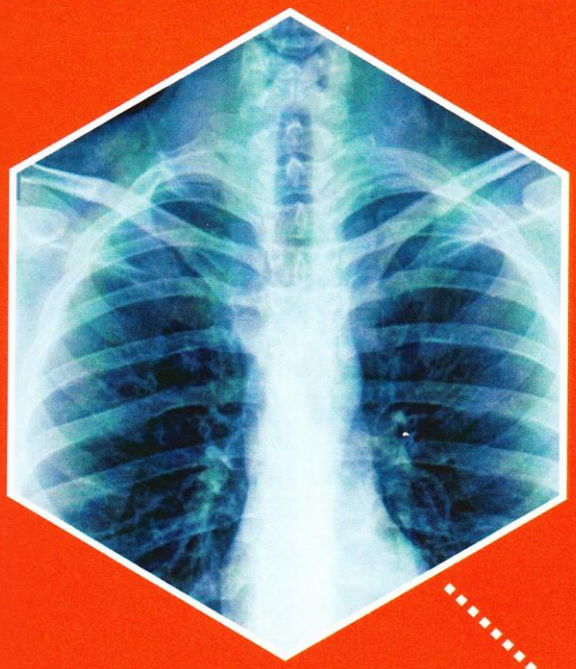

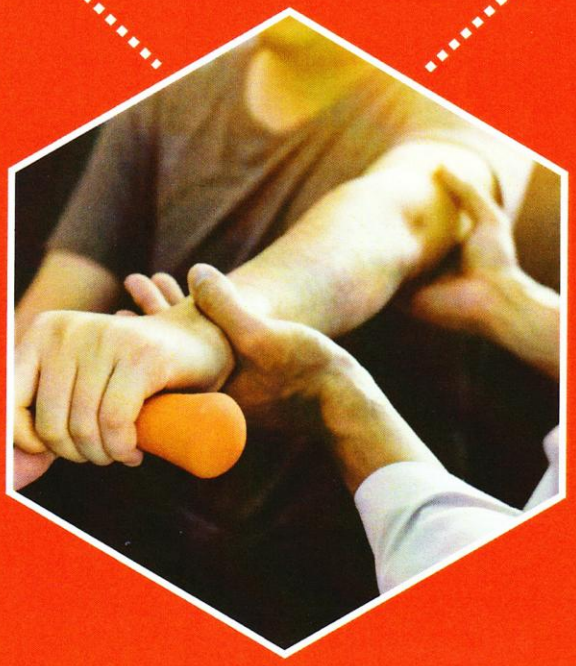

Strategy 2025 - 2028

Achieving Equity: Innovating Lung Fibrosis Care in Ireland

Irish Lung Fibrosis Association
www.ilfa.ie

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LIST OF ABBREVIATIONS

CHB	Connolly Hospital Blanchardstown
CUH	Cork University Hospital
GUH	Galway University Hospital
HSE	Health Service Executive
ICB	Integrated Care Boards
ILD	Interstitial Lung Disease
ILFA	Irish Lung Fibrosis Association
KPI	Key Performance Indicator
MDTs	multidisciplinary teams
MMUH	Mater Misericordiae University Hospital
NOCA	National Office of Clinical Audit
PBS	Pharmaceutical Benefits Scheme
PIP	Personal Independence Payment
TUH	Tallaght University Hospital
UHL	University Hospital Limerick

A Message from ILFA's Board Chair

Founded in 2002, for more than 20 years the Irish Lung Fibrosis Association (ILFA) has supported patients and the lung fibrosis community with education, advocacy, research, and direct services. As ILFA's Board Chair, I have the privilege and the responsibility of advocating for a community of people whose voices are too often overlooked. Lung fibrosis is a devastating disease, but what exacerbates its toll is the reality that not every patient receives the care they need.

This report brings to light a troubling truth: care for people living with lung fibrosis is not equitable. Where you live, your income, and even your understanding of how to navigate the health system can all affect how quickly you're diagnosed, what treatments you receive, and ultimately, how long and how well you live.

At ILFA, we hear this every day from patients and their families. Some benefit from rapid referrals and cutting-edge treatments, but many wait in limbo—undiagnosed, unsupported, and unsure where to turn. For a progressive disease like lung fibrosis, these delays are not just frustrating, they can shorten peoples' lives.

Inequitable care is not just a clinical issue; it is a social justice issue. It reflects deeper systemic gaps that must be addressed if we are to achieve Sláintecare's aim to provide compassionate and effective care in every community across Ireland.

ILFA is an award-winning patient-centred charity that helps people at all stages of the lung fibrosis journey. Part of the support we provide is in advocating for the needs of our patient community and we are committed to challenging this status quo. We believe that every person with lung fibrosis deserves timely diagnosis, access to the care they need, and the chance to live with dignity and hope.

This report is a call to action—for policymakers, healthcare professionals, researchers, and all of us involved in lung health—to confront the barriers that prevent equitable care and to work together to develop sustainable solutions.

We are grateful to the patients, healthcare professionals, and other critical stakeholders who shared their experiences. Their voices are central to this strategy and to our mission.

Thank you for taking the time to read, reflect, and act.

Eddie J. Cassidy

Chair, ILFA Board of Directors

A Message from a Patient

When my breathing difficulties started six years ago, I did not know the challenges that lay ahead in getting a diagnosis and subsequently receiving treatment and support. I quickly realised that my journey was going to be difficult and complicated. In facing the public health system bureaucracy, I found myself often feeling that I wasn't getting the care I need.

I did not have the privilege of an early diagnosis - it took 18 months to be diagnosed with lung fibrosis. When I was finally diagnosed, I was informed that it was extremely unlikely that I would be eligible for a lung transplant when an opportunity might arise because of my advancing age. To this day I still wonder whether an earlier diagnosis would have resulted in a different transplant outcome.

There is no cure for lung fibrosis, but once diagnosed, patients should receive specialist care that includes anti-fibrotic drugs which can slow disease progression. Unfortunately, specialist care is limited to just eight centres in Ireland, most of which are in Dublin. In addition, it is strongly recommended that Pulmonary Rehabilitation commences as soon as possible to enable the body to strengthen itself in dealing with the advancing disease. Unfortunately, most patients aren't provided Pulmonary Rehabilitation.

I live in West Kerry and as a result must travel great distances to receive specialist care – the cost of which is borne entirely by me. Even though I have a medical card which reimburses the cost of medications and other therapies, I am dreading the time when I will need supplemental oxygen. Apart from the restriction it will place on my daily life, I am worried I won't be able to afford the higher electricity costs required to run oxygen equipment.

I have met other patients who wait months and in some cases years for a correct diagnosis. Once it is received, then geography and income are more likely to determine the quality and speed of care than the severity of their symptoms. It's not fair that lung fibrosis patients may not get the same care and treatment that is often available to patients with other diseases that are not imminently terminal like lung fibrosis.

This groundbreaking document sheds light on the stark inequities that exist across our health system. It gives voice to patients who often go unheard and holds a mirror up to the structures that need urgent change. Most importantly, it offers a path forward—one where healthcare is not a privilege, but a right.

As the lead for ILFA's Patient and Public Involvement (PPI) group, I believe strongly that patients should have the opportunity to contribute to research like this - research that will hopefully result in lasting change. As someone living with this condition, I want to see a future where no one is left behind. A future where every person, regardless of their background, has access to the expert care they need. I believe we can get there, but only if we acknowledge the disparities and commit to closing the gaps.

Thank you for reading this document. And thank you for standing with people like me.

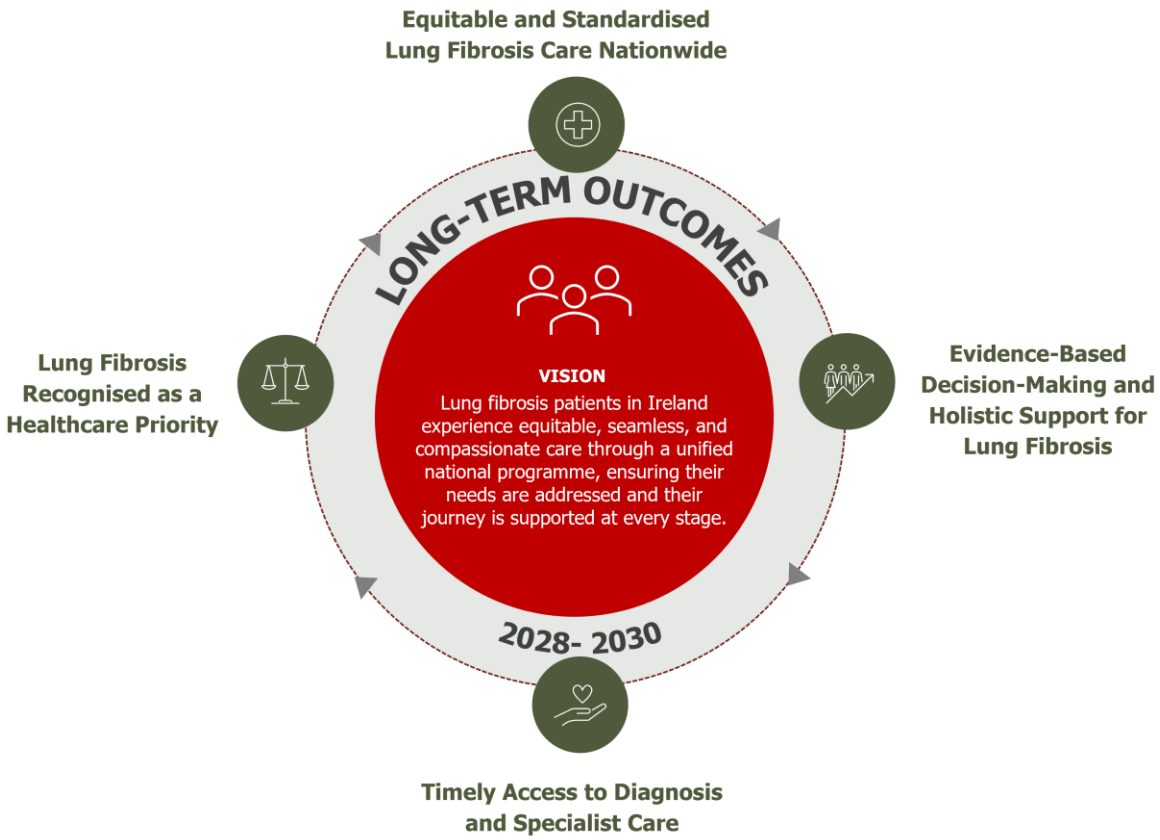
Seán Ó Sé

Lung Fibrosis Patient and Leader of ILFA's Patient and Public Involvement (PPI) Group

Executive Summary

Lung fibrosis is a chronic, progressive, and life-limiting condition with a prognosis as severe as many cancers, yet it remains under-recognised and under-prioritised in Ireland's healthcare system. Patients face delays in diagnosis, inconsistent access to multidisciplinary care, financial strain from treatment costs, and a lack of psychological and rehabilitation support. With no national clinical programme, structured referral pathways, or central registry, care remains fragmented and inequitable, leaving many without the support they need.

The Irish Lung Fibrosis Association (ILFA) envisions a future where all lung fibrosis patients receive seamless, high-quality, and compassionate care through a fully integrated national programme, ensuring equity, consistency, and better patient outcomes.



This strategy sets out the key priorities needed to achieve this vision, including:

- The establishment of a National Lung Fibrosis Clinical Programme to deliver structured, standardised, and equitable care.

- Expansion of specialist services and multidisciplinary teams (MDTs) to improve diagnostic accuracy, treatment coordination, and long-term management.
- A fully funded national registry to drive data-driven decision-making, research, and resource planning.
- Greater investment in rehabilitation, psychological support, and financial relief for oxygen-dependent patients.
- Stronger political and public awareness efforts to ensure lung fibrosis is prioritised within healthcare policy and funding decisions.

This strategy provides a clear, phased roadmap, structured around short-term outputs (2025-2026), medium-term outcomes (2027-2028), and long-term systemic improvements to drive meaningful change. Strengthening advocacy efforts, policy engagement, and collaboration with healthcare providers will be critical in achieving these goals.

SECTION 1. INTRODUCTION

1.1. Background

The Irish Lung Fibrosis Association (ILFA) has been at the forefront of advocating for the lung fibrosis community, pushing for more equitable care, resources, and support networks to meet the complex needs of lung fibrosis patients and their families. Through its focused efforts, ILFA has raised awareness about the chronic, progressive nature of lung fibrosis and the critical gaps in Ireland's current healthcare framework for treating the disease. The organisation's mission extends beyond patient support, as it actively champions systemic change in how lung fibrosis is managed and prioritised within Ireland's healthcare system.

ILFA's advocacy targets several specific areas to improve lung fibrosis care quality and accessibility, calling for government-backed funding and policies to address systemic inequities. ILFA's 2025 Pre-Budget Submissions requested[1]:

- **National Clinical Care Pathway:** National Clinical Care Pathway: ILFA urged the government to establish a structured Clinical Care Pathway for lung fibrosis as a preliminary step toward achieving a dedicated Clinical Programme. While the pathway aims to standardise care quality across Ireland and ensure consistent, high-quality care for patients regardless of location, it is not sufficient to fully address the needs of lung fibrosis patients. A dedicated Clinical Programme remains essential to deliver the level of specialised care necessary for lung fibrosis patients.
- **National ILD Audit and Registry:** ILFA sought €150,000 in dedicated funding for the National Office of Clinical Audit (NOCA) to conduct an audit, the first step in establishing a registry. A registry would enhance data collection on lung fibrosis prevalence, treatment outcomes, and resource needs, enabling better planning and resource allocation across the healthcare system. Once the audit establishes the registry structure, an additional €200,000 in annual funding will be needed to maintain the registry.
- **Pulmonary Rehabilitation Access:** ILFA proposed €1.5 million in funding to expand pulmonary rehabilitation programs to address the needs of lung fibrosis patients. This funding would provide lung fibrosis patients with vital therapeutic support, improving quality of life and potentially reducing reliance on hospital and emergency services.
- **Financial Relief for Oxygen Therapy:** Recognising the high electricity costs incurred by patients using oxygen concentrators, ILFA advocated for a tax rebate program for lung fibrosis patients, similar to existing rebates for kidney dialysis patients, to alleviate financial strain and ensure access to essential oxygen therapy.

This strategy builds on ILFA's previous advocacy work by examining the current landscape of lung fibrosis care in Ireland, assessing critical gaps in resources, accessibility, and treatment quality that significantly impact patients and their families. Given that lung fibrosis is a chronic, progressive, life-limiting condition, the review underscores the urgent need for targeted improvements in Ireland's healthcare system to bring care in line with international standards and to ensure that no matter where a patient lives, they are able to receive the

[1] Irish Lung Fibrosis Association (ILFA). (2025). Pre Budget Submission- Equitable Care for Lung Fibrosis Patients.

care they need to affordably manage their condition. Through comprehensive stakeholder consultations and comparative insights from countries with established lung fibrosis management programs, this strategy highlights best practices and feasible solutions, including structured care pathways, multidisciplinary teams, and support networks, to guide a more equitable and effective approach to lung fibrosis management in Ireland.

1.2. Context

Lung fibrosis, also known as pulmonary fibrosis or Interstitial Lung Disease (ILD), is a serious health challenge in Ireland due to its chronic and rapidly progressing nature. Its prognosis is as severe as many serious cancers, with a median survival rate of three years after diagnosis. Primarily affecting those over the age of 60, lung fibrosis has long struggled for adequate attention and resources. A lack of resources has led to inequitable care, where some patients receive adequate care but many others are excluded resulting in a substantial emotional and financial burden for patients and caregivers. Although advocacy efforts and medical advances have contributed to some improvements, care for lung fibrosis patients in Ireland remains substandard, with services lagging behind international standards and revealing significant regional and systemic disparities. These challenges underscore an urgent need for improvements in care quality and accessibility within Ireland's healthcare framework.

Prevalence of Lung Fibrosis in Ireland

In Ireland, an estimated 5,000 individuals are living with lung fibrosis, based on a prevalence of 100 cases per 100,000 people. The disease places a heavy burden on patients and their families, affecting them physically, psychologically, and financially. Findings indicate that patients frequently experience severe breathlessness, chronic fatigue, and muscle loss, which limit their ability to perform daily activities or maintain independence. Families often report significant emotional distress as they witness the progression of the disease and take on increasing caregiving responsibilities. Financially, many patients are unable to work, and families face the ongoing costs of treatments and care, compounding the challenges of managing this debilitating condition.

Each year, approximately 1,000 new cases of lung fibrosis are diagnosed in Ireland. These patients are distributed across eight specialist centres, with each centre managing around 556 patients annually. In addition, each centre sees about 111 new cases per year and screens 222 individuals annually for potential lung fibrosis. The rising number of cases places immense pressure on these centres, stretching their resources and capacity to manage both existing and new patients effectively. Waiting lists have become a significant issue, with many patients experiencing delays of two to three months before being seen. These delays complicate timely diagnosis and treatment, further exacerbating the challenges faced by patients and healthcare providers.

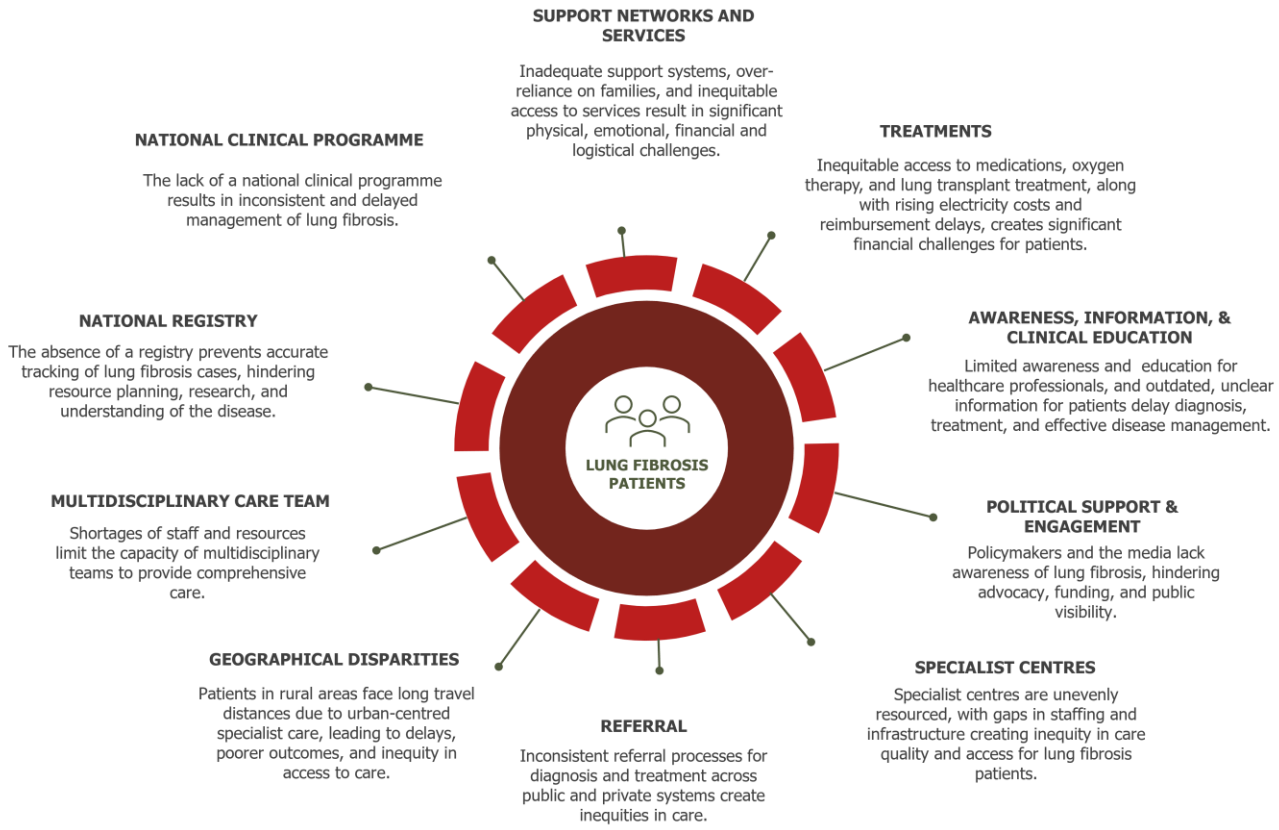
Current Services Offered

Ireland currently has eight specialist centres providing care for patients with ILD, including lung fibrosis located in Galway University Hospital (GUH), Cork University Hospital (CUH), University Hospital Limerick (UHL), St Vincent's University Hospital, Tallaght University Hospital (TUH), Beaumont Hospital, Connolly Hospital Blanchardstown (CHB) and the Mater Misericordiae University Hospital (MMUH). Services typically include MDT assessments comprising respiratory consultants, pulmonologists, radiologists, and specialist nurses, as well as access to advanced diagnostic tools such as high-resolution CT scans and pulmonary function tests.

The centres provide disease-modifying treatments like antifibrotic medications, such as Pirfenidone and Nintedanib, which are used to slow the progression of lung fibrosis. Symptom management, including oxygen therapy and palliative care, is also offered, alongside pulmonary rehabilitation programmes aimed at improving patients' quality of life and physical endurance. However, the availability and consistency of these services vary significantly between centres, with some better resourced than others, leading to disparities in access and care quality.

1.3 Issues to be Addressed

This section outlines the key challenges affecting lung fibrosis care in Ireland, highlighting systemic issues that impact patient outcomes, access to services, and overall disease management. While progress has been made in certain areas, gaps remain in service provision, coordination, and policy support. Addressing these challenges is essential to ensuring equitable, timely, and high-quality care for all individuals affected by lung fibrosis.



Support Networks and Services

Families bear a significant emotional, physical, and financial burden in caring for lung fibrosis patients, particularly as the disease progresses and disability increases. Without adequate community-based services, caregivers are left to manage complex medical needs with little training, respite support, or financial assistance, leading to stress, burnout, and isolation. Limited access to pulmonary rehabilitation, psychological counselling, and nutrition services further restricts effective disease management, particularly outside urban centres, forcing many to travel long distances or forgo essential care. Addressing these gaps requires dedicated funding and stronger collaboration between healthcare providers and patient organisations to ensure patients receive consistent, high-quality care that supports both their medical and emotional needs.

Treatment

Limited access to antifibrotic medications and oxygen therapy, combined with rising electricity costs and reimbursement delays, creates a significant financial strain for lung fibrosis patients. While treatments are covered under existing schemes, long reimbursement wait times and upfront costs pose barriers, particularly for those without a medical card. Access also varies across hospitals, with some centres better equipped to prescribe and monitor treatments, leaving many patients facing delays in receiving essential care. Reimbursement for oxygen therapy often takes weeks, while high electricity costs for concentrators further add to financial pressures. Recent policy changes requiring reassessments before continued oxygen provision have led to unnecessary hospital visits and longer waiting times. Additionally, access to lung transplantation is restricted, with older patients often excluded from consideration due to age-based eligibility criteria rather than individual clinical assessments. Without more efficient reimbursement processes, improved funding structures, and equitable transplant eligibility, patients will continue to struggle with affordability and timely access to critical therapies.

Awareness, Information, and Clinical Education

Limited training for healthcare professionals and outdated patient resources such as the lack of clear, up-to-date information on symptom management and treatment options, contribute to delays in diagnosis, treatment, and disease management. General practitioners often lack the expertise to recognise lung fibrosis early, leading to misdiagnoses and inappropriate referrals, while many respiratory physicians do not have the specialised knowledge required for complex cases. The absence of standardised training for primary care providers further limits early detection and timely intervention. Additionally, outdated clinical information, including inaccurate mortality data, weakens decision-making and reinforces gaps in best practices. For patients and families, unclear and distressing information creates confusion and anxiety, as existing resources often focus on end-of-life care rather than symptom management and treatment options. Beyond clinical settings, there is limited awareness of lung fibrosis in workplaces, leaving employers unprepared to support affected employees. Raising public awareness, including workplace education on prevention and accommodation, could improve early recognition of symptoms, facilitate workplace adjustments, and enhance overall disease management. The availability of clear, accurate, and balanced education—both for healthcare professionals and patients—is critical to improving early diagnosis, access to care, and overall disease management.

Political Support and Engagement

Limited awareness among policymakers and the media has left lung fibrosis overlooked in public health discussions, restricting advocacy efforts and funding opportunities. Policymakers have not

prioritised lung fibrosis within national health strategies, resulting in a lack of dedicated resources and slow progress in improving care pathways. Advocacy groups have struggled to gain traction with decision-makers, underscoring the need for a more structured approach to building political support. Meanwhile, minimal media coverage further limits public awareness, making it difficult to shift perceptions and drive action. Unlike other conditions with strong public engagement, lung fibrosis remains largely invisible, particularly as the patient population is older and less likely to engage in widespread advocacy. Strengthening media engagement and reframing the narrative to highlight the real-world impact on patients and families could increase public interest, encourage political commitment, and secure better resource allocation.

Specialist Centres

Specialist centres for lung fibrosis are under-resourced and lack the necessary infrastructure to provide consistent, high-quality care. Some centres have better staffing and facilities, while others struggle to deliver essential services, resulting in delays in diagnosis, treatment, and ongoing management. These gaps lead to disparities in care depending on location, with many patients facing long wait times or limited access to multidisciplinary support. Strengthening resources and infrastructure across all specialist centres is essential to ensuring equitable access to timely and effective care for lung fibrosis patients in Ireland.

Referral

Inconsistent referral processes for diagnosis and treatment across public and private healthcare systems create inequities in care for lung fibrosis patients. Public patients often experience long waiting times, particularly in regions without specialist centres, while private patients may access quicker initial consultations but face challenges in securing multidisciplinary care. In the private sector, referrals to public specialist centres are often dependent on individual clinician relationships rather than a structured process, leading to further inconsistencies. The lack of clear referral pathways and standardised criteria results in delays in accessing essential services such as specialist assessments, oxygen therapy, and pulmonary rehabilitation. A more coordinated and transparent referral system is needed to ensure timely, equitable access to diagnosis and treatment for all patients.

Geographical Disparities

Patients in rural areas face significant barriers to accessing specialist lung fibrosis care due to the concentration of all eight specialist centres in urban areas, leading to delays in diagnosis and treatment. Long travel distances place a financial and physical burden on patients, particularly older individuals and those with severe symptoms, while the limited availability of multidisciplinary teams outside major cities further exacerbates these

challenges. Although virtual rehabilitation and remote monitoring have provided some relief, these services remain inconsistent and underdeveloped. Expanding access through regional lung fibrosis services and a hub-and-spoke model for diagnostics in level 3 and 4 hospitals could help address these disparities, but sustained investment in staffing, infrastructure, and digital health solutions is essential to ensure equitable and high-quality care nationwide.

Multidisciplinary Care Teams

Shortages of staff and resources prevent multidisciplinary teams from delivering comprehensive lung fibrosis care. Effective diagnosis and management require input from radiologists, histopathologists (biopsy specialists), respiratory nurses, physiotherapists, dieticians, psychologists, social workers, occupational therapists, and speech and language therapists. However, many specialist centres operate with minimal personnel. Some hospitals rely on a single respiratory physician or nurse to manage cases, limiting patient access to specialised care and delaying essential interventions. The lack of trained MDT members increases pressure on existing staff, contributing to delays in diagnosis, inconsistent care, and a heightened risk of burnout among healthcare professionals. Without targeted investment in staffing and resources, particularly in rural and underserved areas, the ability of MDTs to provide timely and coordinated care will remain severely limited.

National Registry

The absence of a national lung fibrosis registry limits Ireland's ability to track disease prevalence, monitor patient outcomes, and allocate healthcare resources effectively. Current data collection is fragmented and often incomplete, with cases frequently grouped under broader ILD categories, leading to misclassification. Previous efforts to establish a registry have faced ethical and funding challenges, leaving Ireland without the comprehensive data needed for healthcare planning and research. A fully funded national registry, integrated with enhanced IT systems, would provide accurate data, support research, and enable better healthcare planning to improve patient care and outcomes.

National Clinical Programme and Care Pathway

Lung fibrosis care in Ireland lacks a national clinical Programme, resulting in inconsistent service delivery and delayed diagnoses. While the HSE acknowledged the need for a national Programme following ILFA's 2020 request, progress has been limited due to funding and infrastructure challenges. Care pathways that exist are basic and vary significantly by region, with patients in some areas receiving comprehensive multidisciplinary care while others face long delays and limited access. The proposed ILD Scheduled Care Pathway offers a framework for improvement but requires clear implementation plans and adequate funding. A fully developed and resourced national clinical programme is essential for

standardising care, reducing disparities, and ensuring timely treatment for all lung fibrosis patients, regardless of location.

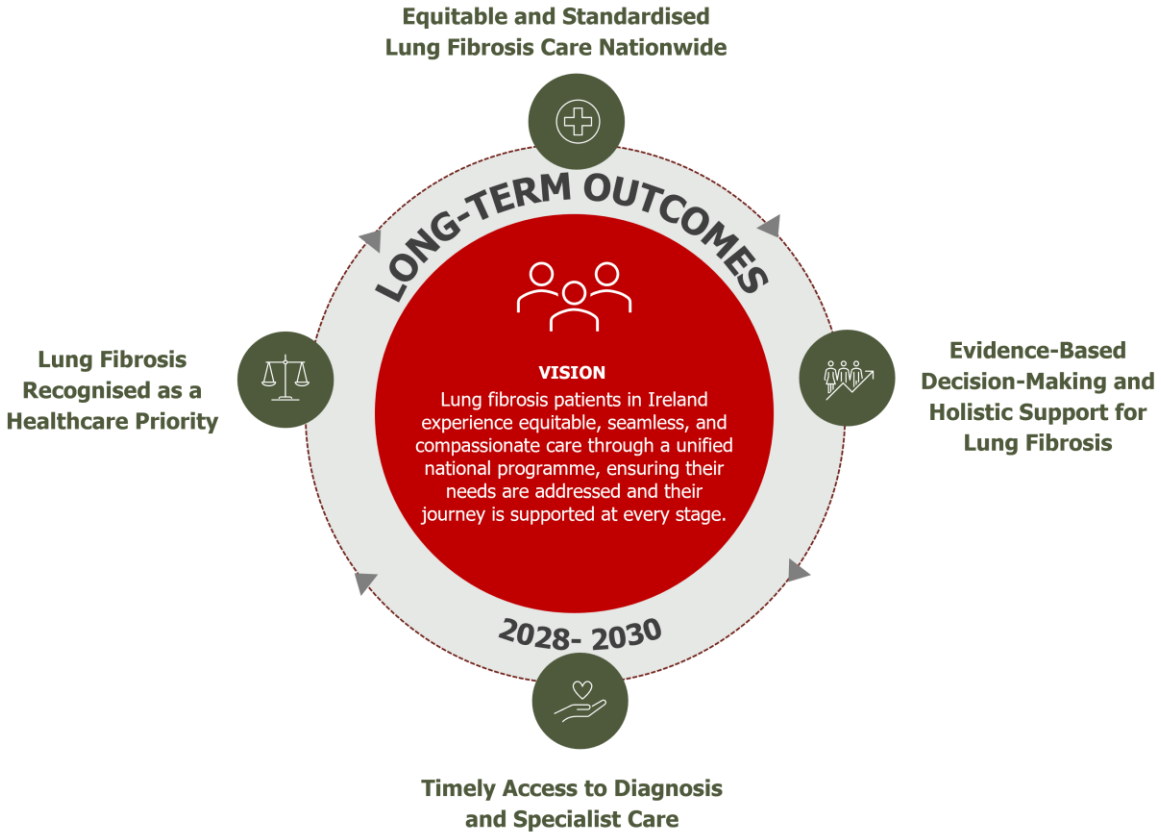
1.4 Benchmarking Ireland Against Global Standards

Ireland's approach to lung fibrosis care remains fragmented compared to leading international models in Germany, Denmark, the UK, Canada, and Australia. Key challenges include the lack of a national registry, inconsistent diagnostic and referral pathways, and inequitable access to specialist care, multidisciplinary teams, and treatment options. While some progress has been made, Ireland continues to fall short in several areas critical to effective disease management, particularly in structured care planning, service coordination, and patient support. Benchmarking against global standards highlights opportunities to adopt best practices, strengthen resource allocation, and develop a more coordinated approach to lung fibrosis care. Further details on international benchmarking can be found in Appendix 2.

SECTION 2. Future Of Lung Fibrosis Care in Ireland

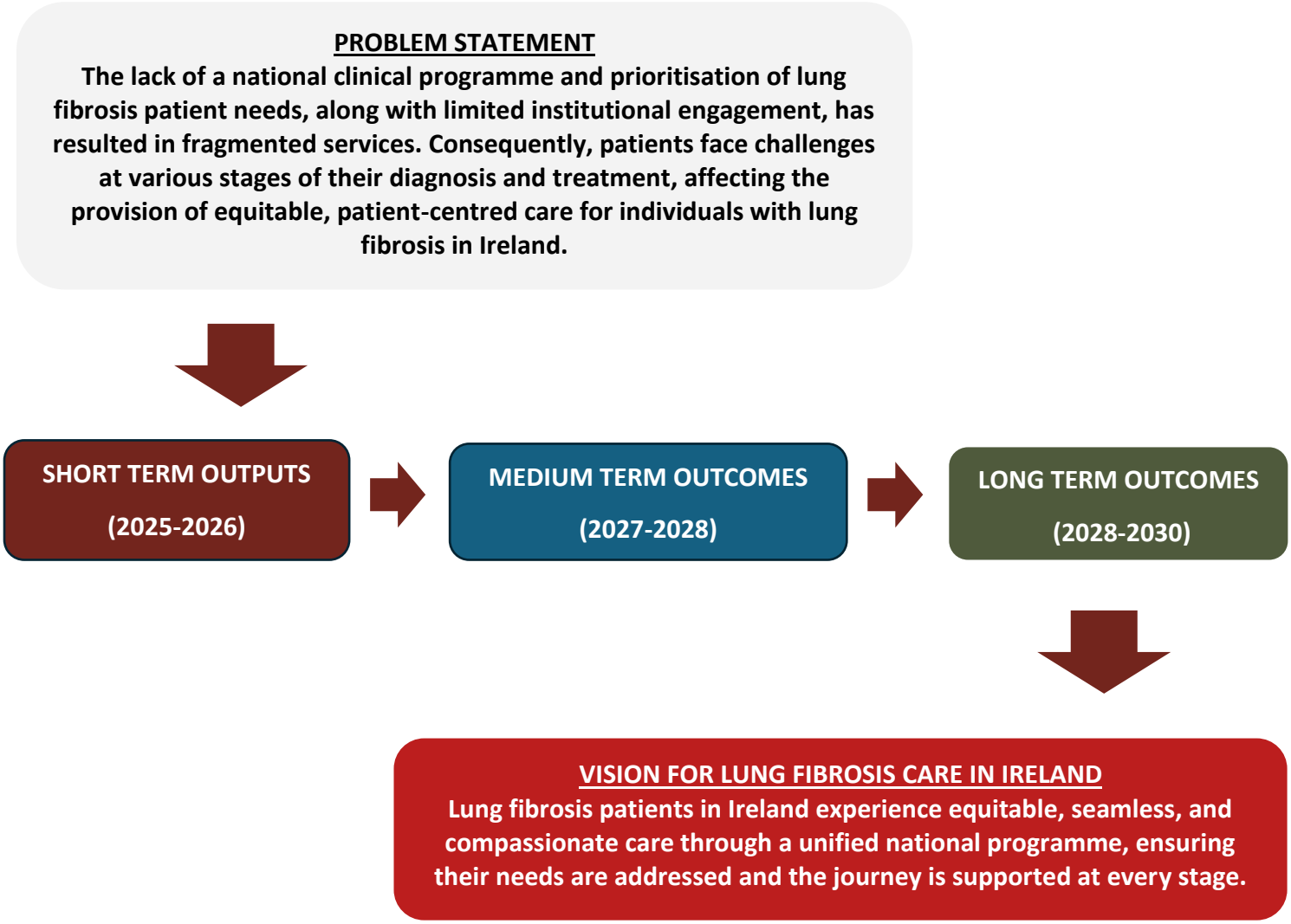
2.1. Vision For Lung Fibrosis in Ireland

ILFA's vision for lung fibrosis care in Ireland emphasises equitable, seamless, and compassionate support for all patients through a unified national programme. It envisions a healthcare system where all patients, regardless of location or circumstances, receive timely, high-quality, and consistent support. Through a unified national programme, care pathways would be structured, accessible, and designed to prioritise patient needs, ensuring seamless transitions across diagnosis, treatment, and long-term management.



2.2 Future Requirements

Achieving long-term improvements in lung fibrosis care requires a structured approach, where long and medium-term outcomes and short-term outputs build towards lasting change. Each stage is designed to strengthen services, improve access, and enhance support systems, ensuring continuous progress. This phased approach demonstrates how targeted investments and actions will lead to a more effective, sustainable, and patient-centred lung fibrosis care system.



2.21 Long Term Outcomes

Achieving ILFA's vision for lung fibrosis care in Ireland requires delivering these four long-term outcomes:

A Clinical Programme to Standardise Lung Fibrosis Care Nationwide

A structured national clinical programme ensures consistent, well-coordinated lung fibrosis management across all regions, eliminating disparities in care. Dedicated funding supports equitable access to specialist services, including rehabilitation, psychological support, and nutrition services, ensuring all patients receive comprehensive care regardless of location. Simplified reimbursement systems further remove financial barriers. Multidisciplinary teams, including radiology and pathology specialists, improve diagnosis and reduce treatment delays. Standardised referral processes across public and private sectors would minimise regional disparities, especially in rural and underserved areas, while stronger collaboration among providers would streamline patient pathways.

Timely Access to Diagnosis and Specialist Care

All lung fibrosis patients receive timely, accurate diagnoses and high-quality care through well-resourced multidisciplinary teams across all regions. Standardised protocols and dedicated resources ensure that every patient benefits from expert assessments, coordinated treatment plans, and access to specialised care regardless of location. Strengthened MDT capacity supports early intervention, optimised disease management, and improved patient outcomes, creating a more equitable and effective healthcare system for lung fibrosis in Ireland.

Evidence-Based Decision-Making and Holistic Support for Lung Fibrosis

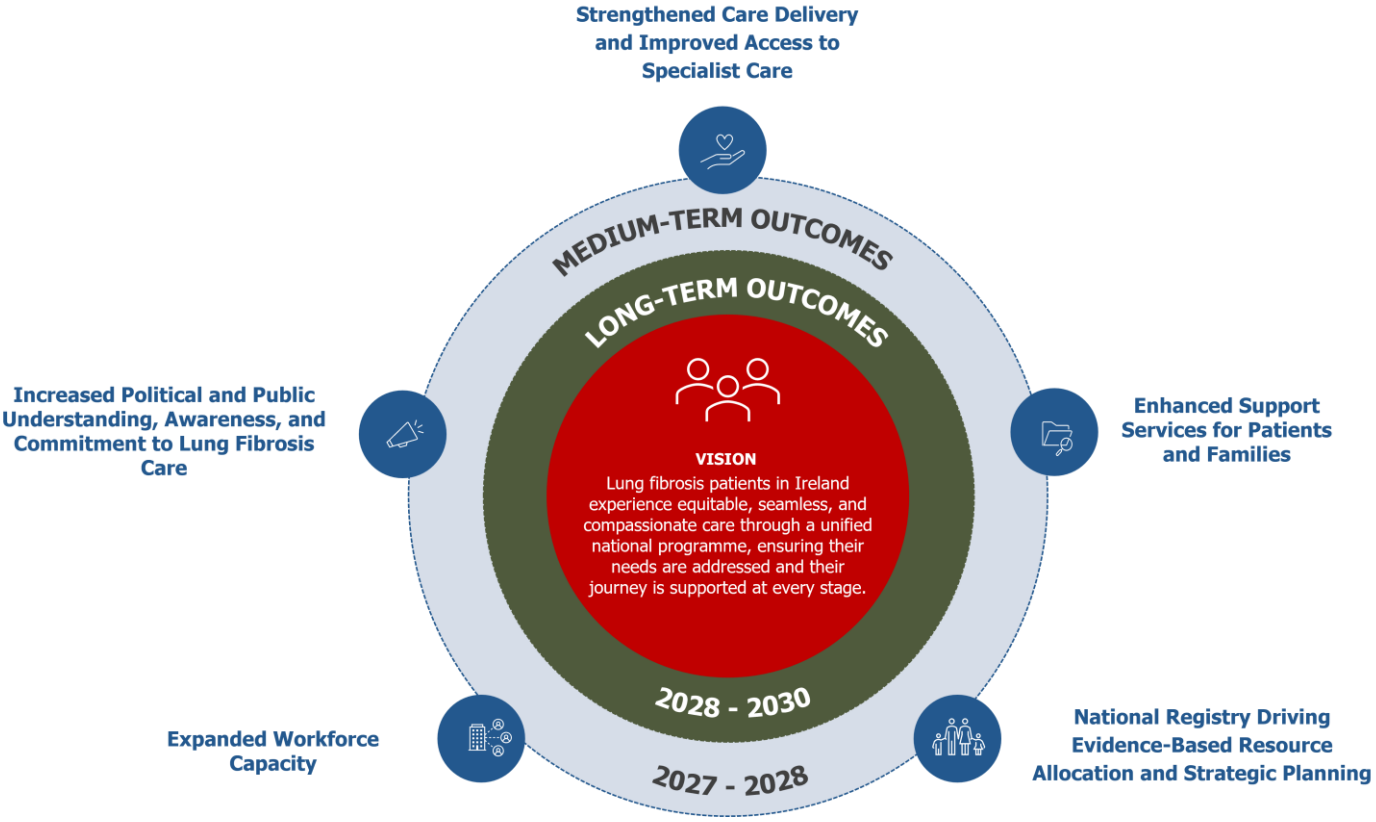
Evidence-based decision-making is enabled through a centralised registry that tracks lung fibrosis cases, ensuring accurate data for research, resource allocation, and care planning. Universal access to counselling provides patients and their families with essential psychological and emotional support, helping them navigate the challenges of the disease. Community-based support networks strengthen local resources, offering peer connections and practical assistance to improve patient well-being and reduce caregiver burden.

Lung Fibrosis Recognised as a Healthcare Priority

Public and political awareness of lung fibrosis is strengthened, ensuring the condition is prioritised in healthcare funding, policy development, and advocacy efforts. Increased recognition leads to sustained investment in research, treatment, and support services, aligning lung fibrosis care with other chronic diseases. Greater visibility in public discourse fosters improved understanding, reducing stigma and driving long-term commitments to better patient outcomes.

2.22 Medium Term Outcomes

The medium-term outcomes from 2027 to 2028 represent the expected impact of short-term outputs, leading to improved workforce capacity, standardised care pathways, and greater access to essential services. These outcomes mark a transition towards a more structured and equitable lung fibrosis care system, building the necessary foundations for long-term change.



Strengthen Care Delivery and Improved Access to Specialist Care

The implementation of a national care pathway strengthens lung fibrosis management by ensuring a structured and consistent approach across all regions. Enhanced coordination between healthcare providers improves referral processes and multidisciplinary collaboration, reducing regional disparities in access to specialist services. Regional care hubs expand access for patients in rural and underserved areas, providing locally coordinated services that minimise travel burdens and ensure timely diagnosis, treatment, and ongoing support closer to home.

Enhance Support Services for Patients and Families

Expanded support networks provide consistent psychological and practical assistance to lung fibrosis patients and their families, ensuring access to rehabilitation, mental health services, nutrition support, and financial relief through streamlined reimbursement systems. These integrated services help patients manage their condition more effectively while reducing the burden on caregivers.

Centralise Registry Driving Evidence-Based Resource Allocation and Strategic Planning

The centralised registry is fully utilised to inform evidence-based decision-making, enabling accurate resource allocation, strategic planning, and improved service delivery for lung fibrosis care. Comprehensive data collection provides insights into disease trends, treatment outcomes, and service demands, supporting ongoing research and innovation to enhance patient care and long-term healthcare planning.

Expand Workforce Capacity

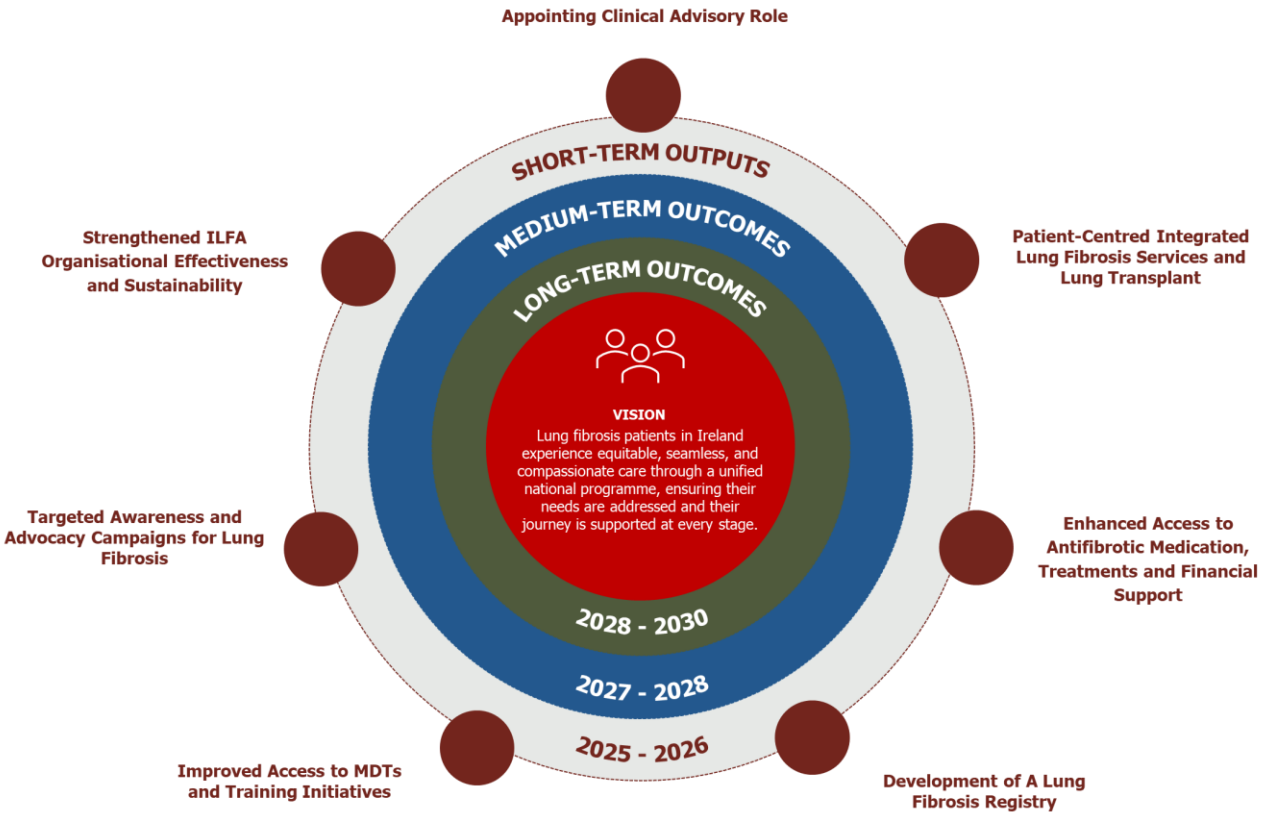
Expansion and upskilling of the healthcare workforce support the consistent delivery of high-quality lung fibrosis care. Increased staffing of specialist roles, including respiratory consultants, nurses, physiotherapists, and dietitians, ensures that MDTs are well-equipped to provide timely diagnosis, treatment, and ongoing management for patients across all regions.

Increase Political and Public Understanding, Awareness, and Commitment to Lung Fibrosis Care

Greater political and public understanding, awareness, and commitment to lung fibrosis care drive sustained funding growth and policy prioritisation. As recognition of the disease and its impact strengthens, lung fibrosis is increasingly integrated into national healthcare planning, ensuring stable resources for research, specialist services, and patient support. Improved engagement with policymakers and the public fosters long-term advocacy efforts, leading to more consistent investment, better service provision, and enhanced access to high-quality care for all patients.

2.23 Short Term Outputs

The short-term outputs for 2025 – 2026 are the identified actions and developments necessary to initiate progress towards improved lung fibrosis care. They represent the first critical steps in establishing a more structured, accessible, and sustainable system for lung fibrosis patients in Ireland.



Appoint the Clinical Pathway Advisory Role

The advisory role is key in establishing a national lung fibrosis Clinical Programme with structured pathways, clear guidelines, and key performance indicators that would standardise lung fibrosis care nationwide. Appointing this role to develop health targets and provide a governance framework would ensure consistent implementation of the Programme design.

Patient-Centred Integrated Lung Fibrosis Services Including Lung Transplant

An integrated, patient-centred care approach is vital to ensure equitable access to counselling, rehabilitation, physiotherapy, dietetic support, social work, occupational therapy, and speech and language therapy within community care settings. Dedicated state funding should expand these services, reducing reliance on urban centres and improving

local accessibility. A hub-and-spoke model would enable level 3 and 4 hospitals to conduct initial lung fibrosis assessments, supported by additional staffing and community-based diagnostics. Expanding access to dieticians and respiratory physiotherapists in rural hospitals would strengthen local expertise. Comprehensive lung transplant pathways should be integrated within the care model, ensuring timely referral, pre-transplant optimisation, and post-transplant support for eligible patients. Virtual rehabilitation classes, on-site counselling, and peer support networks would provide accessible, tailored care, ensuring continuity and reducing patient isolation.

Enhance Access to Antifibrotic Medication, Treatments and Financial Support

Ensuring timely and equitable access to antifibrotic medication and treatments requires streamlined reimbursement processes that reduce delays and financial strain for lung fibrosis patients. Revising medical card eligibility to include all lung fibrosis patients would eliminate barriers to accessing essential medications while implementing direct payment systems for antifibrotic treatments and oxygen therapy would prevent patients from facing upfront costs that can impact adherence to treatment. Additionally, introducing electricity subsidy programmes and tax rebates for the cost of running home oxygen equipment would help reduce the financial strain on patients. These measures would ensure that individuals relying on long-term oxygen therapy can maintain safe and uninterrupted access to essential treatment without facing excessive utility costs.

Develop A Lung Fibrosis Registry

A fully funded lung fibrosis registry is essential for accurately tracking disease prevalence, incidence, treatment outcomes, and gaps in care. Leveraging Ireland's centralised healthcare system and relatively small population, the registry would enable data-driven planning, improving patient care and resource allocation. Implementing advanced IT infrastructure with standardised templates, automated error-checking, and Electronic Health Record (EHR) integration would ensure accurate data capture and minimise inconsistencies. Mandatory reporting and periodic audits would enhance data reliability, while a dedicated research component would facilitate clinical studies, contribute to global advancements, inform national healthcare strategies, and support personalised treatment approaches.

Improve Access to MDTs and Training Initiatives

Improved access to multidisciplinary teams is key to delivering timely, high-quality lung fibrosis care. Strengthening MDT capacity with radiologists, respiratory nurses, and dieticians would enhance diagnosis and ongoing management. Expanding training for GPs, respiratory physicians, and healthcare providers across both public and private sectors would improve prevention, early detection and care coordination. Regional training hubs

and mentorship programmes would develop local expertise, reducing reliance on urban centres. Additionally, communication skills training and updated educational materials would support healthcare providers in managing patient care and fostering trust.

Target Awareness and Advocacy Campaigns for Lung Fibrosis

Raising awareness among policymakers, healthcare professionals, employers, and the public is essential to prioritising lung fibrosis in public health discussions and policy decisions. Targeted awareness campaigns should highlight the progressive nature of the disease, its impact on patients, and the need for improved care. Efforts should also focus on prevention, particularly among individuals in high-risk occupations and hobbies, ensuring that those most vulnerable receive appropriate education and early screening. Collaborations with advocacy groups would share real-life stories and data-driven insights to engage key audiences. Hosting briefings and workshops would provide stakeholders with the knowledge to drive change. Integrating lung fibrosis information into HSE materials, workplace health initiatives, and public health channels would ensure consistent, widespread dissemination, fostering greater understanding and engagement.

Strengthen ILFA Organisational Effectiveness and Sustainability

Enhancing ILFA's effectiveness requires robust operational systems and a sustainable funding model. Strengthening financial stability through diverse revenue streams, strategic partnerships, and long-term planning will ensure resilience. Investing in staff development, optimising organisational systems, and enhancing stakeholder engagement will improve efficiency. Clear performance metrics and strong governance oversight will support long-term impact and credibility.

SECTION 3. Implementation Plan

3.1. Actions

Short-term Outputs (2025 - 2026)	
Outputs	**Actions**
Appoint the Clinical Pathway Advisory Role	• The development of a formal national Clinical Programme for lung fibrosis supported by comprehensive guidelines and a dedicated national policy to standardise care across regions. This programme should include a Clinical Lead for Lung Fibrosis, health outcome targets, administrative support, and a governance framework.
	• The establishment of a structured, comprehensive care pathway with clear implementation plans and guidelines on essential infrastructure. Include dedicated MDTs with radiology and pathology specialists to enhance diagnostic accuracy and speed.
	• The development of Key Performance Indicators (KPIs) to create benchmarks for clinics, enabling the identification of resource requirements, consistent service delivery, and regular evaluation of care outcomes.
	• The implementation of a standardised referral process across public and private sectors to reduce inconsistencies and ensure equitable, streamlined access to care, especially in rural and underserved areas.

Short-term Outputs (2025 - 2026)	
Outputs	**Actions**
Patient-Centred Integrated Lung Fibrosis Services and Lung Transplant	• Dedicated state funding to expand lung fibrosis services, including psychological counselling, physiotherapy, pulmonary rehabilitation, dietetic support, social work, occupational therapy, and speech and language therapy within community care settings to provide holistic patient support.
	• Integrate lung fibrosis patients into existing rehabilitation and support programmes, reducing reliance on urban centres and promoting equitable access across underserved regions.
	• Increase availability of dieticians and respiratory physiotherapists in rural hospitals, focusing on building local expertise to alleviate pressure on central facilities. Routine blood tests, X-rays, pulmonary function tests, and 6-Minute Walk Tests should be available in community settings, along with dedicated oxygen clinics, to improve access and reduce pressure on specialist centres.
	• Develop a hub-and-spoke model for diagnostic and treatment services, enabling level 3 and 4 hospitals to conduct initial lung fibrosis assessments. This model should enhance community-based diagnostics by providing additional staffing and resources, such as radiologists, physicians, and MDTs, to improve localised care delivery.
	• Establish community-based initiatives such as rehabilitation classes, on-site counselling, and dietetic clinics to provide tailored, accessible support.
	• Develop a comprehensive support framework that provides access to counselling, peer support groups, family-focused therapies, caregiving training, and rehabilitation services, ensuring consistent and holistic support for patients and carers.
	• Develo a structured lung transplant pathway, ensuring timely identification, referral, and pre- and post-transplant care for eligible lung fibrosis patients. This should include dedicated transplant coordination teams, optimised referral criteria, and long-term rehabilitation support to improve patient outcomes.
	• Establish a nationwide support network with regional hubs and virtual resources, offering peer mentorship programmes, transport assistance, financial guidance, and trained care coordinators to reduce isolation and improve access to services.

Short-term Outputs (2025 - 2026)	
Outputs	**Actions**
Enhance Access to Antifibrotic Medication, Treatments and Financial Support	• The streamlining of the reimbursement processes for antifibrotic medications to reduce delays, ensuring timely financial support for lung fibrosis patients.
	• Revision of medical card eligibility criteria to include all lung fibrosis patients, guaranteeing equitable access to essential antifibrotic treatments.
	• Implementation of direct payment systems for oxygen therapy and antifibrotic treatments to minimise financial strain on families and improve treatment adherence.
	• Introduction of electricity subsidy programmes and tax rebates to offset the high costs of operating home oxygen equipment, ensuring patients can maintain uninterrupted access to essential therapy without financial strain.

Short-term Outputs (2025 - 2026)	
Outputs	**Actions**
Develop a Lung Fibrosis Registry	• The development of a fully funded centralised lung fibrosis registry to track prevalence, treatment outcomes, and care gaps. Leverage Ireland's centralised healthcare system and small population to improve patient care and enable data-driven planning and research.
	• The implementation of advanced IT infrastructure with dedicated administrative support to ensure accurate coding and data capture for lung fibrosis cases. This should include standardised templates, automated error-checking, and integration with EHRs.
	• The establishment of mandatory reporting and periodic audits to verify data accuracy and completeness. Use the data to support resource allocation and research initiatives.
	• Engage with the HSE to ensure the registry includes processes to create tailored care plans and customised support services, improving the individualised care experience for lung fibrosis patients.

Short-term Outputs (2025 - 2026)	
Outputs	**Actions**
Improve Access to MDTs and Training Initiatives	• The increased investment in MDTs for lung fibrosis care by prioritising targeted recruitment and retention strategies for key roles, including radiologists, respiratory nurses, and dieticians.
	• Expanded targeted training programmes for general practitioners, respiratory physicians, and healthcare providers in both public and private sectors, focusing on prevention, early recognition, diagnosis, and management of lung fibrosis. Include modules on streamlined referral pathways and multidisciplinary coordination.
	• The development of a communication skills programme to equip healthcare providers with strategies to discuss the progressive nature of lung fibrosis, treatment options, and symptom management. This approach should foster trust, reduce stigma, and support ongoing patient care.
	• The establishment of mentorship programmes within the lung fibrosis care system to support the development of junior healthcare professionals and encourage expertise-sharing among experienced staff.
	• The creation of regional training hubs to enhance local expertise in rural and underserved areas, reducing the reliance on urban centres and promoting equitable distribution of specialised care.
	• The standardisation of educational materials on lung fibrosis for GP conferences, medical forums, and private healthcare training, ensuring the latest research, diagnostic criteria, and treatment options are accessible. Include a quality review and feedback system to regularly update training materials.
	• Leverage lung fibrosis resources to provide ongoing education and support to healthcare professionals, ensuring a consistent standard of care across all regions.

Short-term Outputs (2025 - 2026)	
Outputs	**Actions**
Targeted Awareness and Advocacy Campaigns for Lung Fibrosis	• Undertake a stakeholder mapping exercise to identify key influencers, potential allies, and areas for collaboration to drive advocacy efforts effectively.
	• Strengthen stakeholder relationships by engaging with policymakers, healthcare professionals, researchers, and media to build long-term support for lung fibrosis initiatives.
	• Develop and implement risk management strategies to protect ILFA's reputation, ensuring clear messaging, proactive media engagement, and alignment with evidence-based research.
	• Develop an annual awareness and advocacy plan with clear Key Performance Indicators (KPIs) to measure reach, engagement, and policy influence.
	• Develop a comprehensive awareness initiative highlighting the progressive nature of lung fibrosis, its impact on patients, and the need for prioritisation in public health discussions.
	• Collaborate with patient advocacy groups to create real-life patient stories, case studies, and data-driven presentations for targeted campaigns.
	• Host advocacy events, including briefings and workshops for policymakers, healthcare professionals, and the public, to improve understanding and engagement with lung fibrosis.
	• Integrate lung fibrosis information into HSE materials and public health communication channels, ensuring widespread dissemination and accessibility.

Short-term Outputs (2025 - 2026)	
Outputs	**Actions**
Strengthened Organisational Effectiveness and Sustainability	• Conduct a comprehensive review of existing systems to identify and address organisational needs.
	• Diversify revenue streams through strategic partnerships, grants, and innovative fundraising initiatives.
	• Develop a long-term financial plan, including contingency reserves, to ensure stability during economic fluctuations.
	• Implement a development programme to ensure staff have the necessary skills and capabilities to deliver on ILFA's strategic objectives while fostering a culture of continuous improvement.
	• Launch targeted communication campaigns to strengthen relationships with key stakeholders, including funders, clients, and partners
	• Establish clear performance metrics to evaluate and optimize team and system effectiveness.
	• Ensure governance oversight and compliance is in keeping with good practice

SECTION 4. Critical Success Factors

The critical success factors outline the key enablers necessary to improve lung fibrosis care in Ireland. Achieving better outcomes requires coordinated efforts across patients, service providers, and ILFA, ensuring timely diagnosis, equitable access to care, sustainable funding, and stronger advocacy. Addressing these factors will drive progress towards a more integrated and patient-centred healthcare system.

Lung Fibrosis Patients

Patients experience improved outcomes when they receive timely and accurate diagnoses, ensuring early intervention and access to appropriate care. Equitable access to standardised care pathways and multidisciplinary teams enables consistent, high-quality treatment regardless of location. The financial burden associated with medications and oxygen therapy, is minimised, allowing patients to focus on managing their condition without additional stress. Integrated psychological and community support further enhances quality of life, addressing the emotional and practical challenges of living with lung fibrosis.

Funding

Service providers can deliver high-quality care when funding, resources, and infrastructure are distributed fairly across all regions, ensuring consistency in service delivery. Streamlined referral and care pathways minimise delays and inefficiencies, allowing patients to access the right care at the right time. Sufficient staffing levels, supported by targeted recruitment and training, help reduce burnout and sustain workforce capacity. Access to a national registry enables data-driven decision-making, improving care planning, resource allocation, and long-term patient outcomes.

Policy Makers

A structured clinical programme for lung fibrosis ensures coordinated care delivery, supported by national guidelines and key performance indicators (KPIs) that drive consistency and equity across all regions. Evidence-based decision-making is strengthened through a central registry, providing reliable data to inform policy and resource allocation. Increased public awareness elevates lung fibrosis as a healthcare priority, reinforcing the need for sustained investment. The measurable impact of funding and strategic reforms demonstrates the effectiveness of policy decisions, ensuring long-term improvements in patient outcomes and service provision.

ILFA

ILFA's role as a leading advocate for lung fibrosis care is strengthened through effective engagement with policymakers and healthcare providers, ensuring sustained influence on care improvements. Strong partnerships drive meaningful policy changes and service enhancements, while increased public and professional awareness elevates lung fibrosis as a

healthcare priority. Tangible progress in achieving equity and better outcomes for patients nationwide reinforces ILFA's impact and advances its mission to improve the care landscape.

Appendices

Appendix 1 - Methodology

Project Objectives

The Irish Lung Fibrosis Association (ILFA) has commissioned Prospectus to conduct an independent review of the current care landscape for lung fibrosis patients, aiming to secure agreement and support amongst key stakeholders around future lung fibrosis service arrangements and requirements by:

- Addressing and highlighting the gaps in current lung fibrosis care.
- Confirming the model of care and delivery requirements for future service provision.

This project was entirely funded by ILFA through fundraising and donations.

Project Scope

This independent review, commissioned by the ILFA, was undertaken from May to November of 2024. The scope for this project includes:

- **International Comparative Review:** A high-level analysis comparing lung fibrosis care practices in Ireland with global best practices to identify gaps and suggest improvements.
- **Stakeholder Consultations:** Consultations with both internal and external stakeholders to gather insights, validate findings, and ensure broad-based support for the recommended changes.
- **Overview of Lung Fibrosis Impact in Ireland:** A comprehensive report detailing how lung fibrosis affects individuals in Ireland, comparing its impact to other similar diseases, and advocating for equitable attention and resources.
- **Recommendations and Implementation Planning:** Targeted recommendations for lung fibrosis care enhancement and a high-level implementation plan to support the achievement of ILFA's future objectives.
- **Continuity of Care Analysis (Care Pathway):** An analysis of the continuity of care challenges within the Health Service Executive (HSE), identifying key issues and proposing solutions based on the contextual understanding of lung fibrosis patient needs.
- **Specialised Care Needs Assessment:** Insights into the unmet needs for specialised lung fibrosis, including how these needs can be integrated into new regional healthcare structures.

- **Final Report:** A focused report that outlines disparities in lung fibrosis care and services across Ireland, setting a clear path forward to deliver high-quality services for lung fibrosis patients

Prospectus's approach to the Lung fibrosis review involved four steps, ensuring a thorough and effective review process.

Throughout these stages, the designated ILFA leads played a crucial role in monitoring progress, conducting regular status meetings with the Prospectus team, and facilitating internal and external communications on engagement with the plan.

Engage: In the initial phase, the scope and objectives of the project were defined to provide a clear framework for the review, setting out roles, responsibilities, and deliverables for all involved parties. Initial insights were gathered using a SWOT analysis to understand the strengths, weaknesses, opportunities, and threats associated with lung fibrosis care.

Review – As Is: During the second phase, desk-based research was conducted to review the current requirements and standing of IPF services. This included a high-level assessment of international comparators and targeted consultations with key stakeholders. Findings from both desk-based research and consultations were collated. A workshop was held to confirm findings and analysis with ILFA personnel, resulting in draft research findings, insights from stakeholder consultations, and identification of key issues to be addressed.

Confirm – To Be: All findings from the previous steps were analysed to develop conclusions and formulate draft recommendations. These draft recommendations were discussed and agreed upon in a second workshop, leading to the development of a high-level implementation plan. The focus was on establishing future strategies and actions necessary for improving lung fibrosis care.

Report: In the final phase, the comprehensive final report was compiled, including detailed analysis and recommendations based on the findings and stakeholder input.

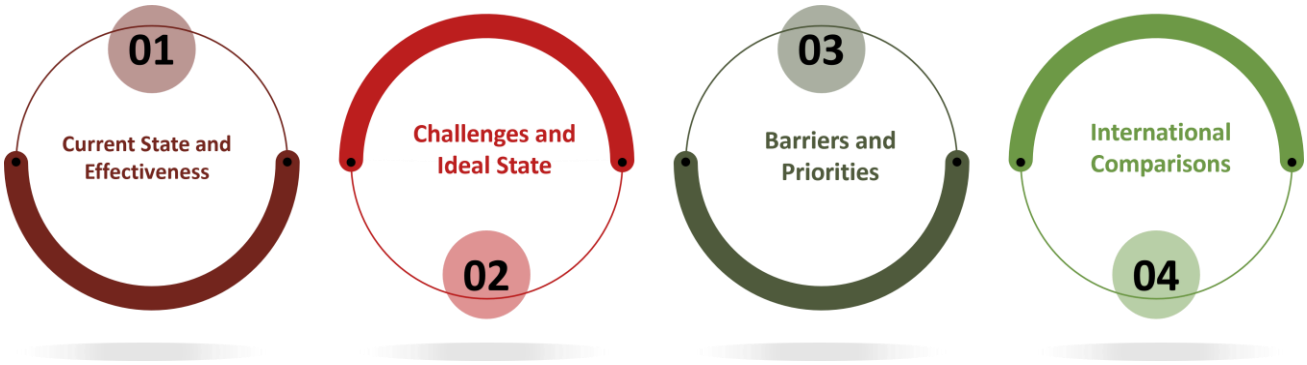
Participants In the Review

To ensure a comprehensive understanding of the current landscape of lung fibrosis care in Ireland, a stakeholder mapping exercise was conducted to identify key individuals and groups with relevant expertise, roles, and responsibilities. Stakeholders invited to participate in interviews represent a cross-section of professional insights and patient perspectives, covering various aspects of care delivery, patient support, and advocacy. A total of 11 patients from pulmonary fibrosis support groups nationwide took part in the consultation process.

Data Collection

The data collection for this review was conducted primarily through qualitative methods, specifically utilising semi-structured interviews and focus groups to gather in-depth information. Semi-structured interviews were designed to allow flexibility in discussion while ensuring all relevant topics were covered. Focus groups were organised specifically for patients to facilitate broader discussions and capture diverse perspectives on lung fibrosis care. These sessions enabled patients to share their personal experiences and insights, providing a richer and more varied set of data.

The interviews followed four main themes to obtain specific details on the review's topics:



- **Current State and Effectiveness**: Exploring the current state of lung fibrosis services in Ireland and identifying effective elements and areas for improvement.
- **Challenges and Ideal State**: Discussing the major challenges within the current care system and envisioning the ideal scenario for lung fibrosis care in Ireland.
- **Barriers and Priorities**: Identifying barriers to achieving the ideal state and establishing immediate priorities for improvement.
- **International Comparisons**: Examining how lung fibrosis care is managed in other countries and discussing successful international practices that could be adapted for use in Ireland.

Data Analysis

Following the data collection phase, the analysis phase was conducted to assess the current state of lung fibrosis care in Ireland. This commenced with the verbatim transcription of interviews and focus group discussions, forming a detailed textual database. The material was then subject to thematic analysis, identifying sub-themes including key strengths, areas for development, and potential improvements within the lung fibrosis care system.

To enhance the findings, triangulation was employed by comparing the qualitative data with existing documentation to identify best practices, gaps, and opportunities for improvement. The outcomes of this analysis led to the formulation of targeted recommendations aimed at enhancing lung fibrosis care services and addressing identified areas for development and gaps.

Strategic Development Process

This review played a critical role in shaping the strategic development process for ILFA's approach to lung fibrosis care in Ireland. By identifying key gaps, challenges, and opportunities within the current care landscape, the findings provided a strong evidence base to guide the envisioned future direction of lung fibrosis care in Ireland. The insights gathered from international benchmarking, stakeholder consultations, and data analysis have directly informed the development of strategic priorities, ensuring a structured and targeted approach to improving lung fibrosis services, advocating for necessary policy changes, and enhancing patient outcomes nationwide.

Appendix 2 - Benchmarking Ireland Against Global Standards

In examining international comparators, the table below provides a summary of Ireland's positioning in relation to Denmark., Germany, the UK, Canada and Australia.

- **Green:** Indicates that Ireland is aligned with best practices.
- **Amber:** Highlights areas where Ireland has made some progress but still falls short of international standards.
- **Red:** Marks areas where Ireland lags significantly behind

CATEGORY	IRELAND	DENMARK	GERMANY
National Registry	No dedicated LF registry. This limits data on prevalence, treatment effectiveness, and care gaps, impacting policy development and patient outcomes.	DANILDA registry collects data on all ILD types, helping identify diagnostic/treatment bottlenecks and contributing to standardised national policies, enhancing Danish PF management.	Participates in the the European IPF Registry (eurILDreg) and INSIGHTS-IPF Registry, collecting extensive data on prevalence, treatment outcomes, and disease progression to inform research and clinical practice.
Diagnostic Accuracy and Referral Pathways	Inconsistent referral pathways from GPs to specialists and limited access to HRCT, particularly in rural areas, contribute to significant diagnostic delays. The lack of a structured care pathway in Ireland results in overwhelmed tertiary centres and uneven service quality across the country.	Advanced diagnostics at tertiary ILD centres facilitate early diagnosis and timely management through streamlined referral pathways. These centres, linked to multidisciplinary teams (MDTs), provide both routine and complex care while integrating into European networks to share resources and access specialised expertise.	A structured referral system integrates HRCT, cryobiopsy, and MDT assessments, ensuring early and accurate diagnosis, with referrals directed to ILD specialist centres
National Plans and Policies	No specific national plan for PF. Ireland's care is fragmented, with inconsistent funding allocations and no unified strategy.	European Reference Network participation allows Denmark to leverage EU resources and research, ensuring patients benefit from Europe-wide advancements in PF care.	The German Respiratory Society provides national guidelines for ILD management, aligning care across regions and promoting best practices for early intervention and treatment
Multidisciplinary Teams (MDTs) and Specialist Centres	Limited MDT access and specialist centres, with notable gaps in rural and underserved areas. Irish MDTs lack allied health support, unlike international standards.	Integrated MDT approach within tertiary centres provides access to comprehensive care with specialists, covering routine to complex cases effectively.	19 accredited ILD centres offer MDT-based care, including respiratory physicians, radiologists, pathologists, and allied health professionals, ensuring comprehensive disease management
Treatment and Symptom Management	Limited access to antifibrotic drugs and structured rehabilitation programs. Symptom management is fragmented, with few holistic care options.	Lifestyle modifications integral to PF care, combining antifibrotic drugs, rehab, and nutritional and psychological support for holistic management.	Patients have access to antifibrotic therapies (nintedanib, pirfenidone), pulmonary rehab, and integrated symptom management plans, improving quality of life and slowing disease progression
Regular Monitoring, Follow-Up, and Clinical Trials	Inconsistent follow-up and monitoring. Limited clinical trial access and most follow-up occurs in urban centres, impacting rural access.	Emphasis on follow-up and proactive monitoring with clinical trials infrastructure that allows access to innovative treatments, supported by EU partnerships.	National ILD registries support structured follow-ups with PFTs and HRCT, while Germany's strong clinical trial network ensures access to emerging therapies.
Support Services, Reimbursement, and Telemedicine	Limited support services, telemedicine, and reimbursement schemes. COVID-19 expanded telemedicine options but hasn't been fully integrated. Financial support is limited to general healthcare coverage.	Telemedicine, home care support, and comprehensive reimbursement ensure equitable PF care across income levels. Denmark's outreach services further reduce regional disparities.	A well-established telemedicine framework improves access to specialist care, and Germany's universal healthcare system ensures reimbursement for essential treatments, rehabilitation, and home oxygen therapy.

CATEGORY	UK	CANADA	AUSTRALIA
National Registry	British Thoracic Society ILD Registry collects extensive data, driving national healthcare strategies.	CARE-PF Registry supports epidemiological research and informs healthcare planning.	AILDR registry gathers comprehensive data from 23 sites, informing research on ILD and enhancing management strategies through high-quality data collection.
Diagnostic Accuracy and Referral Pathways	Structured pathways guiding patients from GPs to ILD specialists, combined with a tiered model of ILD centres, enable accurate diagnosis through MDT involvement. This ensures appropriate care levels, optimises resource use, and reduces wait times for patients with complex cases.	A structured referral pathway enables GPs to refer patients to 16 ILD specialists, facilitating comprehensive diagnostics and multidisciplinary evaluations. This MDT-based system ensures regional and specialist care, reducing the burden on larger centres and improving access to timely, effective care.	Emphasising HRCT and MDT assessments, structured pathways ensure accurate diagnostics by guiding patients from primary care to advanced evaluations, with MDTs offering comprehensive diagnostic support. The National Strategic Action Plan for Lung Conditions further integrates all aspects of care for underserved populations through built-in evaluation frameworks, promoting equitable and effective management.
National Plans and Policies	Health and Care Act 2022 establishes Integrated Care Boards (ICBs) to improve ILD care coordination across primary and community-based services, reducing disparities.	CAREP-PF data guides policy development to align ILD standards across provinces, ensuring accessible care.	National Strategic Action Plan provides a comprehensive framework, from disease prevention to equitable care, ensuring sustainable resource allocation for PF.
Multidisciplinary Teams (MDTs) and Specialist Centres	MDTs integrated into tiered ILD centres, providing a comprehensive team-based approach at all PF care levels.	MDTs across 16 ILD centres collaborate to provide comprehensive care with specialists, dietitians, and mental health experts included in patient plans.	Structured MDTs across Australia's ILD centres ensure all aspects of care are managed holistically, addressing both physical and psychological needs.
Treatment and Symptom Management	Comprehensive treatment protocols including antifibrotic drugs, rehab, and lifestyle modification supported by MDTs for symptom management.	Antifibrotic drugs available nationwide, with structured rehab programs, lifestyle counselling, and regular monitoring.	Standardised protocols provide holistic care with symptom management, addressing patient needs in rural and urban areas equitably.
Regular Monitoring, Follow-Up, and Clinical Trials	Regular monitoring protocols with PFTs, HRCT, and clinical trials infrastructure for continuous care.	Routine monitoring with structured assessments and access to clinical trials, allowing tailored adjustments to treatment plans.	Regular follow-up embedded in national plan, with clinical trial opportunities through partnerships, improving care adaptability.
Support Services, Reimbursement, and Telemedicine	Telemedicine, rural-friendly reimbursement schemes (e.g., PIP, Attendance Allowance), and home-based support ensure accessibility across regions.	Telemedicine and financial assistance available, with comprehensive support programs to ensure continuity of care in home-based settings.	PBS subsidises antifibrotic drugs, telemedicine supports rural access, and community outreach provides education and access to care.

National Registry

Ireland currently lacks a dedicated national registry for lung fibrosis which significantly limits the country's ability to systematically track disease progression, assess treatment efficacy, and conduct epidemiological studies that could inform national health policies. In contrast, the UK, Australia, Canada and Denmark have established well-regarded registries, such as the British Thoracic Society ILD Registry, Canada's CARE-PF registry, Denmark's DANILDA registry Germany's eurILDreg and INSIGHTS-IPF Registry and Australia's AILDR registry that have transformed their approaches to lung fibrosis management. These registries gather comprehensive datasets, covering patient demographics, treatment responses, and longitudinal outcomes, which are crucial for evidence-based decision-making and policy development.

Diagnostic Accuracy and Structured Referral Pathways

In Ireland, diagnostic and care pathways for lung fibrosis lack consistency and structure, with fragmented steps and limited referrals from primary care to ILD centres. This contrasts with countries like the UK, Denmark, Germany, Australia, and Canada, which prioritise streamlined pathways and diagnostic accuracy. Denmark centralises all suspected ILD cases to tertiary centres for specialised imaging and diagnostics, while Australia and Canada emphasise multidisciplinary evaluations and detailed data collection to personalise treatment plans. The UK's tiered pathway categorises patients based on care complexity, ensuring appropriate management at local or specialised centres. Australia's National Strategic Action Plan for Lung Conditions integrates lung fibrosis care into a broader framework, focusing on equitable access and underserved populations, highlighting the gaps in Ireland's comparatively underdeveloped care pathway.

National Plans and Policies

The absence of a national clinical programme for lung fibrosis in Ireland means there is no specific national policy or strategic framework dedicated to managing the disease. Other countries have introduced targeted policies that enhance lung fibrosis management and provide a clear roadmap for healthcare providers and policymakers. Australia's National Strategic Action Plan for Lung Conditions, for example, is an integrated framework that addresses everything from disease prevention to equitable access and research, with specific provisions for the lung fibrosis population. This plan ensures that national resources are allocated to ILD services and that lung fibrosis management aligns with best practices. Similarly, the UK's Health and Care Act 2022 introduced Integrated Care Boards (ICBs) to facilitate cross-sector coordination between ILD centres and community-based services, providing a more seamless care experience for patients and addressing regional disparities. Denmark's participation in the European Reference Network provides access to a wealth of

expertise and resources, strengthening national standards and allowing Danish patients to benefit from Europe-wide advancements in lung fibrosis care.

Multidisciplinary Teams (MDTs) and Specialist Centres

Ireland's multidisciplinary teams (MDTs) in Lung fibrosis care remain limited, with less structured integration compared to the extensive MDT frameworks in countries like the UK, Canada, and Australia. In these countries, MDTs are deeply embedded in ILD treatment pathways, and teams include respiratory specialists, radiologists, pathologists, respiratory nurses, and allied health professionals, such as physiotherapists, dietitians, and mental health experts. For instance, the UK's three-tiered system structures MDTs within specialist centres at different levels of care, ensuring that patients receive the right level of support based on their needs. Similarly, Australia's MDTs are highly structured and focus on involving allied health professionals, such as dietitians and psychologists, to provide holistic patient care. Denmark similarly has three tertiary ILD centres with MDTs that cater to routine and complex lung fibrosis cases, maintaining a high standard of patient care across the country.

Treatment and Symptom Management

Ireland's treatment and symptom management resources for lung fibrosis patients remain limited compared to the comprehensive frameworks in the UK, Canada, and Denmark, where multifaceted care includes antifibrotic therapies, pulmonary rehabilitation, and continuous monitoring to manage disease progression and improve quality of life. In these countries, treatment pathways extend beyond medication to include physical training, educational sessions, and psychological support as part of pulmonary rehabilitation, empowering patients to actively manage their condition. Antifibrotic drugs like nintedanib and pirfenidone are widely accessible and form the cornerstone of lung fibrosis treatment across the UK, Canada, Denmark, and Australia, often complemented by nutritional guidance and lifestyle modifications. Denmark's approach particularly highlights lifestyle counselling, integrating dietary and exercise support to provide a holistic and patient-centred approach to managing lung fibrosis.

Regular Monitoring, Follow-Up, and Clinical Trials

In Ireland, regular monitoring and follow-up for lung fibrosis patients are inconsistently available, with limited access to clinical trials, which restricts opportunities for new treatments. In contrast, the UK, Denmark, and Canada implement structured monitoring protocols, using routine pulmonary function tests, imaging, and symptom evaluations to closely track disease progression and make timely treatment adjustments. Canada's approach includes scheduled assessments, such as PFTs and six-minute walk tests, to proactively manage symptoms and lung function, while Denmark combines regular follow-

up with lifestyle modification programs, allowing providers to respond effectively as the disease advances. Clinical trials play an essential role, particularly in Canada and Denmark, where patients gain access to emerging treatments that may slow disease progression or enhance quality of life. Registries like Canada's CARE-PF and Denmark's DANILDA further support clinical trial recruitment and enable global data sharing, advancing medical knowledge and strengthening local patient care.

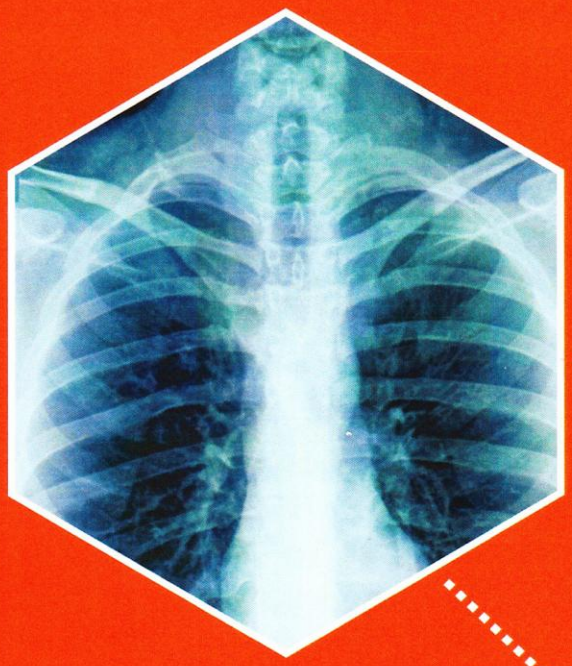
Support Services, Reimbursement, and Telemedicine

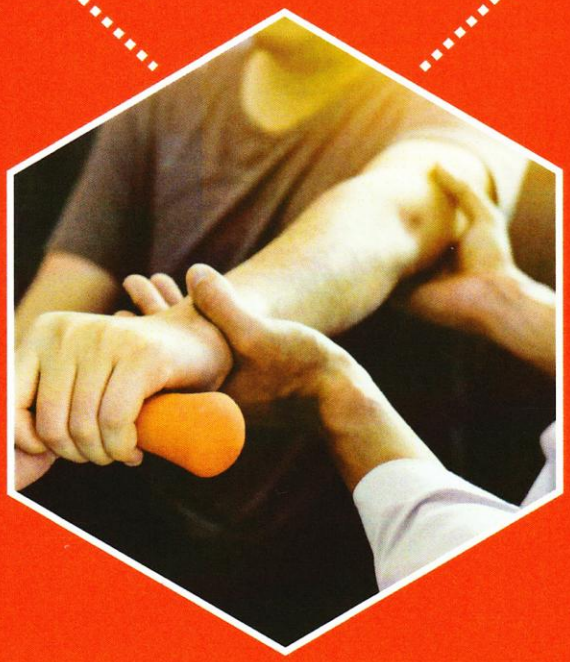
Ireland's support services for lung fibrosis patients are minimal and lack the extensive infrastructure seen in other countries, especially regarding telemedicine, reimbursement schemes, and community-based programs. Countries like the UK, Australia, and Denmark have incorporated telemedicine as a vital part of PF care, enabling patients in remote areas to consult specialists and manage their conditions effectively. Denmark and Australia have integrated home-based care services and community outreach programs, that extend educational resources and rehabilitative services to rural areas, reducing the geographic disparities often seen in lung fibrosis care.

In terms of financial assistance, each country provides some form of reimbursement or subsidy. The UK offers support through the Personal Independence Payment (PIP) and Attendance Allowance schemes, while Australia's Pharmaceutical Benefits Scheme (PBS) subsidises antifibrotic medications. Denmark's national health system ensures that patients receive access to essential medications, oxygen therapy, and rehabilitation programs without significant out-of-pocket expenses, supporting equitable access to lung fibrosis care across income levels. In the UK, oxygen electricity costs are free of charge.

Summary

Ireland faces significant challenges in managing lung fibrosis compared to countries like Denmark, Germany, the UK, Canada, and Australia, particularly in the absence of a centralised registry, structured diagnostic pathways, and a national clinical programme. These countries have established comprehensive frameworks that integrate multidisciplinary teams, advanced treatment pathways, regular monitoring, and extensive support services. By addressing gaps in resource allocation, patient monitoring, and equitable access to care, Ireland has the opportunity to enhance its lung fibrosis care and align with international best practices.





Irish Lung Fibrosis Association

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