Pulmonary Fibrosis State of the Nation Summary **2026**

Action for Pulmonary Fibrosis

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.

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.

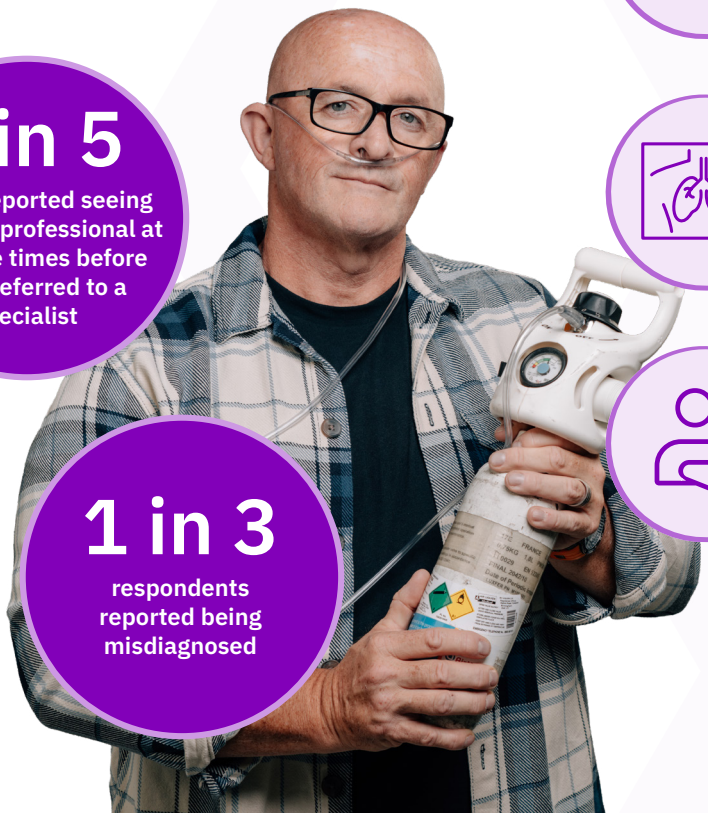
Delays and misdiagnosis

Early and accurate diagnosis and treatment of pulmonary fibrosis 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).

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

Nearly half of all respondents waited more than six months to receive a confirmed diagnosis and more than one third waited over a year. Almost one in five respondents reported having to raise their symptoms with a medical professional at least five times before being referred to a specialist.

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

Post-diagnosis support

Access to services such as pulmonary rehabilitation, dietetics, palliative care and psychological support can have a noticeably positive impact on 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.

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

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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%

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

Action for Pulmonary Fibrosis's State of the Nation report provides one of the most comprehensive pictures of pulmonary fibrosis care in the UK. It shows that the current model of care is not delivering timely or equitable support for patients. The evidence presented supports one of the core priorities in the NHS 10 Year Health Plan for England: bringing care closer to home.

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. Action for Pulmonary Fibrosis is committed to using this report as a catalyst for change.

Progress must be visible, measurable and delivered urgently.

Our community cannot wait.

APF's Commitment

Drive system change: Hold decision-makers accountable for progress and work with policymakers and healthcare leaders to implement a standardized national lung care pathway.

Provide trusted information and education: Offer reliable information and free educational resources to improve awareness, diagnosis, treatment, and prevention of pulmonary fibrosis.

Improve understanding through data and research: Advocate for better data collection (e.g., national ILD audits) and fund research to generate insights and solutions for pulmonary fibrosis.

Promote equity and patient-centred care: Put the needs and voices of people affected by pulmonary fibrosis at the centre of care and decision-making.

Address inequalities in access and outcomes: Take proactive steps to reduce imbalances in healthcare access and improve overall patient outcomes.

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