Future Health Research

Breathing new life into lung health policy

A call to action to deliver on the WHO Lung Health Resolution and improve outcomes for people with Pulmonary Fibrosis

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About this report

This research report sets out how Governments and policymakers can use the World Health Organisation's (WHO) Lung Health Resolution to improve the awareness, diagnosis, care and treatment of pulmonary fibrosis (PF).[1]

The resolution presents a unique opportunity to focus minds on improving the lives of those diagnosed with PF, a debilitating and deadly lung condition.[2] This is the first time PF has been included within a global health resolution and this research report sets out how the ambitions in the resolution can be translated into action. The report is in two parts:

1. An overview of PF and its impact on patients, their families, health systems and the wider economy
2. How the WHO Lung Health Resolution can be translated into action that improves outcomes for patients with PF (see figure 1 below)

The report has been informed by an extensive evidence and literature review, expert group meeting and interviews with experts in PF and lung health across the world (see Appendix).

PF is an umbrella term for 200 different types of chronic, progressive interstitial lung diseases (ILDs) characterised by scarring and thickening of lung tissue. Existing data and evidence worldwide is patchy, with many studies focused on its prevalent form, idiopathic pulmonary fibrosis (IPF). The report makes clear where studies relate to IPF or other specific forms of PF.

Figure 1: Translating the WHO Lung Health resolution into improved outcomes for PF patients

About the author

Richard Sloggett is the Founder and Programme Director of Future Health – a health specialist policy research centre – and has over fifteen years of experience in healthcare policy. At the 75th World Health Assembly (WHA) Richard published *The power of connection*, a research paper exploring how countries can develop more interconnected approaches to cardiovascular, renal and metabolic diseases to meet the needs of patients.[3]

From 2018-19 he was Special Advisor to the UK Secretary of State for Health and Social Care.

During his time in the UK Government, Richard worked on major health policy decisions including a ten year health service reform plan. Richard's work with the Secretary of State also included work on the 2019 G7 primary care declaration.

Alongside his work at Future Health Richard is undertaking his doctoral thesis in preventative healthcare systems at the University of Liverpool.

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Executive summary

Lung diseases represent one of the world's most significant health challenges. Chronic respiratory conditions killed 17 million people in 2021 — a burden that is, in the words of the Forum of International Respiratory Societies, 'huge and largely unrecognised.'[4]

The impact from lung diseases is growing rapidly. COPD cases are projected to rise by 23% worldwide between 2020 and 2050, from 480 million to 592 million people.[5] Lung cancer incidence and mortality are expected to rise to at least 4.62 million new cases and 3.55 million deaths per year by 2050.[6]

The drivers of this trajectory are well understood. Air pollution contributes to seven million deaths annually and exacerbates respiratory diseases — and its impact is extending rather than contracting in many parts of the world.[7] Tobacco use, while declining in high-income countries, continues to rise in parts of the Global South. Occupational exposures — to dust, chemicals and toxins — remain poorly regulated across large parts of the global economy. Demographic change is also important: as populations age, the incidence of progressive lung conditions increases, along with deaths and disability-adjusted life years.[8]

The financial cost to health systems and economies is substantial, and falls disproportionately on the countries least equipped to bear it. COPD alone is projected to cost the global economy over $4.3 trillion between 2020 and 2050 — with low- and middle-income countries absorbing over half of these costs.[9] Such data capture only part of the true toll: in lower-resource settings, chronic lung conditions drive severe work productivity and activity impairment, including indirect costs — from premature mortality, workforce exit, and lost output — with middle-income countries bearing the highest economic burden as a share of GDP.[10] [11]

The result is a compounding challenge — more people at risk, more cases, more deaths, more costs — which is all outpacing health system capacity.

PF — and its most prevalent form, idiopathic pulmonary fibrosis (IPF) — is a progressive, irreversible scarring of the lungs for which no cure exists. It is a condition whose public health significance is systematically understated, and whose patients bear a mortality burden comparable to the most aggressive cancers. Incidence and mortality are both rising.[12] [13] Global Burden of Disease analysis projects that crude death rates from interstitial lung diseases (ILDs) — chronic lung disorders that cause inflammation and scarring of the lung tissue including IPF — will increase by approximately 83% by 2050, driven primarily by ageing.[14]

> The consequence is that for millions of patients globally, a diagnosis of PF is effectively a sentence of progressive respiratory decline and early death, with no cure and limited systemic support.

The prognosis for patients diagnosed with IPF remains stark. Median survival after diagnosis is 2.5 to 5 years, comparable to — and in some presentations worse than — many malignant tumours.[15] [16] Available treatments, including antifibrotic agents, can slow functional decline but do not reverse fibrosis or restore lost lung capacity, and access to these therapies remains limited across much of the world.[17] The consequence is that for millions of patients globally, a diagnosis of PF is effectively a sentence of progressive respiratory decline and early death, with no cure and limited systemic support.

With rising incidence and mortality, action on PF now needs to be locked into the global health response to improving lung health.

The adoption of resolution WHA78.5 — 'Promoting and prioritizing an integrated lung health approach' — by the 78th WHA in May 2025 represents the most significant advance in global lung health governance in a generation.[18] It is the first WHA resolution to address the full spectrum of respiratory diseases under a single integrated framework.[19]

The resolution calls on Member States to develop or strengthen national strategies addressing both communicable and non-communicable lung diseases, with primary care as the principal point of entry, and for Member States to align work across departments to support integrated implementation. With only 19 countries currently on track to meet the Sustainable Development Goal target of reducing premature NCD mortality by one third by 2030, the resolution arrives at an important time — providing both a political mandate and a practical policy architecture for expanded action.[20]

For PF the resolution creates a clear opportunity for action. The resolution's invitation to Member States to map their lung health priorities and develop integrated plans is an opening to ensure that PF is explicitly named, resourced, and tracked within national lung health plans.[21]

The resolution comes at a time of change in PF care and treatment. Investment in research is unlocking potential new treatments, innovative technologies are supporting faster diagnosis, and there are evolving models of care and pathways being developed that can deliver more co-ordinated care and improved quality of life for patients.

This research report sets out a four part framework for how countries can utilise the resolution on lung health to integrate action on PF into their response through:

- Enhancing prevention and increasing awareness amongst healthcare professionals and the public
- Ensuring the earlier diagnosis of the condition
- Delivering more co-ordinated and integrated care for patients
- Investing in research and unlocking access to new innovative treatments

In taking action across this framework countries can ensure that the resolution delivers improved clinical outcomes and quality of life for patients with PF and their families.

Pulmonary Fibrosis and its impact

A progressive, irreversible scarring of the lungs for which no cure exists and that affects every aspect of a person's life

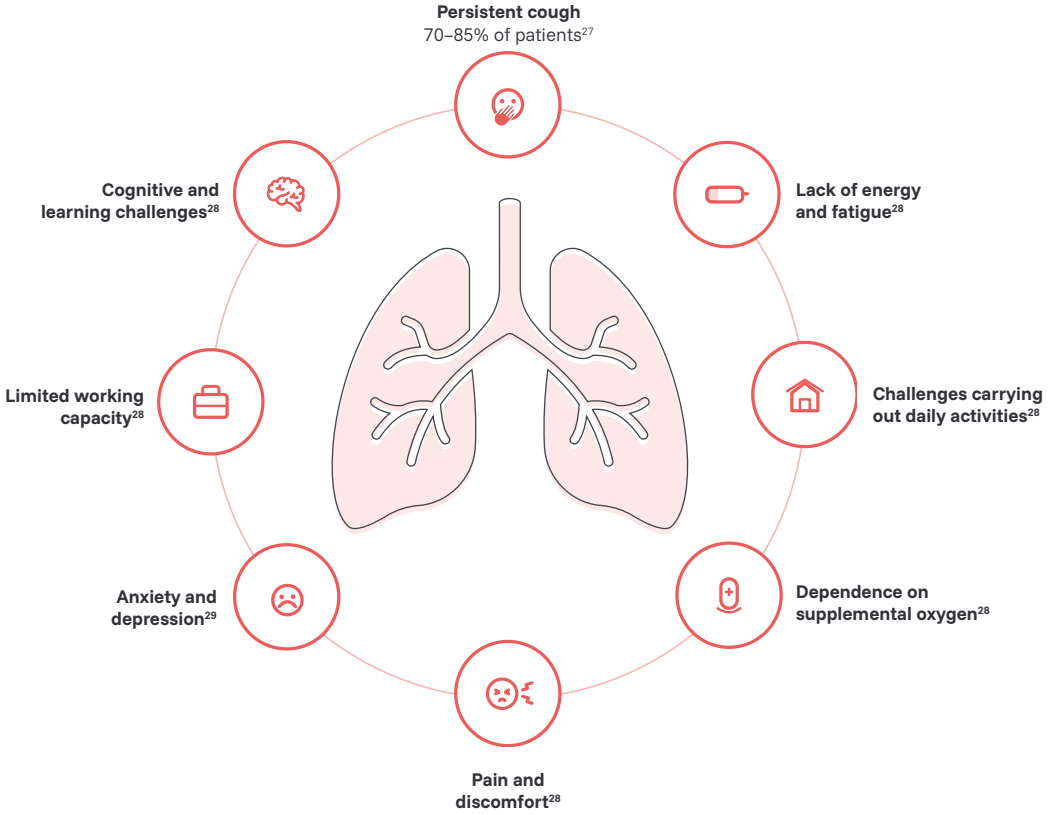
3M+
people living with its most prevalent form, idiopathic pulmonary fibrosis (IPF) worldwide[22]

2.5–5
years median survival after IPF diagnosis[23]

RISK FACTORS [24] [25] [26]

- Individuals of a certain age at higher risk — 50+
- Exposure to high levels of air pollution
- Those who have been exposed to toxins such as asbestos and silica through particular professions, certain medications or radiation therapy
- People with autoimmune diseases like rheumatoid arthritis and scleroderma
- Individuals with a family history of the condition

SYMPTOMS AND IMPACT



CHALLENGES

Low awareness[30] [31]

Surveys highlight limited clinical and public awareness of PF

Late diagnosis[32] [33]

Patients are misdiagnosed with other conditions such as COPD, asthma and bronchitis. There are delays in diagnosis of up to two years

Lack of access to specialists and connected care[34]

PF patients require specialist care; but this specialist care can be geographically distant from where patients live, resulting in inequalities of care access - particularly in the Global South

Beyond specialist treatment and primary care management patients with PF often require a range of different services and support including: pulmonary rehabilitation, psychological support, timely access to ambulatory oxygen therapy (AOT) and long-term oxygen therapy (LTOT), and end of life planning and palliative care. However care is often fragmented and disjointed

Limited investment in research and variable treatment access[35] [36]

Many patients still face delays in receiving antifibrotic therapies that can slow disease progression

Investment in research in PF remains a relatively low priority

CARERS

Studies have shown **60.5%** of patients rely on an unpaid carer for an average of **30 hours per week**. **20.3%** of patients require a paid carer for an average of **8 hours per week**.[37]

HEALTH SYSTEMS

Studies have shown **significantly higher** rates of **hospitalisation and emergency admissions** for those with IPF.[38]

ECONOMY

Studies have shown that a **quarter** of IPF patients **retire early** due to illness.[39]

Summary of key recommendations

IMPROVING GLOBAL LUNG HEALTH[40]

Delivery of Lung Health Resolution commitments

Future Health Research PF policy recommendations

ENHANCING PREVENTION AND INCREASING AWARENESS

4) Create and enforce adequate regulations protecting workers from occupational risk factors impacting lung health

6) To strengthen national capacities for an integrated approach on lung health, considering adaptation of relevant existing and evidence-based WHO tools to create an evidence-based and cost-effective integrated lung health package of interventions suitable for all patients, according to their individual need

- Ensure that health and safety laws for industries that present a higher risk for people in developing PF are in place and are robust
- Increase awareness of PF amongst clinicians and other healthcare professionals by including the condition in medical training and education, with a particular focus on increasing earlier diagnosis in the primary care setting
- Deliver targeted public awareness raising campaigns on the signs and symptoms of PF
- Utilise existing awareness programmes for other lung health conditions such as lung cancer and COPD to educate the public about PF

EARLIER DIAGNOSIS

5 (b) Developing evidence-based clinical and public health guidelines for cost-effective measures for early detection, diagnosis and treatment of communicable and noncommunicable lung diseases, including the use of innovative technologies

- Publish national PF clinical guidelines improving the early detection and accurate diagnosis of the condition, set out how these guidelines can be incorporated into wider lung health pathways
- Develop and evaluate targeted screening programmes for populations who have been exposed to toxins likely to cause PF (such as asbestos and silicosis) as well as those who may be genetically predisposed and those with other conditions with a raised risk (such as rheumatoid arthritis)
- Include PF in wider screening programmes for lung conditions such as lung cancer and ensure workforce training programmes and new technologies, including data and AI tools for identifying PF, are in place
- Create clinical guidelines and pathways to support referrals from specialisms with high rates of PF co-morbidities such as rheumatology
- Ensure equitable access to the latest innovative diagnostic equipment and swift referral for patients to a specialist centre

INTEGRATED CARE

2) Incorporate an integrated approach to lung health into primary healthcare services towards the attainment of universal health coverage, inclusive of comprehensive lung health services, with effective referral pathways to secondary and tertiary care, when appropriate

- Consider working with relevant partners to establish specialist centres for PF treatment and care, backed by funding incentives for achieving best practice care
- Establish and resource a national framework for supplemental oxygen access for patients with PF that ensures timely and equitable access
- Build a model multidisciplinary team (MDT) for PF patients that can deliver a multi-professional, co-ordinated and integrated approach to in-person and remotely co-ordinated care
- Putting patients, peer support and patient experience and feedback at the heart of PF services, using this to drive service transformation and improvement

INVESTING IN RESEARCH AND IMPROVING ACCESS TO TREATMENTS

7) to improve access to and affordability and availability of safe, effective and quality medicines, vaccines and health technologies using the WHO Model List of Essential Medicines and the WHO Model List of Essential In Vitro Diagnostics with an emphasis on cost-effectiveness, sustainable allocation of resources and evidence-based approaches

- Governments and health systems should work to ensure greater equity of access to existing treatments that improve PF patient outcomes
- Governments and policymakers should use the Lung Health Resolution to increase their levels of investment in lung health research, including PF. Patients should be actively engaged in discussions on the priorities for such research funding
- Policymakers should look to develop or collaborate internationally in developing innovative trial design opportunities - for example through platform trials - to accelerate and expand access to new PF trials and treatments for patients
- Governments and health systems should collaborate on efforts to improve healthcare data on lung conditions such as PF through joint registries and research activities

About Pulmonary Fibrosis

PF is a progressive lung disease characterised by abnormal scarring (fibrosis) of lung tissue that progressively limits people's ability to breathe and function normally.[41] [42] It is classified as a form of ILD.[43] Symptoms typically occur between the ages of 50 and 70, with the majority of people being over 60 at the time of clinical presentation.[44]

While the exact cause of PF is unknown, there are certain risk factors which can contribute to its development. These include:

- Individuals of a certain age (over 50)[45]
- Exposure to high levels of air pollution[46]
- Those who have been exposed to toxins such as asbestos and silica through particular professions, certain medications or radiation therapy
- People with autoimmune diseases like rheumatoid arthritis and scleroderma
- Individuals with a family history of the condition[47]

Data on the impact of PF remains patchy and variable. PF encompasses a broad spectrum of conditions varying in cause, prognosis, and treatment response. The most common and severe form is IPF, but other types include Non-Specific Interstitial Pneumonia (NSIP), Hypersensitivity Pneumonitis and Connective tissue disease-associated ILD.[48]

IPF is estimated to affect three million people worldwide or 17.7 people per 100,000 globally.[49] [50] Rates of IPF are rising which can be attributed to an ageing population and exposure to pollution.[51] [52]

Once diagnosed the average survival of someone with IPF is between three to five years, but this varies depending on a number of factors including age, physical fitness and treatment options.[53] [54] The mortality rate from the condition is high, with 50% of patients likely to die within two to three years.[55] IPF has a worse five year survival rate than many cancers, including breast, prostate, colon, skin cancer, and lymphoma.[56]

An estimated 17,000 people die from IPF across the EU each year – though given challenges with diagnosis this is likely to be an under-reporting.[57] Mortality rates are rising — a study from 1999 to 2012 across ten countries globally found a 2-3% annual increase.[58]

Many patients with PF have co-morbidities. Research from Central and Eastern Europe has shown that 90% of patients with IPF have at least one comorbidity, with more than one-third (37.8%) having four or more. The most common disease-specific comorbidities identified were arterial hypertension (53.0%), diabetes mellitus (24.0%), hyperlipidaemia (23.5%), coronary heart disease (23.3%), and gastroesophageal reflux (21.1%).[59]

Finally there are particular challenges for people with PF in the Global South where there is limited access to specialists as well as diagnostic equipment and tests, which means the condition can often go undiagnosed.[60] This is particularly concerning as 80% of the world's population who are exposed to dangerously high levels of air pollution – which is a significant contributing factor to the development of PF – live in the Global South.[61]

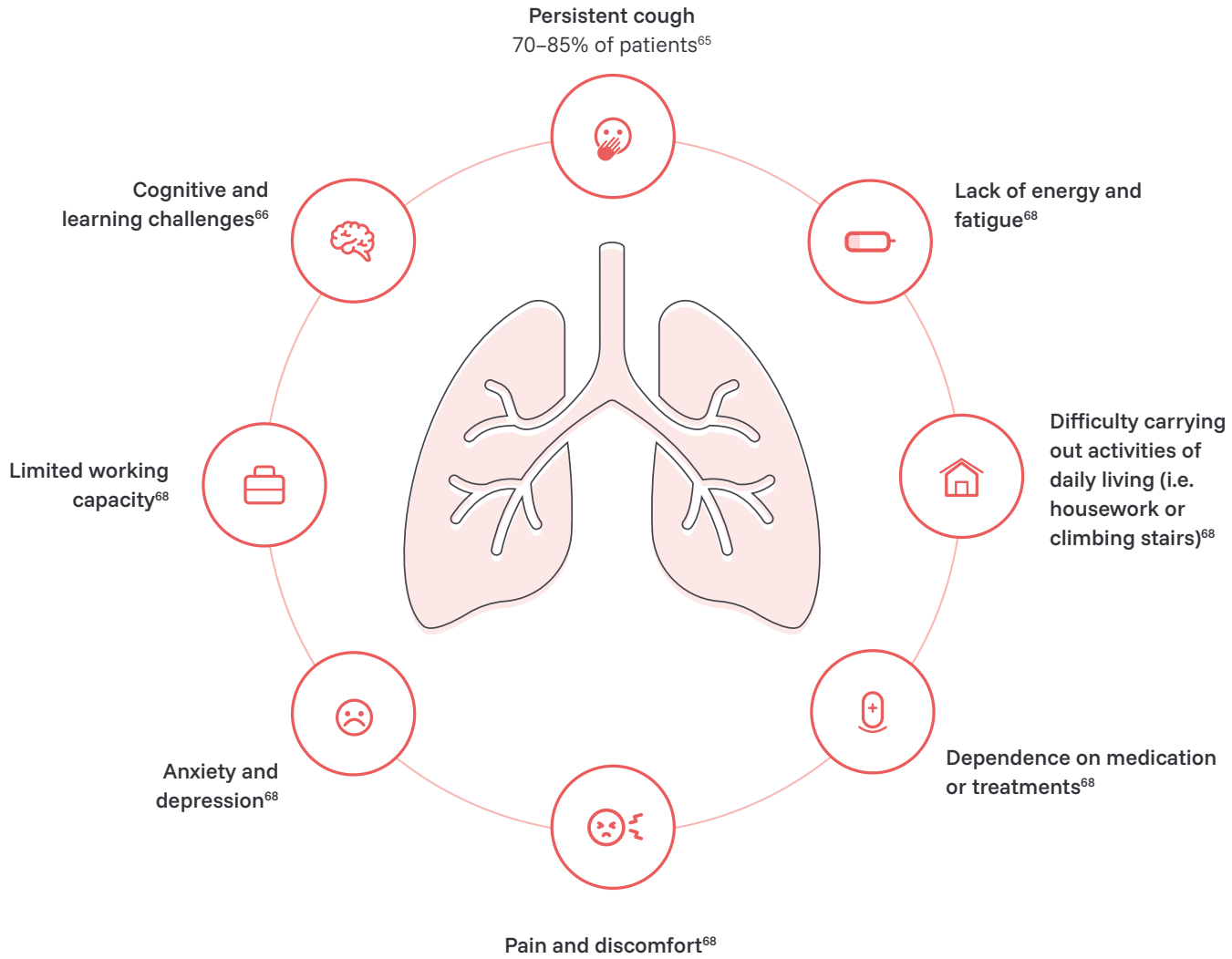
The impact of pulmonary fibrosis on patients, carers, health systems and economies

THE IMPACT ON PATIENTS

People with PF suffer from symptoms including increasing breathlessness, cough and fatigue before dying from lung failure or a related cause. Cough is often the first symptom affecting upwards of 70-85% of IPF patients.[62] Many people with PF are diagnosed late or misdiagnosed leading to worse outcomes.[63] [64]

Figure 2: Challenges for PF patients

Research has shown that those living with PF commonly face the following challenges:



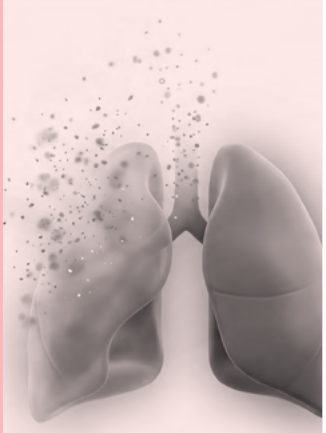
Case study: Steve's story

"I was diagnosed with Idiopathic Pulmonary Fibrosis (IPF) when I was 59 years old and looking forward to my retirement.

IPF is a devastating lung scarring disease with a life expectancy of three to five years - worse than most common cancers. When I was diagnosed, my only symptom was a persistent tickly cough, but I quickly started to become breathless. After a short while, walking up the stairs at home became all but impossible and in time, even walking more than 50m on the flat was a challenge and I had to stop frequently to catch my breath. I was put on ambulatory oxygen so that I could continue exercising, but soon I needed oxygen 24/7 and became stuck at home. My world became smaller and smaller, and I was expecting to die soon from respiratory failure. As a friend living with advanced IPF put it to me the other day – "most people with IPF slowly suffocate to death".

Also, along with the majority of IPF patients, I suffered from a severe, debilitating cough, which made social life difficult. As you suffer with the disease so does your family and it's not surprising that mental health and depression is common.

As I began thinking about end-of-life care, I was extremely fortunate to be one of the only 1-2% of IPF patients to receive a lung transplant. The operation went well and, while I was recovering, I found myself becoming increasingly angry about the level of care IPF patients receive compared to cancer patients and the relative lack of research into new treatments. I decided to do something about it and became a patient advocate. I have been doing this for over nine years and despite many great patient organisations around the world, there is so much we still need to do to STOP this disease and ultimately find a cure."[67]



Reduced life expectancy and social isolation also has an impact on patients. Studies have shown that there is a significant psychological impact of living with chronic lung diseases which may, in some cases, be worse than patients with cancer.[68] Lack of certainty with regards to disease prognosis – which is common in cases of PF – is associated with increased levels of depression and anxiety for patients.[69] The need for supplemental oxygen can also severely impact patients' independence and in turn can have significant psychological impacts.[70]

Research has shown that health inequalities contribute to worse outcomes for PF patients.

A study led by the University of East Anglia in the UK found that patients from the most deprived group had a 36% increased risk of death than those in the least deprived group.[71] Patients with IPF from lower socio-economic backgrounds often find their disease progresses more quickly.[72]

A study of 1,904 patients from the Pulmonary Fibrosis Foundation's database of patients with PF across the United States found that 'black patients were consistently younger than hispanic and white patients at diagnosis and were more likely to be hospitalised, receive a lung transplant, and die at younger ages.'[73] Another US study found lower rates of anti-fibrotic therapy were prescribed to black people than other racial groups.[74]

PF can also cause severe financial strain on patients and their families/carers due to high direct medical costs (medication, hospitalisations, oxygen) and indirect costs like lost income. Families can face debt or bankruptcy, often exacerbated by rising energy bills for home oxygen, travel for care, and the need for home modifications, resulting in substantial financial anxiety.[75] [76]

IMPACT ON CARERS AND FAMILIES

Studies have shown that 20.3% of patients with IPF require support from a paid carer, for an average duration of eight hours per week, while 60.5% of patients need support from an unpaid carer such as a partner, family member, or neighbour, for 30 hours per week.[77]

Often patients and caregivers have additional caring responsibilities such as for children or grandchildren which can add further pressures on time, resources and emotional wellbeing.

PF can substantially impact unpaid caregivers' quality of life in terms of sleep and health, daily activities, emotional well-being, social life, and finances.[78] A study in Ireland found that carers commonly reported stress, worry and feelings of inadequacy.[79]

THE IMPACT ON HEALTH SYSTEMS AND ECONOMIES

Health system costs

PF has a significant impact on health systems – driving up overall costs and utilisation of healthcare resources. Examples of health system costs associated with PF include:

- A need for specialist clinical diagnosis and medication
- Primary care consultations for ongoing care management
- Possible emergency admissions related to exacerbations
- Inpatient stays for respiratory failures or infections
- Oxygen therapy at home and other care in the community programmes such as pulmonary rehabilitation programmes
- End of life care support

A systematic review of nine studies found total annual costs for diagnosis, follow-up management (hospitalisation and outpatients costs) and treatment of exacerbations per patient with PF ranged between a median of €25,613 in France, a mean annual cost of €32,934 in Spain and an average of €34,530 across several EU countries.[80]

For comparison COPD annual costs in the US range from $1,425 in patients with no exacerbations to $12,765 in patients with two or more exacerbations; while in Europe COPD costs range from €1,963 in Belgium to €10,701 in Norway.[81] [82]

For non-small cell lung cancer – the most common form of lung cancer – costs can range from $67,000 during the first year of treatment, to as much as $109,000 during the last year of life in the US; while in the Netherlands it averages €48,443 per year.[83] [84]

Hospitalisations are a major driver of costs.[85] In a US study of over-65s accessing Medicare, 48.7% of IPF patients required hospitalisation annually compared to 20.8% amongst the wider Medicare population; while 39.6% with IPF visited emergency departments compared to 17.5% in the wider population.[86]

ILDs are also now the most common cause of lung transplants globally accounting for over 40%. IPF alone is responsible for 32%.[87] Depending on the country where the transplant takes place, this can cost anywhere from $120,000 to $1.4m.[88]

Pharmacological treatment is also a significant driver of costs for ILDs and in particular IPF – however evidence shows that efforts to reduce comorbidities and to treat the condition earlier may reduce overall costs, particularly as a result of reduced hospitalisations.[89]

The following summarises some of the evidence of PF related health system costs available by country.

United States

Annual healthcare costs of IPF in the US have been estimated to be $2 billion.[90] All-cause healthcare costs for IPF patients in the US average $59,379 per patient annually, with 36.6% of these costs ($21,732) being respiratory-related.[91]

Mean annual costs for Intensive Care Unit (ICU) admission and inpatient care were $10,098 and $13,975 respectively, per patient.[92]

Medicare data reveal that IPF patients have 134% higher total medical costs compared to those without the condition ($20,887 vs. $8,932 annually).[93]

China

In China the median direct medical costs for IPF are estimated to be 9387.3 Yuan per hospital admission.[94]

Canada

A study in Canada highlighted that healthcare costs begin escalating years before diagnosis, with annual costs rising from $2,721 per patient five years before diagnosis to $7,049 two years before diagnosis, ultimately reaching $12,978 in the year following diagnosis.[95]

Spain

A Spanish study estimated the annual patient cost of IPF at €26,435.[96]

Germany

A study in Germany found that on average patients visited their physician 14 times or more and had two hospitalisations per year following their initial IPF diagnosis. The same study found that the direct costs were €15,721 per year of which 55.7% or €8,754 per year were due to hospitalisations.[97]

Wider economic costs

PF also has wider economic impacts and costs – particularly with regards to employment and productivity, though the evidence on this is more limited.

Studies have shown that 26.7% of IPF patients retire early due to illness.[98] More broadly an estimated 48% of those with progressive ILDs have a permanent disability and 23% have lost their job due to their disability.[99]

Canada

A study of patients with ILDs in Canada found that there was a productivity loss of 7.8 hours per week with an annual productivity loss of 11,610 Canadian dollars per employee. It also found that employment figures in an age and sex matched population were 23% and 18% lower for those with ILDs in people aged 25-54 and over 55 years respectively.[100]

The opportunity of the WHO Lung Health Resolution

Despite the impact of PF on patients, their families, healthcare systems and economies, the condition remains a relatively low health policy priority globally. PF has historically struggled to secure importance within policymaker efforts to improve lung health and receives far less recognition and funding than comparable conditions with a similar level of impact such as ovarian cancer.[101]

At the WHA in May 2025, the WHO adopted the Lung Health Resolution: *Promoting and prioritizing an integrated lung health approach.*[102]

The resolution recognises the importance of tackling PF for the first time in global policy – alongside other lung conditions – to deliver on global health goals for reducing mortality rates from non-communicable diseases (NCDs).[103] [104] The resolution includes specific guidance on preventative action member states can take to improve lung health, as well as encouraging the development of guidelines for the early detection, diagnosis and treatment of lung diseases including PF.

Figure 3: The WHO Lung Health Resolution[105]

The Lung Health Resolution urges member states:

(1) to develop integrated national policy for an integrated approach to lung health, encompassing both communicable and noncommunicable lung diseases, through multisectoral collaboration and multidisciplinary collaboration by incorporating whole-of-government and whole-of-society approaches, ensuring engagement from all relevant sectors including health, environment, labour, education and finance;

(2) to incorporate an integrated approach to lung health into primary healthcare services towards the attainment of universal health coverage, inclusive of comprehensive lung health services, with effective referral pathways to secondary and tertiary care, when appropriate;

(3) to strengthen awareness of the health impacts of air pollution and enhance national air quality standards and monitoring capacity;

(4) to create and enforce adequate regulations protecting workers from occupational risk factors impacting lung health;

(5) to strengthen existing, or establish new, comprehensive integrated approach lung health programmes including: (a) strengthening health promotion, primary preventive services – particularly tobacco and vaping control, reducing indoor and outdoor air pollution exposure – and vaccination programmes for preventable respiratory infections; (b) updating or developing evidence-based clinical and public health guidelines for cost-effective measures for early detection, diagnosis and treatment of communicable and noncommunicable lung diseases, including the use of innovative technologies; (c) updating or developing evidence-based information mechanisms for policy-making and programme monitoring, evaluation and learning;

(6) to strengthen national capacities for an integrated approach on lung health, considering adaptation of relevant existing and evidence-based WHO tools to create an evidence-based and cost-effective integrated lung health package of interventions suitable for all patients, according to their individual needs;

(7) to improve access to and affordability and availability of safe, effective and quality medicines, vaccines and health technologies using the WHO Model List of Essential Medicines and the WHO Model List of Essential In Vitro Diagnostics with an emphasis on cost-effectiveness, sustainable allocation of resources and evidence-based approaches including by increasing national capacities, and with a focus on building effective regulatory systems, manufacturing capacities and/or procurement strategies and policies for fair pricing to address both communicable and noncommunicable lung diseases, including tuberculosis, pneumonia, influenza and COVID-19, as well as chronic obstructive pulmonary disease, asthma, pulmonary fibrosis and lung cancer.

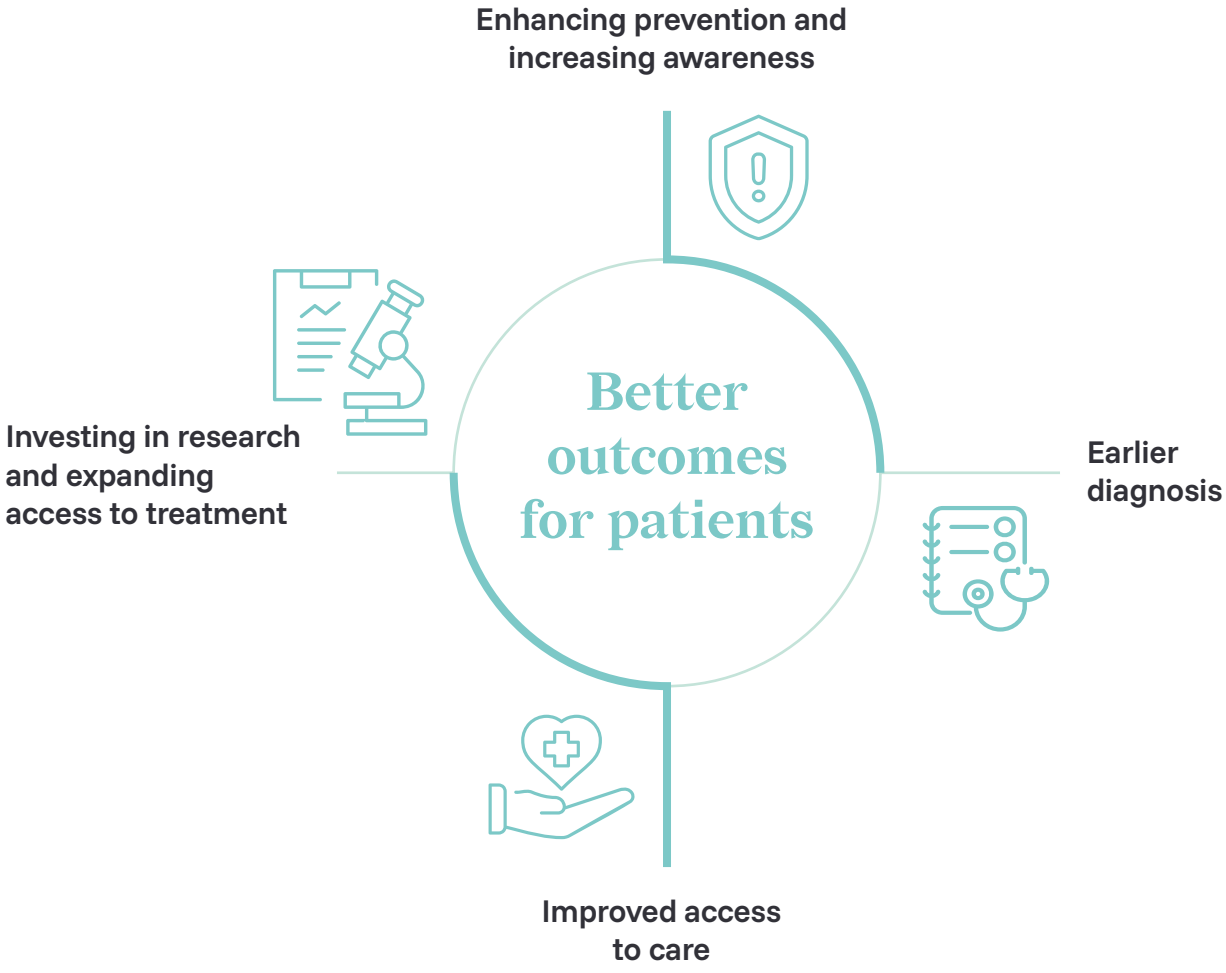
Translating the WHO Lung Health Resolution into action that improves outcomes for patients with Pulmonary Fibrosis

As part of this research, Future Health undertook a wide ranging consultation with stakeholders with expertise in PF across different parts of the world.[106] The Lung Health Resolution was seen by respondents to be a helpful framework for change, though there were challenges identified regarding how governments and policymakers could best apply the proposed actions in different geographies and health systems.[107]

For example, delegates at the European Lung Foundation's patient organisation networking day stated that: "without clear strategies for dissemination and integration into policy and practice, several were concerned that the resolution's impact may remain largely symbolic rather than delivering tangible improvements in access, quality of care, and patient outcomes."[108]

The following seeks to address this challenge, by identifying opportunities for improvements across the care pathway for patients with PF.

Figure 4: Translating the Lung Health Resolution into improved outcomes for patients with PF[109]



Enhancing prevention and increasing awareness

Enhancing prevention and increasing awareness

THE CHALLENGE

Despite the increasing number of people affected by PF, awareness of the condition remains low amongst both healthcare professionals and the general public.[110] This is despite the links between PF and common societal challenges including an ageing population and air pollution.

A global survey of primary care physicians found that just over one in five had a satisfactory self-perceived level of knowledge of PF. When compared with other core ILDs (hypersensitivity pneumonitis, sarcoidosis, connective tissue disease related-ILD and drug-induced ILD) , IPF had the worst recorded performance in the survey with just 48.5% of GPs recognising the importance of velcro-type crackles in suggesting a possible diagnosis.[111] [112]

Public feedback from a survey commissioned by Boehringer Ingelheim found a common belief that smoking is the primary cause of the condition – an incorrect belief indicating levels of stigma associated with PF.[113]

Separate US survey data show that a vast majority of Americans (86%) do not know the symptoms of PF. Amongst those over 60 years of age — who are most at risk — 91% do not know the symptoms and 96% have never discussed PF with their doctor.[114]

This low level of awareness causes delays to patients seeking medical support, late diagnosis and poorer outcomes.[115] Early diagnosis and treatment is particularly important for PF patients as current treatments can only slow the progression of the disease rather than halt the disease or reverse the damage it has caused to the lungs.[116]

OPPORTUNITIES FOR IMPROVEMENT

To address the PF knowledge gap, policymakers should prioritise improved education amongst both the clinical community and the public.

Particular attention should be focused on increasing awareness amongst those working in primary care – so that symptoms are more quickly recognised and investigated. There are some good examples of short training modules co-created between patient groups and healthcare professionals to improve education in the UK and US.[117] [118] Some countries like the UK are also beginning to include PF education in standard medical training; however there is still a need to ensure existing practitioners receive appropriate ongoing education as well.[119] Younger doctors have been shown to be more likely to identify PF as the most prevalent ILD globally (65%), compared to those over 45 (40%).[120] A simple training step that could be taken is to teach primary care practitioners to recognise the characteristic sound of fine velcro crackles – a hallmark of PF.[121]

In Ireland, the Irish Lung Fibrosis Association (ILFA) has taken an active role in primary care education via sharing patient leaflets both with GPs and patients – encouraging patients to take leaflets with them to their GP appointments (see figure 5 below).[122]

Figure 5: Example patient leaflet from ILFA[123]

How is pulmonary fibrosis treated?

Unfortunately there is no cure for IPF. The treatments recommended by your doctor are used to slow down or prevent the disease progressing and to improve your symptoms.

A **lung transplant** is the only effective treatment for IPF but this is not a suitable option for everyone. It involves a major operation and depends on the severity of the patient's IPF and general health. If you are being considered for a lung transplant, you will be assessed in the National Lung Transplant Centre in the Mater Misericordiae University Hospital in Dublin.

The **medications** Perfinidone and Nintedanib can slow down the formation of scar tissue in the lungs and the rate of disease progression. However, they cannot cure IPF or reverse the damage that is already there.

Your doctor may prescribe other medications to help you manage your symptoms and any other health problems you may have.

If your blood oxygen levels are low, your doctor will prescribe **medical oxygen**. Oxygen can help you manage your breathlessness and improve your quality of life. Your oxygen needs may change over time, so tell your doctor, nurse or physiotherapist if you are more breathless.

Please see our leaflets *The treatment of Idiopathic Pulmonary Fibrosis and Oxygen and Idiopathic Pulmonary Fibrosis* for more information.

Tips for managing your health and keeping well

IPF can affect you physically and emotionally but you can make positive lifestyle changes to help you cope with the challenges of living with this condition.

The most important things you can do are to learn more about your lung condition, take a proactive approach to managing your health and try to stay positive.

Lifestyle tips to help you manage your IPF

- **If you smoke, stop.** Ask your doctor for help. Ask your family and friends not to smoke around you or in your home to protect you from the effects of second-hand smoke.
- **Stay as active as possible.** Exercise is very important for people with a lung condition and will help you to stay fit and strong. Exercise can also help improve your mood and emotional wellbeing. Contact ILFA to order your free exercise DVD and walking pack called *The 2000 Steps a Day Challenge*.
- **Join a pulmonary rehabilitation class.** These classes are a good way for IPF patients to take part in a supervised exercise programme. Ask your doctor to refer you to a class if there is one in your area.
- **Eat healthy foods and maintain a healthy weight.** Being overweight can put pressure on your chest and stomach muscles making it harder to breathe and causing you to be more tired. Some patients will lose weight as their IPF progresses. If this happens to you, it is important to get advice to prevent too much weight loss.
- **Continue to socialise and enjoy your hobbies.** It is important to carry on with these activities as much as you can. It is ok to take things slowly.
- **Ask your doctor for help if you are struggling physically or emotionally.** If you think you would like to have counselling, ask your doctor to refer you to a counsellor or psychologist.
- **Join a lung fibrosis support group** to meet others with IPF and learn from their experiences. You can join the ILFA mailing list to receive our free newsletter and keep up to date with developments.

ILFA has a wide range of resources for patients and carers. These include:

- The ILFA 2000 Steps a Day walking pack
- The ILFA Exercise DVD for lung fibrosis patients
- Information leaflets including:
  - The treatment of Idiopathic Pulmonary Fibrosis
  - Oxygen and Idiopathic Pulmonary Fibrosis
  - Getting the most out of your hospital appointments
  - Advice for carers of people with Idiopathic Pulmonary Fibrosis
  - Weight Management and Nutrition for Pulmonary Fibrosis

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Plain English

Irish Lung Fibrosis Association
Registered charity number: 20053437
Company registration number: 367940

Irish Lung Fibrosis Association

What is Pulmonary Fibrosis?

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Policymakers should explore opportunities to work collaboratively with PF country patient groups to encourage more educational activities such as this as part of efforts to improve awareness amongst primary care practitioners.

Targeted public awareness campaigns can also help raise the salience of the condition amongst those most at risk of developing PF including:

- Those who have been exposed to toxins such as asbestos and silica through particular professions, certain medications or radiation therapy
- People with autoimmune diseases like rheumatoid arthritis and scleroderma
- Individuals with a family history of the condition[124]

There are examples of campaigns being run in the US with labour unions in particular high-risk industries to educate people about PF and the associated risk factors.[125] Another example is the 'Breathe Freely' campaign which raises awareness about occupational lung disease in the construction and manufacturing industries in the UK.[126] Alongside this, governments should ensure that health and safety laws are in place for these high-risk industries that can support more preventative action on PF – such as that taken in Australia (case study below).

Case study: Australia's world first ban on engineered stone

Silicosis — caused by inhaling respirable crystalline silica dust — is a progressive, fatal and entirely preventable lung disease that shares the same fibrotic endpoint as PF. In Australia, a surge in cases among workers cutting and shaping engineered stone kitchen worktops, most of them under 35, prompted a sustained campaign by clinicians, patient organisations and affected families, documented in The Lancet Respiratory Medicine in 2024.[127] Safe Work Australia concluded that there was no safe level of silica exposure from engineered stone and recommended an outright prohibition. In July 2024, Australia became the first country in the world to ban the manufacture, supply, processing and installation of engineered stone, with imports banned from January 2025.[128] The Cancer Council estimates the ban will prevent approximately 100 lung cancers and 1,000 silicosis cases over the lifetime of Australian workers.[129]

Many PF patient organisations run existing campaigns for PF awareness month in September each year – including the European PF Federation and ILFA.[130] [131] The US-based PF Foundation, as well as running annual awareness activities, have also developed a suite of patient education materials.[132] [133] The Lung Foundation Australia co-ordinates landmarks across Australia to light up blue on 25th September as part of PF awareness raising activities.[134]

Governments and health systems should consider amplifying these campaigns as well as identifying opportunities to integrate PF awareness within wider lung health awareness campaigns – such as for lung cancer and COPD.

Recommendations for policymakers

- Increase awareness of PF amongst the medical community by including the condition in medical training and education, with a particular focus on increasing earlier diagnosis in the primary care setting
- Deliver targeted public awareness campaigns on the signs and symptoms of PF
- Utilise existing awareness programmes for other lung health conditions such as lung cancer and COPD to educate the public about PF
- Ensure that health and safety laws for industries that present a higher risk for people in developing PF are in place and robust

Earlier diagnosis

Earlier diagnosis

THE CHALLENGE

Early diagnosis of PF is crucial to ensure timely treatment initiation to slow down disease progression.[135]

Currently, PF is too often diagnosed late and/or misdiagnosed. A global research study found variation in diagnostic delay between countries ranging from 0.8 years in Germany to 2 years in Japan. The researchers also found that patients underwent 7-10 clinical tests before diagnosis.[136] Late diagnosis of over a year has been directly linked with worse progression free survival.[137] This is in contrast to lung cancer which is typically diagnosed much more quickly after first symptoms arise (median of 3-4 months).[138]

PF diagnosis can be delayed because symptoms may initially be less pronounced. The most common symptoms are breathlessness, cough and fatigue, which can be mistaken for other conditions such as COPD, asthma and bronchitis.[139] [140] Patients often undergo unnecessary treatment due to misdiagnosis – the most common being antibiotic use (32%) and systemic corticosteroids (21.8%).[141] Experts have also highlighted that some patients are inappropriately prescribed inhalers as a result of misdiagnoses.[142]

Some patients may have more than one respiratory disease – studies have shown that between 25% and 37% of patients with IPF have COPD.[143] [144] In such instances patients may well receive an accurate COPD diagnosis but have an IPF diagnosis missed due to an assumption that their PF symptoms are attributable to the COPD diagnosis only.[145] Misdiagnoses and their associated treatment deplete finite healthcare resources and lead to further disease progression.[146]

There are a lack of established guidelines for screening people for PF who are at increased risk, leaving people often having symptoms for many years without receiving a diagnosis.[147]

In order to receive a diagnosis, PF patients need to access specialist diagnostic equipment like a CT scan which can cause further delays due to a lack of availability in some countries.[148] Patients with PF need to see specialists to ensure they receive an accurate diagnosis and appropriate treatment but this may involve a long wait or it may not always be possible due to the absence of specialists in some countries.[149] Another challenge can be the availability of radiographers to perform and interpret the scan.

Examples of the diagnosis challenge by country and region are set out below.

United States

A 2015 survey of 600 patients in the United States with PF found that:

- Over half (55%) had at least one wrong diagnosis before they were correctly diagnosed
- Over one-third (38%) had at least two wrong diagnoses before they were correctly diagnosed
- The most common wrong diagnoses were asthma, bronchitis and pneumonia
- About one-third (30%) visited their primary care doctor at least four separate times before they were referred to see a lung specialist (pulmonologist)
- Three-quarters (75%) visited at least three different doctors before they were correctly diagnosed
- Nearly every person had one or more procedures that they did not need done one or more times (CT, echocardiogram, surgical lung biopsy, and bronchoscopy)
- Many patients were prescribed antibiotics, steroids, or asthma medications that they did not need[150]

A separate study in the United States found a median delay to diagnosis of 2.2 years.[151]

Europe

A European survey found that 40% of patients took over a year or more to receive a final diagnosis with the greatest delay occurring during stage 1 (initial presentation to a doctor upon onset of symptoms).[152] A 2019 Danish study found a diagnostic delay of 2.1 years.[153]

OPPORTUNITIES FOR IMPROVEMENT

Late diagnosis is driven by a number of factors including lack of public and professional awareness and information on PF (see previous section), poor and/or delayed access to specialists and diagnostic equipment as well as a lack of screening at risk populations.[154]

To address these barriers policymakers should focus on the following priorities:

1. **Establish clear national clinical guidelines and pathways for PF** that support earlier diagnosis and disease identification building from international best practice approaches. These guidelines should include how they can be best incorporated into wider lung health pathways of care[155]
2. **Develop and evaluate targeted screening programmes for those at higher risk of PF.** This could include those with familial history, those more exposed to toxins (e.g. certain professions) and those with conditions such as connective tissue diseases (such as rheumatoid arthritis) that carry a substantially elevated risk of the condition. The St Antonius ILD Centre of Excellence and the UMC Utrecht Clinical Genetics Department have put in place a clinical protocol to screen for early pulmonary disease in asymptomatic, high-risk relatives over the age of 18. The current clinical screening protocol involves high resolution CT (HRCT) of the chest at a five-year interval and an annual medical examination comprising history, pulmonary function testing, blood tests, and physical examination[156]
3. **Unlock the potential of new data and AI tools to identify those people at heightened PF risk earlier.** An example is an algorithm which has been developed to predict the future risk of IPF based on comorbidity signatures in electronic medical records. The algorithm named the zero-burden comorbidity risk score for IPF (ZCoR-IPF) was shown to identify a diagnosis 1-4 years before conventional diagnosis[157]
4. **Utilise existing screening progammes such as those for lung cancer so they can support the identification of PF.**[158] A lung cancer screening programme in England found the most common ILD abnormality to be IPF.[159] New technology presents opportunities here too. ScreenDx is an FDA approved AI algorithm which can detect cases of PF through CT imaging.[160] This technology enables additional screening to be undertaken in a resource efficient way when a patient has undergone a CT scan. This technology could be deployed to assess CT imaging from other screening programmes such as for lung cancer and COPD
5. **Embedding PF screening within wider lung health programmes will potentially require additional training and support for radiologists to assist them in identifying PF.** This has been undertaken in Thailand through the development of a HRCT protocol for ILDs with an accompanying checklist[161]
6. **Create clinical guidelines and pathways to support referrals from specialisms with high rates of PF co-morbidities.** One example is rheumatology. The American College of Rheumatology has introduced guidelines to screen, monitor and treat ILD in patients with rheumatic conditions, with experts noting that 'early detection and hastened referral to care, in collaboration with pulmonology, is critical for the best patient outcomes' and that 'because symptoms of ILD can be subtle or result from other common diseases, the diagnosis of ILD can be delayed'[162]
7. **Expand access to emerging technologies** like eNose which may be able to detect PF through a breath test and incorporate it into standard health checks.[163] Other innovation such as molecular classifiers, exhaled breath analysis and artificial intelligence (AI) to analyse CT scans and pulmonary function test results, could all present opportunities to transform the diagnostic pathway, though these will need further validation before wider use[164] [165] [166] [167]
8. **Ensure patients can be swiftly referred to a specialist and that specialist diagnostic equipment is available (pulmonary tests and CT scans) through specialist centres** – in the UK the creation of Community Diagnostic Centres (CDCs) are helping to transform pathways in this manner. Elsewhere evidence has shown that the use of mobile units to deliver CT scans has dramatically improved the diagnosis of lung health issues such as lung cancer and COPD in harder to reach and marginalised communities.[168] Evolving these programmes to identify PF earlier presents opportunities for the earlier screening of higher risk communities

Recommendations for policymakers

- Publish clear national PF clinical guidelines improving the early detection and accurate diagnosis of the condition, and set out how these guidelines can be incorporated into wider lung health care pathways
- Develop and evaluate targeted screening programmes for populations who have been exposed to toxins (such as asbestos and silicosis) likely to cause PF as well as those who may be genetically predisposed and those with other conditions with a raised risk (such as rheumatoid arthritis)
- Include PF in wider screening programmes for lung health conditions such as lung cancer and ensure workforce training programmes and new technologies, including data and AI tools for identifying PF, are in place
- Create clinical guidelines and pathways to support referrals from specialisms with high rates of PF co-morbidities such as rheumatology
- Ensure equitable access to the latest innovative diagnostic equipment and swift referral for patients to a specialist

Improved access to specialist and integrated care

Improved access to specialist and integrated care

THE CHALLENGE

PF patients often face significant variation in the quality of care they have access to. This variation comes in a range of different forms:

1. *Access to services* – PF patients require specialist care; but this specialist care can be geographically distant from where patients live, resulting in inequalities of care access.[169] Such challenges are particularly acute in the Global South where there are a general lack of specialists and specialist diagnostic equipment. Within developed nations, PF care is often concentrated in urban areas presenting difficulties for those living in rural communities, particularly as their condition deteriorates and travel becomes increasingly difficult. For example in Ireland there are only eight specialist PF centres and five of these are in Dublin.[170] Responses to a European wide survey from patients with IPF and healthcare professionals found that along with delays in diagnosis; access to specialists and pharmacological treatment have been identified as important gaps in current care[171]
2. *Access to supplemental oxygen* – Despite being vital for those living with PF, supplemental oxygen is not always readily available for patients. Even in Global North countries access can be restricted, as has happened through recent changes to the Medicare tariff in the US where a campaigning coalition is pushing US lawmakers for action to address this.[172] There are also challenges for patients in managing the costs of running home oxygen services – particularly in light of rising global energy prices
3. *Quality of care* – Patients with PF have reported that following their diagnosis, communication could be more sensitive and supportive.[173] Many patients have also reported the need for improved information on their diagnosis and treatment, including side effects and how to manage them.[174] Healthcare professionals in a Belgian research study expressed a general desire for the care and management of patients with PF to be more proactive.[175] Other studies have shown that areas of unmet need for people with PF include symptom relief, and improved access to palliative care[176]
4. *Integrated care* – Beyond specialist treatment and primary care management, patients with PF often require a range of different services and support including: pulmonary rehabilitation, psychological support, timely access to ambulatory oxygen therapy (AOT) and long-term oxygen therapy (LTOT), and end of life planning and palliative care. However, care is often fragmented and disjointed.

   Studies have shown that whilst patients are often referred for pulmonary rehabilitation, many do not in practice have access to the programme[177]

OPPORTUNITIES FOR IMPROVEMENT

There is clearly a need to:

- Improve access to care for PF patients – including supplemental oxygen
- Better co-ordinate and join-up patient care
- Improve the quality of care patients receive

Access to care

In America, the PF Foundation has established 86 accredited centres for PF care. Each centre must meet a set of quality care criteria to be accredited – including levels of staffing, specialist access, MDT models of care, access to lung transplants and clinical trials. They must also work with the PF Foundation to distribute educational materials and undertake community outreach.

The PFF Care Centre Network aims to:

- Improve the Diagnosis Process
- Enhance Quality of Care
- Accelerate Research
- Effectively advocate for the PF Community[178]

In Europe, the European Reference Network on Rare Respiratory Diseases (ERN-LUNG), brings together 79 healthcare providers across 25 countries, providing patients with access to interdisciplinary member teams and online second opinions on complex rare lung cases.[179] ERN-LUNG includes a dedicated ILD core network, working on clinical guidelines and best practice of care, registries and biobanks, quality management, and cross-border care.[180]

Such a model of pooling expertise and best practice presents an opportunity to spread high quality care more equitably across countries; particularly if accompanied with funding incentives for those delivering higher quality care.

In addition, the development of 'second tier' or intermediate specialist services working alongside primary ILD centres is increasingly recognised as essential to making specialist ILD care more equitable and accessible.

Case study: OneVoiceILD[181]

In England, the OneVoiceILD movement — a coalition of clinicians, patients and patient organisations led by Action for Pulmonary Fibrosis — has published a nationally endorsed Integrated Care Pathway setting out a vision for transforming ILD care and calling for it to be held to the same standards as cancer care. One of the pathway's key recommendations is the creation of new Tier 2 specialist centres, designed to alleviate capacity pressures on existing Tier 1 centres while providing expert care closer to patients' homes.[182] The case for this structural expansion is pressing: ILD specialist centres in England have seen new patient referrals increase by more than two to five times since the NHS England ILD service specification was published in 2017.

Action for Pulmonary Fibrosis has also developed a practical Business Case Toolkit to support non-specialist centres in making the case to their payor for increased ILD staffing and resourcing, recognising that system-level change will require both clinical leadership and sustained investment.[183] This tiered model — with Tier 2 centres working in structured partnership with Tier 1 specialist units — offers a foundational framework for countries seeking to improve ILD care delivery.

Particularly where there are geographical challenges, digital technologies and innovation present openings to redesign care pathways and bring care closer to patients, reducing inequality of access to specialists, treatment burden and supporting overall quality of life improvements.[184] One example is the use of acoustic devices such as electronic stethoscopes which, if accessible in primary care with suitable clinical information and aids, could help speed up diagnosis.[185] Another, is home spirometry and virtual wards for managing patients remotely outside the hospital setting.[186]

To improve access to supplemental oxygen, policymakers should establish and resource a national framework for supplemental oxygen access for patients with pulmonary fibrosis that ensures: (i) timely assessment against standardised eligibility criteria at point of specialist diagnosis; (ii) provision of both static home oxygen and portable oxygen equipment as standard, supporting patient mobility and quality of life; (iii) full coverage within national health benefit packages without financial barriers to access; (iv) a named clinician responsible within the ILD multidisciplinary team for oxygen review and prescription; and (v) equitable access regardless of geographic location, with dedicated commissioning arrangements for rural and remote populations.

Co-ordination of care

An effective way of delivering services for PF patients is through a multi-disciplinary team (MDT). Research has shown that an MDT approach can establish a diagnosis in 76% of cases when a prior diagnosis was uncertain.[187] Studies have also found that MDTs are essential in not only diagnosing patients but in providing high quality care with input from a wide variety of specialists including pulmonologists, radiologists, pathologists (when a lung biopsy is performed), rheumatologists, specialist nurses, physiotherapists and pharmacists.[188] [189] Another study found that the use of a care coordinator during the 'routine management of IPF patients may improve patient satisfaction, spare physician time and lead to annual cost-savings.'[190] [191]

The Respirology ILD Program in Calgary, Canada is a leading MDT initiative dedicated to comprehensive clinical care, education, and research. It is structured around four core pillars: clinical care, education, research and patient and caregiver support.[192]

An MDT approach is being piloted in England where multidisciplinary team meetings are being held virtually to bring specialists together around the needs of patients.[193] This remote model has the potential to expand access to higher quality more co-ordinated care for patients.

Health systems should also work to provide access to wider services such as pulmonary rehabilitation, psychological support, occupational therapy when disabled at home and early end-of-life planning. As genetic understanding of PF increases, genetic counselling will also be important as part of care planning.

An example of an innovative and more holistic care model is the 'Triple A Care Model for patient centred care'. This includes improving 'access' to care through heightened awareness and the adoption of new digital technologies, a more 'anticipatory' care model that enables a continuous assessment of patient needs and care planning, along with an 'act' domain where patients get the treatments and end of life care they need.[194]

Co-ordinated care is particularly important for patients with PF who often have more than one co-morbidity. Identifying and treating these co-morbidities will require more patient rather than condition centred models of care to be deployed.[195] PF patients are also immunocompromised so it is vital that they receive available vaccinations and other healthcare protection available.

One approach to improving existing care for PF patients is to use patient reported outcome measures to better understand patient needs and support shared decision making with clinicians. Measures have been developed covering the following domains: perceived effectiveness, perceived side-effects, ease of use and satisfaction.[196]

Providing those with PF with the opportunity to connect with other patients has also been shown to provide benefits. This could be through peer support groups, online forums, or attendance at pulmonary rehabilitation programmes.[197] Collaborations between health systems and patient group charities have also opened up new research opportunities based on patient needs and feedback.[198]

Recommendations for policymakers

- Consider working with relevant partners to develop specialist centres for PF treatment and care, backed by funding incentives for delivering best practice care
- Establish and resource a national framework for supplemental oxygen access for patients with PF that ensures timely and equitable access
- Build an in-person and remotely functional MDT for PF patients that can deliver a multi-professional, coordinated and integrated approach to care including the opportunity of peer support
- Put patient feedback at the heart of PF services, utilising this to drive service transformation and improvement

Investing in research and expanding access to treatment

Investing in research and expanding access to treatment

THE CHALLENGE

While there is currently no cure for PF, pharmacological interventions such as antifibrotic therapies and non-pharmacological interventions such as oxygen therapy or pulmonary rehabilitation can help slow disease progression.[199] There have been two antifibrotic therapies in the last 12 years, but they cannot fully halt disease progression or reverse it. This makes it essential that treatment initiation is undertaken as quickly as possible.[200]

Many patients still face delays in receiving antifibrotic therapies, worsening outcomes and quality of life. A study in Finland found only half of patients were on antifibrotic therapies and that the average first dose was administered just over a year after diagnosis.[201] Studies of registry data in the United States have highlighted treatment rates for patients with IPF with anti-fibrotic medications, of between 58% and 70%.[202] Survey data from European respiratory physicians show that 40% of patients with a confirmed diagnosis of IPF do not receive treatment with an anti-fibrotic therapy.[203]

There are a number of reasons why access to antifibrotic treatment for patients with PF is so variable:

1. *Clinical conservatism* – Low levels of treatment uptake might be attributable to a 'watch and wait' approach adopted by both physicians and patients in the context of mild or moderate disease with one study finding that 71% of patients with 'mild' IPF did not receive an approved antifibrotic versus 41% and 60% of patients with 'moderate' and 'severe' IPF, respectively[204] [205]
2. *Side effects from treatment* – There are established issues with patient tolerance to medication and associated side effects. One study found that 73% of patients prescribed treatment for IPF – and followed for two years after initiating treatment – experienced side effects such as nausea and fatigue.[206] A Finnish study found that patients were likely to be discontinued from treatments within their first year with side effects a major factor[207]
3. *Drug availability and cost* – Data on IPF patients in central and Eastern European countries found significant differences in drug availability between countries – possibly resulting from high costs when introducing new treatments.[208] A study on the availability of rare disease treatments in China showed that many treatments were simply not available; or if they were, patients often faced reimbursement rates below 50% from medical insurance plans[209]

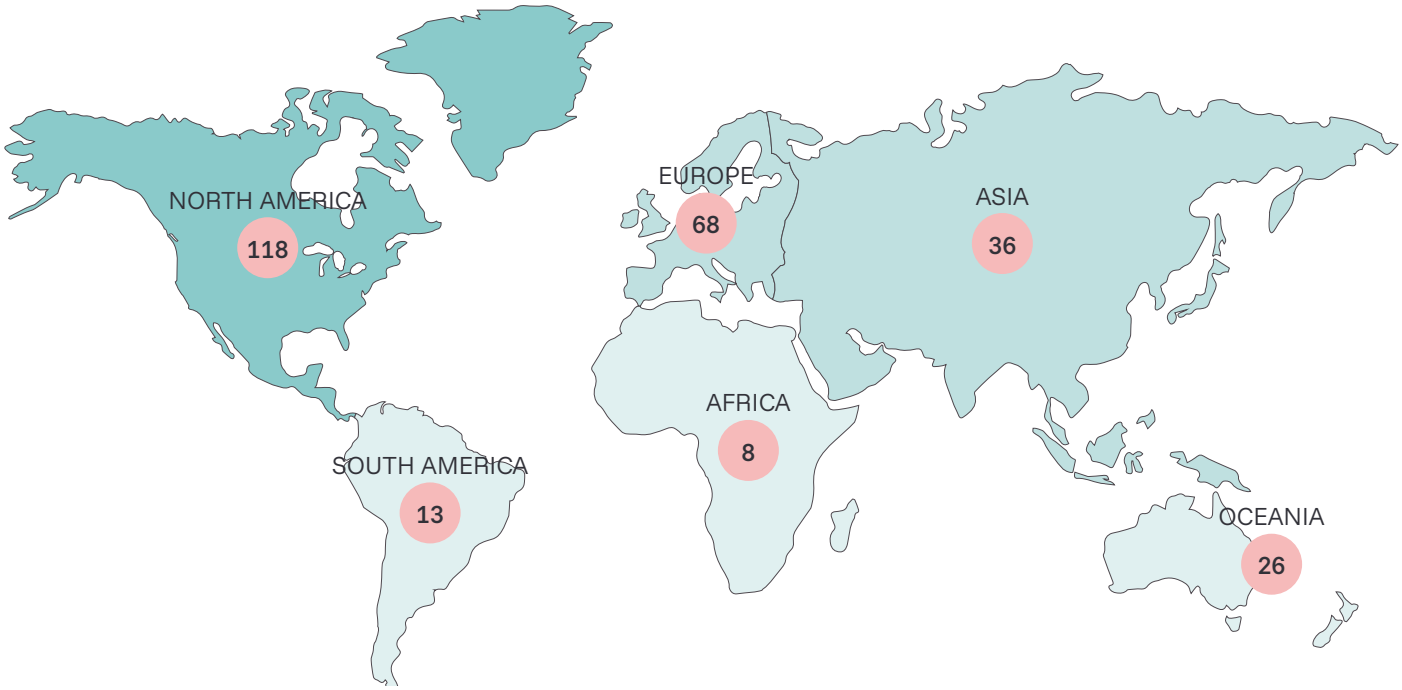
Historically PF has not received significant attention for research investment and funding along with other respiratory conditions.[210] This has not been helped by poor health system and population data on PF prevalence and health system activity, with big gaps across a number of countries around the world.[211]

OPPORTUNITIES FOR IMPROVEMENT

There is an urgent need to ensure patients can access existing clinically effective treatments for PF, as well as ensuring investment flows into research, to bring forward new therapies that can help prevent progession, and ultimately reverse the process of fibrosis. [212] While the knowledge of genetics and fibrotic processes is improving, sustained effort, over many years, is needed by researchers, pharmaceutical companies, clinicians, patient organisations and regulators to maintain the momentum and achieve these aims.

Positively, research into and discovery of new treatments for PF has increased in recent years. Clinicaltrials.gov lists 191 active or recruiting interventional trials currently taking place across 269 research sites as per figure 6 below.[213] It is important to note that whilst a number of treatments are undergoing clinical trials, many will have multiple trial sites across the world.

Figure 6: Active or recruiting interventional clinical studies taking place on PF across different regions



As figure 6 highlights whilst there are a number of trials ongoing for PF there remains widespread inequity of access.

New research into PF will require increased funding – both from a private and public perspective. PF currently receives proportionately less funding than diseases which have a similar impact and life expectancy such as ovarian cancer. Within the respiratory group of diseases PF is also under-prioritised with regards to funding and research.[214] Governments and policymakers should use the Lung Health Resolution to increase their levels of investment in lung health research, including PF.[215] [216]

Such investment will need to be supported by efforts to improve the recruitment of patients to PF clinical trials – which is a challenge.[217] For example, research has shown that it can often take over two years to recruit study populations for IPF trials.[218]

To help address this and expand both the number and reach of clinical trials for PF, innovative trial models should be considered. The use of a platform trial model could enable the evaluation of multiple treatments against a common control arm. This design improves efficiency by sharing infrastructure, data, and control arm patients across multiple interventions simultaneously.[219] Work is underway at Imperial University in London to develop the first international platform trial in ILDs aimed at accelerating identification of effective and novel therapies in fibrotic ILD (FILD).[220]

Involving patients in research activity will be critical to ensuring the full range of patient needs are met. An online survey of patients, carers and healthcare professionals in the UK identified five areas to prioritise for future research and investment: early diagnosis, drug and non-drug treatments, survival and symptom management.[221] A similar survey in Australia found that the top ranked priorities focused on medications to reverse scarring in the lungs, improving lung function, interventions aimed at alleviating symptoms, prevention of PF, and the best exercise programme for PF.[222] These insights should be used help drive the prioritisation of future research funding.

A good practical example of how to ensure research is focused on what matters most to patients is a patient involvement group like the ILFA Patient and Public Involvement (PPI) Research Advisory Group aimed at connecting researchers and patients to inform research opportunities.[223]

Alongside these opportunities there is also a need to explore real world evidence opportunities such as:

- Examining how best to deploy existing treatments with regards to timing, duration and combinations through collection of real world evidence and research[224] [225]
- Using improved epidemiological data and understanding of the related risk factors such as genetics, toxin exposure and comorbidities to improve diagnosis rates[226]

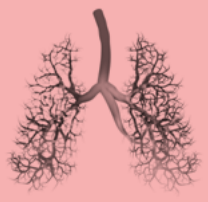
- Research into the benefits/limitations of certain care and services aimed at improving PF patient quality of life such as: pulmonary rehabilitation, psychological support, cough management and end of life care

The poor quality and paucity of data held by many health systems on PF is a major barrier to progress and international collaboration presents an opportunity to address this.

A good example is the Australian and New Zealand ILD registry – albeit the securing of funding and overcoming data connectivity between primary and secondary care have caused challenges.[227] Another is the Asian Pacific Society of Respirology which aims to improve the clinical practice and management of patients with ILDs through education, research and professional development.[228]

Recommendations for policymakers

- Governments and health systems should work to ensure greater equity of access to existing treatments that improve PF patient outcomes
- Governments and policymakers should use the Lung Health Resolution to increase their levels of investment in lung health research, including PF. Patients should be actively engaged in decisions on the priorities for such research funding
- Policymakers should look to develop or collaborate internationally in developing innovative trial design opportunities — for example through platform trials — to accelerate and expand access to new PF trials and treatments for patients
- Governments and health systems should collaborate on efforts to improve healthcare data on lung conditions such as PF through joint registries and research activities



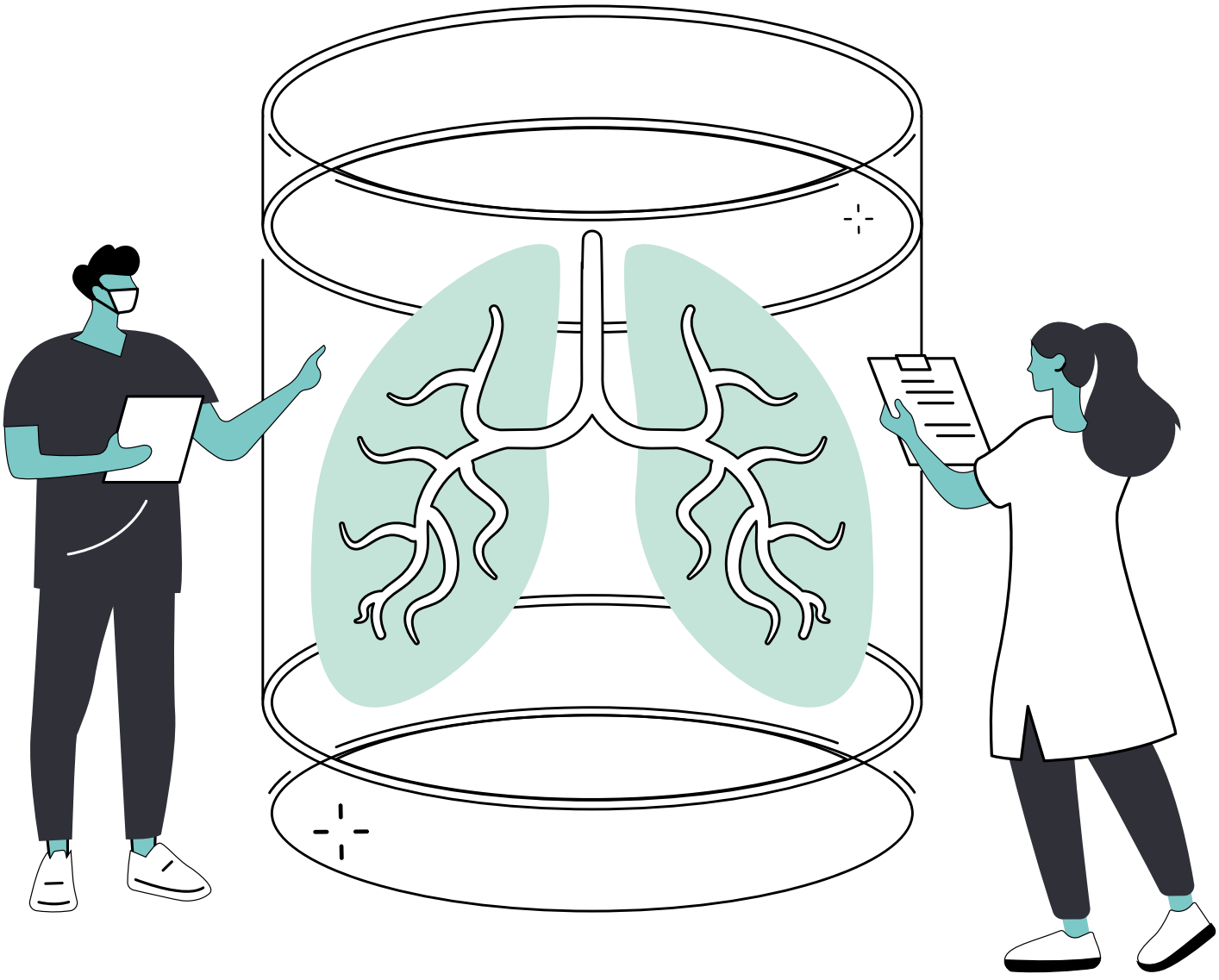
Conclusion

The WHO's Lung Health Resolution presents a clear opportunity for new action and progress to improve global lung health and patient outcomes.

For the first time PF is included within such a global health resolution and with the prevalence of the condition increasing, the devastating associated personal and family impacts of the disease and wider associated health system and economic costs there is a chance for governments and policymakers to use the resolution to make a decisive intervention.

The four part framework in this research paper aims to support countries in taking such action.

By enhancing prevention and increasing public and health professional awareness, accelerating rates of earlier diagnosis, building new models of care and investing in research and unlocking access to new treatments, outcomes for patients with PF and their families around the world will improve.



Appendix

METHODOLOGY AND CONSULTATION

Future Health undertook research in two parts.

The first was an extensive evidence and literature review. This report draws on a systematic review of over 100 peer-reviewed articles, clinical studies, policy documents, and grey literature sources relating to pulmonary fibrosis. Sources were identified through searches of major academic databases and repositories, with selection criteria prioritising recency, methodological rigour, and policy relevance. The review was designed to capture the breadth of current evidence across epidemiology, clinical management, health economics, patient impact and research innovation in PF.

The evidence and literature review was then used to develop a draft evidence paper for consultation. This draft evidence paper was then shared with a small group of experts. Expert feedback was gathered through an expert group meeting in September 2025.

Feedback on the evidence paper was then used to develop a broader policy framework with recommendations. This was used to engage with a wider set of consultees from a variety of geographies between December 2025 and February 2026. Feedback at this stage was either provided via a Microsoft Teams call with researchers or via a written consultation response.

This feedback was then collated, analysed and used to develop this final research report.

The following sets out the individuals who kindly contributed to the consultation process. All views in this report are those of Future Health alone and should be attributed as such.

PF EXPERT ROUNDTABLE DISCUSSION ATTENDEES

NAME	ROLE, ORGANISATION
Dr Marlies Wijsenbeek – Lourens	Pulmonary physician, Centre of Interstitial Lung Diseases, Erasmus MC, University Medical Centre, Rotterdam (Netherlands)
Dr Joyce Lee	Professor, Medicine-Pulmonary Sciences & Critical Care, Uni-versity of Colorado (US)
Professor Richard Hubbard	Emeritus Professor, University of Nottingham (UK)
Professor Kevin Flaherty	Professor of Medicine in the Division of Pulmonary and Criti-cal Care Medicine, Department of Internal Medicine at the University of Michigan in Ann Arbor, Michigan (US)
Steve Jones	Board member of Action for Pulmonary Fibrosis (APF) and the European Pulmonary Fibrosis Federation (EU-PFF) (UK/EU)

WIDER CONSULTATION RESPONDENTS

NAME	ROLE, ORGANISATION
Maureen O'Donnell	CEO, Irish Lung Fibrosis Association (Ireland)
Kate Gates	Chief Operating Officer, Pulmonary Fibrosis Foundation (US)
Bradley Price	Director of Policy, Research and Involvement, Action for Pulmonary Fibrosis (UK)
Professor Michael Kreuter	Professor of Pulmonology, Mainz centre for Pulmonary Diseases (Germany)
Dr Maria Molina	Scientific Director of the Bellvitge Biomedical Research Institute (Spain)
Dr Gina Amanda	Respiratory Physician, Jakarta (Indonesia)
Dr Amornpun Wongkarnjana	King Chulalongkorn Memorial Hospital, Bangkok (Thailand)
Dr Yet Khor	Clinical Senior Lecturer, University of Melbourne (Australia)
Dr Wang Zheng	Chair, Unit of Interstitial Lung Disease Group at Respiratory Society of Chinese Medical Association (China)
Pippa Powell	Director, European Lung Foundation (Europe)
Ren Yanhong	Vice Chair of Interstitial Lung Disease Group at the Respiratory Society of Chinese Medical Association (China)

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