Interstitial Lung Disease Care Pathway

Optimum integrated clinical care pathway for adults in England with ILD.

ONE VOICE ILD

Supported by

Action for Pulmonary Fibrosis

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Contents

OneVoiceILD is a movement committed to bringing together the PF community as one to identify and address system-wide challenges to make sure services meet the specific needs of people with PF. *The Secretariat is provided by Action for Pulmonary Fibrosis.*

Action for Pulmonary Fibrosis (APF) is a patient-driven charity. APF's vision is to stop lives being lost to pulmonary fibrosis.

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- The pathway was created by the pathway mapping steering group

Executive Summary

The current respiratory commissioning model is not fit for purpose for interstitial lung disease (ILD) services. With increasing demand, it is not future-proofed to ensure those eligible for treatment can receive it or to tackle growing inequalities of care.

This report sets out a transformative integrated pathway approach to the organisation of ILD services, tackling the current challenges to equitable and timely delivery of care.

All Integrated Care Boards (ICBs) should commission services that enable access to joined-up ILD care close to home.

A suitably funded, networked workforce aligned to operational flow is needed for effective operational delivery and quality assurance.

This optimum integrated care pathway is a key opportunity for commissioners and providers of health and care services to understand the needs of people living with ILD.

There is clear and unwarranted variation in access to services, with long delays to diagnosis and treatment and basic quality standards are not being met. Certain forms of ILD have outcomes comparable to ovarian, bladder or blood cancers, making delays to starting progression-slowing treatment a factor in avoidable earlier death. Transformation is needed to tackle increasing workloads within specialised ILD services and fast-track access to specialist care.

Change will be achieved through a number of key recommendations designed to improve the quantity and quality of ILD services, bringing care closer to place, and enabling joined-up care from community care through to specialist centres.

Although services usually have dedicated interdisciplinary support, variation in the workforce across England means ILD care provision is under-resourced. The changes outlined will require investment in the specialist workforce within health and social care alongside education to support community services.

KEY RECOMMENDATIONS

A regional integrated care model, with new specialist prescribing centres, and appropriate resourcing.

Joined-up approach to ILD care across the whole pathway.

Improved data collection, audit and governance.

Creation of a timed pathway for suspected ILD.

LIVED EXPERIENCE FROM PEOPLE WITH ILD

"It's an awful thing to say but I wish it was cancer. There would be more support if I had cancer."

"I waited months to be seen, meanwhile my condition was deteriorating."

"The treatment and frequency of appointments, scans etc, seems to be a postcode lottery."

USEFUL LINKS

Action for Pulmonary Fibrosis (2023) 'I wish it was cancer' – Experience of pulmonary fibrosis in the UK:

→ **www.actionpf.org/news/people-with-lived-experience-of-pf-at-the-heart-of-survey-set-to-influence-change**

Introduction

This report sets out a transformative vision for the way in which ILD services should be organised across the UK – through an integrated pathway approach.

As a less common respiratory condition, patients with ILD continue to receive delays in diagnosis and fragmented care. As a progressive disease with outcomes comparable with many cancers, time is of the essence to ensure accurate diagnosis and access to progression-slowing treatment.

Evidence from the recent "I wish it was cancer" patient experience report and the Interstitial Lung Disease Service Evaluation demonstrate that there is high need to address significant unwarranted variation in care across all areas of ILD services.

There is also an enormous physical and mental burden on those affected by ILD. Long delays to diagnosis and poor access to specialist care can result in significant anxiety, poorer quality of life and decreased life expectancy.

An ageing population and incidental findings from Targeted Lung Health Checks also contribute to an increasing workload for specialist centres, further compounding existing issues.

For the first time, people with lived experience of pulmonary fibrosis, specialist clinicians, nurses, and allied health professionals from all regions of the UK have come together to create a transformative vision for the way ILD is provided.

The optimum pathway is a key opportunity for commissioners and providers of health and care services to understand the needs of people with ILD. This will require investment in the specialist workforce within health and social care alongside education to support community services.

USEFUL LINKS

Action for Pulmonary Fibrosis (2023) 'I wish it was cancer' – Experience of pulmonary fibrosis in the UK:

→ **www.actionpf.org/news/people-with-lived-experience-of-pf-at-the-heart-of-survey-set-to-influence-change**

Interstitial Lung Disease Interdisciplinary Network (2023) Interstitial Lung Disease Service Evaluation:

→ **www.ild-in.org.uk/learning-resources/ild-in-service-evaluation/**

About Interstitial Lung Disease (ILD)

- ILD is a broad spectrum of conditions, characterised by inflammation or fibrosis of the alveolar wall with impairment of gas exchange.
- The most severe form of these diseases are progressive fibrosing ILDs, also known as pulmonary fibrosis (PF). In these cases, the lungs become progressively stiffer and smaller, eventually leading to low oxygen levels in the blood.
- Unlike many other respiratory conditions PF is a terminal diagnosis. Some subtypes such as idiopathic pulmonary fibrosis (IPF) have outcomes similar to ovarian, bladder or blood cancers. IPF alone accounts for 1% of all deaths in the UK.
- ILDs can be linked to genetics, environmental factors, viral infections like COVID-19, connective tissue diseases such as rheumatoid arthritis and scleroderma, or may have unknown cause (known as idiopathic).
- The age-standardised incidence rate of ILD in the UK is estimated to be 10.91 per 100,000 for men and 6.7 per 100,000 for women.
- The most common of these conditions are idiopathic pulmonary fibrosis (IPF), sarcoidosis and hypersensitivity pneumonitis.
- There are also a myriad of less common ILDs each with an estimated incidence of between 0.1–5 per 100,000 individuals per year.
- Treatment options are incredibly limited. Lung transplant is the only curative option, and pharmacological treatments are not well tolerated, with severe side effects.

USEFUL LINKS

British Thoracic Society (2021) BTS ILD Registry Annual Report 2021 – A Summary. Available at:

→ **https://www.brit-thoracic.org.uk/quality-improvement/bts-ild-registry/**

Salciccioli J, Marshall D, Goodall R, et al. Interstitial lung disease incidence and mortality in the UK and the European Union: an observational study, 2001–2017. ERJ Open Research. 2022 Jul; 8 (3).

	Ovarian Cancer	IPF
New cases (annually)	7,500	6,000
Deaths (annually)	4,100	5,000
5 year survival	43%	45%

What needs to change?

USEFUL LINKS

NICE (2015) Quality standard [QS79] Idiopathic pulmonary fibrosis in adults:

→ **www.nice.org.uk/guidance/qs79**

Slow and inaccurate diagnosis

Diagnosis is not being made as quickly or efficiently as possible, leading to worse outcomes. The later the diagnosis, the greater impact on both length and quality of life. There is much misdiagnosis with common respiratory conditions, with some patients waiting more than 12 months for their first appointment with a general respiratory clinician, with further waits for specialist care.

Unwarranted variation in waiting times

There is a postcode lottery for waiting times from receipt of new patient referral to first appointment with an ILD specialist to initiation of treatment.

Inequity of access to services

People living with ILD are not receiving timely access to the support services they require. This highlights the need for prompt referral and diagnosis with ongoing support delivered in an integrated service.

Lack of treatment plan

More often than not, patients do not receive a care and treatment plan. Often there is a failure to refer patients to relevant voluntary and community sector organisations for support (such as Action for Pulmonary Fibrosis).

Failure to meet NICE standards

The NICE Quality Standard QS79 states patients should be referred to a specialist nurse, and have access to oxygen assessment, pulmonary rehabilitation and palliative care. These standards are not met for many.

Under-resourced ILD services

There is currently an inadequate workforce within services to meet demand. Referrals to ILD centres have increased significantly since NHS England produced the ILD service specification and resourcing has not kept pace.

Fragmented care

There is limited joined-up care and available care may only address some symptoms. There is significant geographic variation in accessing different elements of care.

Long waits for treatment

Long waits exist for access to antifibrotic treatments. In England, only specialist centres can prescribe antifibrotic drugs which creates a backlog of people waiting for care.

How will change be achieved?

USEFUL LINKS

Interstitial Lung Disease Interdisciplinary Network (2023) Interstitial Lung Disease Service Evaluation:

→ **www.ild-in.org.uk/learning-resources/ild-in-service-evaluation/**

A regional integrated care model for ILD

A fully integrated system-wide care pathway across all areas of care is crucial to achieving optimal care and addressing each patient's needs. New ways of working such as virtual multidisciplinary team (MDT) meetings between all tiers alongside remote and digital monitoring needs to be explored and adopted, taking into account the digital literacy of each patient and their family.

New ILD specialist centres

New ILD specialist centres within regional networks will be created with the ability to prescribe and monitor antifibrotic drugs for some conditions.

This will increase ILD service capacity, reduce waiting times for patients, and ensure people living with ILD have access to services and treatment as close to home as possible.

Increased ILD workforce

Sufficient workforce is essential to ensuring the quality of disease management and specialist care, particularly in specialist respiratory clinicians, nurses, pharmacists and radiologists, alongside access to allied health professionals such as respiratory physiotherapists, occupational therapists, dieticians, and psychologists.

CHALLENGES

Lack of data

There has been a lack of explicit data on ILD services and patient referrals until the ILD service evaluation was published in 2023 indicating service capacity issues.

Integration

Integration between the regional and local respiratory services, primary care and community care enablers to deliver the optimum pathway include specialist networking, virtual consultation and education which would greatly facilitate communication between clinicians and improve patient care.

Workforce

There is a lack of adequately trained and retained ILD workforce across specialist settings. This is particularly true of radiology, pharmacy, and nursing.

Key recommendations

Model of care

The creation of a new, regional model of care for ILD. This includes the creation of new Tier 2 prescribing centres to manage demand, with the support of existing specialist centres.

Timed pathway

A timed pathway from referral through diagnosis should be designed and incentivised to ensure rapid and accurate diagnosis.

Data collection

Data collection should be improved, with generated data used to inform policy recommendations and clinical guidance, to enable service improvement, and to understand and address health inequalities.

Diagnosis and treatment

People with ILD should receive an accurate diagnosis and access to specialist medicines and supportive care, closer to home where possible.

Resource

Commissioning of ILD services should reflect the increasing number of new patient referrals to specialist centres. Services should be adequately resourced to manage diagnosis, as well as the prescribing and monitoring of any fibrotic and immunosuppressant medicine.

Referral for support

People with ILD should receive care by appropriately trained and competent multidisciplinary healthcare professionals at every stage of the pathway. They should be made aware of all support services, including those from the voluntary sector such as Action for Pulmonary Fibrosis.

Accessibility

Local care providers should undertake investigations as close to home as possible. ILD specialist centres should have access to full results when new patients are referred and where follow up is required. Treatment and clinic visits should be as close to place as possible.

Quality standards

Quality standards should be created for all ILDs, including a provision for psychological care. Currently, these only exist for IPF through NICE Quality Standard QS79, which outlines a minimum level of care with access to a specialist nurse, personalised pulmonary rehabilitation, oxygen services and palliative care.

Workforce capacity and training

Ensure that there is capacity within the workforce to deliver care and that the workforce have the required competencies to manage patients.

USEFUL LINKS

NICE (2015) Quality standard [QS79] Idiopathic pulmonary fibrosis in adults:

→ **www.nice.org.uk/guidance/qs79**

Regional networks

There is currently a wide variation in access to specialised ILD care, and limited capacity to manage patients within the existing 24 specialist centres in England.

To ensure high-quality ILD care is delivered as close to home as possible, care should be organised into regional networks. Clinical networks are already operating successfully in the NHS, combining the experience of multi-disciplinary working, lived experience and clinical leadership to improve delivery of care and integration across primary, secondary and tertiary care.

Delegation of the commissioning of specialised services to Integrated Care Boards (ICBs) now provides an opportunity to join up currently fragmented commissioning pathways "planned with people with ILD" so that services are coordinated to achieve best outcomes and manage local need not just demand.

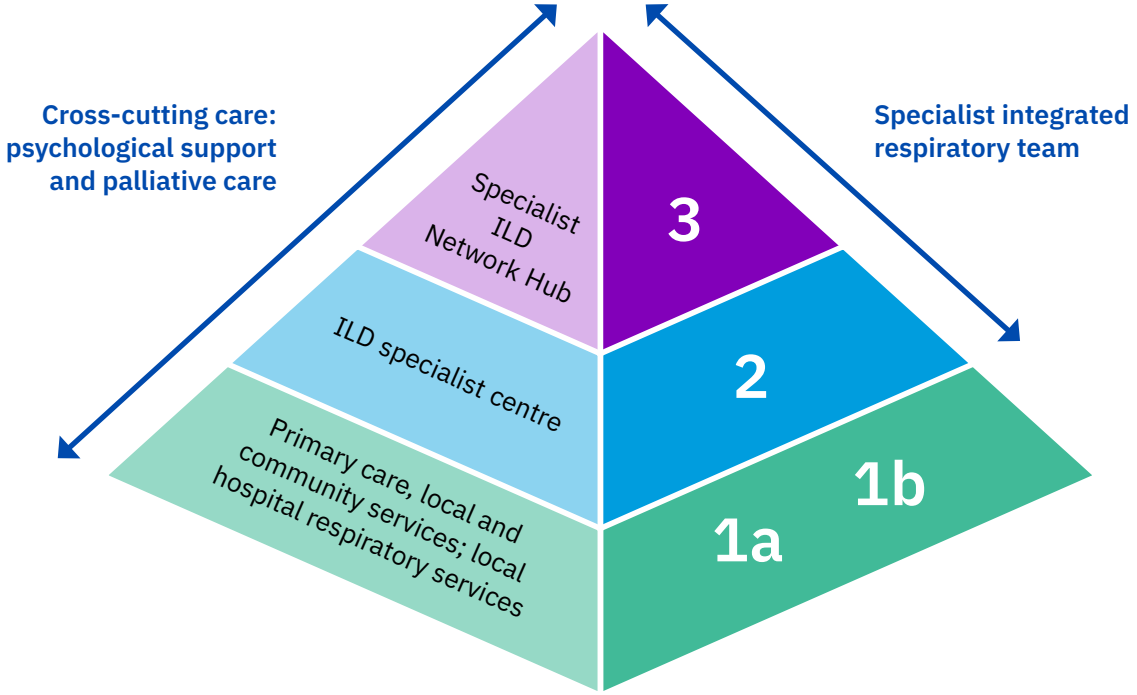
1 **ILD services can be integrated into population-wide respiratory pathways.**

2 **Integrated Care Boards (ICBs) can assess their existing services and improve access to specialist skills through mapping existing specialised services and flows. Over time they should consider which elements can be delivered more efficiently more locally or by consolidating relationships with some external providers.**

3 **ICBs can commission both specialised and non-specialised respiratory services based on whole population need, including historically ignored aspects such as pulmonary rehabilitation and psychology services which, when done well, reduce emergency hospital admissions.**

4 **Clear and appropriate access to specialist advice and decision-making support with embedded referral management that optimise patient pathways (rather than simple demand management).**

Tiered approach



Each region should have a number of Tier 2 specialist centres (many of which will need to be commissioned), and at least one Tier 3 specialist centre with additional expertise in the management of complex disease.

Through this networked approach it will be possible to ensure all patients have access to a multidisciplinary disease-specific management plan with care taking place closer to home.

Tier 3

Regional ILD specialised services with wide-ranging prescribing services and additional expertise in management of complex disease.

Tier 2

ILD specialised services with medic-to-medic input and virtual MDT clinic support. Service includes ILD lead, ILD MDT and respiratory nurses with ILD expertise, and ILD pharmacist. Services will only achieve Tier 2 prescribing status when appropriate workforce and competencies are in place.

Tier 1a / 1b

General respiratory hospital services, community respiratory teams, primary care, outpatient remote monitoring, virtual consultations, supported self-management.

Benefits for health and care systems

REDUCING INEQUALITY

Facilitating more consistent and equitable ILD services

- Consistent adoption of standards for service delivery and systematic diagnosis/case-finding.

FINANCIAL EFFICIENCY

Enabling ILD services to deliver the right care at the right time to the right patients

- Providing care closer to home reduces avoidable demand on specialist units and non-elective admissions streamlining operational delivery.
- Reversing the trend of increasing waits by enabling providers to collaborate and assist with waiting list recovery through mutual aid within ICBs and more locations delivering services.

IMPROVING QUALITY

Sharing and extending skills through collaboration

- Make best use of existing resources, e.g. shared job roles between providers and routine MDT working across ICS or multi-ICS regions, with concomitant upskilling.
- Digital and remote-based solutions to share skills across the system where there are specific skill/role shortages, e.g. radiology and psychology.

ENVIRONMENTAL IMPACT

Use of remote consultations

- Remote consultations reduce footfall on the hospital, reduce C02 emissions and demand on hospital parking alongside increasing workforce capacity. They also offer an opportunity for patients to feel they are contributing positively to the environment. One video appointment prevents 3.1 kg of C02, the equivalent to the CO2 absorbed by 186 trees per day.

USEFUL LINKS

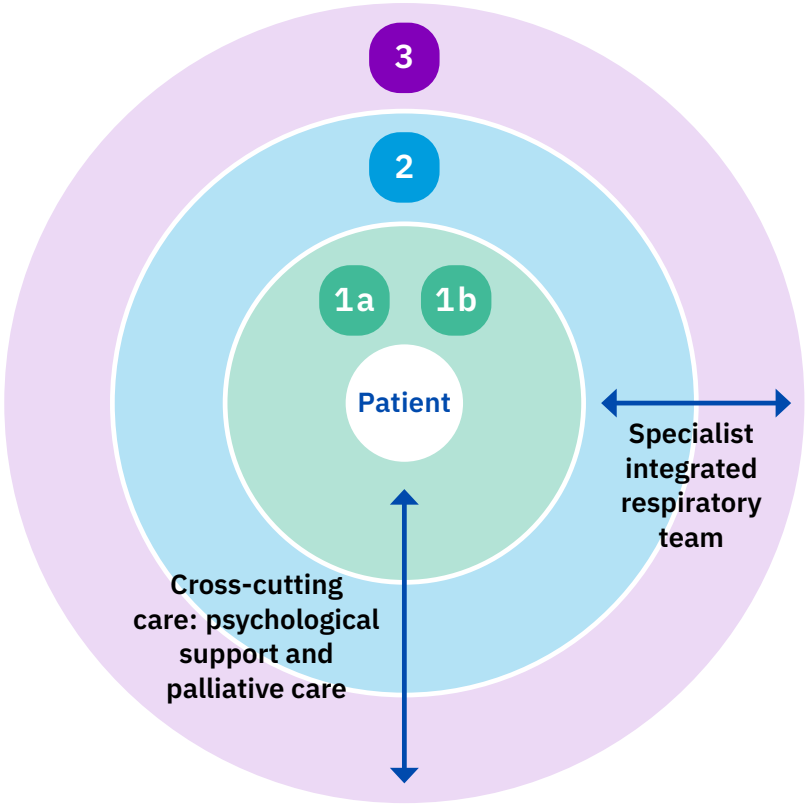
BUPA (2023)

→ **www.bupa.com/news/stories-and-insights/2023/bupa-develops-toolkits-to-support-sustainable-healthcare**

Integrated ILD care

People with ILD need the integrated support of teams working in coordination to provide quality care, close to home. This can be facilitated through regional ILD networks.

Staff work and communicate across the respiratory pathway.



Tier 3

Specialist ILD Network Hub

- Regional specialist ILD centres
- Wide ranging prescribing service
- All services available in Tiers 1 and 2 plus additional expertise in management of complex disease
- Access to clinical trials
- Responsibility for regional network support, education, and pathways

Tier 2

ILD specialist centre

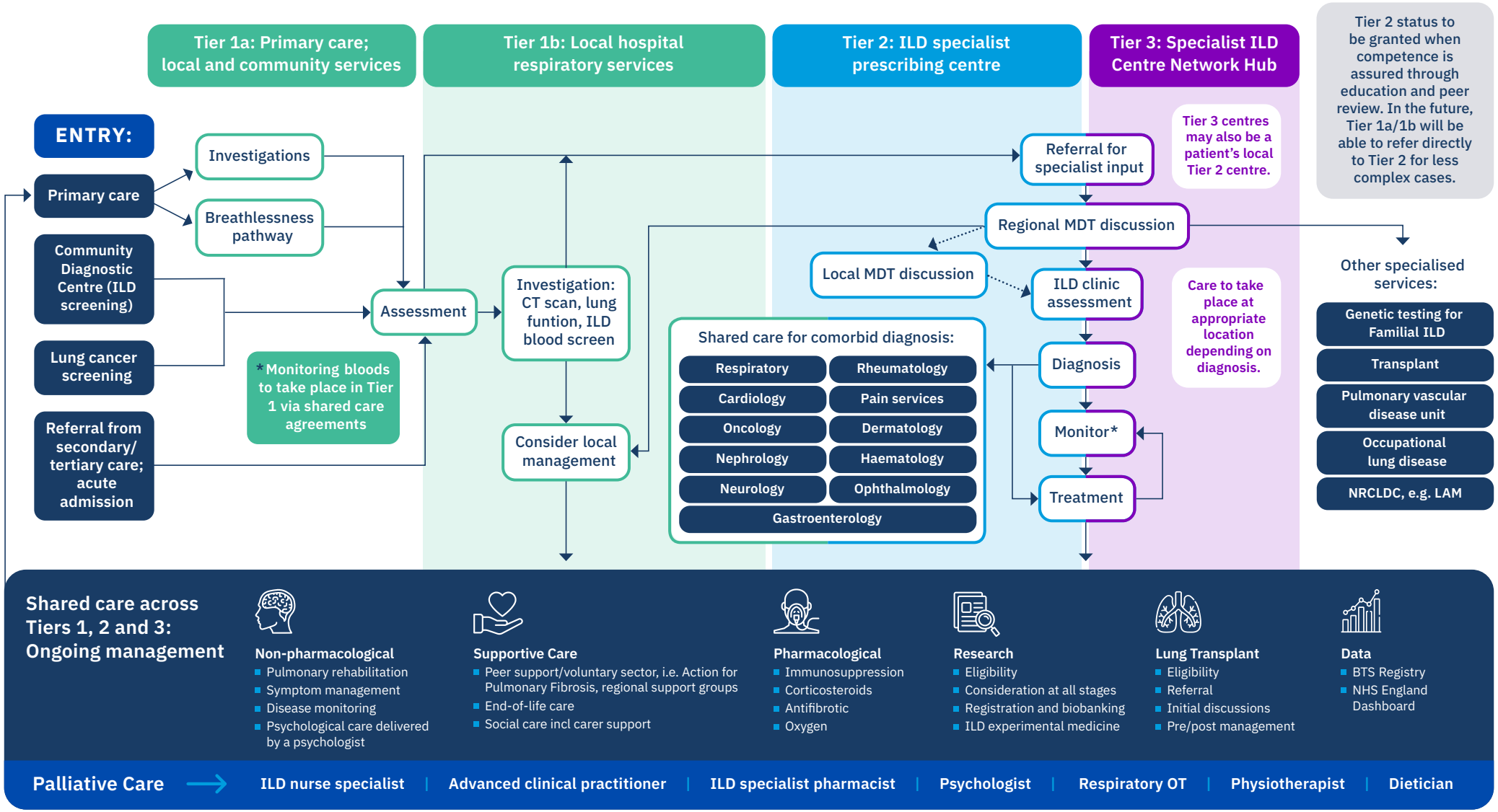
- Specialist ILD centres delivering high-quality ILD care
- Respiratory physician with ILD expertise
- Respiratory nurse with ILD expertise
- Pharmacist with ILD expertise
- Local ILD MDT
- Data submission to NHS dashboards
- Where possible, offer access to clinical trials

Tier 1a / 1b

Primary care; local and community services; local hospital respiratory services

- Hospital outpatients and community clinics
- Voluntary data submission to NHS dashboard
- Community, primary care, outpatients, remote monitoring, virtual consultations
- Supported self-management:
  - Technology and digital devices
  - Oxygen and pulmonary rehabilitation services
  - Patient education: smoking, diet, exercise, immunisation
  - Carer support
  - Social prescribing
  - Information and support from the voluntary sector, e.g. Action for Pulmonary Fibrosis

Optimum integrated care pathway for ILD

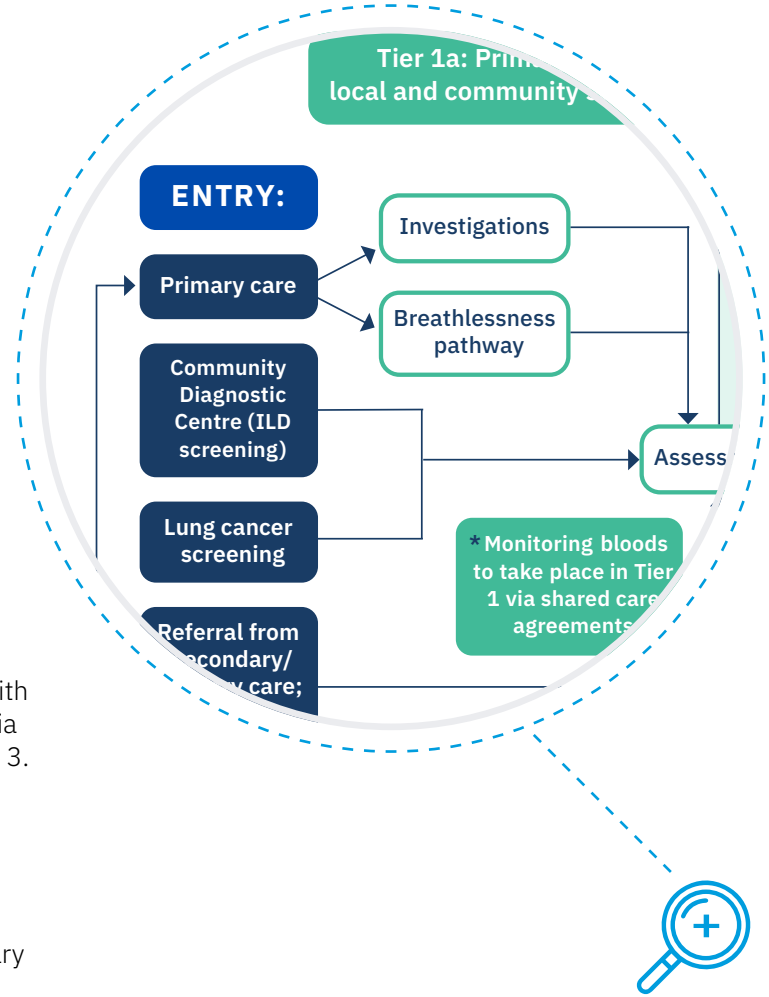


BTS: British Thoracic Society | CT: computerised tomography | GP: general practitioner | ILD: interstitial lung disease | LAM: lymphangioleiomyomatosis
MDT: multidisciplinary team | NRCLDC: National Rare Cystic Lung Disease Centre | OT: occupational therapist

Care pathway: first presentation to diagnosis

GUIDING PRINCIPLES

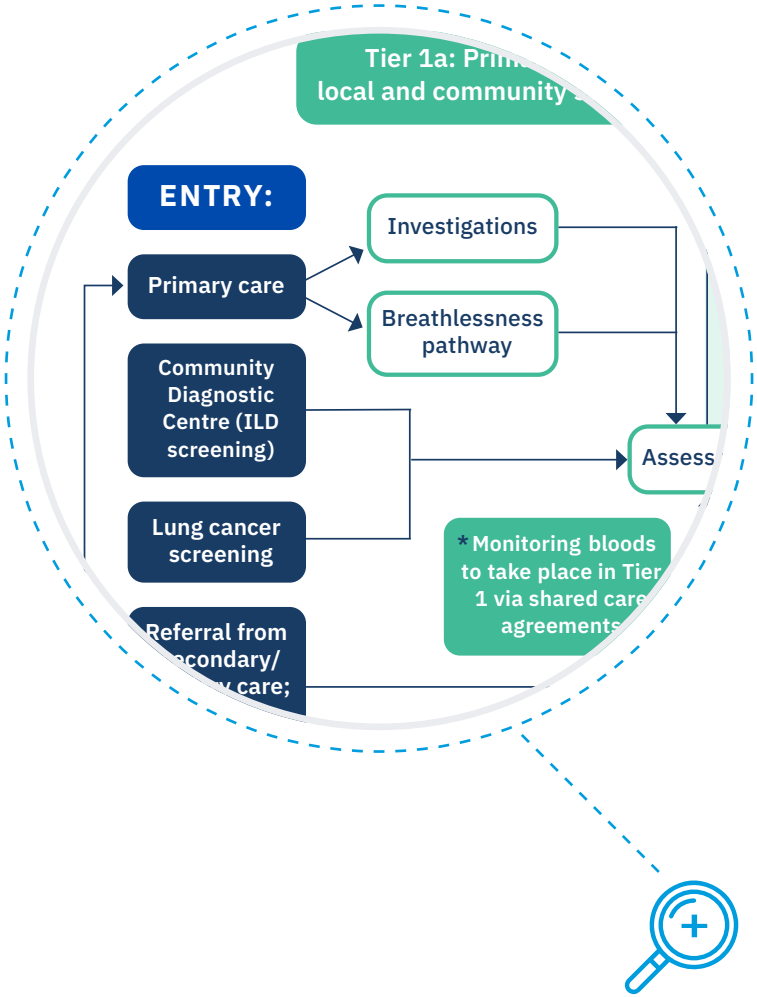
- When a patient is referred to their local clinic this could be in a Tier 1, 2 or 3 service depending on their location. Tier 3 services have their own local populations thus may also be a local service.
- People with ILD should have an accurate and timely diagnosis in order to access timely and appropriate treatment. Referral may be via primary care, the breathlessness pathway, a diagnostic hub or a screening programme.
- People seen by general respiratory physicians or other doctors who do not have specific ILD expertise may have the diagnosis confirmed following virtual medic-to-medic consultation with competent ILD specialist clinicians in Tier 2 or via virtual MDT meetings with ILD specialists in Tier 3.
- At diagnosis patients should be given a care and treatment plan which will be delivered locally and a contact point for further information and follow up which includes a specialist respiratory nurse with ILD expertise, plus referral to voluntary sector organisations for support, such as Action for Pulmonary Fibrosis.



Care pathway: first presentation to diagnosis

NETWORKED MODEL

- A joined-up, regionally networked ILD services would see a model whereby specialist consultants only see new patients at diagnosis.
- The ILD team is multi-professional and it may be appropriate for some appointments to occur with the specialist nurse or ILD pharmacist, depending on clinical need. Tasks undertaken by these professionals should be reviewed to ensure they are an appropriate use of their time.
- For example, pharmacists can undertake safety monitoring and prescribing, with blood tests performed in Tier 1a/1b. Primary care education in ILD should be provided to increase GP-to-specialist communication.
- The additional support from healthcare professionals in the Additional Roles Reimbursement Scheme in primary care should not be overlooked.



Care pathway: specialist components of care

DEFINING SPECIALIST CARE

- With service transformation, prescribing care of people with ILD will not just be in the remit of regional ILD centres but with appropriate education and governance include Tier 2 specialist services with the support of the regional ILD network hub.
- Effective networking, education and communication can allow Tier 2 services to prescribe and provide antifibrotics as well as undertaking healthcare and symptom management.
- Community respiratory teams and health and care workers can also provide care much earlier in the patient journey (which to date has been limited). Providing more support closer to home will support the expansion of specialist service capacity.

ILD care offer from suitable competent services:

TIER 3

Treatment coordination, provision and monitoring.

TIER 2

Following receipt of referral letter:

- Patients seen within 8 weeks
- Treatment starts within +/- 12 weeks

TIER 1

Local monitoring.

ILD SERVICE

- Single point of contact
- Face-to-face appointment within 4 weeks of diagnosis
- Care planning and shared decision making with wider multidisciplinary team at place
- Inclusion in ILD register

Care pathway: specialist components of care

GUIDING PRINCIPLES

- All patients with ILD should be assessed for their eligibility for treatment as early as possible after diagnosis or after any significant change in symptoms.
- All patients from diagnosis onward should be assessed for symptomatic treatments, psychological support and palliative care by healthcare professionals with ILD expertise.

ENABLERS

- Antifibrotic treatment can be delivered by a network of clinical staff linked virtually to operating in the community with access to an IT system that supports safety monitoring.
- Blood tests should be taken in a location close to home. Results must be easily available to the treating team, for example through systems like Patient Knows Best.
- Routine prescribing can be undertaken by a nurse or pharmacist with the necessary experience and prescribing qualification.
- Treatments like antifibrotics that require Blueteq approval can be sanctioned via a virtual MDT with medic-to-medic consultations. IT sharing of patient records and investigation results is essential for effective shared care.

Care pathway: from diagnosis to symptom management

SYMPTOM MANAGEMENT

- People with ILD should be offered a comprehensive review as needed, with a healthcare professional who has expertise in ILD and is appropriate to manage symptoms.
- It is important that the managing team meet on a regular basis (which can be virtual).
- People with ILD should be assessed for ability to self-manage and self-refer for patient-initiated follow-up (PIFU) without the need for frequent or regular follow-up. Some new technologies, such as home spirometry, may enable this.

NON-PHARMACOLOGICAL TREATMENT

- Pulmonary rehabilitation
- Symptom management
- Psychological care

PHARMACOLOGICAL TREATMENT

- Immunosuppression
- Corticosteroids
- Antifibrotic
- Oxygen
- Treatment for cough and reflux

SUPPORTIVE CARE

- Peer support/voluntary sector, i.e. Action for Pulmonary Fibrosis, regional support groups
- End-of-life care
- Social care including carer support

Care pathway: from diagnosis to symptom management

GUIDING PRINCIPLES

All people with ILD should have:

- A clear care plan agreed through shared decision making with a named clinical care coordinator.
- Access to education and opportunities for self-management.
- A single point of contact for access to the ILD service which should be led by a non-clinical administrator.
- Access to a respiratory nurse with ILD expertise.
- Access to pulmonary rehabilitation, assessment for oxygen therapy and palliative care services.
- Access to services that provide rapid access for assessment of changes in condition where appropriate.
- Encouragement to maintain physical activity and advice on lifestyle issues, e.g. smoking.
- Consideration for active clinical research trials at all stages of care.

USEFUL LINKS

NICE (2015) Quality standard [QS79] Idiopathic pulmonary fibrosis in adults:

→ **www.nice.org.uk/guidance/qs79**

ENABLERS

- ILD services should be delivered by a network of healthcare professionals who are operating in the community and are linked virtually. Services should be supported by dedicated administrative support to provide coordination and triage. Technology can allow patients to access their clinical records and care plan.
- Research should be integrated into clinical care, with a focus on facilitating opportunities to participate and promote active clinical research. This can be used to promote disease understanding by identifying effective treatment, monitoring and diagnostics.

Improving the ILD specialist workforce

Unwarranted variation in the ILD workforce is increasingly apparent in relation to the increase in new patient referrals and new prescriptions for antifibrotic and immunosuppressant medicines. Some professionals, such as specialist pharmacists, are underrepresented even within the specialist centres, despite the need for their expertise and NICE recommendations.

To maintain standards within new specialist centres, appropriate expertise must be mandated within the multidisciplinary team. This will also require training of existing respiratory and other clinical professionals within a network through the sharing of specialist expertise.

A regional network of care will make more effective use of existing clinical resource, reducing duplication of work, double appointing, and wasted resources on incorrect diagnoses and mismanagement of care.

The ILD Interdisciplinary Network have core recommended workforce standards for ILD care:

- Specialist ILD physicians
- Radiologist(s) in specialist ILD team
- Pathologist(s) in specialist ILD Team
- ILD specialist nurse
- ILD/MDT coordinator
- ILD Specialist pharmacist
- Palliative care consultant
- Psychologist
- Respiratory physicians with interest in ILD and nurse specialist.

Working relationship with:

- Specialist rheumatologist with interest in connective tissue disease

USEFUL LINKS

Interstitial Lung Disease Interdisciplinary Network (2023) Interstitial Lung Disease Service Evaluation:

→ **www.ild-in.org.uk/learning-resources/ild-in-service-evaluation/**

The ILD-IN Service Evaluation (2023) has highlighted significant service understaffing for ILD services.

Whilst we recognise existing workforce challenges in the NHS, a considerable expansion in nursing support in ILD is required to increase service capacity and ensure patients receive a diagnosis and treatments like antifibrotic medications quickly.

Audit and data

There is currently a significant lack of data available on ILD service provision. In many areas, outpatient coding for ILD is poor, meaning that services don't know how many people with ILD are in their area.

Limited data is available through the British Thoracic Society ILD Registry and NHS data dashboard, and the ILD-IN service evaluation. However, this is not used effectively to monitor and change care.

A yearly audit of the optimum pathway will ensure standards can be maintained and improvements highlighted. Services could complete a retrospective audit of patients referred for diagnosis and antifibrotic therapy before and after full implementation.

Several areas are needed to improve the quantity and quality of data relating to this pathway and ILD care:

- Further investment into generating evidence to inform policy recommendations and clinical guidance for ILD.
- Dedicated funding from national research bodies to drive research and innovation in ILD.
- Greater depth of current and accurate real-world information to inform ILD policy/guidelines and their implementation, and a digital strategy for implementation.
- Data to understand and address healthcare inequalities using the Core20PLUS5 framework.

USEFUL LINKS

Interstitial Lung Disease Interdisciplinary Network (2023) Interstitial Lung Disease Service Evaluation:

→ **www.ild-in.org.uk/learning-resources/ild-in-service-evaluation/**

This enables data-led decision making to achieve:

1. Service-level improvement
2. Accurate prevalence and incidence data
3. Quantification of healthcare burden in ILD
4. Greater opportunity to benchmark between services and at a national level.

Next steps

1 OneVoiceILD and APF (Action for Pulmonary Fibrosis) will work with NHS England at a national, regional, and local level to drive implementation of the pathway.

2 OneVoiceILD will collaborate with regions on pilot projects which look to increase service resource, improve diagnostic timelines, and develop a regional integrated care pathway in the areas.

3 The NHS England Specialist Respiratory Clinical Reference Group should update the Service Specification to reflect the changes outlined in this document.

4 Competencies and training opportunities for specialist roles, such as ILD nurses, pharmacists, and radiologists, should be created.

5 A timed pathway for suspected ILD should be developed and implemented. This should include a faster diagnosis standard from first referral through diagnosis and treatment.

6 OneVoiceILD will work with stakeholders in the devolved nations to understand how the recommendations of this report could be adapted for use in their health systems.

Pathway mapping steering group

Ahmed Fahim	Wolverhampton
Chris Huntley	Birmingham
Helen Morris	Manchester
Helen Parfrey	Papworth
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Nazia Chaudhuri	Northern Ireland
Nicky Simler	Papworth
Pilar Rivera Ortega	Manchester
Robina Coker	Imperial London
Steve Jones	Patient and Public Voice
Yussef Haider	Lancashire South Cumbria

80+

professional responses received and incorporated

The pathway was circulated to ILD regional service leads, GPs and commissioners for comment with over 80 responses received and incorporated. Lived experience input was sought at every stage.

1200+

lived experience participations in the ‘I wish it was cancer’ report to inform this work

References

Action for Pulmonary Fibrosis (2023) 'I wish it was cancer' – Experience of pulmonary fibrosis in the UK:

→ www.actionpf.org/news/people-with-lived-experience-of-pf-at-the-heart-of-survey-set-to-influence-change

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British Thoracic Society (2021) BTS ILD Registry Annual Report 2021 – A Summary. Available at:

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BUPA (2023)

→ www.bupa.com/news/stories-and-insights/2023/bupa-develops-toolkits-to-support-sustainable-healthcare

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Getting It Right First Time (2021) Respiratory Medicine – GIRFT Programme National Specialty Report:

→ www.gettingitrightfirsttime.co.uk/wp-content/uploads/2021/11/Respiratory-Medicine-Oct21L.pdf

Interstitial Lung Disease Interdisciplinary Network (2023) Interstitial Lung Disease Service Evaluation:

→ www.ild-in.org.uk/learning-resources/ild-in-service-evaluation/

NHS England (2017) Interstitial Lung Disease (Adults) Service Specification:

→ www.england.nhs.uk/publication/interstitial-lung-disease-adults-service-specification/

NICE (2018) Technology appraisal guidance [TA504] Pirfenidone for treating IPF:

→ www.nice.org.uk/guidance/ta504

NICE (2016) Technology appraisal guidance [TA379] Nintedanib for treating IPF:

→ www.nice.org.uk/guidance/ta379

NICE (2023) Technology appraisal guidance [TA864] Nintedanib for treating IPF when forced vital capacity is above 80% predicted:

→ www.nice.org.uk/guidance/TA864

NICE (2011) Quality standard [QS13] End of life care for adults:

→ www.nice.org.uk/guidance/qs13

NICE (2015) Quality standard [QS79] Idiopathic pulmonary fibrosis in adults:

→ www.nice.org.uk/guidance/qs79

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Thank you to everyone who helped shape this pathway. Together, speaking with One Voice, we can transform ILD care.

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