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UK ILD Registry

Annual Report 2024

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FOREWORD: DATA SHARED TO IMPROVE CARE

It is a great testament to participating centres that the UK ILD Registry is the largest global registry of its kind. Despite the challenges that we all face in the current healthcare environment of rising demand and limited resources, we ultimately strive to deliver the best quality of care for our ILD patients. Data are integral to our understanding of disease prevalence and trajectory, which help with the delivery and development of our ILD services. It is thus the vision of our steering group that UK ILD Registry data can and should support better health for patients living with ILD, providing a valuable resource for healthcare professionals to enable them to deliver optimal care.

The activities outlined in this report focus on our steering group's strategy to engage stakeholders, encouraging them to acknowledge the value of the Registry to inform the planning and improvement of ILD services. As part of this work we are focusing on benchmarking, creating resources for hospitals to compare their own performance to other services and to agreed standards. Some of this benchmarking is included in this report, and participating sites have access to additional benchmarking reports directly through the Registry website – all of which is intended to inform discussions with hospital managers, enacting real and meaningful change in ILD services.

We believe the UK ILD Registry can be used to advance our understanding of the distribution, care pathways and burden of ILDs. Data from the Registry have been presented at national and international respiratory congresses and published in peer reviewed journals, and we would like to encourage clinicians and researchers to interrogate the wealth of data within the Registry to ask key research and clinical questions. The steering group is actively encouraging our participating centres to submit data access requests, particularly focusing on equitable care provision and on the use of antifibrotics in ILD care.

We continue to promote the immense value of the UK ILD Registry with NHS organisations and with patient charities such as Action for Pulmonary Fibrosis and SarcoidosisUK, with the goal of advocating on behalf of our ILD community. Through engaging key stakeholders we aim to ensure adequate resources are provided to participating and non-participating centres to facilitate continued engagement with the Registry.

Sustainability of Registry participation is a key focus of the steering group, as we are acutely aware sites face continued challenges engaging with the UK ILD Registry due to limited time and resources. We want to engage with our stakeholders, understanding the barriers services face and forging partnerships to develop robust models to facilitate data entry. This will ensure the Registry is accurate and representative of the whole ILD population.

To this end, as Chair of the Registry steering group, I encourage you to get in touch and get involved so that together we can continue to improve the UK ILD Registry for the benefit of all the ILD patients we serve.

Dr Nazia Chaudhuri
Chair, BTS Interstitial Lung Disease Registry Steering Group

I was delighted to be asked to comment for and endorse this ILD registry report. As respiratory healthcare professionals the reason we get up and go to work every day is simple: to make our patients' lives better. This is the reason we give our best every day, the reason we never stop learning, and the reason we entered this career in the first place. We work hard to ensure our patients have the best possible care, and one crucial aspect of this is making sure our services are meeting the high standards we know we can achieve together.

This is why I am incredibly pleased this report – the first for the expanded UK ILD Registry – presents service-level benchmarking data. The role of data in shaping services cannot be overstated, because without accurate, relevant data we can neither measure our performance nor advocate for the resources we need to drive our standards up. Notably this report highlights that patients are typically waiting for longer than the proposed eight weeks for their first visit with a specialist; something our services need appropriate resourcing to improve. We should all read this report and consider how we can evolve our services to improve. This survey is also a tool do drive new understanding in ILD through research. Registry data is powerful and informs as to the impact our interventions have in real practice and not just in randomised controlled trials. It is a challenge to us that 97% or patients want to be involved in research, and we need to rise to this to provide them with the opportunities.

I am deeply grateful to the doctors, nurses and all members of the ILD teams across the country who have contributed data to this report, and even more so to the many patients who joined the UK ILD Registry. I encourage you to share this report with your commissioners and hospital managers, to use the data presented here to ensure your ILD teams have access to the resources they need to support better lung health for all our patients with ILD

Dr Richard Russell
Chair, BTS Board of Trustees

PART 1 – THE UK ILD REGISTRY

1.1 REGISTRY VISION AND AIMS

The BTS Lung Disease Registry Programme was launched in February 2013, initially including two separate registries: the UK IPF Registry and the UK Sarcoidosis Registry. In February 2023, ten years later, these registries were combined into a new, expanded UK ILD Registry. The new registry includes all the records from the previous registries, and it has also expanded to include any other ILD with evidence of fibrosis.

In 2024 a new vision and aims were written for the UK ILD Registry, focusing on how data can be leveraged to improve patient care through three main routes: benchmarking of services, improving understanding of ILDs, and ensuring the availability and reliability of data in the Registry. All UK ILD Registry activities fall under these aims.

The UK ILD Registry is a database that holds information about the health of people with interstitial lung disease (ILD) across the UK. It Is used by hospitals and researchers to monitor the quality of services and improve the quality of patient care.

Most patients in the Registry have fibrosis (scarring) of the lungs. Some have inflammation inside their lungs (sarcoidosis). All patients in the Registry have agreed to take part.

Our Vision: Using data to support better lung health for all with ILD

Aim 1

To provide and promote data monitoring tools for benchmarking services, enabling improvement and equitable service provision.

Covered in this report in
Part 3: Benchmarking

Aim 2

Using data to advance understanding of distribution, care pathways and burden of ILDs.

Covered in this report in
Part 4: Research and Clinical Trials

Aim 3

Registry data entry is sustainable, and data collected are appropriate, accurate and representative of the whole ILD population.

Covered in this report in
Part 1: The UK ILD Registry
Part 2: The Patient Cohort

1.2 PARTICIPATING SITES

The UK ILD Registry is open to all secondary and tertiary care institutions in England, Scotland, Wales and Northern Ireland. The data cut examined in this report was taken on 31st December 2024, at a time when 91 sites across 74 Trusts/Health Boards had obtained approval to participate. This current full list of 93 sites with approval to participate is included on page 33. These include:

Sites from 63 of the 217 healthcare trusts in England

✓ 26 English prescribing centres, which are commissioned by NHSE to prescribe antifibrotic medications for ILD.

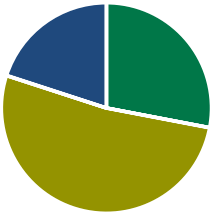
✓ 48 English non-prescribing centres, which can treat ILD but not prescribe antifibrotics.

Sites from 13 of the 27 health boards in the devolved nations

✓ 19 centres from devolved nations – Scotland, Wales and Northern Ireland – which are mostly able to prescribe antifibrotics.

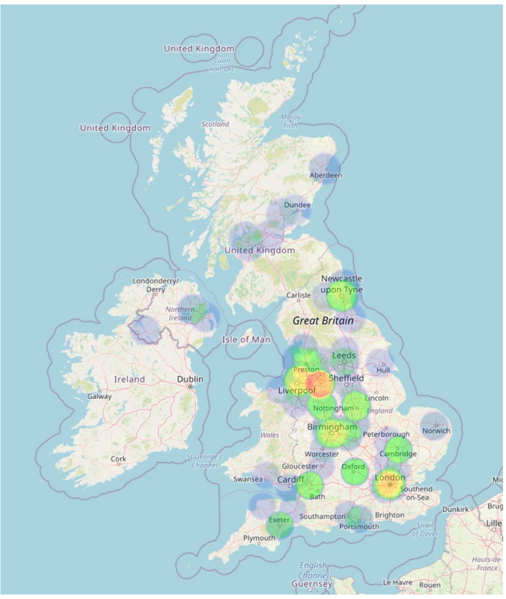
Sites in devolved nations
20% of participating sites.

English non-prescribing sites
52% of participating sites.



English prescribing sites
28% of participating sites. Every English prescribing centre has approval to participate.

For the majority of hospitals, participation in the Registry is voluntary, which means that how many cases they enter into the Registry – or if they even take part – is dependent on the resources they have available. The Registry is mandated for English prescribing centres.



Participating sites have entered data into the Registry from across the UK. This heat map represents the locations from which cases have been entered since the Registry launched in 2013.

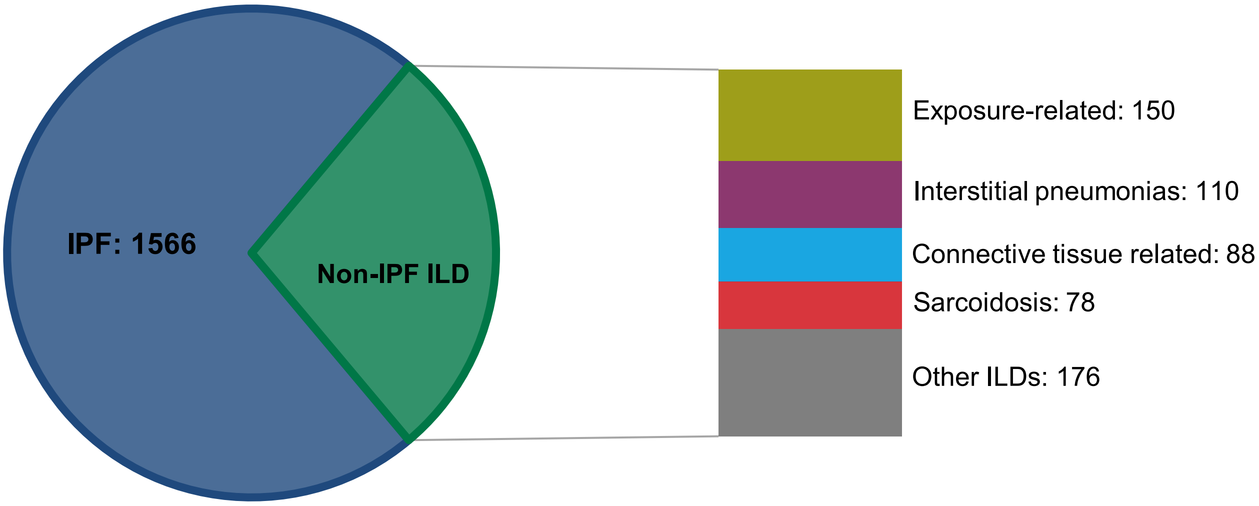
Heat map shows circles of 20-mile radius around participating centres.

<200 cases ▬ >1,000 cases

The heat map represents absolute numbers of cases, with no adjustment made for population size.

1.3 REGISTRY PARTICIPATION IN 2024

There were 2,238 new cases submitted in 2024. Where the ILD was identified, more than two thirds were cases of IPF (70%) while just under a third (30%) were non-IPF ILDs.

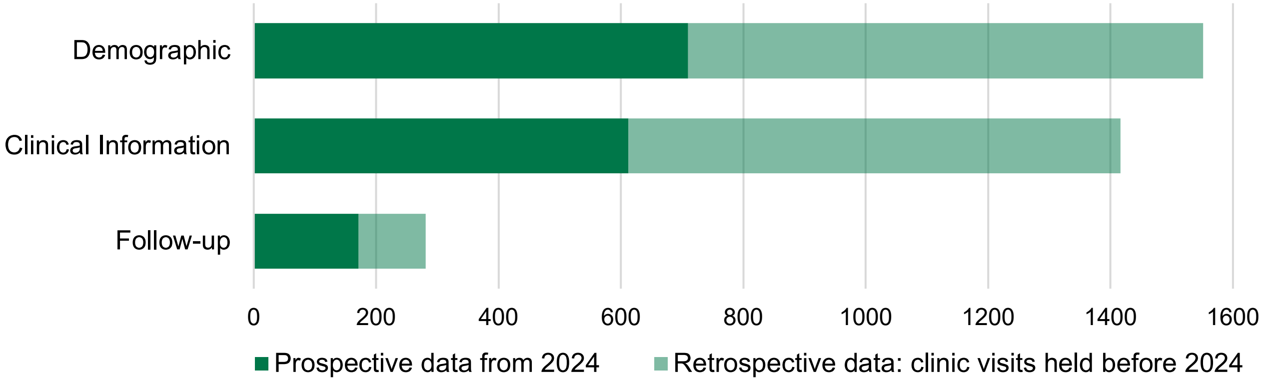


For each patient there are three sets of data which may be entered manually: demographic and clinical information (relating to the first clinic visit) and follow up information (from subsequent clinic visits). Further details of what is included in each set of questions is given on page 29.

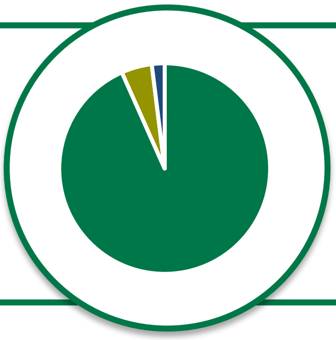
The Registry team regularly reviews whether data can be sourced by other means, reducing the burden of data entry on participating sites. However, due to the variety of electronic systems used by hospitals and the nature of the data collected in the Registry it is not possible at this time. However, initiatives such as aligning Registry questions with NHSE ILD Quality Dashboard items help minimise the general burden of data entry (e.g. the Registry collates dashboard data).

Registry data can be entered retrospectively as well as prospectively. Of the 2,238 new cases entered in 2024, 1,105 represented new prospective ILD referrals in 2024. Additionally, by the end of Q1 2025, a further 202 cases had been submitted where the first clinic visit was held in 2024.

	Prospective (clinic visit held in 2024)	Retrospective (clinic visit before 2024)	Total entered in 2024
Demographic	1,105	1,133	2,238
Clinical Information	1,003	1,000	2,003
Follow-up	254	155	409



The majority of cases (93.3%) were submitted by English prescribing centres. This is likely because English prescribing centres are required to participate in the UK ILD Registry.



Centres in devolved nations submitted 2.0% of records.

English non-prescribing sites submitted 4.7% of records.

English prescribing sites submitted 93.3% of records. This means patients are more likely to meet anti-fibrotic eligibility criteria.

Top 5 contributors in 2024 *(by total number of new patients entered into the Registry)*

English prescribing centres	Centres in the devolved nations Scotland, Wales and Northern Ireland	English non-prescribing centres
Royal Victoria Infirmary, Newcastle	University Hospital Llandough, Llandough	Royal Lancaster Infirmary, Lancaster
Wythenshawe Hospital, Manchester	South West Acute Hospital, Enniskillen	Wansbeck General Hospital, Ashington
Aintree University Hospital, Liverpool	Antrim Hospital, Antrim	Royal Blackburn Hospital, Blackburn
Royal Devon & Exeter Hospital, Exeter		Blackpool Victoria Hospital, Blackpool
Royal Brompton Hospital, London		Burnley General Hospital, Burnley

Most consistent contributors *(months with submissions in 2024)*

12 months – New Cross Hospital, Queen Alexandra Hospital, Royal Brompton Hospital, Aintree University Hospital

6-11 months –Heartlands Hospital, Churchill Hospital, Glenfield Hospital, Guy's Hospital, Nottingham City Hospital, Papworth Hospital, Royal Devon & Exeter Hospital, Royal Preston Hospital, Royal Victoria Infirmary, Southampton General Hospital, Southmead Hospital, St James' University Hospital, Queen Elizabeth Hospital Birmingham, University Hospital Llandough, Royal Stoke University Hospital, Wansbeck General Hospital, Wythenshawe Hospital

3-5 months – Antrim Hospital, Blackpool Victoria Hospital, Burnley General Hospital, Castle Hill Hospital, Midland Metropolitan Hospital, Kingston Hospital, Lister Hospital, Musgrove Park Hospital, Norfolk and Norwich University Hospital, North Tyneside General Hospital, Royal Blackburn Hospital, Royal Lancaster Infirmary, University Hospital Coventry, Worcestershire Royal Hospital

1.4 HOW TO JOIN THE UK ILD REGISTRY

The UK ILD Registry is open to recruitment in perpetuity, and there are lots of ways to get involved, whether as a clinician, researcher or patient:

- **I am a clinician…**
  Contact BTS directly at registry@brit-thoracic.org.uk – the team will help you obtain local Caldicott approval and will give you everything you need to get started. If you're based in Scotland, Caldicott approval is already in place nationally through the Scottish Public Benefit and Privacy Panel.

- **I am a researcher…**
  Researchers can apply to access data from the new BTS UK ILD Registry, which includes all records from the previous UK IPF and UK Sarcoidosis Registries. Full details of this BTS Data Access Request Process are available at www.brit-thoracic.org.uk/quality-improvement/bts-clinical-data-policy-and-data-access/.

- **I am a patient…**
  If you're interested in joining the Registry please speak with your consultant, who will be able to let you know if your hospital is signed up. The medical team at your hospital will be able to answer your questions in the first instance, and if you would like anything clarified please do get in touch with the Registry team at BTS.

You can also spread awareness by sharing Registry reports and other information on social media. Be part of the conversation at @BTSrespiratory

PART 2 – THE PATIENT COHORT

2.1 INCLUSION CRITERIA AND PATIENT CONSENT

Inclusion criteria

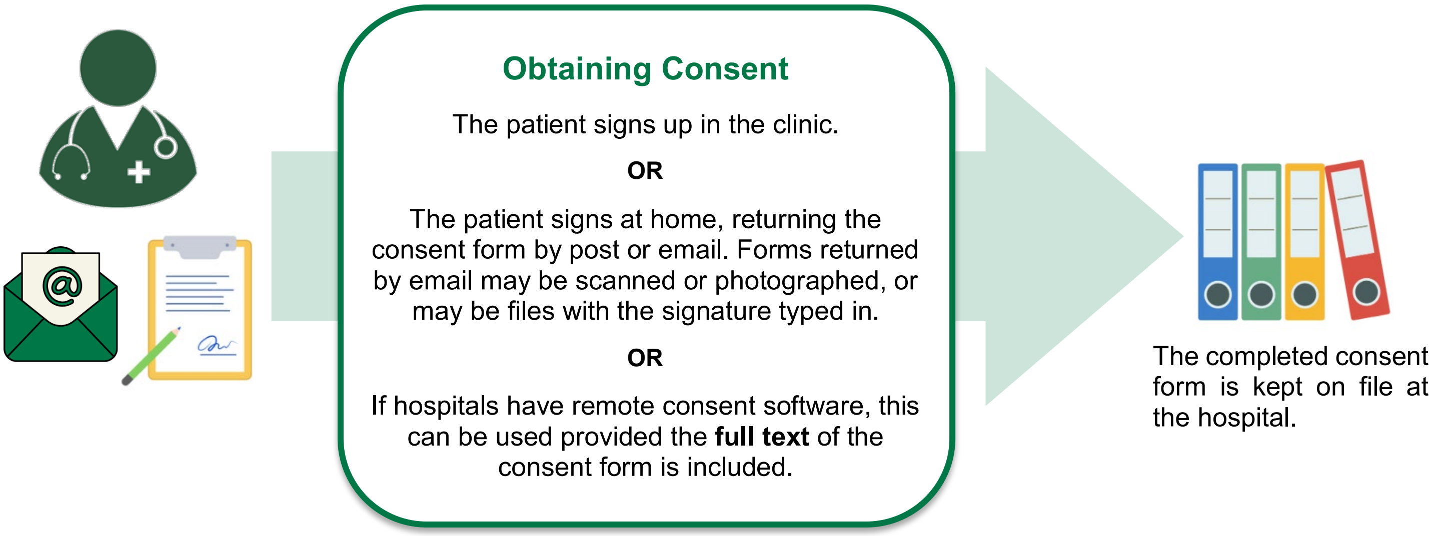
As of 21st February 2023, patients may be included in the new, expanded Registry if they meet all three of the following criteria:

- ✓ First seen in clinic at the participating centre from 1st January 2013.
- ✓ Patients with a new or historic diagnosis of either:
  a. any ILD with evidence of fibrosis, including definite or strongly suspected IPF, *OR*
  b. any sarcoidosis with pulmonary involvement, with or without fibrosis.
- ✓ Informed, written consent has been obtained.

As with the previous UK IPF and UK Sarcoidosis Registries, data may be included both prospectively and retrospectively.

Obtaining patient consent

There are a number of routes through which patients may provide their informed, written consent. Whichever route is used, hospitals should make sure patients fully understand the consent form and have a chance to discuss any queries or concerns they have.



Obtaining Consent

The patient signs up in the clinic.

OR

The patient signs at home, returning the consent form by post or email. Forms returned by email may be scanned or photographed, or may be files with the signature typed in.

OR

If hospitals have remote consent software, this can be used provided the **full text** of the consent form is included.

The completed consent form is kept on file at the hospital.

The patient information and consent forms are now available in Welsh, available for download at: https://www.brit-thoracic.org.uk/quality-improvement/lung-disease-registries/bts-ild-registry/.

2.2 HEADLINE FIGURES 2024

91 hospitals from across the UK had obtained Caldicott approval to participate in the Registry.

91

393

393 users had access to the Registry. These are the doctors, nurses, coordinators and administrative staff who volunteer to enter all patient data.

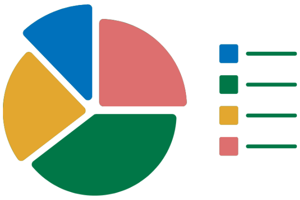
2,238 new cases were added to the Registry. The total number of patients in the UK ILD Registry is now **10,358.**

2,238

73.6 years

75% male

Three quarters of patients were male, and one quarter female. The mean age was **73.6 years** (± 10.9), ranging from 28 to 97. It is important to consider the spread of affected age groups when diagnosing.



41%

41% have at least one comorbidity.
The most common are hypertension (38% of patients), diabetes (18%), ischaemic heart disease (14%), gastro-oesophageal reflux disease (14%) and hiatus hernia (11%).

95.4% of patients are of White ethnicity, while 3.4% are Asian, 0.4% are Black and 0.8% are mixed race or from other ethnicities. This is likely due to geographical populations and not necessarily representative of the UK population.

95%
white

13%

13% of patients were offered involvement in a clinical trial, although 97% of patients would like to be considered for clinical trials.

72% of patients with IPF received antifibrotic therapy at presentation, with 51% of patients receiving nintedanib and 21% receiving pirfenidone.

72%

2.3 THE PATIENT PERSPECTIVE

The UK ILD Registry is intended to improve care for patients across the UK, and the importance of involving the patients and patient advocates in Registry planning, management and oversight cannot be overstated.

The Registry Steering Committee includes roles for representatives from patient charities, and a (currently vacant) role for a patient representative with firsthand experience living with ILD. These volunteers give their time generously, and they have an enormous impact on the Registry.

Patient perspective at BTS

The patient perspective is embedded not only in the UK ILD Registry, but across the whole of BTS.

The BTS Board includes a lay trustee, and lay volunteers were involved in developing the Registry.

SarcoidosisUK is pleased to support the BTS ILD Registry and bring patient voices to the Steering Group. Sarcoidosis remains a rare disease, with poor awareness, and we recognise the importance of the Registry in providing healthcare metrics to improve patient outcomes.

Data is becoming increasingly important to the research community, and we believe the Registry is an essential tool as efforts continue to understand the causes of sarcoidosis and work towards finding a cure.

Graham Bloye
Senior Executive, SarcoidosisUK

The BTS UK ILD Registry is a catalyst for change—turning individual experiences into the collective knowledge we need to drive progress. For too long, gaps in access, limited treatment options, and inconsistent care have held patients back. With better data, we can accelerate breakthroughs, improve services, and ensure every patient receives the care they deserve."

Dr Clare Hodkinson
PF patient and Action for Pulmonary Fibrosis Research Funding & Impact Manager

Holistic care is crucial for patients, since living with ILD can affect so many aspects of their lives. Services such as helplines and support groups provide a vital community for patients and caregivers not only to receive advice but also to share experiences, coping strategies and emotional burdens.

The UK ILD Registry includes a question designed to gather information on what other services patients are signposted to, be they medical services (e.g. mental health) or other services. Healthcare professionals are encouraged to inform patients of the wide variety of both medical and non-medical services which are available to them.

How many patients were signposted to other services at presentation in 2024?

44%	44%	22%	38%	62%	17%	21%
Helplines	Support groups	Mental health services	Charities	Other	None	Unknown

PART 3 – BENCHMARKING

Centres can benchmark their services against a set of agreed standards or against the performance of similar services. Benchmarking figures included here for 2024 relate only to cases where the first clinic visit was in 2024, they do not include earlier cases added retrospectively during 2024.

3.1 NHSE ILD QUALITY DASHBOARD METRICS

NHS England (NHSE) commissions certain ILD centres in England to provide services where antifibrotic medication can be prescribed to patients with ILD. These centres are required to submit key metrics to the NHSE ILD Quality Dashboard, using IPF as a surrogate marker for the wider ILD service.

All centres which participate in the Registry – regardless of whether or not they are English prescribing centres – can view their performance against the dashboard items through the user-downloadable *NHSE ILD QD* report. The report collates data for items one to six below, while items seven to nine (in red) are site-wide responses collated outside the Registry.

NHSE ILD Quality Dashboard Metrics

1 IPF referral discussed at ILD MDT
2 IPF patients offered or received ILD Specialist Nurse input
3 IPF patients assessed for pulmonary rehabilitation needs
4 IPF patients assessed for their palliative care needs
5 IPF referral waiting times
6 IPF patients assessed for their oxygen needs
7 UK IPF Registry completion
8 New incident IPF cases
9 Clinical trial activity (a Y/N answer per site)

This annual report details the first six elements of benchmarking from the NHSE ILD Quality Dashboard, linking them directly back to the NICE Quality Standard for IPF [1]. This Quality Standard identifies five Quality Statements, which are high priority areas for quality improvement

While these dashboard metrics broadly align with the Quality Statements they have some differences. A short description of each metric is given on the following page, along with an explanation of how it differs from the Quality Statements for IPF.

	NHSE ILD Quality Dashboard Items Sites may download data for items 1 to 6 through the Registry site.		**NICE IPF Quality Statements** From the NHSE Quality Standard for IPF in adults.	**Differences**
❶	**IPF referrals discussed at ILD MDT** *Percentage of new IPF referrals discussed at ILD MDT within 2 months of first assessment in the specialised service.*	❶	People are diagnosed with IPF only with the consensus of a multidisciplinary team (MDT) with expertise in interstitial lung disease.	The dashboard item fully aligns with the Quality Statement. The dashboard item specifies 'within 2 months of first assessment' to accommodate services which hold the diagnostic MDT after the first clinic visit.
❷	**IPF patients offered or received ILD Specialist Nurse input** *Percentage of new IPF referrals who were offered or received ILD Specialist Nurse input within 2 weeks of first attendance in the service.*	❷	People with IPF have an interstitial lung disease specialist nurse available to them.	The dashboard item relates to availability of a specialist nurse at presentation, whereas the Quality Statement is intended to ensure the availability of a specialist nurse at all stages of the care pathway.
❸	**IPF patients assessed for pulmonary rehabilitation needs** *Percentage of new patients with IPF assessed for their pulmonary rehabilitation needs.*	❹	Pulmonary rehabilitation (PR) programmes provide services that are designed specifically for IPF.	The dashboard asks whether PR needs have been assessed, which is something hospitals can control and monitor. The Quality Statement covers the design of PR programmes, which hospitals cannot control or monitor.
❹	**IPF patients assessed for their palliative care needs** *Percentage of new patients with IPF assessed for palliative care needs.*	❺	People with IPF and their families and carers have access to services that meet their palliative care needs.	The dashboard asks whether palliative care needs have been assessed (easy to measure). This differs from the Quality Statement, which promotes that patients, families and carers have their needs met (difficult to measure).
❺	**IPF referral waiting times** *Average wat for new IPF referrals to be seen in the specialist ILD clinic from the date the referral letter was received at the centre.*			
❻	**IPF patients assessed for their oxygen needs** *Percentage of new patients with IPF who have had their oxygen needs assessed (both long term and ambulatory oxygen).*	❸	Patients with IPF have an assessment for home and ambulatory oxygen therapy at each follow-up appointment and before they leave hospital following an exacerbation of the disease.	The dashboard item refers to patients with IPF who have their oxygen needs assessed and managed at **presentation**. The Quality Statement relates specifically to assessment for oxygen needs at **follow-up** visits.
❼	**UK IPF Registry completion** *Of those in the denominator [new incident IPF cases], the number of patients whose clinical information dataset has been included in the UK IPF Registry.*			
❽	**New incident IPF cases** *The number of new IPF cases which came to clinic in the reporting period.*			
❾	**Clinical trial activity** *Have you actively recruited patients to an ILD clinical trial in the last 6 months? Yes/No (answered once per site, not per patient).*			

3.2 WAIT TIMES

Wait times for IPF cases in 2024

The NHSE ILD Quality Dashboard – which focuses on IPF as a surrogate marker for the wider ILD service – suggests that patients be seen in clinic within eight weeks (54 days) of referral, due to the cancer-like outcomes experienced by those with IPF.

IPF wait times in 2024

Across all centres the mean time from referral to presentation was **132 days**, with **38%** experiencing symptoms for >24m before their first visit to the hospital ILD clinic.

English prescribing

Mean wait:
131 days

38%
symptoms >24m

Devolved nations

Mean wait:
Too few records to report

<5 cases, so cannot report
symptoms >24m

English non-prescribing

Mean wait:
89 days

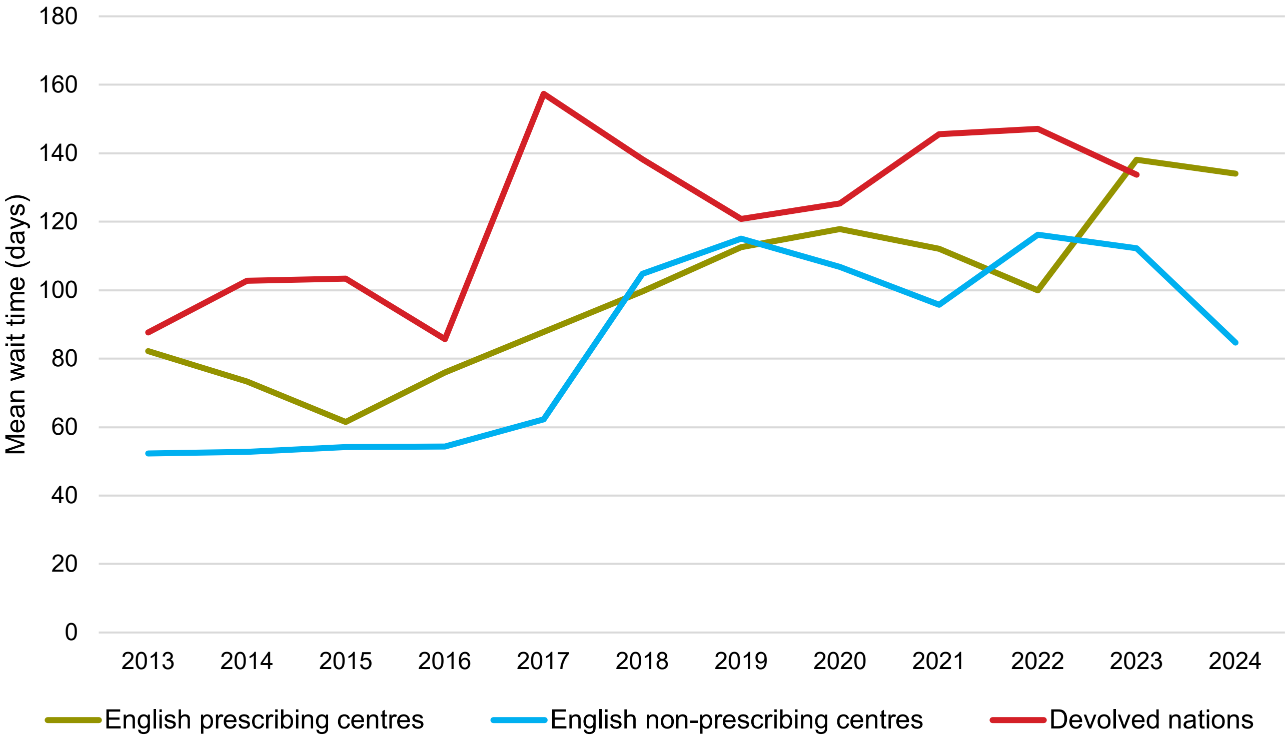
13%
symptoms >24m

Changes to wait times over the lifetime of the Registry for all ILDs

There has been a gradual increase in mean wait from referral to presentation over the lifetime of the Registry for all ILDs. However, large standard deviations indicate that wait times varied significantly within each year.

	2013 – 2024		**2024 only**	
	Wait time (days)	Standard deviation	Wait time (days)	Standard deviation
All centres	109.3	± *111.0*	133.8	± *107.4*
English prescribing	109.7	± *109.4*	134.1	± *105.1*
English non-prescribing	90.6	± *117.9*	84.7	± *66.8*
Devolved nations	134.1	± *132.5*	Too few records entered to provide data	

Mean hospital wait times over the lifetime of the Registry (both IPF and non-IPF ILD)



How can clinicians identify their hospital's wait time?

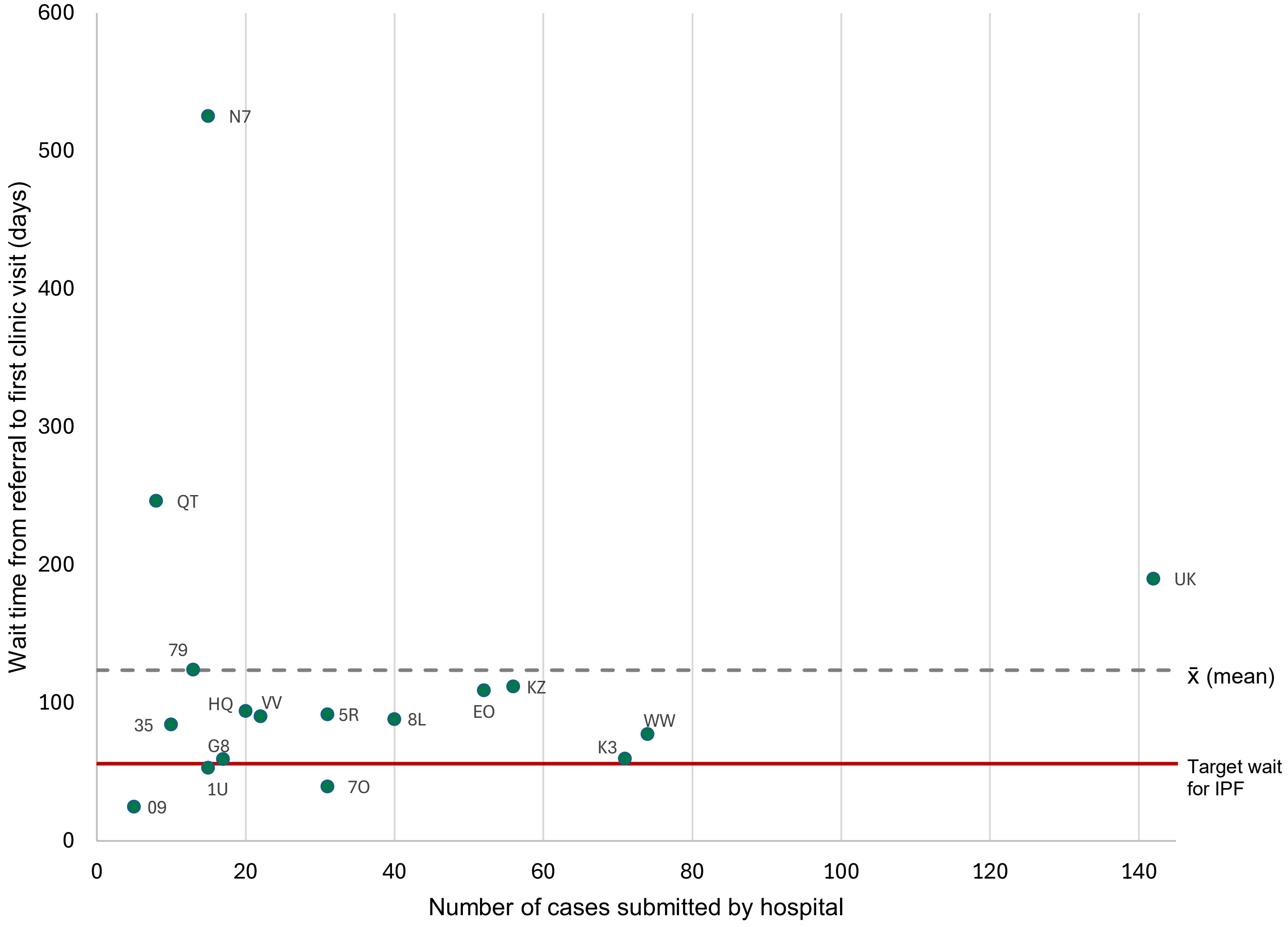
If you are a clinician whose hospital participates in the UK ILD Registry, you can find out the mean wait time for IPF cases – for any period you choose – by downloading the *NHSE ILD Quality Dashboard Data* report from the *Reports/Statistics tab*. This report is available to all sites across the UK.

Wait times at individual hospitals in 2024

For the first time since its launch, the UK ILD Registry is reporting against key benchmarking metrics by publishing anonymised site-level data. Scatter plots are presented in this section showing performance of individual sites against the number of cases submitted. Each of these charts indicates both the mean performance of all sites (x̄) and the target performance.

Wait times are shown below for 17 centres only, as only 17 centres had submitted data for five or more patients seen during 2024. Only five centres were in line with the target wait time of 54 days (centres 09, 1U, G8, 7O and K3), meaning more than two thirds of the centres shown here were not meeting the target wait times. Survival time is strongly linked to the speed with which patients are prescribed appropriate treatments, so the wait times highlighted here are clearly suboptimal. Patients who are not directly referred from primary care to a prescribing centre will also be subject to the additional delay of undergoing two referrals, firstly from primary care and secondly from non-prescribing secondary care.

Wait times for individual centres in 2024 (both IPF and non-IPF ILD)
Hospitals with under 5 cases are not shown in the chart. Not all sites entered data.



How can clinicians identify their hospital ID?

If you are a clinician who participates in the Registry, your anonymised hospital ID is shown when you log into the UK ILD Registry site.

3.3 NICE QUALITY STANDARD FOR IPF

The National Institute for Health and Care Excellence (NICE) published a Quality Standard for IPF in 2015 [1]. This document highlighted five Quality Statements – detailed below – considered to be key markers of effective patient care and service provision. NICE provides evidence-based guidance to support health and social care in England and Wales; however, the information can still be relevant and useful for services in Scotland and Northern Ireland.

The UK ILD Registry holds data relating to these statements, making it possible for participating sites to benchmark their services against these agreed standards.

1. **People are diagnosed with IPF only with the consensus of a multidisciplinary team (MDT) with expertise in interstitial lung disease.**
2. **People with IPF have an interstitial lung disease specialist nurse available to them.**
3. **Patients with IPF have an assessment for home and ambulatory oxygen therapy at each follow-up appointment and before they leave hospital following an exacerbation of the disease.**
4. **Pulmonary rehabilitation (PR) programmes provide services that are designed specifically for IPF.**
5. **People with IPF and their families and carers have access to services that meet their palliative care needs.**

How can clinicians find out how their hospital performs against these standards?

UK ILD Registry questions do not always fully align with the Quality Statements. The following pages explain what the relevant Registry questions are and how they differ. Through the *Reports and Statistics* page on the Registry site you can view the following information for these standards for any period you choose:

- Your hospital against all sites nationally for **all cases** (*Institution v National* report).
- Your hospital against other sites of the same type nationally for **all cases** (*Institution v Similar Sites* report)

The following pages include anonymised hospital-level data. If you are a clinician participating in the Registry, your anonymised hospital ID is shown when you log into the UK ILD Registry site. Your hospital's raw data are also available through the *Data Export* page on the Registry site. When reviewing these figures please remember not all sites will have entered data.

IPF Quality Statement 1: People are diagnosed with IPF only with the consensus of a multidisciplinary team (MDT) with expertise in interstitial lung disease.

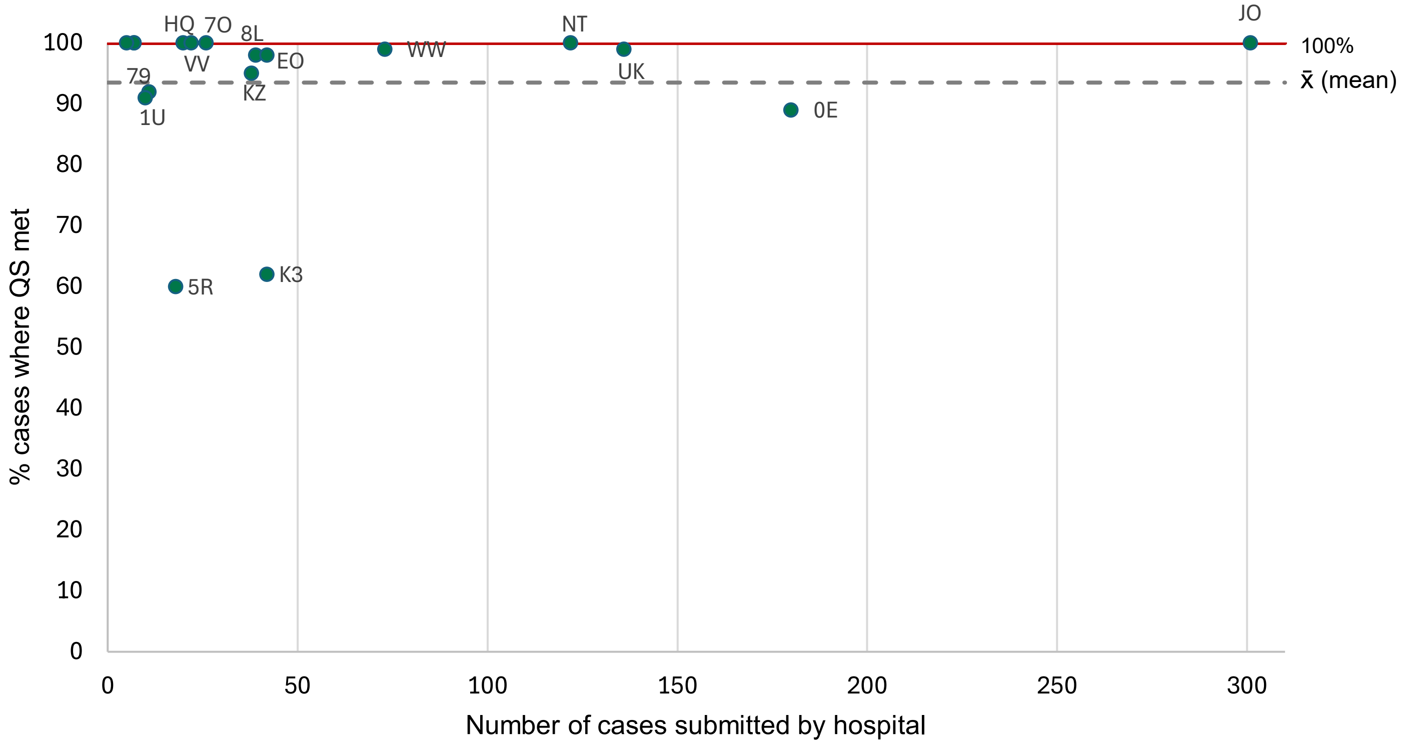
UK ILD Registry question: At first clinic visit the Registry asks if the patient's case was discussed at a multidisciplinary team meeting as part of the diagnosis. This quality statement is considered to be met when the response is *Yes*.

How do Registry data differ from the Quality Statement?
The Registry question fully aligns with the Quality Statement. However, rather than a simple *Yes/No* response the Registry also includes the response *Awaiting MDT*.

What might affect a hospital's performance?
Some hospitals hold their MDT *after* the first clinic visit, using information obtained during that visit to support the discussion. These hospitals would be acting in line with the statement but would be represented here as not meeting it. Each hospital's figures should be considered in relation to how the individual service is run.

	2013 – 2024		**2024 only**	
	IPF *(n)*	Other ILD *(n)*	IPF *(n)*	Other ILD *(n)*
All centres	93.1% *(6,104)*	92.6% *(975)*	93.6% *(880)*	94.7% *(232)*
English prescribing	93.6% *(5,615)*	93.1% *(904)*	93.5% *(859)*	94.5% *(222)*
English non-prescribing	90.0% *(376)*	84.9% *(62)*	100% *(19)*	100% *(10)*
Devolved nations	81.9% *(113)*	100% *(9)*	<5 cases	No data

Percentage compliance for all cases in 2024 (both IPF and non-IPF ILD)
Hospitals at 100% with <20 cases are not individually labelled. Hospitals with <5 cases are not shown. Only 18 hospitals entered data for five or more patients seen during 2024.



Congratulations to the hospitals which met this standard for 100% of all cases in 2024:

JO, 09, HQ, NT, 35, QT, 7O, VV

IPF Quality Statement 2: People with IPF have an interstitial lung disease specialist nurse available to them.

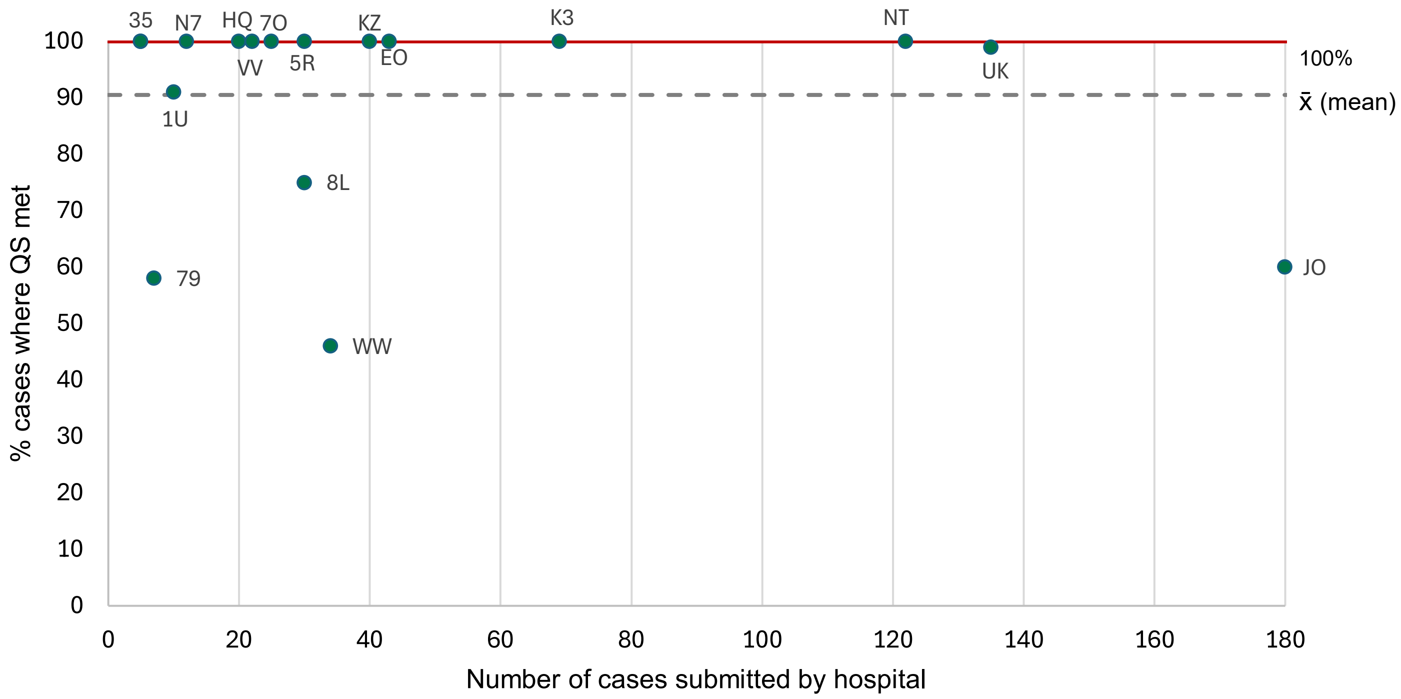
UK ILD Registry question: At first clinic visit the Registry asks whether the patient was offered interaction with an ILD specialise nurse at the time of diagnosis. This statement is considered to be met when the response is *Yes*.

How do Registry data differ from the Quality Statement?
The Registry holds data on the availability of a specialist nurse at the time of diagnosis, whereas the Quality Statement is intended to ensure the availability of a specialist nurse at all stages of the care pathway.

What might affect a hospital's performance?
Factors affecting a hospital's performance include the number of patients registered at the clinic and the resourcing available. Any increase in patient numbers resulting from the lung cancer screening programme identifying cases of ILD is likely to have an impact on nurse availability.

	2013 – 2024		**2024 only**	
	IPF *(n)*	Other ILD *(n)*	IPF *(n)*	Other ILD *(n)*
All centres	90.6% *(3,936)*	72.3% *(701)*	89.2% *(839)*	67.5% *(162)*
English prescribing	91.0% *(3,598)*	71.8% *(637)*	89.0% *(819)*	66.5% *(153)*
English non-prescribing	92.1% *(257)*	80.8% *(59)*	100% *(19)*	90.0% *(9)*
Devolved nations	70.4% *(81)*	55.6% *(5)*	<5 cases	No data

Percentage compliance for all cases in 2024 (both IPF and non-IPF ILD)
Hospitals with <5 cases are not shown.
Only 18 hospitals entered data for five or more patients seen during 2024.



Congratulations to the hospitals which met this standard for 100% of all cases in 2024:

5R, EO, 35, KZ, N7, NT, 7O, K3, 09, VV, 0E, HQ

IPF Quality Statement 3: Patients with IPF have an assessment for home and ambulatory oxygen therapy at each follow-up appointment and before they leave hospital following an exacerbation of the disease.

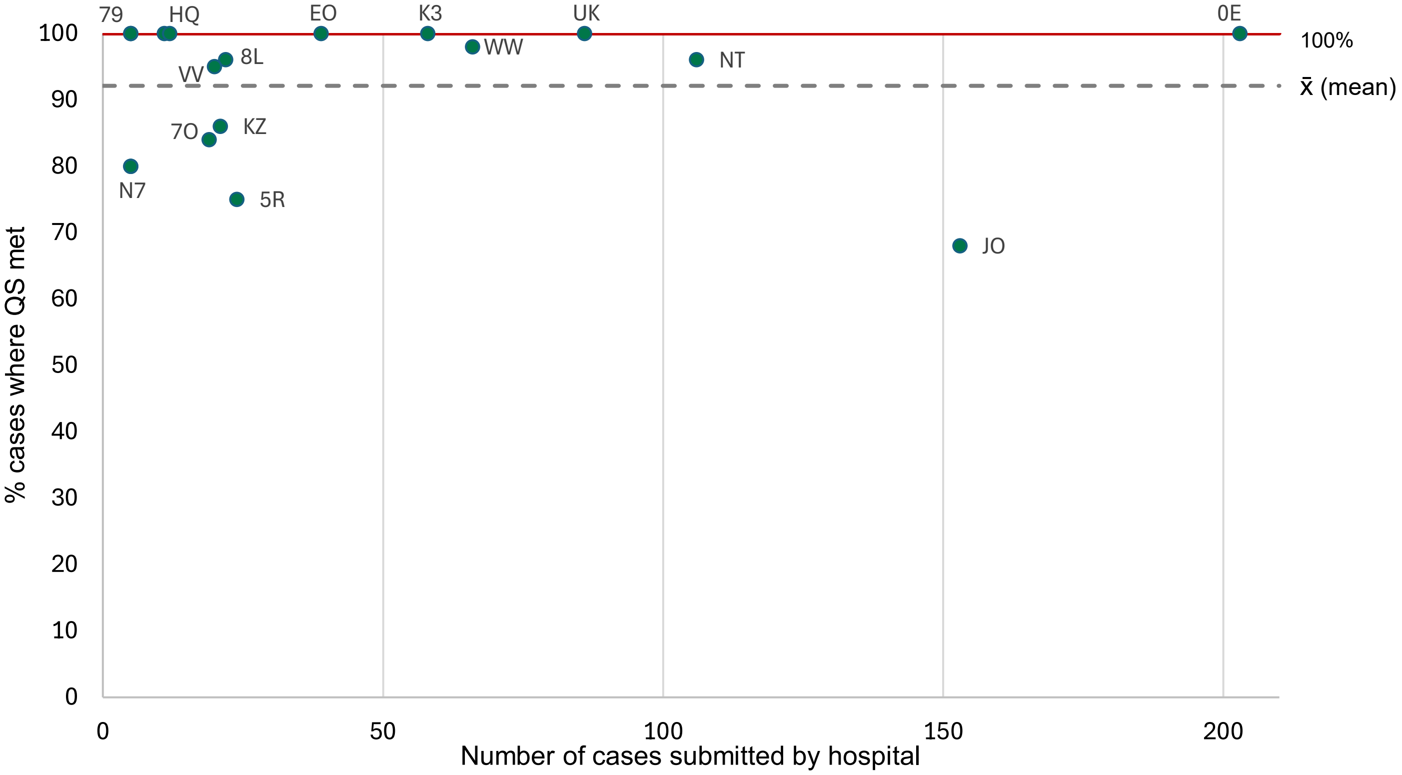
UK ILD Registry question: Patients with IPF have an assessment for home and ambulatory oxygen therapy at each follow-up appointment and before they leave hospital following an exacerbation of the disease.

How do Registry data differ from the Quality Statement?
The Registry question covers assessment for any oxygen therapy at follow up clinic visits (including ambulatory and home oxygen) but does not cover assessments made during separate hospital stays for an exacerbation of the disease.

What might affect a hospital's performance?
Factors affecting a hospital's performance include the number of patients registered at the clinic and the resourcing available. Additionally, as not all patients in the Registry have follow-up information entered, the cohort included in this analysis is smaller than for the other statements.

	2013 – 2024		**2024 only**	
	IPF *(n)*	Other ILD *(n)*	IPF *(n)*	Other ILD *(n)*
All centres	87.9% *(3,884)*	83.0% *(824)*	91.9% *(867)*	83.4% *(193)*
English prescribing	87.6% *(3,523)*	82.8% *(738)*	91.7% *(846)*	83.1% *(183)*
English non-prescribing	88.3% *(247)*	84.0% *(75)*	100% *(19)*	90% *(10)*
Devolved nations	94.7% *(114)*	*90.9 (11)*	*<5 cases*	No data

Percentage compliance for all cases in 2024 (both IPF and non-IPF ILD)
Hospitals at 100% with <20 cases are not individually labelled. Hospitals with <5 cases are not shown. Only 18 hospitals entered data for five or more patients seen during 2024.



Congratulations to the hospitals which met this standard for 100% of all cases in 2024:

HQ, 79, K3, 1U, 0E, UK, 09, EO

IPF Quality Statement 4: Pulmonary rehabilitation (PR) programmes provide services that are designed specifically for IPF.

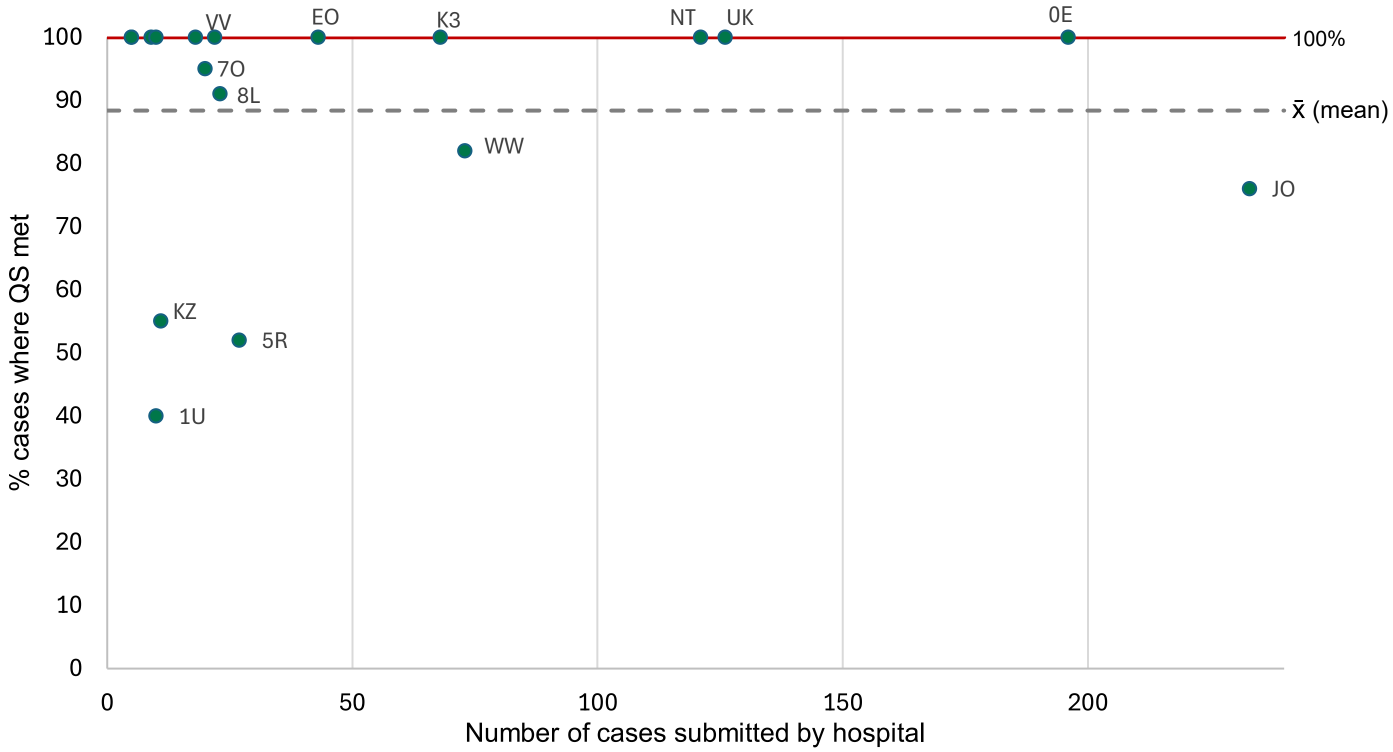
UK ILD Registry question: The Registry asks whether an assessment for PR needs was carried out at first clinic visit and at follow-up. This statement is considered to be met when the response at first clinic visit starts with *Yes*.

How do Registry data differ from the Quality Statement?
Yes – significantly. The UK ILD Registry does not hold data on whether PR programmes provide services designed specifically for patients with IPF. Instead, the Registry determines whether PR needs have been considered and assessed, focusing here on assessment at presentation.

What might affect a hospital's performance?
Factors affecting a hospital's performance include the number of patients registered at the clinic and the resourcing available within the clinic. Crucially, this assessment of PR needs does not guarantee the patient will have access to PR locally, as currently the Registry does no hold information on related services such as PR.

	2013 – 2024		**2024 only**	
	IPF *(n)*	Other ILD *(n)*	IPF *(n)*	Other ILD *(n)*
All centres	88.8% *(4,512)*	70.1% *(863)*	92.8% *(843)*	81.2% *(186)*
English prescribing	89.3% *(4,084)*	82.6% *(642)*	92.6% *(823)*	80.8% *(177)*
English non-prescribing	82.1% *(319)*	29.9% *(201)*	100% *(18)*	88.9% *(9)*
Devolved nations	89.9% *(109)*	75.0% *(20)*	<5 cases	No data

Percentage compliance for all cases in 2024 (both IPF and non-IPF ILD)
Hospitals at 100% with <20 cases are not individually labelled. Hospitals with <5 cases are not shown. Only 18 hospitals entered data for five or more patients seen during 2024.



Congratulations to the hospitals which met this standard for 100% of all cases in 2024:

VV, N7, K3, HQ, 09, UK, NT, 35, 79, EO, 0E

IPF Quality Statement 5: People with IPF and their families and carers have access to services that meet their palliative care needs.

UK ILD Registry question: The Registry asks whether an assessment for palliative needs was carried out at first clinic visit and at follow-up. This statement is considered to be met when the response at first clinic visit is *Yes*.

How do Registry data differ from the Quality Statement?

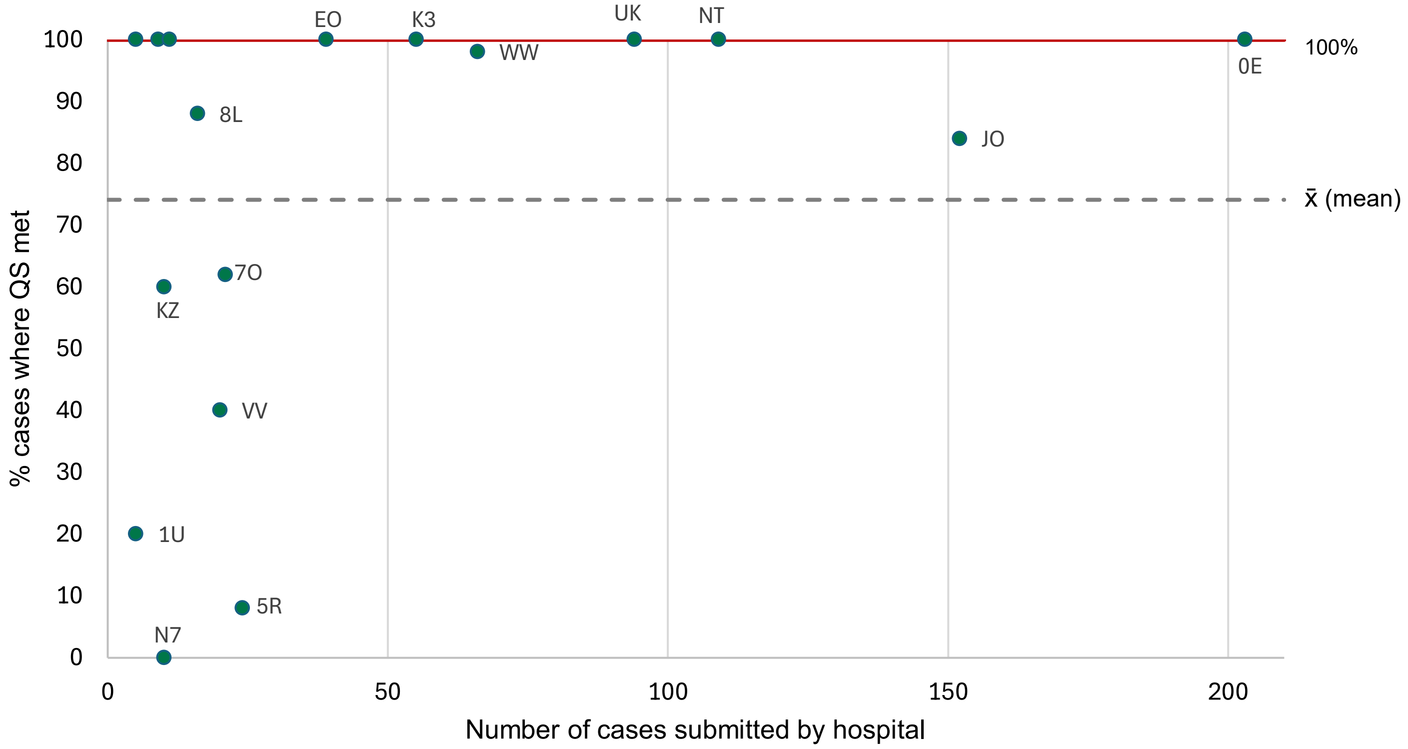
Yes – significantly. The Registry question asks a broad question about assessment of patient needs, whereas the statement asks if the needs of the patient, their family and their carers have been met. In February 2023 a new question was added to the Registry to seek more granularity around what kind of palliative care has been considered and addressed (e.g. advanced care planning, non-pharmacological interventions, spiritual and psychosocial needs, etc.).

What might affect a hospital's performance?

Factors affecting a hospital's performance include the number of patients registered at the clinic and the resourcing available.

	2013 – 2024		**2024 only**	
	IPF *(n)*	Other ILD *(n)*	IPF *(n)*	Other ILD *(n)*
All centres	77.6% *(4,854)*	68.5% *(696)*	89.6% *(854)*	79.2% *(183)*
English prescribing	77.6% *(4,439)*	68.4% *(624)*	89.4% *(836)*	79.0% *(176)*
English non-prescribing	79.2% *(307)*	75.4% *(65)*	100% *(16)*	85.7% *(7)*
Devolved nations	74.1% *(108)*	14.3% *(7)*	<5 cases	No data

Percentage compliance for all cases in 2024 (both IPF and non-IPF ILD)
Hospitals at 100% with <20 cases are not individually labelled. Hospitals with <5 cases are not shown. Only 18 hospitals entered data for five or more patients seen during 2024.



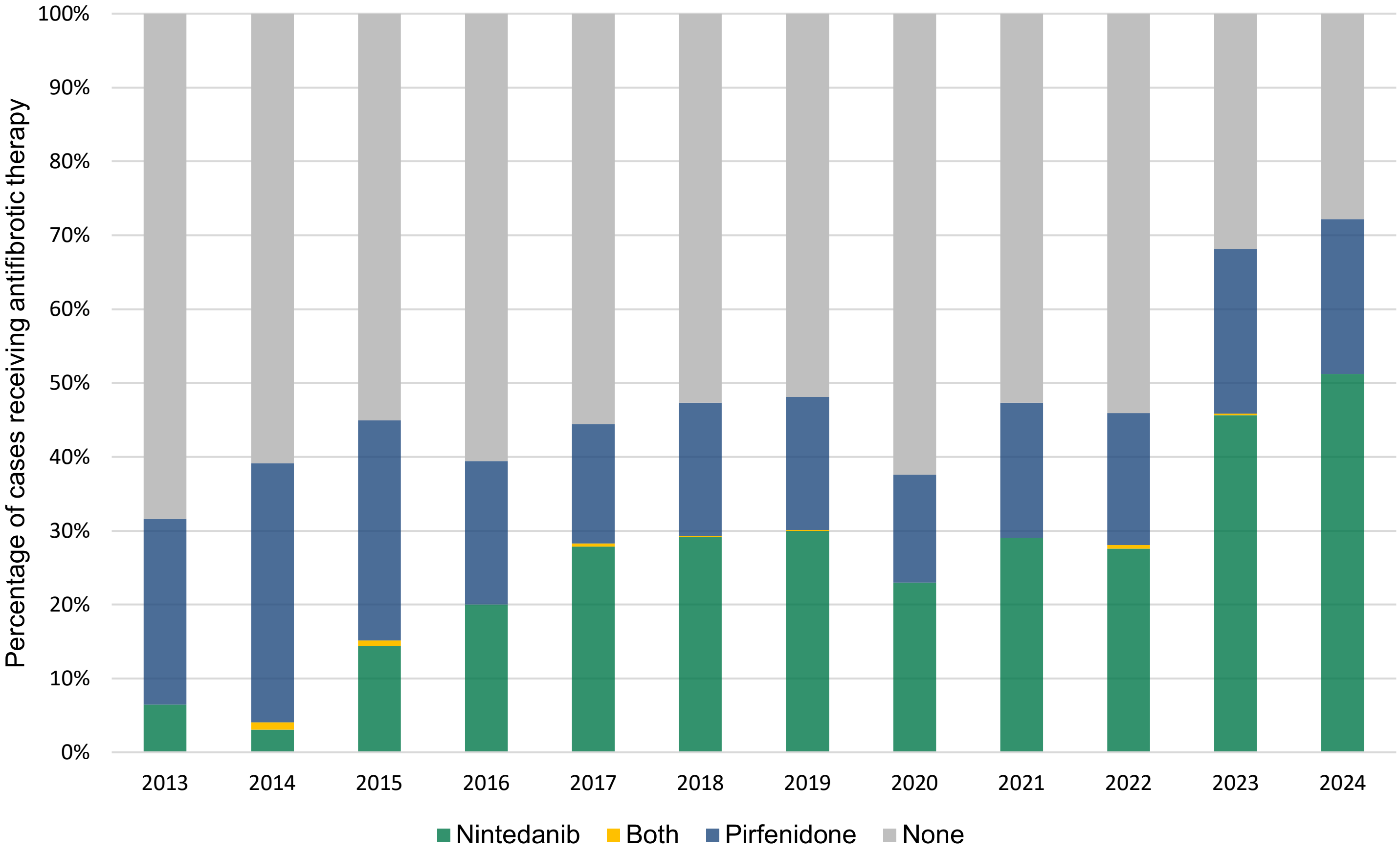
Congratulations to the hospitals which met this standard for 100% of all cases in 2024:

EO, UK, 09, HQ, K3, NT, 0E, 79

3.4 ANTIFIBROTIC PRESCRIPTIONS

Pirfenidone has been approved by NICE for the treatment of patients with IPF in England and Wales since April 2013 [2], and nintedanib since January 2016 [3]. In 2024, 72% of patients with IPF received antifibrotic therapy at presentation, with the recent increase in antifibrotic use potentially linked to the updated NICE guidance which permitted the use of nintedanib for those with over 80% FVC [4].

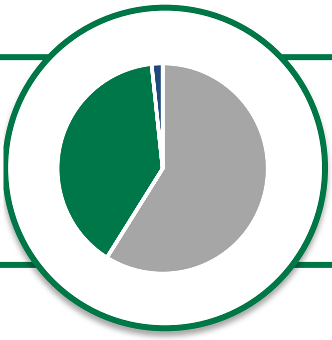
Antifibrotic use at presentation – IPF cases only



Antifibrotic use at presentation in 2013-2024 – non-IPF ILDs only

Pirfenidone
Prescribed in 1.7% of cases.

Nintedanib
Prescribed in 39.5% of cases.



None
In 58.9% of cases no antifibrotic therapy was prescribed at presentation..

How can clinicians find out about antifibrotic use at their hospital?

If you are a clinician who participates in the Registry, you can view details about your hospital’s antifibrotic use – for any period you choose – by downloading the *Institution v National* or *Institution v Similar Sites* reports from the *Reports/Statistics tab*.

PART 4 – RESEARCH AND CLINICAL TRIALS

Research is essential to improving understanding of the epidemiology and progression of ILDs, as well as identifying and describing the impact of treatments and service provision on patient outcomes. Research is the ultimate tool through which patient wellbeing, care and outcomes are improved.

4.1 ACCESSING NATIONAL REGISTRY DATA

The BTS Data Access Request Process was launched in 2020. Through this process, organisations may apply to access data for the purpose of research.

All UK ILD Registry data are available from the full lifetime of the Registry (from January 2013 onwards). Applications are made directly to BTS and reviewed by the BTS Quality Improvement Committee (QIC). To date 14 applications have been approved.

Data access at BTS

The UK ILD Registry is not the only BTS dataset researchers can apply to access.

Data from the MDR-TB Clinical Advice Service are available, as are data from all clinical audits conducted from 2018.

The number of records currently available is:

- 10,358 demographic records (7,876 of which are for IPF)
- 8,407 clinical information records (6,700 of which are for IPF)
- 5,138 follow-up records, representing 2,153 unique patients (4,499 of which are for IPF, representing 1,842 patients)

A brief overview of the BTS Data Access Request Process is shown below, from initial application through to eventual data destruction. Full policies and documents relating to this process can be found at: https://www.brit-thoracic.org.uk/quality-improvement/bts-clinical-data-policy-and-data-access/

Application

Download and complete the application form.

If you are not sure if the Registry has enough patients suitable for your study, complete the short scoping form to find out.

Review and Outcome

The completed application will be reviewed by the BTS Quality Improvement Committee (QIC).

The application may be approved, more information may be requested, or it may be rejected.

Successful Applicants

Complete a data sharing agreement and pay the data access fee (details available on the BTS website).

Encrypted data will then be securely transferred. After research has concluded, data must be destroyed, If you are interested in applying to access national UK ILD Registry data, or any other BTS dataset, please contact bts@brit-thoracic.org.uk. Successful data access requests have a small fee attached.

Recently approved data access requests are listed below. The full list of successful applications made to date is available at https://www.brit-thoracic.org.uk/quality-improvement/bts-clinical-data-policy-and-data-access/

Recent successful applications
Is lymphopenia detected in Sarcoidosis associated with the disease activity? – a retrospective analysis of the BTS Sarcoidosis Registry **– Dr Andrew Achaiah (Gloucestershire Hospitals)** *on behalf of the ILD Registry Steering Group*
Is change in FEV1:FVC ratio associated with adverse clinical outcomes in patients with Idiopathic Pulmonary Fibrosis? **– Dr Andrew Achaiah (Gloucestershire Hospitals)** *on behalf of the ILD Registry Steering Group*
Does distance from Specialist centre impact presentation, management and treatment of patients with sarcoidosis **– Dr Nazia Chaudhuri (Western HSC Trust)** *on behalf of the ILD Registry Steering Group*
Phenotyping Pulmonary Sarcoidosis with CT **– Dr Paul Minnis (Northern HSC Trust)** *on behalf of the ILD Registry Steering Group*

4.2 CLINICAL TRIALS

Clinical trials are a vital tool for improving the treatment and care available to patients, especially for ILDs known to have poor outcomes and limited treatment options. Only 13% of patients are offered involvement in clinical trials.

When patients sign up to the UK ILD Registry they are asked if they would be willing to be contacted about clinical trials for which they would potentially be suitable. BTS can pass information about clinical trials on to the sites which participate in the Registry.

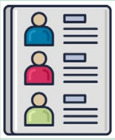
I am running a clinical trial – how can BTS help me?

BTS can circulate a message to participating clinicians on your behalf, and those clinicians can then contact you and discuss potentially offering patients the chance to be involved in your study.

Contact BTS at registry@brit-thoracic.org.uk to request your message be circulated to participating clinicians. Your request will be considered by the Chair of the BTS Quality Improvement Committee. There is no cost attached to this service.

4.3 WHAT DATA ARE INCLUDED IN THE REGISTRY?

When a patient consents to take part in the UK ILD Registry, the hospital adds more information to their Registry record each time they visit the ILD clinic. A lot more information is available in the Registry than is presented in this report.

Demographic data	**Clinical information**	**Follow up**
 Entered once, at presentation	 Entered once, at presentation	 Entered multiple times *(requested every 12 months)*
The demographic dataset includes: • Age and sex. • Ethnicity. • Diagnosis. • Referral date and date of presentation. • Family history of ILD. • Mortality data.	The clinical information and follow up datasets are almost identical. Information relating specifically to diagnosis is only collected in the clinical information dataset. Clinical data include: • Symptoms, and duration of symptoms prior to presentation. • Comorbidities, smoking status and exposure history. • Referral to other services or non-clinical support. • Height, weight and lung function tests (FEV1, FVC, TLCO, KCO). • Blood tests and biopsy results. • HRCT results (category data, not imaging data). • MDT and extra-pulmonary needs assessment. • Drug treatments, and details of antifibrotic use/adverse effects. • Lung transplantation details. • Oxygen needs assessment and oxygen use. • Pulmonary rehabilitation needs assessment and referral. • Palliative care needs assessment and referral. • ILD specialist nurse involvement. • Clinical trial involvement.	

These data are then collated at BTS, and information from across the whole of the UK is used to gain fresh insights into the epidemiology of ILD in the UK. It is also used to understand and improve service provision, and is used in ILD research to improve patient treatment and outcomes.

4.4 PUBLICATIONS

Organisations may apply to access UK ILD Registry data for the purpose of research. Details of how this process works are included on page 27.

Previous publications which have made use of Registry data include:

Publication	Journal
Fahim A, Loughenbury M, Stewart I, *et al.* (2025[5]) Idiopathic pulmonary fibrosis in the United Kingdom: Findings from the British Thoracic Society UK Idiopathic Pulmonary Fibrosis Registry	BMJ Open Respiratory Research *Journal Paper* *PMID: 39971593*
Crooks R, McCall M, Minnis P, *et al.* (2024[6]) Phenotyping pulmonary sarcoidosis with CT descriptors using BTS ILD registry data	Thorax *Conference Abstract*
Ho L-P, Loughenbury M, Casimo L, *et al.* (2024[7]) Sarcoidosis in the United Kingdom: Findings from the first decade of the UK ILD Registry	European Respiratory Journal *Conference Abstract*
Fahim A, Loughenbury M, Agnew S, *et al.* (2024[8]) Idiopathic Pulmonary Fibrosis in the United Kingdom: Findings from the first decade of the largest single-country IPF Registry	European Respiratory Journal *Conference Abstract*
Shankar R, Hadinnapola CM, Clark AB, *et al.* (2024[9]) Assessment of the impact of social deprivation, distance to hospital and time to diagnosis on survival in idiopathic pulmonary fibrosis. Respiratory medicine 227:107612.	Respiratory Medicine *Journal Paper* *PMID: 38677526*
Naftel J, Kinsella E, Wood N, Fletcher S (2023[10]) Comparison of antifibrotic availability for patients on the BTS IPF Registry using existing and new prescribing criteria	European Respiratory Journal *Conference Abstract*
Spencer L, Loughenbury M, Chaudhuri N, *et al.* (2021[11]) Idiopathic Pulmonary Fibrosis in the UK: Analysis of the British Thoracic Society Electronic Registry between 2013 and 2019.	ERJ Open Research *Journal Paper* *PMID: 33532476*
Molyneaux P, Loughenbury M, Welham S, *et al.* (2020[12]) Eligibility for antifibrotic therapy of patients in British Thoracic Society (BTS) UK IPF Registry varies according to the reference values used to calculate FVC.	European Respiratory Journal *Conference Abstract*
Thillai M, Chang W, Chaudhuri N, *et al.* (2019[13]) Sarcoidosis in the UK: insights from British Thoracic Society registry data.	BMJ Open Respiratory Research *Conference Abstract*
Spiteri M, Chang W, Chaudhuri N, *et al.* (2017[14]) First insights from the BTS idiopathic pulmonary fibrosis (IPF) Registry.	European Respiratory Journal *Conference Abstract*
Coker R, Chang W, Chaudhuri N, *et al.* (2017[15]) Sarcoidosis in the UK: Insights from the BTS interstitial lung disease registry	European Respiratory Journal *Conference Abstract*

There are 11 publications which make use of Registry data, and several more research projects underway. Publications using Registry data have been cited 60 times.

NOTES AND ACKNOWLEDGEMENTS

Registry Ethics Approval, Information Governance and Data security

Ethical approval for the British Thoracic Society Interstitial Lung Disease Registry Programme (22/EE/0235) has been granted by the NRES Committee East of England. It was first granted in October 2012, then renewed in October 2017 and again in November 2022. Patient consent must be obtained before any patient information is entered into the BTS ILD Registry. Information for patients and copies of consent forms are available on the BTS website at:
https://www.brit-thoracic.org.uk/quality-improvement/lung-disease-registries/bts-ild-registry/.

Participating centres are required to confirm their Caldicott Guardian has approved their participation in the Lung Disease Registry before they can enter data.

All patient identifiable data (e.g. name, date of birth, postcode) are encrypted at the point of entry. Therefore, identifiable data can only be accessed by the hospital team directly responsible for caring for the patient. No patient identifiable data are available to BTS ILD Registry administrators. The British Thoracic Society Information Governance Policy and associated data security policy documents are available on the BTS website at:
https://www.brit-thoracic.org.uk/about-us/governance-documents-and-policies/

Notes on data and percentages/denominators

Throughout this report figures are displayed as percentages and as exact figures (of the format *numerator/denominator*). Where figures are presented in the form *numerator/denominator* the denominator may vary for a number of reasons.

When reading this report please be aware that:

- Denominators in this report always exclude cases where no response was entered;
- Unless otherwise stated, denominators in this report exclude cases where the saved response was ‘not known’ or ‘not recorded’; and
- Percentage figures are rounded to the nearest whole number throughout this report. This means rounding errors may lead to some total percentages adding up to 99% or 101%.

Acknowledgements

The BTS Lung Disease Registry Programme is funded by the British Thoracic Society. A grant (2012-2014) from the Healthcare Quality Improvement Partnership (HQIP) contributed to the initial development of the Interstitial Lung Disease Registry and this support is gratefully acknowledged.

The Society is grateful for financial assistance provided from Boehringer Ingelheim and InterMune for the enhancement of the data collection software (2014).

The Society would like to thank the clinicians, nursing staff and administrative staff who diligently consented patients, collated information and submitted data to the Registry. Our sincerest thanks to all the patients who have kindly consented to take part in the Registry – none of this work would be possible without their support.

The BTS Interstitial Lung Disease Registry is supported by:

Action for Pulmonary Fibrosis – www.actionpf.org/

SarcoidosisUK – www.sarcoidosisuk.org

BTS Lung Disease Registry Steering Group Membership 2024/5:

Dr Nazia Chaudhuri	Chair
Dr Andrew Achaiah	Trainee Respiratory Physician Representative
Mr Graham Bloye	SarcoidosisUK
Dr Felix Chua	Consultant Respiratory Physician
Dr Giles Dixon	Trainee Respiratory Physician Representative
Dr Sophie Fletcher	Consultant Respiratory Physician
Dr Richard Hewitt	Consultant Respiratory Physician
Dr Clare Hodkinson	Action for Pulmonary Fibrosis
Dr Fasihul Khan	Consultant Respiratory Physician
Dr Paul Minnis	Consultant Respiratory Physician
Miss Helen Morris	Nurse Representative
Ms Marium Naqvi	Pharmacist
Dr Evelyn Palmer	Trainee Respiratory Physician Representative
Dr Iain Stewart	Volunteer Member
Dr Gavin Thomas	Consultant Respiratory Physician
Miss Sally Welham	BTS Chief Executive
Mr Miguel Souto	BTS Head of Clinical Programmes
Miss Maria Loughenbury	BTS Lung Disease Registry Manager

PARTICIPATING SITES

The following organisations participate in the BTS Interstitial Lung Disease Registry – our thanks to all involved:

England

Addenbrooke's Hospital, Cambridge University Hospitals NHS Foundation Trust
Aintree University Hospital, University Hospitals of Liverpool Group
Blackpool Victoria Hospital, Blackpool Teaching Hospitals NHS Foundation Trust
Burnley General Teaching Hospital, East Lancashire Hospitals NHS Trust
Castle Hill Hospital, Hull University Teaching Hospitals NHS Trust
Central Middlesex Hospital, London North West University Healthcare NHS Trust
Charing Cross Hospital, Imperial College Healthcare NHS Trust
Cheltenham General Hospital, Gloucestershire Hospitals NHS Foundation Trust
Chorley and South Ribble Hospital, Lancashire Teaching Hospitals NHS Foundation Trust
Churchill Hospital, Oxford University Hospitals NHS Foundation Trust
Countess of Chester Hospital, Countess of Chester Hospital NHS Foundation Trust
Croydon University Hospital, Croydon Health Services NHS Trust
Darlington Memorial Hospital, County Durham and Darlington NHS Foundation Trust
Doncaster Royal Infirmary, Doncaster and Bassetlaw Teaching Hospital NHS Foundation Trust
Ealing Hospital, London North West University Healthcare NHS Trust
George Eliot Hospital, George Eliot Hospital NHS Trust
Glenfield Hospital, University Hospitals of Leicester NHS Trust
Gloucestershire Royal Hospital, Gloucestershire Hospitals NHS Foundation Trust
Good Hope Hospital, University Hospitals Birmingham NHS Foundation Trust
Guy’s Hospital, Guy’s and St Thomas’ NHS Foundation Trust
Hammersmith Hospital, Imperial College Healthcare NHS Trust
Harrogate District Hospital, Harrogate and District NHS Foundation Trust
Heartlands Hospital, University Hospitals Birmingham NHS Foundation Trust
Hexham General Hospital, Northumbria Healthcare NHS Foundation Trust
Hinchingbrooke Hospital, North West Anglia NHS Foundation Trust
King's College Hospital, King’s College Hospital NHS Foundation Trust
King’s Mill Hospital, Sherwood Forest Hospitals NHS Foundation Trust
Kingston Hospital, Kingston and Richmond NHS Foundation Trust
Lister Hospital, East and North Hertfordshire NHS Trust
Liverpool Heart and Chest Hospital, Liverpool Heart and Chest Hospital NHS Foundation Trust
Medway Maritime Hospital, Medway NHS Foundation Trust
Midland Metropolitan Hospital, Sandwell and West Birmingham NHS Trust
Musgrove Park Hospital, Somerset NHS Foundation Trust
New Cross Hospital, The Royal Wolverhampton NHS Trust
Norfolk and Norwich University Hospital, Norfolk & Norwich University Hospitals NHS Foundation Trust
North Devon District Hospital, Royal Devon University Healthcare NHS Trust
Northern General Hospital, Sheffield Teaching Hospitals NHS Foundation Trust
North Middlesex University Hospital, Royal Free London NHS Foundation Trust
North Tyneside General Hospital, Northumbria Healthcare NHS Foundation Trust
Northwick Park Hospital, London North West University Healthcare NHS Trust
Nottingham City Hospital, Nottingham University Hospitals NHS Trust
Royal Papworth Hospital, Royal Papworth Hospital NHS Foundation Trust
Peterborough City Hospital, North West Anglia NHS Foundation Trust
Queen Alexandra Hospital, Portsmouth Hospitals University NHS Trust
Queen Elizabeth Hospital, University Hospitals Birmingham NHS Foundation Trust
Queen Elizabeth Hospital, Gateshead Health NHS Foundation Trust
Royal Blackburn Teaching Hospital, East Lancashire Hospitals NHS Trust
Royal Brompton Hospital, Guy’s and St Thomas’ NHS Foundation Trust
Royal Derby Hospital, University Hospitals of Derby & Burton NHS Foundation Trust
Royal Devon and Exeter Hospital, Royal Devon University Healthcare NHS Foundation Trust
Royal Free Hospital, Royal Free London NHS Foundation Trust
Royal Lancaster Infirmary, University Hospitals of Morecambe Bay NHS Foundation Trust
Royal Preston Hospital, Lancashire Teaching Hospitals NHS Foundation Trust
Royal Stoke University Hospital, University Hospitals of North Midlands NHS Trust

Royal Victoria Infirmary, Newcastle Hospitals NHS Foundation Trust
Russells Hall Hospital, The Dudley Group NHS Foundation Trust
Solihull Hospital, University Hospitals Birmingham NHS Foundation Trust
Southampton General Hospital, University Hospital Southampton NHS Foundation Trust
Southmead Hospital, North Bristol NHS Trust
St Bartholomew’s Hospital, Barts Health NHS Trust
St James' University Hospital, The Leeds Teaching Hospitals NHS Trust
St Mary's Hospital, Imperial College Healthcare NHS Trust
Torbay Hospital, Torbay and South Devon NHS Foundation Trust
University College Hospital, University College London Hospitals NHS Foundation Trust
University Hospital, University Hospitals Coventry & Warwickshire NHS Trust
University Hospital of North Tees, North Tees & Hartlepool NHS Foundation Trust
Wansbeck Hospital, Northumbria Healthcare NHS Foundation Trust
Whiston Hospital, Mersey and West Lancashire Teaching Hospitals NHS Trust
Worcester Royal Hospital, Worcestershire Acute Hospitals NHS Trust
Wythenshawe Hospital, Manchester University NHS Foundation Trust

Scotland

Aberdeen Royal Infirmary, NHS Grampian
Forth Valley Royal Hospital, NHS Forth Valley
Glasgow Royal Infirmary, NHS Greater Glasgow and Clyde
Lorn & Islands Hospital, NHS Highland
University Hospital Monklands, NHS Lanarkshire
Ninewells Hospital, NHS Tayside
Perth Royal Infirmary, NHS Tayside
Royal Alexandra Hospital, NHS Greater Glasgow and Clyde
Vale of Leven District Hospital, NHS Greater Glasgow and Clyde

Wales

Glan Clwyd Hospital, Betsi Cadwaladr University Health Board
Morriston Hospital, Swansea Bay University Health Board
University Hospital Llandough, Cardiff and Vale University Health Board
Wrexham Maelor Hospital, Betsi Cadwaladr University Health Board

Northern Ireland

Altnagelvin Area Hospital, Western Health and Social Care Trust
Antrim Area Hospital, Northern Health and Social Care Trust
South West Acute Hospital, Western Health and Social Care Trust
The Ulster Hospital, South Eastern Health and Social Care Trust

If you would like to know more about the BTS UK Interstitial Lung Disease Registry please visit the BTS website at:
https://www.brit-thoracic.org.uk/quality-improvement/lung-disease-registries/bts-ild-registry/

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Appendix 1:

Healthcare Quality Improvement Action Plan 2025

ILD Healthcare Quality Improvement Action Plan 2025
Actions for healthcare teams to take to improve lung health for patients with ILD

Introduction

Interstitial Lung Disease (ILD) is a broad term for a group of more than 200 disorders that cause inflammation and scarring (fibrosis) of the lung tissue, making it difficult to breathe. Diagnosis and management require specialist care, and early detection/diagnosis and access to evidence-based care are essential.

ILD care presents a complex clinical landscape, with a range of different centres dealing with a broad spread of diseases with varying aetiology and progression. The multidisciplinary nature of ILD care, combined with the additional healthcare and emotional needs experienced by patients, means there are many potential actions which could impact health and wellbeing.

Healthcare Quality Improvement Actions

There are innumerable potential actions which can be undertaken by healthcare teams, researchers, patient charities and patients to achieve better lung health for those with ILD. The driver diagram and descriptions over the next two pages show a total of twenty actions which can be undertaken by the whole ILD community working collaboratively and holistically to improve lung health for patients.

In order for hospital teams to focus their attention and resource there are seven elements which have been selected for benchmarking. These elements align with the following key documents and tools:

- S The NICE Quality Standard for IPF
- D The NHSE ILD Quality Dashboard
- R The UK ILD Registry

Key Performance Indicators

This action plan highlights seven key elements from the NHSE ILD Quality Dashboard. These elements can all be measured using the UK ILD Registry, and they are all ultimately linked to the NICE Quality Standard for IPF. The UK ILD Registry Annual Report includes anonymised site-level data benchmarking against these metrics.

Whatever size your centre is these benchmarking metrics are intended to maximise the impact of your service on patient health. All ILD centres in the UK are asked to focus on:

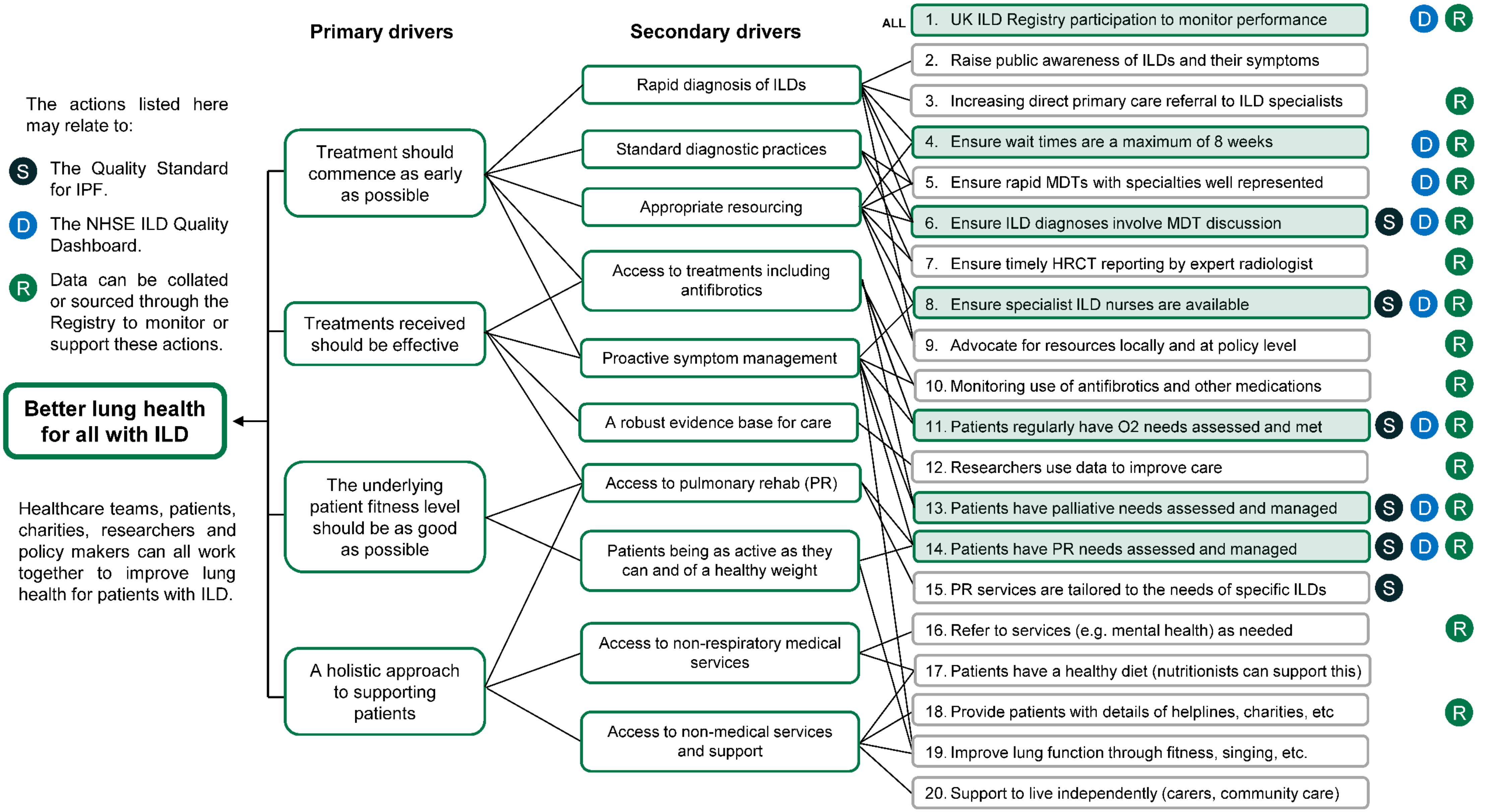
Resourcing	1	Ensure wait times are a maximum of 8 weeks
	2	Ensure ILD diagnoses involve MDT discussion
	3	Ensure specialist ILD nurses are available
Assessment and action	4	Patients regularly have O2 needs assessed and met
	5	Patients regularly have palliative (symptom) needs assessed and managed
	6	Patients have pulmonary rehabilitation needs assessed and managed
Benchmarking	7	UK ILD Registry participation to monitor performance

Since local challenges and service availability will vary significantly, the specific timescales for ILD centres to reach these seven steps will vary significantly. English specialist centres, English district general hospitals and hospitals in the devolved nations will face different challenges. Expecting a small district general hospital (DGH) to work to the same timetable to reach the same level of specialist ILD nursing resource as a specialist centre would be impractical. The key message is that all sites should work towards full compliance with these Seven Steps for Superior Care.

UK ILD Registry: ILD Healthcare Quality Improvement Drivers

British Thoracic Society

This drivers diagram describes the positive actions which may be taken by healthcare teams, researchers, patients and charities to ensure better lung health for all with ILD. Healthcare teams should pay particular attention to the Key Performance Indicators which are key benchmarking metrics intended to maximise impact.



The actions listed here may relate to:

- S The Quality Standard for IPF.
- D The NHSE ILD Quality Dashboard.
- R Data can be collated or sourced through the Registry to monitor or support these actions.

Better lung health for all with ILD

Healthcare teams, patients, charities, researchers and policy makers can all work together to improve lung health for patients with ILD.

Primary drivers

- Treatment should commence as early as possible
- Treatments received should be effective
- The underlying patient fitness level should be as good as possible
- A holistic approach to supporting patients

Secondary drivers

- Rapid diagnosis of ILDs
- Standard diagnostic practices
- Appropriate resourcing
- Access to treatments including antifibrotics
- Proactive symptom management
- A robust evidence base for care
- Access to pulmonary rehab (PR)
- Patients being as active as they can and of a healthy weight
- Access to non-respiratory medical services
- Access to non-medical services and support

ALL	1. UK ILD Registry participation to monitor performance		D	R
	2. Raise public awareness of ILDs and their symptoms			
	3. Increasing direct primary care referral to ILD specialists			R
	4. Ensure wait times are a maximum of 8 weeks		D	R
	5. Ensure rapid MDTs with specialties well represented		D	R
	6. Ensure ILD diagnoses involve MDT discussion	S	D	R
	7. Ensure timely HRCT reporting by expert radiologist			R
	8. Ensure specialist ILD nurses are available	S	D	R
	9. Advocate for resources locally and at policy level			R
	10. Monitoring use of antifibrotics and other medications			R
	11. Patients regularly have O2 needs assessed and met	S	D	R
	12. Researchers use data to improve care			R
	13. Patients have palliative needs assessed and managed	S	D	R
	14. Patients have PR needs assessed and managed	S	D	R
	15. PR services are tailored to the needs of specific ILDs	S		
	16. Refer to services (e.g. mental health) as needed			R
	17. Patients have a healthy diet (nutritionists can support this)			
	18. Provide patients with details of helplines, charities, etc			R
	19. Improve lung function through fitness, singing, etc.			
	20. Support to live independently (carers, community care)			

ILD Healthcare Quality Improvement Drivers: Descriptions

British
Thoracic
Society

1	D R	**UK ILD Registry participation to monitor performance** Participation is required for English specialist centres as part of the NHSE ILD Quality Dashboard (with a minimum of 70% IPF cases to be entered). The UK ILD Registry is included in the HQIP Quality Accounts. If your site has not yet signed up for the Registry please visit the BTS website.
2		**Raise public awareness of ILDs and their symptoms** Patient charities and advocacy groups play an essential roll in raising public awareness of ILDs and their symptoms, driving early diagnosis.
3	R	**Increasing direct primary care referral to ILD specialists** Improving wider workforce training and raising awareness of ILDs in primary care can increase the likelihood of direct referral to secondary care respiratory specialists, significantly reducing overall patient wait times. If you work in primary care consider targeted training programmes.
4	D R	**Ensure wait times are a maximum of 8 weeks** Wait time from referral to presentation should be no more than 8 weeks, due to the cancer-like outcome of some ILDs. This is included as part of the NHSE ILD Quality Dashboard and can be monitored in the UK ILD Registry as part of the user-downloadable *NHSE ILD Quality Dashboard Data* report available to all users. Centres where patients wait for more than 8 weeks can use their data to demonstrate a need for greater resource.
5	D R	**Ensure rapid MDTs with specialties well represented** The NHSE ILD Quality Dashboard states that "*As a minimum [the MDT] should include respiratory ILD physicians and a thoracic radiologist. It should also include a thoracic pathologist if tissue biopsies are available for review. The MDT panel could also include an ILD nurse, a physiotherapist, palliative care team members, etc.*"
6	S D R	**Ensure ILD diagnoses involve MDT discussion** MDT discussion being a requirement of diagnosis is included in the NICE Quality Standard for IPF, is included in the NHSE ILD Quality Dashboard and may be monitored in the UK ILD Registry. Due to the nature of service delivery, specialist prescribing centres are more likely to meet this standard than DGHs.
7	R	**Ensure timely HRCT reporting by expert radiologist** HRCT scans are an important tool for diagnosis and can help reduce the need for biopsies. The proportion of patients receiving HRCT scans can be monitored in the UK ILD Registry.
8	S D R	**Ensure specialist ILD nurses are available** Ensuring a specialist ILD nurse is available for patients is included in the NICE Quality Standard for IPF and the NHSE ILD Quality Dashboard and may be monitored in the UK ILD Registry. GIRFT noted that specialist ILD nurses are rarely available outside specialist clinic settings. Sites can use data to demonstrate need for improved nursing resource locally.
9	R	**Advocate for resources locally and at policy level** Data from the UK ILD Registry can be used to benchmark delivery against agreed standards and against similar sites. This information can then be used to advocate for improved resourcing (e.g. advocating for additional specialist ILD nurse posts), for improved tariffs or for changes in commissioning/policy.
10	R	**Monitoring use of antifibrotics and other medications** The UK ILD Registry can be used to monitor patient treatments both locally and nationally, helping hospitals to know if their patients are receiving optimal care. This includes identifying why patients have not been given antifibrotic therapy. In the UK ILD Registry user-downloadable *Summary site vs national data* report sites can view breakdowns of the treatments their patients are receiving.
11	S D R	**Patients regularly have O_2 needs assessed and met** Assessing and meeting the oxygen needs of patients (including home oxygen) is included in the NICE Quality Standard for IPF (specifying renewed assessment at each follow up visit) and the NHSE ILD Quality Dashboard (focusing on assessment at presentation) and can be monitored in the UK ILD Registry.
12	R	**Researchers use data to improve care** All healthcare teams entering data into the UK ILD Registry are directly supporting the work of researchers both now and in the future. Researchers may apply to access UK ILD Registry data through the BTS Data Access Request Processs. Through this and other sources (such as the HDR-UK BREATHE Hub) researchers can use data to support evidence-based care. Clinical trials teams can also ask the UK ILD Registry team to send details of their trials to sites participating in the Registry..
13	S D R	**Patients have palliative needs assessed and managed** Assessing and meeting the palliative care needs of patients is included in the NICE Quality Standard for IPF, is included in the NHSE ILD Quality Dashboard and can be monitored in the UK ILD Registry. The UK ILD Registry also collects data detailing palliative care discussions, including interventions for cough or breathlessness, advanced care planning or referral to specialist palliative teams.
14	S D R	**Patients have PR needs assessed and managed** Assessing and/or meeting the PR needs of patients is included in the NICE Quality Standard for IPF (which covers PR meeting specific ILD needs), in the NHSE ILD Quality Dashboard and can be monitored in the UK ILD Registry. GIRFT noted that PR availability varied significantly across the country.
15	S	**PR services are tailored to the needs of specific ILDs** The NICE Quality Standard for IPF specifies that PR courses should be available which are tailored specifically for patients with IPF. GIRFT specifically noted that the availability of PR for IPF varied significantly across the country, even between neighbouring CCGs.
16	R	**Refer to services (e.g. mental health) as needed** The UK ILD Registry collects data on patients being informed of other services such as mental health services. Clinicians should consider the full range of patient needs at clinic visits.
17		**Patients have a healthy diet (nutritionists can support this)** Patients maintaining a well balances diet and ensuring all their nutrition needs are met will help their overall wellbeing, leading to improved outcomes.
18	R	**Provide patients with details of helplines, charities, etc.** The UK ILD Registry collects data on patients being signposted to non-clinical services, specifically including support groups, helplines and patient charities. These additional services offer patients vital emotional support and practical advice. All patients should ideally be signposted to these services, which are offered by charities such as Action for Pulmonary Fibrosis, SarcoidosisUK and Asthma + Lung UK.
19		**Improve lung function through fitness, singing, etc.** Patients can help improve symptoms by keeping fit (even gentle exercise) and taking up activities such as singing (e.g. in a local choir). These activities support overall fitness, lung function and breathing control.
20		**Support to live independently (carers, community care)** Depending on the severity of symptoms it may be that home support, home adaptations or assistive technologies would help patients to live independently. Patient charities and support groups could advise on possible actions, including mobility aids, managing home oxygen, adjustable beds, or applying for financial support. Consider approaching charities such as Action for Pulmonary Fibrosis, SarcoidosisUK and Asthma + Lung UK, or the local council or social services.