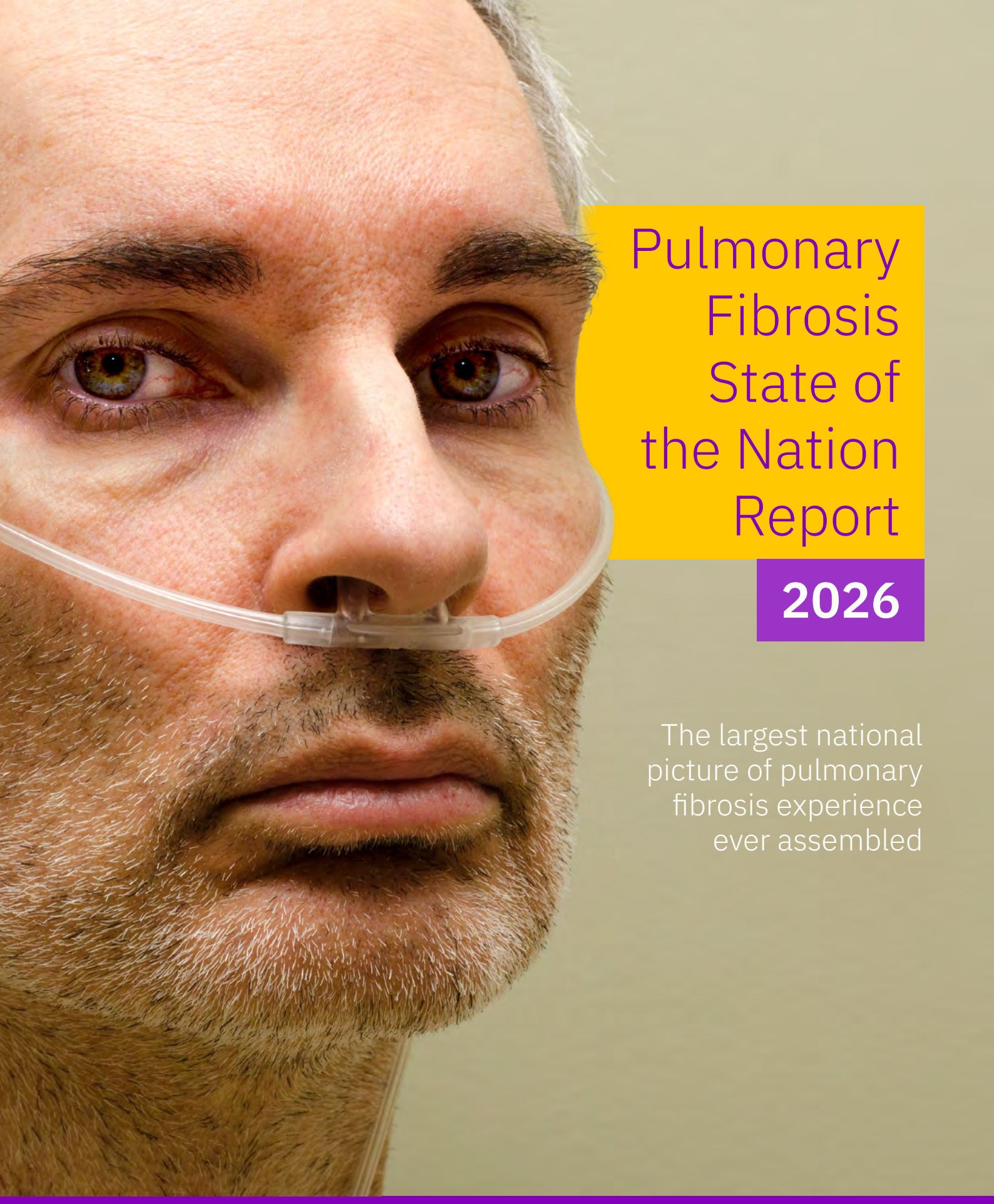


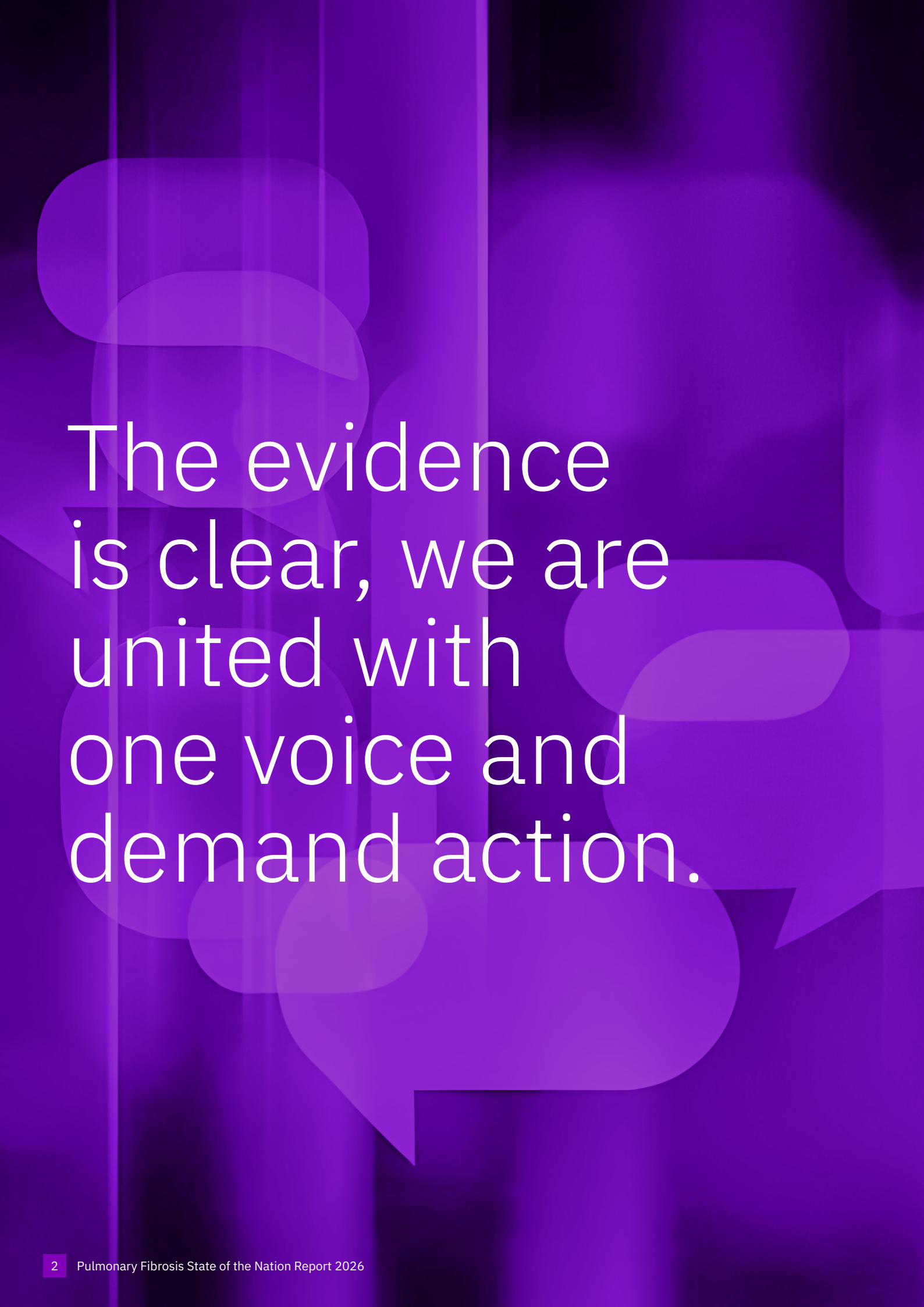
Pulmonary Fibrosis State of the Nation Report

2026

The largest national picture of pulmonary fibrosis experience ever assembled

actionpf.org

Action for Pulmonary Fibrosis


The evidence is clear, we are united with one voice and demand action.

Action for Pulmonary Fibrosis

Contents

Executive Summary

Pulmonary fibrosis (PF) is a terminal lung condition with outcomes comparable to many cancers. Despite this, people affected by PF face long delays to diagnosis, a postcode lottery for access to specialist care and treatment and limited access to the support they desperately need to live well.

Even though up to 150,000 people in the UK are currently living with this devastating illness, there are no dedicated programmes in place to ensure fast and accurate diagnosis, nor equitable access to treatments and supportive care. [1,2]

This report, backed by a survey of over 1,200 individuals, highlights key aspects of the current care pathway, including: time to referral; consultation and diagnosis; distance to treatment centre; rates of misdiagnosis; and access to treatment and supportive services. It also identifies gaps in care between the aims of current models of PF care and patient experience and outcomes.

Delays and misdiagnosis

Early and accurate diagnosis and treatment of PF is essential to maximise quality of life and slow disease progression for as long as possible. Alarmingly, one in three respondents were misdiagnosed with typical symptoms like breathlessness and persistent cough being mistaken for less severe conditions like asthma or chronic obstructive pulmonary disease (COPD).

Additionally, many cited having to attend multiple medical appointments before being referred and had difficulty accessing specialist care. This results in people with suspected PF not only facing extended delays for diagnosis, but many progressing to a point where disease-slowing treatments are no longer effective.

33%
of respondents waited over a year for a confirmed diagnosis

1 in 5
people reported seeing a medical professional at least five times before being referred to a specialist

1 in 3
respondents reported being misdiagnosed

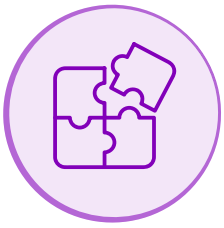
[1] Incidence and prevalence of asthma, chronic obstructive pulmonary disease and interstitial lung disease between 2004 and 2023: harmonised analyses of longitudinal cohorts across England, Wales, South-East Scotland and Northern Ireland | Thorax

[2] Incidence and survival of interstitial lung diseases in the UK in 2010–2019 - PMC

Post-diagnosis support

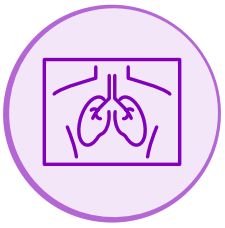
Access to services such as pulmonary rehabilitation, dietetics, palliative care and psychological support are designed to improve symtom management and quality of life. However, access to these services is a ‘postcode lottery’ and PF treatment is often poorly integrated with the rest of an individual’s healthcare.

Equally, patients face significant shortfalls in provision of information, communication and coordination of care, with nearly 40% reporting that the information they received at diagnosis did not adequately prepare them for what to expect from their condition or care.



7%

of respondents reported that their PF care was well coordinated with their primary care



28%

of respondents were not informed about pulmonary rehabilitation

52%

of respondents were not told about the benefits of physiotherapy or occupational therapy

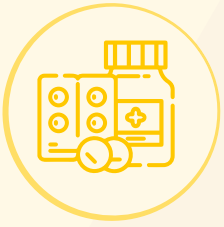
Access and experience of treatment

The survey also identified a strong link between distance to the treatment centre and speed of diagnosis. Among respondents who received a diagnosis within three months, 40% lived within 20 miles of their specialist centre, whereas almost half of those living more than 100 miles away waited up to two years for a confirmed diagnosis.

This highlights the extent of geographical inequalities in PF care across the UK and demonstrates their direct impact on patient experience and outcomes. Many patients must also travel while on oxygen, manage symptoms of exhaustion due to their condition and shoulder the additional financial burden of transport costs.

~50%

Almost half of people living more than 100 miles away from their treatment centre waited up to two years for a confirmed diagnosis



75%

reported experiencing multiple side effects of antifibrotic treatment

Conclusion

These findings show that the current model of pulmonary fibrosis care is not delivering timely or equitable support for patients. Too many people face avoidable delays, inconsistent standards and unequal access to specialist care depending on where they live. Everyone living with pulmonary fibrosis should receive fast diagnosis, effective treatment and the right support, as close to home as possible. Action is now urgently needed to strengthen ILD services across all four UK nations through clear time-bound pathways and consistent standards of care. This report sets out the evidence for change, and the priorities that must now be delivered.

Foreword

A diagnosis of pulmonary fibrosis is life changing. It is a progressive, terminal condition and for many people in our community, time becomes the most precious thing they have. Every breath matters. Yet too often, people affected by pulmonary fibrosis are left waiting. Waiting to be believed. Waiting for a diagnosis. Waiting for access to the care and support that could help them live better, for longer.

This report is built on the experiences of our community from across the UK. People living with pulmonary fibrosis, those who care for them and those who have been bereaved have come together to share what they have faced. Their voices tell a clear and consistent story. The system is not moving fast enough, care is not equal and too many people are being left behind.

Pulmonary fibrosis has outcomes comparable to many cancers but people with pulmonary fibrosis do not experience the same urgency of response. Delays, misdiagnosis, fragmented care and postcode lotteries are not inevitable features of a complex disease. They reflect how services are currently organised and delivered. Our community does not have time to wait for gradual change. Different choices are needed now.

At Action for Pulmonary Fibrosis, we believe that lived experience must shape the services designed to support it. This report highlights the case for change clearly. Care must be brought closer to home and specialist expertise must be shared, not siloed. Alongside this, clear, consistent pathways must exist in every UK nation so that where someone lives no longer determines the care they receive.

That is why we created OneVoiceILD. It is our programme for bringing people affected by pulmonary fibrosis together with clinicians, the NHS, policymakers, commissioners, researchers and industry.

This report does more than expose the issue; it calls for immediate change.

Its purpose is simple: to agree what good care should look like and to make sure it is delivered consistently across the UK. However, agreement alone is not enough. OneVoiceILD can only succeed if every part of the system moves with urgency and accepts accountability for delivery. Our community cannot afford delay.

We will continue to press for faster and more accurate diagnosis so people are not repeatedly turned away, misdiagnosed or treated for conditions they do not have. We will continue to campaign for equal access to treatment and support, including specialist nursing, pulmonary rehabilitation, psychological support and palliative care aswell as the medicines that can slow disease progression. We will continue to put lived experience at the centre of everything we do, using evidence to drive improvement and to hold the system to account.

This report does more than expose the issue; it calls for immediate change. To the NHS, to government, to clinicians and to everyone who shapes services, our community is ready to work with you. We need you to move faster and to show that change is happening. Lives depend on it.

Daniel Saxton
Chief Executive Officer

About Pulmonary Fibrosis

What is pulmonary fibrosis?

Pulmonary fibrosis is a terminal form of interstitial lung disease (ILD) that involves scarring of the lung lining. Over time, scarring causes the lungs to stiffen and lose their ability to fully expand, making breathing progressively more difficult. PF is a devastating illness that eventually robs individuals of their independence and quality of life.

The course of PF can vary depending on the individual and subtype of disease, with both progression and outcomes varying widely. Lung scarring cannot be reversed, and current treatments only slow the progression of the disease. Supportive approaches such as pulmonary rehabilitation, oxygen therapy, and in some cases lung transplantation, can also play an important role in expanding and improving quality of life for people living with PF.

What causes pulmonary fibrosis?

- Idiopathic pulmonary fibrosis (IPF) is the most common and severe form of PF. Its cause is unknown and it often progresses quickly. IPF is more common in men and people over 70 years of age.[3]
- PF can develop because of other underlying conditions, such as autoimmune diseases like rheumatoid arthritis. These subtypes are most common in women, who are disproportionately affected by auto-immune diseases.
- Long-term exposure to dust, chemicals or other airborne irritants can also lead to PF. Those working in construction, farming or with wood or birds are at higher risk – this is usually classed as occupational PF.
- When PF occurs in several members of the same family, it's known as familial pulmonary fibrosis (FPF).

Formerly considered a 'rare' condition, the prevalence of pulmonary fibrosis is now recognised as being higher than previously thought and the incidence is rising. Recent estimates suggest that up to 150,000 people are living with PF across the UK.[4,5]

Pulmonary fibrosis in the UK

Accurately measuring the impact of PF in the UK is challenging. How patients are recorded on NHS databases differs greatly across regions, teams and even individuals. This lack of consistency directly impacts reliable data collection.

Recent studies combining data sources across levels of care suggest that PF and other interstitial lung diseases (ILDs) are more common than once thought, though true numbers are likely to be even higher than current estimates.

The rise in ILD diagnoses over the past decade is linked to an ageing population, better diagnostic tools and more incidental findings through national screening programmes.

Despite these developments, PF services have not kept pace with rising demand or clinical and technological progress. Many patients who are facing a poor prognosis and no cure are also subject to cumulative delays along the care pathway.

[3] Idiopathic pulmonary fibrosis in the UK: findings from the British Thoracic Society UK Idiopathic Pulmonary Fibrosis Registry

[4] Incidence and prevalence of asthma, chronic obstructive pulmonary disease and interstitial lung disease between 2004 and 2023: harmonised analyses of longitudinal cohorts across England, Wales, South-East Scotland and Northern Ireland | Thorax

[5] Incidence and survival of interstitial lung diseases in the UK in 2010–2019 - PMC

Pulmonary fibrosis prognosis

For people with IPF, the most common form of PF, median life expectancy is just 3–5 years. Outcomes are significantly worse for those living in socially deprived areas, compared to the least deprived areas in their region and for those living further away from a hospital.[6]

For people with progressive forms of PF that are not idiopathic, referred to here as PF-ILD (progressive fibrosing interstitial lung disease), prognosis can vary depending on disease subtype and timing of intervention. Some patients will respond well to immunosuppressive therapies and the early stages of some subtypes with inflammatory causes can be prevented from becoming progressive PF if treated early. For people who develop PF as a secondary condition, fibrosis often becomes the biggest threat to their health, more so than the underlying cause.[7]

Although treatment options have improved with the availability of antifibrotic drugs, these therapies are non-curative and can cause severe and debilitating side effects, such as nausea and diarrhoea. Access to antifibrotics varies widely across the UK, reinforcing existing health inequalities.

The reality of these systematic challenges was exposed in Action for Pulmonary Fibrosis's (APF) 2023 report, "I Wish It Was Cancer", which was, prior to this report, the largest survey ever conducted on PF lived experience.[8]

State of the Nation 2026

I Wish It Was Cancer drew directly from the experiences of over 1,200 PF-affected participants, exposing major shortcomings in PF care across all four nations of the UK and highlighting an urgent need to transform interstitial lung disease (ILD) services.

In response to these challenges, APF brought together the UK's first multi-stakeholder movement to address vital issues in PF care under the name of OneVoiceILD. The following year, OneVoiceILD designed and published a new optimum ILD care pathway for services in England. In parallel, further collaborations have taken place with teams across the devolved nations to develop standardised, patient-focused models of care tailored to each nation's needs and health system. However, significant gaps remain in gathering comprehensive, consistent data on PF, limiting understanding of its true impact and hindering transformation of patient services. To address this, APF conducted an additional national survey to gather robust evidence and highlight the inequalities, inefficiencies and opportunities for improvement in current care provision.

The findings of the State of the Nation survey, presented here, provide a vital evidence base that echoes clinical consensus and lived experience, strengthening the urgent case for nationwide improvements in PF and ILD services.

38%

of participants reported that the delays they faced could have been avoided.

[6] Assessment of the impact of social deprivation, distance to hospital and time to diagnosis on survival in idiopathic pulmonary fibrosis - Respiratory Medicine

[7] Pathophysiology of Pulmonary Fibrosis in the Context of COVID-19 and Implications for Treatment: A Narrative Review - PubMed

[8] People with lived experience of PF at the heart of survey set to influence change – Action for Pulmonary Fibrosis

I had to battle for my mother regularly – others may not have anyone to fight for them. Hopefully this report will mean PF is taken a lot more seriously.

Milan, London
A bereaved carer for his mother who died of pulmonary fibrosis

Survey Methodology

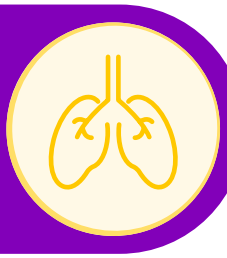
Development

The survey was designed as a patient-led, inclusive process to capture the true experiences and priorities of people affected by pulmonary fibrosis (PF). Initial focus groups included individuals living with PF, carers and bereaved participants using targeted discussions to identify key issues.

Recruitment

Participants were recruited through the APF and OneVoiceILD stakeholder network, PF support groups, respiratory/ILD clinics and social media, to ensure broad and inclusive representation. Materials were available online, over the phone and in paper form and translated where necessary, to support participation by people with accessibility needs and whose first language is not English.

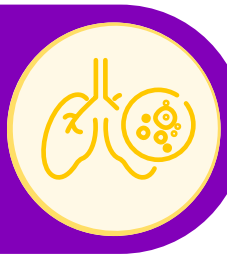
3
had received a **lung transplant**



154
were defined as **carers** of people with PF

176
were **bereaved carers** of people with PF

937
were currently **living with pulmonary fibrosis**



Participant details

In total, **1,270 individuals** were surveyed:

To avoid the same people being counted twice - due to responses from both patients and their carers – and to ensure the data is as representative as possible, **some analyses look only at the responses from patients and bereaved individuals (1,116 people)**. Where we have done this, it has been noted.

More than half (65%) of the responses received represented the experience of people with IPF. The next three most common ILD respondent subtypes were hypersensitivity pneumonitis (HP), rheumatoid arthritis-related ILD (RA-ILD) and connective tissue disorder-related ILD (CTD-ILD).

Distribution and reach

Responses were received from across all four nations of the UK:

- England: 80%
- Scotland: 9%
- Wales: 8%
- Ireland: 3%
- [Devolved: 20%]

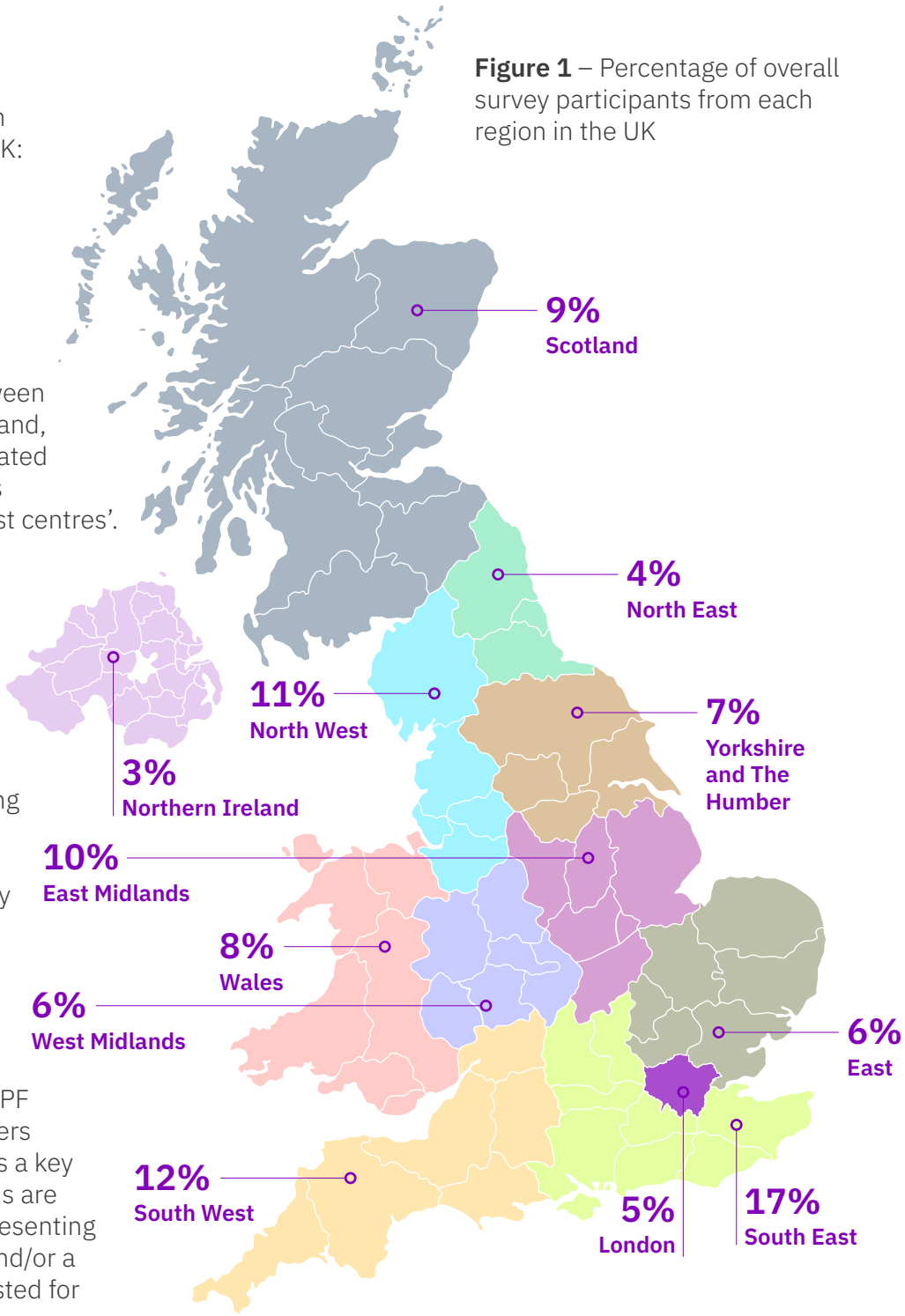
The model of care differs between the devolved nations and England, where ILD services are designated as 'specialist' and treatment is centralised within 24 'specialist centres'.

For this reason, comparisons have been made between services in England and the collective devolved nations.

Overall, 73% of respondents were diagnosed after the age of 65. This reflects the large proportion of respondents living with IPF, which is more common in later life. However, the age at diagnosis differed by subtype, for example, 69% of people with sarcoidosis were diagnosed before the age of 56.

These patterns are consistent with known age trends across PF subtypes, but there were outliers found in each subgroup. This is a key reminder that diagnostic trends are not rules and any individual presenting with breathlessness, fatigue and/or a persistent cough should be tested for potential PF as standard.

Figure 1 – Percentage of overall survey participants from each region in the UK



Results

1. Delays and misdiagnosis

A. Awareness and symptom recognition

1. Low awareness of symptoms amongst people with PF and primary healthcare professionals significantly delayed diagnosis.
2. Almost one in five (17%) reported their symptoms during more than five medical appointments before being referred, with 14% waiting more than a year for specialist referral.

B. Navigating the system

1. Despite the introduction of targeted diagnostic tools such as NHS England's Breathlessness Pathway, referral times remained slightly longer than in devolved nations.
2. In the devolved nations, 36% of those presenting to their GP with PF symptoms were referred to a specialist within 1 month, compared to 34% in England.

C. Misdiagnosis

1. Misdiagnosis of common symptoms, such as breathlessness and a persistent cough, often attributed to other conditions like asthma, COPD or even ageing, further prolongs the time to diagnosis.
2. One in three respondents reported receiving an incorrect diagnosis prior to their PF diagnosis, with 71% being started on treatment for a disease they didn't have.

[This section looks at the answers given by only people living with PF and bereaved by PF (n = 1,116)].

With no cure for lung fibrosis, timely entry onto the appropriate care pathway is essential to enable early intervention that can improve both quality and length of life.

However, unlike for other conditions such as cancer, ILD services across the UK currently operate without nationally mandated timeframes for diagnosis or treatment initiation, so prolonged times to diagnosis are not being addressed.

During delays, the disease can progress beyond the point where antifibrotic therapies - which slow the decline in lung-function - are effective. If lung function declines too much before there is opportunity to be considered for treatment, these disease-slowing treatments are no longer an option.[9,10]

48% of respondents reported waiting more than six months for a confirmed diagnosis, with 34% waiting over a year.

[9] Overview | Nintedanib for treating progressive fibrosing interstitial lung diseases | Guidance | NICE

[10] Overview | Pirfenidone for treating idiopathic pulmonary fibrosis | Guidance | NICE

[11] NHS England » Adult breathlessness pathway (pre-diagnosis): diagnostic pathway support tool

Delays not only increase the risk of disease progression but also reduce the window for treatment, which in turn heightens patient anxieties around their condition. The NHS England Breathlessness Pathway was designed and implemented in 2023, to trigger urgent and appropriate investigations for anyone presenting with breathlessness and address delays and high instances of misdiagnosis.[11] However, tools such as this have so far been unsuccessful in overcoming these challenges and wider restructuring the current model of care and new nationwide standards are needed.

To combat this, diagnosis, treatment initiation and ongoing management should be decentralised and delivered closer to where patients live, wherever they live.

This will reduce travel time, cost and disruption for patients and their families who are likely to be facing difficulties in mobility and financial strain due to this terminal illness.

This will enable earlier, easier, and more equitable access to specialist care. An integrated, regional approach - sharing expertise and responsibility between primary care, local respiratory services and specialist centres - could help reduce delays, speed up referrals and ultimately improve outcomes for people living with PF. This model of care is described in the OneVoiceILD Optimum Care Pathway for ILD services in England. These recommended changes reflect NHS long-term goals for other disease types and highlight that respiratory care – particularly PF services – should be a priority area for urgent transformation.

> A diagnosis like this lifts a curtain on a world you really wish you didn't see. Death doesn't scare me, but living poorly before does.

Meg, Wales
Living with hypersensitivity pneumonitis, a form of pulmonary fibrosis

Results

1A. Awareness and symptom recognition

For a timely diagnosis of any disease, it is essential to recognise the symptoms and speak to a healthcare professional as soon as possible. We often hear from patients that the first time they hear the term pulmonary fibrosis is when they are first diagnosed. This is problematic, as poor awareness and recognition of the condition and its symptoms can prevent people from seeking timely medical advice.

90%

of respondents reported experiencing multiple PF symptoms before diagnosis.

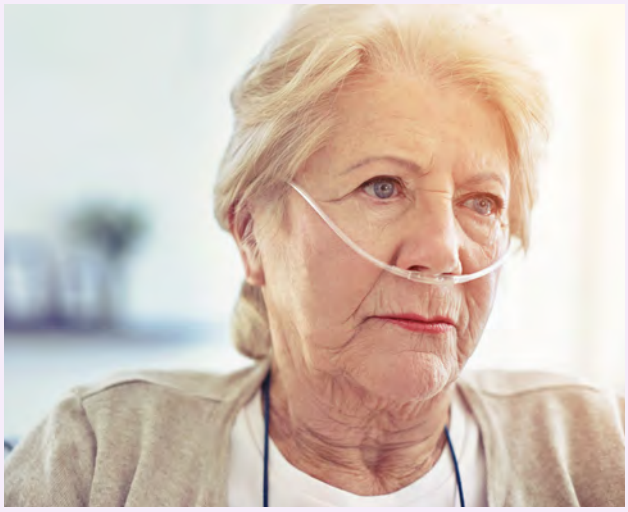
The majority of respondents, 80%, had never heard of PF before they, or the person they cared for, were diagnosed. Surprisingly, those with prior awareness did not consistently seek help earlier – this suggests that additional barriers exist beyond PF awareness that prevent timely reporting and diagnosis. Further investigation is needed to understand what systematic or practical barriers may be preventing people experiencing symptoms from seeking help quickly.

Once patients do seek advice, many then experience long delays in being referred from primary care to a respiratory specialist - often at least several months and up to more than a year - despite presenting with indicative symptoms like breathlessness and persistent cough.

These symptoms are frequently misdiagnosed as asthma, chronic obstructive pulmonary disease (COPD), aging or even psychosomatic conditions. A high rate of misdiagnosis was consistent across the UK.[12]

The results found that despite the Breathlessness Pathway being purpose-designed to speed them up, only 61% of patients in England were referred within three months compared to 64% in Scotland.

This highlights that the national initiative has been insufficient in addressing the challenges in England. This could be due to a disparity around implementation locally, or the lack of specific policy directives to facilitate implementation effectively, such as an updated service specification and commissioning standards. Such directives will be vital to properly facilitate the implementation of the OneVoiceILD optimum integrated clinical care pathway.[13]



[12] Misdiagnosis of PF – see page 4

[13] APF - Transforming ILD services

1B. Navigating the system

Diagnosing PF is complex. Diagnosis typically involves blood analysis, a lung function test (spirometry) and a high-resolution CT scan to confirm the presence of progressive lung scarring.[14] Most of these tests are carried out in a secondary care unit (a local hospital) or an ILD specialist centre, if receiving care in England. Getting to this stage as quickly as possible is essential.

Currently, where a person lives significantly affects access to pulmonary fibrosis (PF) care, creating geographic inequalities. These disparities impact not only the ability to obtain specialist input but also the timeliness of diagnosis. Repeated visits to general practitioners and delays in accessing specialist services can worsen health outcomes and increase the use of healthcare resources.

It's essential to be diagnosed with an exact subtype of PF as they may have different treatments and outcomes. This is complex and requires the right tests and screening from healthcare professionals and may need specialist discussion by a range of ILD experts at a diagnostic multidisciplinary team (MDT) meeting. Local pathways must ensure that all people with suspected PF can access this expertise no matter where they live.

Our analysis shows that while most respondents (73%) initially report symptoms to their GP, almost two thirds (65%) of those in England were subject to **multiple appointments before being referred to a specialist** (63% in Scotland; 71% in Wales).

Specialist referrals often led to further inequalities. While PF-ILD cases were more likely to be referred after just one GP appointment, IPF cases were more likely to require five or more appointments before referral.

Jess's Rule, recently implemented in England, encourages GPs to **reassess patients with ongoing symptoms after three appointments**, helping to reduce repeated consultations without diagnosis. This policy has the potential to **improve diagnostic timelines, reduce regional disparities and ensure faster access to specialist ILD care**.

People who were referred to a specialist from within other respiratory services reported the longest waits for a diagnosis, with almost half of all respondents (48%) waiting a year or more.

This suggests that misdiagnosed conditions are being treated within respiratory care and are going unchecked for prolonged periods of time.

This is underlined by the finding that referral timelines vary by PF subtype. Patients with connective tissue disease–related ILD (CTD-ILD) were most likely to receive prompt specialist assessment, with 81% referred within six months of referral. In contrast, only two-thirds (67%) of people with sarcoidosis were seen within the same timeframe and 13% waited over two years for specialist evaluation.

[14] Quality statements | Idiopathic pulmonary fibrosis in adults | Quality standards | NICE

1B. Navigating the System (continued)

These differences suggest variation in perceived clinical urgency between subtypes and specialties, with rheumatology pathways showing more consistent monitoring and escalation compared with other referral routes.

Delayed referrals are further compounded by subsequent waits to be seen by a specialist. Our survey found that most ILD patients (80%) are seen by a specialist within six months of referral, though access varies by subtype. Patients with CTD-ILD, HP, COVID-19-ILD and IPF are seen fastest (over 50% seen within 3 months), while people with sarcoidosis, NSIP and uncertain diagnoses face longer waits (more than 50% waiting more than 3 months).

The set-up of ILD services is different in England than in the devolved nations, as ILD services are classified as 'specialist' in England and aspects of care – including prescribing of antifibrotic drugs – can only be carried out by specialists within 24 recognised ILD centres. In the devolved nations, ILD is integrated within wider respiratory services. This means that antifibrotic drugs can be prescribed by non-specialists within respiratory units. This makes care more widely available in a geographic sense but can mean that people with PF are cared for by healthcare professionals who are not specialised and may not have interest or experience in ILD care.

Findings confirmed that collectively, ILD services in the devolved nations are performing more efficiently than those in NHS England: more patients are seen within three months in Scotland (58%) and Wales (61%), compared with England (47%). Over a quarter (27%) of people receiving care in England reported what they deemed to be a 'considerable wait'.

Severe diagnostic delays were more pronounced in England, with only 34% diagnosed within 3 months, compared with 51% in Scotland and 42% in Wales.

A regional network approach would enable the sharing of specialist expertise in diagnosis, including subtyping, through the discussion of cases within regional virtual multidisciplinary teams (MDTs). For patients in England, this would reduce the need to travel to already backlogged specialist ILD centres, removing unnecessary delays in care. Across the devolved nations, specialist knowledge would be brought to a local level, while also upskilling healthcare professionals working in general respiratory services.

1C. Misdiagnosis

Misdiagnosis was common within the survey cohort, with nearly a third (32%) of participants reporting an incorrect diagnosis prior to their PF diagnosis. This proportion was seen in both England and the devolved nations; however, misdiagnosis was slightly higher among people with PF-ILD (36%), compared with IPF (30%).

Patterns of initial misdiagnosis also varied by sex: among female participants, the most common incorrect diagnoses were heart disease (63%), asthma (56%) and pneumonia (56%). Male participants were more often misdiagnosed with infection (54%), COPD (53%) and pneumonia (44%).

A substantial proportion of misdiagnosed patients, 33%, did not feel their initial health concerns were believed and taken seriously, compared with 15% of those diagnosed correctly. This highlights the critical role of effective patient–provider communication in achieving accurate diagnoses in people with PF.

33%

of respondents who were misdiagnosed did not feel their health concerns were taken seriously.

Full diagnostic investigations are often delayed, with treatment initially directed toward presumed conditions. As a result, patients can remain under respiratory care teams for extended periods before receiving a definitive, accurate PF diagnosis.

The delay caused by misdiagnosis allows PF to progress unmonitored and unimpeded, increasing the likelihood of acute exacerbations, hospital admissions, other costly urgent care treatments, and ultimately earlier death.

Many misdiagnosed patients received treatment for an incorrect condition prior to their PF diagnosis: over 73% of males and almost 70% of females. Given the most common misdiagnoses, more than 23% of patients were exposed to treatments such as steroids and beta-blockers, which can exacerbate breathlessness and heighten risk of potentially fatal infection.

The high rate of misdiagnosis also further distorts NHS data regarding the prevalence of PF, potentially inflating recorded rates of asthma, COPD and heart disease and under-estimating the PF burden on respiratory services. This directly impacts effective service planning and commissioning.

73% of males and 70% of females received treatment for an incorrect condition.

Results

2. Post-diagnosis support and supportive services

A. Communication and coordination of care

1. Inadequate coordination across community, primary, secondary and specialist tertiary care resulted in fragmented services and insufficient patient support.
2. Only 7% of all survey participants reported that their PF treatment was well co-ordinated with primary care, indicating poor links between service levels.

B. Access and referral to supportive services

1. PF is a progressive disease, making timely access to supportive services critical. Delays can significantly compromise patients' quality of life and functional independence.
2. Over half (51%) of survey participants were not informed about the benefits of physiotherapy or occupational therapy and over a quarter (28%) were not told about pulmonary rehabilitation programs.

The National Institute for Care Excellence (NICE) have outlined a set of five quality care standards for IPF, which were published in 2015 – more than 10 years ago.[15] Four out of five of these standards focus on condition management and access to supportive services, including: ensured access to an ILD specialist nurse, assessment for home and ambulatory oxygen, pulmonary rehabilitation and palliative care. These services provide vital, disease-specific support and information, which are crucial for individuals facing what is a life-altering and life-limiting diagnosis.

However, these statements are guidelines rather than requirements and, unfortunately, they do not reflect the experience of many people diagnosed with PF.

People affected by PF tell us that inadequate guidance from healthcare professionals forces them to seek information on their own, turning to Google searches or social media platforms, which may not always provide clinically accurate or personally relevant advice. Heightened anxiety around their condition can exacerbate breathlessness and reduce the capacity for independent self-management; impacting quality of life and increasing reliance on ILD nurses (for people who have access to one) and urgent care.

The findings of this survey echo those outlined in the 2023 I Wish It Was Cancer report, in which nearly half of the survey participants reported that they were not directed to any sources of information, advice or support.[16] As a result, many were left feeling 'abandoned' and 'anxious' during an already distressing time.

[15] Quality statements | Idiopathic pulmonary fibrosis in adults | Quality standards | NICE

[16] People with lived experience of PF at the heart of survey set to influence change – Action for Pulmonary Fibrosis

2A. Communication and coordination of care

The text below refers to data of people living with pulmonary fibrosis and bereaved carers (n = 1116).

Over a third (39%) of patients and bereaved carers reported that the information they received at diagnosis did not adequately prepare them for what to expect, neither physically nor in terms of their care plan, signalling that feelings of uncertainty do not end with diagnosis.

This gap in communication was slightly wider for those with PF-ILD, as only 37% reported feeling adequately informed, compared to almost half (47%) of those with IPF.

Understanding communication, co-ordination and potential shortfalls between specialist and primary/community care is crucial, as PF-specific expertise is centralised in England and scarce in many areas of the devolved nations. This means that most patients rely on day-to-day care and advice given locally. Given the high prevalence of comorbidities among people with lung disease and the complexities associated with different PF subtypes,it is essential that both patients and GPs have a clear understanding of the PF diagnosis, treatments and management strategies.

Such shared knowledge ensures care is coordinated, patient-centred and managed holistically.

The report highlights that there is a significant communication gap between primary/community care and specialist care. People living with IPF in Wales were most likely to have no GP involvement post-diagnosis, with 83% of participants reporting no ongoing input from a primary care source. Less than 7% of all survey participants reported that their PF treatment was well-co-ordinated with primary care, indicating widespread communication issues between services.

14%, described their GP's support as unclear or unhelpful and 17% reported gaps or delays in their care as a result. This shows a direct impact between co-ordination and patient experience and outcomes.

In England, where ILD care is concentrated in specialist centres, co-ordinated care was reported only half as often (5% vs 10%), highlighting that a centralised model without strong primary–specialist links leads to further fragmentation of care for patients.

Results

2B. Access and referral to supportive services

This section considers experiences reported by all survey participants (n = 1270)

As PF is a progressive disease, receiving timely access to supportive services is critical. Delays or waitlists for physiotherapy, occupational therapy or pulmonary rehabilitation (PR) can significantly compromise patients' quality of life and functional independence.

Palliative care provides many of these key services but, despite the strong case for referring PF patients at the point of diagnosis, there is a high degree of misunderstanding between both patients and clinicians that palliative care is for 'end of life' and not 'symptom control' or 'quality of life'.

One in five (19%) patients reported not having received a referral to palliative care at all.

This is directly at odds with NICE Quality Care Statement 5, which states that patients with IPF, and their families, should have access to services that meet their palliative care needs. Individuals with PF should be prioritised for these services, which are proven to help them live better for longer, rather than being left to deteriorate while awaiting care. They should also be informed about why palliative care is appropriate for them, to avoid misunderstanding of their disease stage.

For people who reported being referred, wait times remained a significant barrier: fewer than half (43%) were able to access pulmonary rehabilitation promptly; 6% could not access it at all due to long waits; and 4% were unable to access physiotherapy or occupational therapy because of wait times. **Extended delays can lead some patients to refuse referrals altogether, progress too far to benefit from treatment or, tragically, pass away before ever receiving care**. The initial barrier, however, is receiving a referral in the first place.

Despite the proven clinical effectiveness of these services, **over half of survey participants (51%) were not informed about the benefits of physiotherapy or occupational therapy and 28% were not told about pulmonary rehabilitation programs**.

In a similarly worrying statistic, 63% reported not being informed about dietetics services, despite the negative impact that persistent coughs and antifibrotic side-effects have on patient appetites.

Considering that some of these responses will be from patients who are under active treatment and may still be waiting for delayed referral(s) to supportive services, we looked separately at survey answers from those individuals bereaved by PF, who have already experienced the entirety of the care pathway.

A significant number of people bereaved by PF (68%) reported that the person they lost had passed away before being able to access psychological support, with 41% having also been unable to access end of life or advanced care planning.

These findings highlight a persistent and concerning gap in access to essential supportive services throughout the PF care pathway, leaving many patients and their families without critical guidance and support.

[17] Quality statements | Idiopathic pulmonary fibrosis in adults | Quality standards | NICE

[18] Side-effects of antifibrotics – see page 5

> The delays in diagnosis and lack of understanding around pulmonary fibrosis can be incredibly isolating when you're searching for answers, referrals and support.

Allan and Lorraine, Aberdeenshire
Brother and sister both living with pulmonary fibrosis

Results

3. Access and experiences of treatment

A. Distance to treatment centre

1. Distances to respiratory centres has been shown to have a significant impact on survival time with people with PF.[19] Geographic inequalities further exacerbate barriers to diagnosis and treatment.
2. The closer patients live to a treating centre, the faster their referral and diagnosis. This is more pronounced in England (67% of patients living within 20 miles), compared to Scotland (82% living within 20 miles) and Wales (~72% within 20 miles).

B. Side-effects of antifibrotic treatment

1. A substantial proportion of patients in England (38%) and especially in the devolved nations (41%) did not feel that they received sufficient information about the effectiveness of antifibrotic treatment.
2. Improving understanding of what these side-effects are, who experiences them and how debilitating they are, will help to inform the approach to tailored treatment plans and direct future drugs research.

The model of care for ILD services in England differs from that in the devolved nations, due to the designation of ILD services as 'specialised.' In England, as antifibrotic treatments can only be prescribed at the country's 24 ILD specialist centres, bottlenecks have developed, causing additional delays. Specialist staff have anecdotally reported to APF that they are under pressure from managing the dual challenges of complex cases alongside the initiation of treatment. Even more so following influx of incidental findings from lung cancer screenings, where they find lung abnormalities related to PF on scans looking for lung cancer.

Although ILD/PF care is integrated into respiratory care across the devolved nations, there are still pockets of populations in proximity to PF expertise and large areas that are not, particularly those in rural locations.

Distance to specialist centres can exacerbate barriers to timely treatment, particularly for a progressive disease like PF, where frequent visits to centres are often required for monitoring, antifibrotic therapy initiation and supportive care.

Previous studies have confirmed this has a direct impact on IPF patient outcomes, with people living furthest from centres having a 34% increased risk of early death. Distance in that single-clinic study by Shankar et al. (2024) was categorised in quintiles from under 4 miles to between 14 and 24 miles. In this survey, which looks at national service provision across levels of care 'local/closest' was deemed within 20 miles and 'furthest away' over 100 miles from centre.

Here we examine patients' self-reported experiences of accessing treatment centres, including the impact of travel and symptom challenges. The below explores interactions with specialist care, highlighting regional disparities, sex-specific symptom patterns and gaps in patient support and information. By analysing these experiences, we aim to identify areas where care pathways could be improved to ensure timely, equitable and patient-centred access to PF services.

Over 55% of people living with PF reported being prescribed antifibrotics at the time of data collection.

[19] Assessment of the impact of social deprivation, distance to hospital and time to diagnosis on survival in idiopathic pulmonary fibrosis - Respiratory Medicine

3A. Distance to treatment centre

This survey found that shorter distances to treating hospital is associated with faster diagnosis. Most patients across all nations reported living within 20 miles of their treatment centre and 40% of those that do are diagnosed within 3 months. As distance increases, so does the proportion of patients who experience diagnostic delays over 6months. This is notable in people living more than 100 miles away, where nearly half report waiting over two years for a diagnosis.

This pattern is even more pronounced in England. While over one-third of patients living within 20 miles are diagnosed within three months, two-thirds of those living more than 100 miles away report waiting more than two years. People receiving care in England are less likely to live near a treating centre, with only 67% of patients living within 20 miles, compared to 82% in Scotland and ~72% in Wales. This likely reflects the model of care in England; those receiving specialist care will be required to travel to designated specialist centres for treatment initiation and in some cases, ongoing follow-up.

In England, one-third of patients living within 20 miles of treating centre are diagnosed within three months, however, two thirds of those living more than 100 miles away are waiting more than two years.

Within England, inequality in proximity to treating centre was also evident between regions. Patients in the North-East of England reported the highest accessibility, with 81% of IPF patients and 91% of non-IPF patients living within 20 miles of a treatment centre. By contrast, the South-East had the lowest, with only 57% and 51% (IPF and non-IPF) of patients living within this distance.

This disparity reflects the size, population distribution and geography of Integrated Care Boards (ICBs) across regions, highlighting clear geographic inequalities in access to PF care.

People receiving care in England are less likely to live in close proximity to treating centre, with only **67% of patients living within 20 miles, compared to 82% in Scotland and ~72% in Wales**.

In the devolved nations, the picture is more variable, likely reflecting smaller sample sizes, but distance still appears to influence diagnostic timelines. The relationship between delay and distance is ultimately less pronounced in the devolved nations, where an integrated care network allows for quicker referrals and less delays to diagnosis.

18% of patients in Scotland and 28% of patients in Wales still live over 20 miles from a treatment centre. This is surprising, as the population of Wales is nearly twice as dense as Scotland's (151 people per km^2 compared to 70 people per km^2). Although there are respiratory services concentrated in the North and South of Wales, a distinct lack of services remains in the East and West. This underscores the fact that for many PF patients across the UK, care is still not 'close to home'. Overall, longer delays are consistently reported by people living further from treatment centres, reinforcing concerns about geographic inequalities in access to specialist expertise across the UK.

Results

3B. Side-effects of antifibrotics

Antifibrotics remain the only disease-slowing treatment for all types of progressive PF and patients may switch between therapies if clinically advised. However, both pirfenidone and nintedanib are associated with significant adverse effects, particularly in the gastrointestinal tract.[20] In the UK, 40% of IPF patients discontinue treatment within 6 months due to debilitating side-effects.[21]

Despite this, a substantial proportion of patients in England (38%) and especially in the devolved nations (41%) did not feel that they received sufficient information about the effectiveness of antifibrotic treatment before starting on it.

Recent research has sought to better understand patterns in tolerability to guide personalised treatment plans and minimise having to stop treatment.[22,23] This is an important area to explore following the approval of nerandomilast, a new antifibrotic treatment which was recently approved for use in the USA. Trials showed that this treatment had a reduced side-effect profile compared to the two treatments currently available in the UK.[24]

Survey data showed that three-quarters (75%) of respondents reported experiencing multiple side-effects due to antifibrotic treatment, with the most common, and life-affecting, being diarrhoea (58%), followed by decreased appetite (52%) and nausea (50%).

Interestingly, symptom patterns appeared to differ by sex: 60% of men reported experiencing diarrhoea, compared with 55% of women, while nausea was more common in women (64%) than in men (42%). These differences raise important questions regarding potential sex-specific side effects, differences in metabolism or variations in how symptoms are reported and perceived.

These findings are relevant to recent investigations into identifying predictors for treatment interruption or discontinuation, such as older age and lower body mass index (BMI) in people receiving nintedanib treatment for systemic-sclerosis associated-ILD and sex in people with IPF.[25,26]

Further research will be essential to support more PF patients to continue treatment and live with a better quality of life for longer.

75% of people on antifibrotic treatment experience multiple side-effects, with diarrhoea being the most debilitating for nearly 40%.

[20] The tolerability and efficacy of antifibrotic therapy in patients with idiopathic pulmonary fibrosis: Results from a real-world study - PubMed

[21] Real-world retrospective observational study exploring the effectiveness and safety of antifibrotics in idiopathic pulmonary fibrosis | BMJ Open Respiratory Research

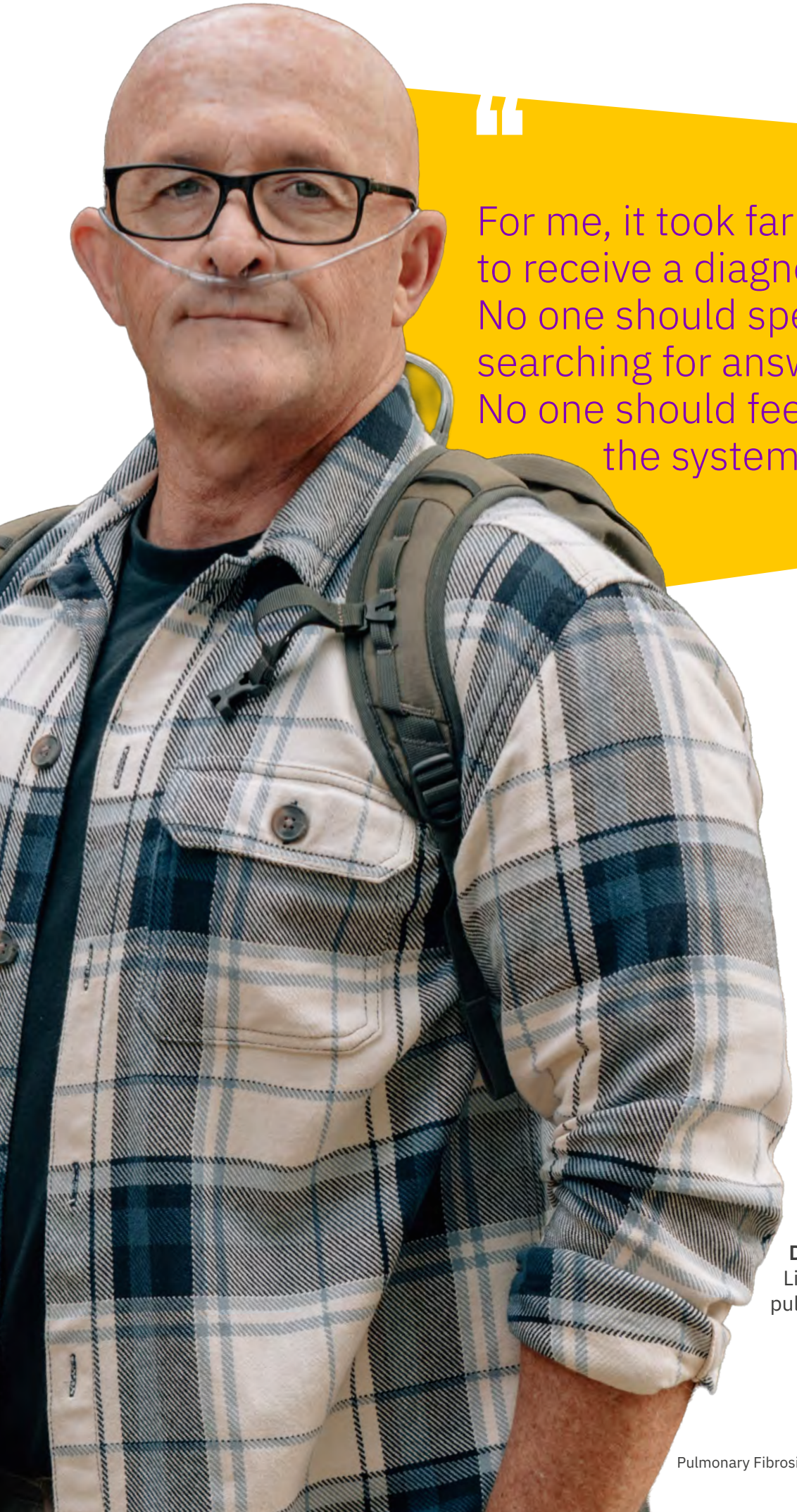
[22] Real-world insights into safety, tolerability, and predictive factors of adverse drug reactions in treating idiopathic pulmonary fibrosis with pirfenidone and nintedanib - Alessio Provenzani, Daniele Leonardi Vinci, Miriam Alaimo, Salvatore Di Maria, Fabio Tuzzolino, Gaetano Floridia, Roberta Di Stefano, Anna Carollo, Adriana Callari, Piera Polidori, Patrizio Vitulo, 2025

[23] The Impact of Comorbidities on the Discontinuation of Antifibrotic Therapy in Patients with Idiopathic Pulmonary Fibrosis | MDPI

[24] FDA approves JASCAYD® (nerandomilast) as first new treatment IPF over decade | Boehringer Ingelheim

[25] P23 Nintedanib in systemic sclerosis-associated interstitial lung disease: real-world multicenter cohort study on tolerability and discontinuation | Thorax

[26] P28 Little women looking into antifibrotic tolerance in relation to weight, dose, female gender and ethnicity | Thorax



> For me, it took far too long to receive a diagnosis. No one should spend years searching for answers. No one should feel lost in the system.

Dave, Bristol
Living with idiopathic pulmonary fibrosis

Our Commitment

This report is just the start of the conversation. The experiences and insights shared in the survey will directly drive our work over the coming years, shaping what we prioritise and how we deliver support.

We will use this evidence to work alongside healthcare professionals, commissioners and policymakers.

Together, we can address gaps and inequalities and push for faster diagnosis and improved access to specialist care, treatment and support for everyone affected by pulmonary fibrosis.

We will continue to amplify the voices behind these findings, because real change only happens when lived experience is listened to, acted on and built into every decision about patient care and services.

Our ambitious new strategy, For Every Breath, For Every Journey, For Every Future, published in January 2026, highlights several areas where we have already committed to action in the next five years, including:

Changing the system • Holding decision makers to account when progress stalls and highlighting improvements where they happen. • Leading the OneVoiceILD network, to engage parliamentarians, policymakers and healthcare commissioners to support the rollout of a standardised, national care pathway.	**Information and education** • Being the leading provider of trusted information and education for everyone affected by pulmonary fibrosis. • Delivering free, accessible education content for healthcare professionals, to improve PF awareness, diagnosis and treatment. • Leading on prevention messaging, including for those at high-risk, aiming to make preventable PF a thing of the past.
Better understanding of pulmonary fibrosis • Lobbying for improved data collection, including a National Respiratory Audit Programme for ILD, to provide accuracy and insight. • Becoming the largest charitable funder of PF research in the UK, supporting studies to tackle issues outlined in this report.	**Equity and patient-centred care** • Putting the needs and voices of those affected by PF at the heart of everything we do. • Taking a bold, proactive approach to improving equity, designing services that actively restore imbalances in access and outcomes.

Progress must be visible, measurable and delivered urgently. Our community cannot wait.

Conclusion

The State of the Nation report provides one of the most comprehensive pictures of the experience of pulmonary fibrosis (PF) care in the UK. Drawing on the responses of more than 1,200 people affected by PF, it reveals a system that is falling short at every stage of the care pathway, from delayed and inaccurate diagnosis to unequal access to treatment and supportive services.

The evidence presented here strongly supports one of the core priorities set out in the NHS 10 Year Health Plan for England: bringing care closer to home. In the context of PF, this means identifying and amplifying specialist expertise and embedding it across regional networks and localised shared-care models. This has the potential to reduce diagnostic delays, improve quality of life and enable earlier, more equitable access to antifibrotic therapies. Crucially, it would also allow patients and their families to receive coordinated, holistic support throughout the course of the disease, rather than navigating a fragmented system alone.

Significant efficiencies could also be achieved through improved recognition of PF symptoms and the implementation of a clear, standardised diagnostic pathway to treat it. Repeated appointments, inappropriate treatments and prolonged uncertainty place unnecessary strain on both patients and an NHS already hugely under pressure, including from rising levels of lung disease. A well-defined diagnostic pathway would reduce misdiagnosis, minimise the use of ineffective or harmful treatments and enable faster access to appropriate care.

Action for Pulmonary Fibrosis is committed to using this report as a catalyst for change. We will continue to lead national collaboration through OneVoiceILD, advocate for policy and commissioning reform and work with health systems to embed standardised pathways, share expertise and reduce variation in care. We will also continue to place people with lived experience at the centre of improvement efforts, using evidence gathered to hold the system to account.

Glossary

Term	Definition
Asthma	A chronic lung condition with symptoms including cough, wheezing, chest tightness and breathing difficulties due to inflammation and tightening of the airways.
Care Pathway	The mapped journey an individual takes from first entering the healthcare system with a suspected illness, to the end of their experience. This includes the diagnostic process, any treatments and therapies, through to cure or end-of-life.
Carer	In this report it used to describe family, friends, formal and informer carers of those living with PF with no assumptions made about the nature of their individual relationship.
COPD	Chronic obstructive pulmonary disease (COPD) is the name for a group of lung conditions that cause breathing difficulties, including emphysema and chronic bronchitis.
CTD-ILD	A form of interstitial lung disease occurring in patients with a connective tissue disease (CTD) (such as rheumatoid arthritis, systemic sclerosis, dermatomyositis, or Sjögren's syndrome), in which fibrosis and inflammation of the lung interstitium are seen on lung imaging of an individual diagnosed with CTD.
HRCT	A specialised form of computed tomography (CT) that uses thin image slices and specific technical settings to produce very detailed images of the lungs and airways. It is the imaging modality of choice for diagnosing and characterising ILD and PF.
Idiopathic	A term meaning no known origin. 'Idiopathic PF' (IPF) refers to those with PF that has not been caused by an identifiable exposure, irritant or other underlying condition. IPF is the most common subtype and the most aggressive form of PF.
ILD	Interstitial lung disease, the collective term for the group of conditions, including PF, that cause inflammation and scarring of the lungs. Some subtypes are named under this categorisation, e.g. ILD caused by inflammation from rheumatoid arthritis becomes 'RA-ILD'.
Incidence	The number of individuals diagnosed with the condition within a defined population and a set amount of time, most commonly per year.

Term	Definition
NSIP	A type of lung disease where the tissue between the air sacs becomes inflamed and sometimes scarred. Unlike other forms of lung scarring, NSIP usually affects the lungs more evenly and in a more predictable pattern. It can occur on its own or as part of another condition, like a connective tissue disease.
PF-ILD	An umbrella term for all forms of interstitial lung disease other than idiopathic pulmonary fibrosis (IPF). These include ILDs with known causes (e.g., CTDILD, hypersensitivity pneumonitis, occupational ILD) and other idiopathic pneumonias that do not meet the diagnostic criteria for IPF. Used in this report in place of PPF (defined below) as the data collected was self-reported and clinical progression over time cannot be confirmed.
PPF	A term for interstitial lung diseases that meet strict clinical criteria for 'disease progression' or worsening of lung function. This term is not used within the report as responses were self-reported and it cannot be clinically confirmed that each person currently meets this criterion.
Prevalence	The number of individuals currently living with the condition within a defined population.
Pulmonary rehabilitation	A supportive therapy that is designed to boost lung function and support those with lung conditions to manage the feeling of breathlessness
Quantitative	Information or data relating to numbers that provides further insight into scale i.e. how common something is.
RA-ILD	A subtype of CTDILD that develops in people with rheumatoid arthritis, characterised by interstitial lung involvement with fibrosis and/or inflammation detectable on imaging and pulmonary function testing.
Spirometry	A standard pulmonary function test that measures the volume and speed of air that a person can inhale and exhale. It is used to assess lung function and detect obstructive or restrictive patterns of respiratory disease.
Standardised	In terms of healthcare, this refers to something that should be done the same way everywhere, regardless of where you are receiving care.
Supportive Services	The collective term for therapies that help an individual to manage their condition and improve their overall wellbeing.

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With thanks

Thank you to all the people who took the time to participate in, recommend or share the Pulmonary Fibrosis State of the Nation Report 2026. Your feedback will help to drive positive change for everyone affected by PF in the UK.

The lived experience experts who shared their stories, including the successes and challenges, to inform the development of the 2026 Pulmonary Fibrosis State of the Nation Report.

The clinical, charity and corporate partners who championed the completion of the 2026 PF State of the Nation survey to their patients, supporters and service users.

The clinical colleagues who work hard each day to provide the best care possible within a system that is not fit for purpose.

Dr Georgie Massen for providing her time and analytical expertise.

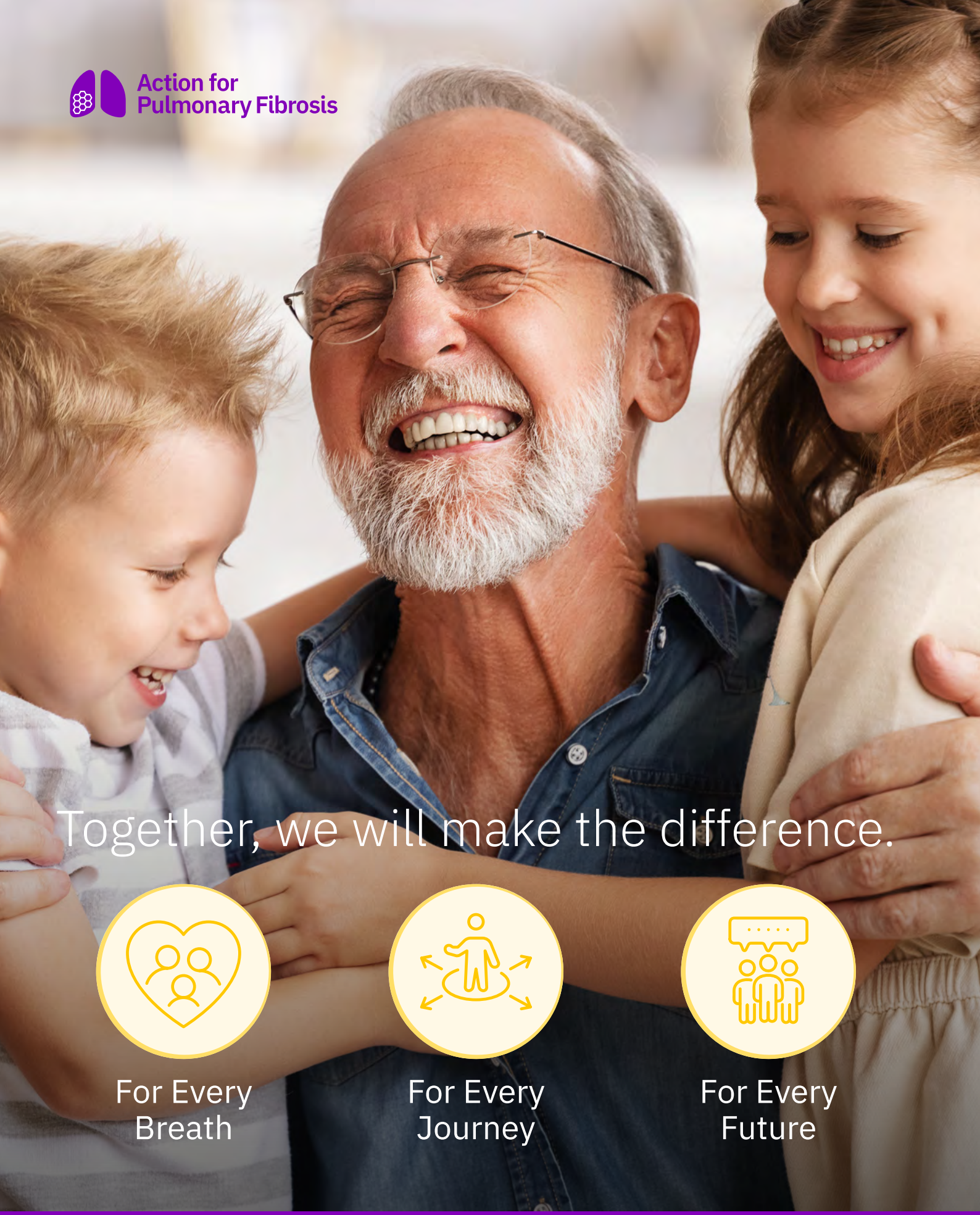
Thank you

About Action for Pulmonary Fibrosis

Action for Pulmonary Fibrosis (APF) is the UK's leading charity dedicated to supporting people affected by pulmonary fibrosis - a complex, progressive lung disease that can dramatically shorten life expectancy. APF provides expert information and support services, as well as driving vital research and campaigning to improve understanding, treatment and care.

Working closely with healthcare professionals, policymakers and people living with pulmonary fibrosis, APF aims to reduce the time to diagnosis, remove barriers to life-saving treatments and ensure that all patients receive the comprehensive support they need. The charity's OneVoiceILD network unites a diverse group of stakeholders to drive consistent standards of care across all regions of the UK.

Action for Pulmonary Fibrosis



Together, we will make the difference.

For Every Breath

For Every Journey

For Every Future

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