NICE National Institute for Health and Care Excellence

NICE quality standard

Idiopathic pulmonary fibrosis in adults

Quality standard

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This standard is based on CG163.

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

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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 source: Data is collected on the percentage of new idiopathic pulmonary fibrosis referrals discussed at an interstitial lung disease multidisciplinary team meeting within 2 months of first assessment in the specialised service by the British Thoracic Society interstitial lung disease (BTS ILD) registry, clinical Information question 2.8: what was the outcome of the multidisciplinary team meeting?, and the NHS England interstitial lung disease (specialised services) quality dashboard (RESP06a-ILD).

What the quality statement means for different audiences

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.

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 in adults: diagnosis and management. NICE guideline CG163

(2013, updated 2017), 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 NICE's guideline on idiopathic pulmonary fibrosis in adults, 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. [NICE's guideline on idiopathic pulmonary fibrosis in adults, 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.

[NICE's guideline on idiopathic pulmonary fibrosis in adults, 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 NICE's full guideline on idiopathic pulmonary fibrosis in adults.

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. [NICE's full guideline on idiopathic pulmonary fibrosis in adults]

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 different audiences

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.

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 in adults: diagnosis and management. NICE guideline CG163 (2013, updated 2017), 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. [NICE's full guideline on idiopathic pulmonary fibrosis in adults 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 different audiences

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.

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 in adults: diagnosis and management. NICE guideline CG163 (2013, updated 2017), 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.

[NICE's guideline on idiopathic pulmonary fibrosis in adults, 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 different audiences

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.

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 in adults: diagnosis and management. NICE guideline CG163 (2013, updated 2017), 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 NICE's full guideline on idiopathic pulmonary fibrosis in adults]

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 different audiences

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.

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 in adults: diagnosis and management. NICE guideline CG163 (2013, updated 2017), 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 NICE's full guideline on idiopathic pulmonary fibrosis in adults and expert opinion]

Update information

Minor changes since publication

July 2022: The data source for statement 1 process measure was updated.

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.

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, this may not always be appropriate in practice. Taking account of safety, shared decision-making, choice and professional judgement, desired levels of achievement should be defined locally.

Information about how NICE quality standards are developed is available from the NICE website.

See our webpage on quality standards advisory committees for details about our standing committees. Information about the topic experts invited to join the standing members is available from the webpage for this quality standard.

NICE has produced a quality standard service improvement template to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE guidance and quality standards apply in England and Wales. Decisions on how they apply in Scotland and Northern Ireland are made by the Scottish government and Northern Ireland Executive. NICE quality standards may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

Diversity, equality and language

Equality issues were considered during development and equality assessments for this quality standard are available. Any specific issues identified during development of the

quality statements are highlighted in each statement.

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.

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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 Thoracic Society
- Pulmonary Fibrosis Trust
- Royal College of Nursing (RCN)
- Royal College of Pathologists
- UK Clinical Pharmacy Association (UKCPA)
- Asthma and Lung UK