2014–15](#)

Domain	Overarching indicators and improvement areas
1 Preventing people from dying prematurely	<p>Overarching indicator</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>1.2 Under 75 mortality rate from respiratory disease*</p>
2 Enhancing quality of life for people with long-term conditions	<p>Overarching indicator</p> <p>2 Health-related quality of life for people with long-term conditions**</p> <p>Improvement areas</p> <p>Ensuring people feel supported to manage their condition</p> <p>2.1 Proportion of people feeling supported to manage their condition</p> <p>Reducing time spent in hospital by people with long-term conditions</p> <p>2.3 i Unplanned hospitalisation for chronic ambulatory care sensitive conditions</p> <p>Enhancing quality of life for carers</p> <p>2.4 Health related quality of life for carers**</p>
4 Ensuring that people have a positive experience of care	<p>Overarching indicator</p> <p>4a Patient experience of primary care</p> <p>i GP services</p>

	ii GP out-of-hours services 4b Patient experience of hospital care Improvement areas Improving hospitals' responsiveness to personal needs 4.2 Responsiveness to in-patients' personal needs Improving people's experience of accident and emergency services 4.3 Patient experience of A&E services
Alignment across the health and social care system * Indicator shared with Public Health Outcomes Framework (PHOF) ** Indicator complementary with Adult Social Care Outcomes Framework (ASCOF)	

Table 3 [Public health outcomes framework for England, 2013–2016](#)

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

Coordinated services

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.

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 with suspected idiopathic pulmonary fibrosis are diagnosed 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 and if they wish their families and carers.

[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.

[Statement 4](#). People with idiopathic pulmonary fibrosis who are suitable are offered pulmonary rehabilitation that includes exercise and educational components tailored to their needs.

[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.

Questions for consultation

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

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

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

Quality statement 1: Diagnosis

Quality statement

People with suspected idiopathic pulmonary fibrosis are diagnosed 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. Because of the severity of idiopathic pulmonary fibrosis and its prognosis, the consequences of misdiagnosis can be serious for people with the condition and their families. Early and accurate diagnosis and treatment can improve the person's quality of life and, in many cases, extend their life.

Quality measures

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.

Data source: Local data collection.

Process

Proportion of people diagnosed with idiopathic pulmonary fibrosis by a specialist multidisciplinary team.

Numerator – the number in the denominator whose condition was diagnosed by a specialist multidisciplinary team.

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 clinical guideline 163 audit support](#).

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

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

Healthcare professionals refer people to a specialist multidisciplinary team with expertise in interstitial lung disease when idiopathic pulmonary fibrosis is suspected.

Commissioners (NHS England through specialised services area teams collaborating with clinical commissioning groups) ensure that they commission services that provide a multidisciplinary team consisting of healthcare professionals with expertise in interstitial lung disease to diagnose people who have suspected idiopathic pulmonary fibrosis.

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

People who have symptoms of idiopathic pulmonary fibrosis are offered diagnosis by a specialist team of healthcare professionals who are skilled and experienced in diagnosing and treating lung diseases.

Source guidance

- [Idiopathic pulmonary fibrosis](#) (NICE clinical guideline 163), recommendations 1.2.2 (key priority for implementation) and 1.2.3.

Definitions of terms used in this quality statement

Interstitial lung disease

A term for a group of lung diseases of known and unknown cause and characterised by varying degrees of inflammation and fibrosis of the lung tissue.

[[NICE full clinical guideline CG163](#), glossary]

Suspected idiopathic pulmonary fibrosis

Idiopathic pulmonary fibrosis should be suspected if a person has these clinical features:

- 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.

[[NICE clinical guideline 163](#), recommendation 1.1.1]

Specialist multidisciplinary team

As a minimum, the multidisciplinary team should include a consultant respiratory physician, a consultant radiologist, an interstitial lung disease specialist nurse and a multidisciplinary team coordinator [[NICE clinical guideline 163](#), recommendation 1.2.3]. The consultant radiologist should be a thoracic radiologist [expert opinion]. In addition, the following members should 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.

See chapter 6.5 (Multidisciplinary Team) in [full guideline](#) for more information on the expertise of the multidisciplinary team.

[[NICE clinical guideline 163](#), recommendation 1.2.3]

Equality and diversity considerations

Specialists in interstitial lung disease may not be available in local hospitals and people with suspected idiopathic pulmonary fibrosis may need to travel to larger specialist centres for diagnosis. To ensure equality of access to care, measures

should be put in place to make it as easy as possible for people to attend specialist centres if necessary, for example by providing transport and offering appointments in centres that are located 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 and if they wish their families and carers.

Rationale

An interstitial lung disease specialist nurse can 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. 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 accessible at all stages of the care pathway to people with idiopathic pulmonary fibrosis, and if they wish their families and carers.

Data source: Local data collection.

Process

Proportion of people with idiopathic pulmonary fibrosis to whom an interstitial lung disease specialist nurse is available.

Numerator – the number in the denominator to whom an interstitial lung disease specialist nurse is available.

Denominator – the number of people with idiopathic pulmonary fibrosis.

Data source: Local data collection.

Process

Proportion of families and carers of people with idiopathic pulmonary fibrosis to whom an interstitial lung disease specialist nurse is available.

Numerator – the number in the denominator to whom an interstitial lung disease specialist nurse is available.

Denominator – the number of families and carers of people with idiopathic pulmonary fibrosis.

Data source: Local data collection

Outcome

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

Data source: Local data collection.

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

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

Healthcare professionals ensure that people with a diagnosis of idiopathic pulmonary fibrosis have access to an interstitial lung disease specialist nurse.

Commissioners (NHS England through specialised services area teams and clinical commissioning groups) use collaborative commissioning to provide an interstitial lung disease specialist nurse, at all stages of the care pathway, to people with idiopathic pulmonary fibrosis and if they wish their families and carers.

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 have a specialist nurse with training and experience in lung disease available to them at all stages of their care.

Source guidance

- [Idiopathic pulmonary fibrosis](#) (NICE clinical guideline 163), 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 or respiratory nurse with expertise in interstitial lung disease would be involved in a service seeing at least 500 people with interstitial lung disease per year or who has completed at least 6 months of specialist training in interstitial lung disease.

[[NICE full clinical guideline CG163](#), diagnosis]

Quality statement 3: Oxygen assessment

Quality statement

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.

Rationale

Oxygen therapy increases the amount of oxygen in the blood to prevent harm. It also relieves symptoms of breathlessness meaning that people with idiopathic pulmonary fibrosis are able to exercise. This is critical in maintaining lung function, allowing people to take part in pulmonary rehabilitation and sustain their quality of life.

Quality measures

Structure

a) Evidence of local arrangements to ensure that people with idiopathic pulmonary fibrosis are assessed for oxygen therapy if they are breathless at rest or on exertion when attending a secondary or tertiary care outpatient respiratory appointment.

Data source: Local data collection.

b) Evidence of local arrangements to ensure that people with idiopathic pulmonary fibrosis are assessed for oxygen therapy if they have been admitted to hospital because of idiopathic pulmonary fibrosis.

Data source: Local data collection.

Process

a) Proportion of people with idiopathic pulmonary fibrosis who are assessed for oxygen therapy if they are breathless at rest or on exertion when attending a secondary or tertiary care outpatient respiratory appointment.

Numerator – the number in the denominator assessed for oxygen therapy.

Denominator – the number of people with idiopathic pulmonary fibrosis attending a secondary or tertiary care outpatient respiratory appointment who are breathless at rest or on exertion.

Data source: Local data collection.

b) Proportion of people admitted to hospital because of idiopathic pulmonary fibrosis who are assessed for oxygen therapy before discharge.

Numerator – the number in the denominator assessed for oxygen therapy before discharge.

Denominator – the number of people admitted to hospital because of idiopathic pulmonary fibrosis.

Data source: Local data collection.

Outcome

Increase of exercise tolerance allowing people with idiopathic pulmonary fibrosis to participate in pulmonary rehabilitation.

Data source: Local data collection.

Outcome

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 highly specialist respiratory centres) ensure that assessment for oxygen therapy is available through a referral pathway for people with idiopathic pulmonary fibrosis. This assessment should be offered to people who are breathless at rest or on exertion, and before discharge to people who are admitted to hospital because of idiopathic pulmonary fibrosis.

Healthcare professionals ensure that they assess people with idiopathic pulmonary fibrosis for oxygen therapy if they are breathless at rest or on exertion, or before discharge if they have been admitted to hospital because 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 oxygen therapy for people who are breathless at rest or on exertion, and before discharge for people who have been admitted to hospital because of idiopathic pulmonary fibrosis. The commissioners should also develop referral pathways for access to oxygen therapy for these people.

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

People who have idiopathic pulmonary fibrosis who get out of breath either when resting, on exertion, or who are admitted to hospital because of idiopathic pulmonary fibrosis, are offered an assessment (before they leave hospital if they have been admitted to hospital) to find out whether they would benefit from oxygen therapy (extra oxygen) to use at home.

Source guidance

- [Idiopathic pulmonary fibrosis](#) (NICE clinical guideline 163), recommendations 1.5.6 (key priority for improvement), 1.5.7 and 1.5.8.

Definitions of terms used in this quality statement

Oxygen assessment

The process of deciding when to prescribe oxygen to a person and how much to give them.

[[NICE full clinical guideline CG163](#), glossary]

Oxygen therapy

Breathing air with a higher concentration of oxygen to increase the amount of oxygen in the blood to prevent harm.

[\[NHS Choices\]](#)

Quality statement 4: Pulmonary rehabilitation

Quality statement

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

Rationale

Pulmonary rehabilitation is often tailored to chronic obstructive pulmonary disease (COPD) and not to idiopathic pulmonary fibrosis. Pulmonary rehabilitation 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 and specifically to the individual as people will attend these sessions at different stages of the disease and therefore need different types of exercise and education.

Quality measures

Structure

Evidence of local arrangements to ensure that pulmonary rehabilitation programmes include exercise and educational components that can be 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 suitable are offered pulmonary rehabilitation that includes exercise and educational components tailored to their needs.

Numerator – the number in the denominator whose pulmonary rehabilitation includes exercise and educational components tailored to their needs.

Denominator – the number of people with idiopathic pulmonary fibrosis suitable for pulmonary rehabilitation.

Data source: Local data collection.

Outcome

Improvements in ability to exercise and reduction in tiredness leading to a better quality of life for people with idiopathic pulmonary fibrosis.

Data source: Local data collection.

Outcome

Reduction in hospital admissions, inpatient hospital days and readmissions.

Data source: Local data collection.

Outcome

Confidence to deal with and manage episodes of breathlessness.

Data source: Local data collection.

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

Service providers (hospitals and highly specialist respiratory centres) ensure that pulmonary rehabilitation that includes exercise and educational components tailored to the person's needs is available for people with idiopathic pulmonary fibrosis.

Healthcare professionals ensure that people with idiopathic pulmonary fibrosis who are suitable receive pulmonary rehabilitation that includes exercise and educational components tailored to the person's needs.

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 for people with idiopathic pulmonary fibrosis that includes exercise and educational components tailored to the person's needs.

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

People who have idiopathic pulmonary fibrosis who are suitable are offered pulmonary rehabilitation programmes that include exercise and educational elements tailored to their needs.

Source guidance

- [Idiopathic pulmonary fibrosis](#) (NICE clinical guideline 163), recommendations 1.5.3 and 1.5.4.

Definitions of terms used in this quality statement

Suitable

People with idiopathic pulmonary fibrosis for whom pulmonary rehabilitation is considered to be appropriate following assessment.

Pulmonary rehabilitation

This is a multidisciplinary programme of care for patients with chronic respiratory impairment. It is individually tailored and designed to optimise each person's physical and social performance and autonomy. Pulmonary rehabilitation includes patient education, exercise training, psychosocial support and advice on nutrition.

[[NICE full clinical guideline CG163](#), glossary]

Equality and diversity considerations

Individually-tailored pulmonary rehabilitation should be available to all people 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 people with disabilities.

Quality statement 5: Palliative care

Quality statement

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

Rationale

Symptoms of idiopathic pulmonary fibrosis, such as debilitating cough, can be difficult to manage and have a detrimental effect on the person's quality of life. There is no curative treatment for idiopathic pulmonary fibrosis other than lung transplantation, which is not suitable for most people. Medication to treat the symptoms of idiopathic pulmonary fibrosis is largely ineffective. People with idiopathic pulmonary fibrosis, and their families and carers, can benefit from the expertise in symptom management and control, and psychological care, that is provided by a palliative care team.

Quality measures

Structure

Evidence of local arrangements to ensure that people with idiopathic pulmonary fibrosis, and their families and carers, have access to the full range of services offered by palliative care teams.

Data source: Local data collection.

Process

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

Numerator – the number in the denominator who have, or whose families and carers have, been referred to palliative care teams.

Denominator – the number of people with idiopathic pulmonary fibrosis.

Data source: British Thoracic Society's [BTS Lung Disease Registry Programme for idiopathic pulmonary fibrosis](#).

Outcome

Satisfaction of people, 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 (hospitals and highly specialist respiratory centres) ensure that a full range of palliative care services is available to people with idiopathic pulmonary fibrosis and, if they wish, their families and carers.

Health and social care practitioners ensure that people with idiopathic pulmonary fibrosis are referred to the full range of services offered by palliative care teams.

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, access to the full range of services provided by palliative care teams.

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

People who have idiopathic pulmonary fibrosis, and their families and carers, are referred to palliative care teams who can offer help and support to manage symptoms, psychological support and information about their condition.

Source guidance

- [Idiopathic pulmonary fibrosis](#) (NICE clinical guideline 163), recommendation 1.5.10.

Definitions of terms used in this quality statement**Palliative care**

Palliative care is care aimed at alleviating symptoms, pain and distress, and hence improving quality of life.

[\[NICE clinical guideline 101 Chronic obstructive pulmonary disease\]](#)

Status of this quality standard

This is the draft quality standard released for consultation from 26 August 2014 to 23 September 2014. It is not NICE's final quality standard on idiopathic pulmonary fibrosis. The statements and measures presented in this document are provisional and may change after consultation with stakeholders.

Comments on the content of the draft standard must be submitted by 5pm on 23 September 2014. All eligible comments received during consultation will be reviewed by the Quality Standards Advisory Committee and the quality statements and measures will be refined in line with the Quality Standards Advisory Committee's considerations. The final quality standard will be available on the [NICE website](#) from January 2015.

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'

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](#). British Thoracic Society (2013).
- [Idiopathic pulmonary fibrosis](#). NICE clinical guideline 163 (2013).

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: audit support](#). NICE clinical guideline 163 (2013).

Related NICE quality standards

Published

- [Smoking cessation: supporting people to stop smoking](#). NICE quality standard 43 (2013)
- [Lung cancer for adults](#). NICE quality standard 17 (2012)
- [Patient experience in adult NHS services](#). NICE quality standard 15 (2012)

- [End of life care for adults](#). NICE quality standard 13 (2011)
- [Chronic obstructive pulmonary disease](#). NICE quality standard 10 (2011).

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:

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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](#).

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