

Foreword

“We are delighted to share this snapshot view of the service provision and workforce dedicated to people with interstitial lung disease (ILD) who are referred to specialist centres in England, with some indication of how this differs in Scotland, Wales and Northern Ireland.

The last few years have seen some exciting developments for people with ILD, including a new definition for progressive pulmonary fibrosis as well as National Institute for Health and Care Excellence (NICE) approval for the use of nintedanib in this condition. Additionally, NICE have expanded their recommendation for the use of nintedanib in people with idiopathic pulmonary fibrosis (IPF) where forced vital capacity (FVC) is above 80% predicted.

ILD service provision and workforce has not necessarily increased to reflect the growing complexity of patients and added pressures to health systems across the United Kingdom. The reality is, staff and services are stretched beyond their limits. This report aims to support services to benchmark against others and understand what high-quality care looks like and how they can improve delivery of such care. It also aims to inform commissioners to create an environment that enables clinicians to deliver equitable care, regardless of where people with ILD live, their background and personal circumstances.

The recommendations throughout this report support the implementation of the NHS Long Term Plan and are aligned with NICE, British Thoracic Society (BTS), Getting It Right First Time (GIRFT) and other organisations committed to the provision of respiratory care.”

Marium Naqvi,
Co-chair Interstitial Lung Disease Interdisciplinary Network (ILD-IN)



This report is informed by data submission from clinical leads, specialist nurses, pharmacists, allied health professionals and other members of the multidisciplinary team in 22 interstitial lung disease (ILD) specialist centres in England. In addition, 10 respiratory specialist services in Scotland, Wales and Northern Ireland contributed data to this report. It is based on retrospective data from January to December 2022. Some services did not provide all the data requested and others reported estimates where data was not readily available. We acknowledge the endeavours of the all the services that contributed to this report. ILD specialist centres in England have been anonymised by letters, which have been shared with the contributors.

A list of eligible services in England that participated are listed below:

Aintree University Hospital, Liverpool	Royal Stoke University Hospital, Stoke-on Trent
Castle Hill Hospital, Hull	Royal Brompton Hospital
Churchill Hospital, Oxford	Royal Devon & Exeter Hospitals
Glenfield Hospital, Leicester	Royal Papworth Hospital
Guy's and St Thomas' Hospitals	Royal Victoria Infirmary, Newcastle
Heartlands & Queen Elizabeth Hospitals	Royal Wolverhampton
Lancashire & South Cumbria Network	Southampton Hospital
Leeds General Infirmary, Leeds	Southmead Hospital, Bristol
Norfolk & Norwich Hospital	St Mary's & Hammersmith Hospitals
Nottingham University Hospital	University College Hospital
Queen Alexandra Hospital, Portsmouth	Wythenshawe Hospital, Manchester

A list of eligible services in Scotland, Wales and Northern Ireland that participated are listed below:

Scotland	Wales	Northern Ireland
NHS Greater Glasgow & Clyde	Cardiff & Vale UHB	Altnagelvin Hospital
NHS Ayrshire & Arran	Aneurin Bevan UHB	Antrim Area Hospital
NHS Lothian	Hywel Dda UHB	South West Hospital
		Southern Health Trust

We acknowledge support from Dr Lisa Spencer (Clinical Reference Group, ILD Lead), Dr Nazia Chaudhuri (British Thoracic Society ILD Special Advisory Group Lead), Dr Alex West (ILD Clinical Lead, Guy's and St THOMAS' Hospitals), Dr Alex Lawrence (ILD Clinical Fellow, Guy's and St Thomas' Hospitals) and Ms Louise Wright (CEO, Action for Pulmonary Fibrosis) and in the development of the ILD specialist centre data collection form and/or review of this report.



Executive Summary

NHS England commissions interstitial lung disease (ILD) services from 23 specialist respiratory centres in England for diagnosis and treatment planning as well as treatment administration and disease monitoring, where necessary.

10,358
new patient referrals to ILD specialist centres in 2022

ILD specialist centres differ in the number of new patient referrals received and the composition of ILD patient cohorts they diagnose. ILD specialist centres in England reported new patient referrals have increased by more than **2-5 times** since the NHS England ILD service specification was published in 2017.

ILD specialist centres in England reported 2883 new antifibrotic and 772 new immunosuppressant medicine prescriptions were issued in 2022. The number of new prescriptions is likely to increase with increased incidence, earlier identification of disease and wider indications for antifibrotic prescribing.

2883
new antifibrotic prescriptions

5059
active antifibrotic prescriptions

772
new immunosuppressant prescriptions

There is variation in the ILD specialist centre workforce in England with some services under resourced when compared to the average.

For every 500 new patient referrals to an ILD specialist centre in England, there are on average:

13 respiratory consultant PAs per week

1 FT specialist registrar or clinical fellow

1.4 WTE clinical nurse specialists

0.7 WTE pharmacist

PAs - programmed activities; 1 PA = 4 hours of work; FT – full-time; specialist registrar and clinical fellow input will often, at least in part, be supernumerary; WTE - whole time equivalent

There is **unwarranted variation in waiting times** from receipt of new patient referral to first appointment with ILD specialist to initiation of therapy. This may be explained by the lack of workforce resource dedicated to ILD in some specialist centres in England. The new to follow-up ratio, average DNA rate and follow-up delay to intended follow up date is reported to be better than suggested in the Getting It Right First Time (GIRFT) report.

1:3
average new to follow-up ratio

4%
median DNA rate

12 weeks
average follow-up delay



Supportive care services in England vary with the main challenges including lack of commissioning of pulmonary rehabilitation, oxygen services and palliative care/symptom management for people with ILD. Supportive care provision is not always tailored to people with ILD and there are often long waiting times to access care locally.

The model of care in Scotland, Wales and Northern Ireland is different; people with ILD are diagnosed and managed in respiratory specialist teams across all hospitals. As more care providers are involved in the diagnosis and management of ILD, it has been difficult to capture data from hospitals in the devolved nations. The responses received suggest lack of workforce resource which impacts on waiting times with greater delays to follow-up than the intended date.

This service evaluation has enabled us to measure ILD service provision and workforce across the United Kingdom from January to December 2022. We have made **key recommendations** to minimise variation and enable the delivery of equitable, high-quality and timely care by multidisciplinary healthcare professionals with adequate time dedicated to people with ILD.

Key Recommendations	<p>Commissioning of ILD services should reflect the increasing number of new patient referrals to specialist centres</p> <p>Services should be adequately resourced to manage the prescribing and monitoring of antifibrotic and immunosuppressant medicine</p> <p>People with ILD should receive care by appropriately trained multidisciplinary healthcare professionals at each stage of the care pathway</p> <p>People with ILD should receive an accurate diagnosis and access to specialist medicines and supportive care, closer to home where possible, in a timely manner</p> <p>Local care providers should undertake investigations locally and ensure ILD specialist centres have access to the full results when new patients are referred and where follow-up is required</p> <p>All patients with ILD should have access to personalised pulmonary rehabilitation, oxygen services and palliative care services, as required</p> <p>To strive towards agreed national standards around workforce dedicated to people with ILD across all health settings</p>
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ILD Services

Interstitial lung disease (ILD) is a collective term representing a diverse group of lung conditions characterised by inflammation and/or irreversible fibrosis in the lungs. These conditions vary in their causes, clinical pathways, severity and prognosis and thus determining incidence and prevalence is challenging.¹

The diagnosis of ILD is often complex as similar clinical and radiological presentations may differ in aetiology and clinical course, which can be unpredictable. Some ILDs develop a progressive fibrosing phenotype, characterised by fibrotic abnormalities on computerised tomography (CT), decline in lung function, worsening symptoms and quality of life, and early mortality. Comorbidities, such as infection, gastro-oesophageal reflux disease, pulmonary hypertension, cardiovascular disease and obstructive sleep apnoea, can pre-exist or develop at any time, and can lead to disease progression and early mortality.⁴

Accurate and early diagnosis, regular monitoring of disease progression and identification of comorbidities ensures people with ILD are offered the most appropriate treatments at the right time. Management of ILD requires a holistic and multidisciplinary approach which includes patient education and support, prescribing and monitoring of high risk and/or high cost medicines, such as antifibrotic and immunosuppressants, managing related adverse reactions and supportive care. People with a progressive fibrosing ILD often have more complex needs due to the burden of symptoms and prescription of multiple agents to manage them. Pulmonary rehabilitation, oxygen therapy and palliative care can improve symptoms and quality of life and should be provided throughout the patient journey.⁵

NHS England commissions ILD services from 23 specialist respiratory centres in England for diagnosis and treatment planning as well as treatment administration and disease monitoring, where necessary. Local commissioners are responsible for supporting primary and secondary care providers to manage people with ILD. The model of care is different in Scotland, Wales and Northern Ireland where people with ILD are diagnosed and managed by respiratory specialist teams across all hospitals. All services identified to contribute to this project have been mapped in figure 1.

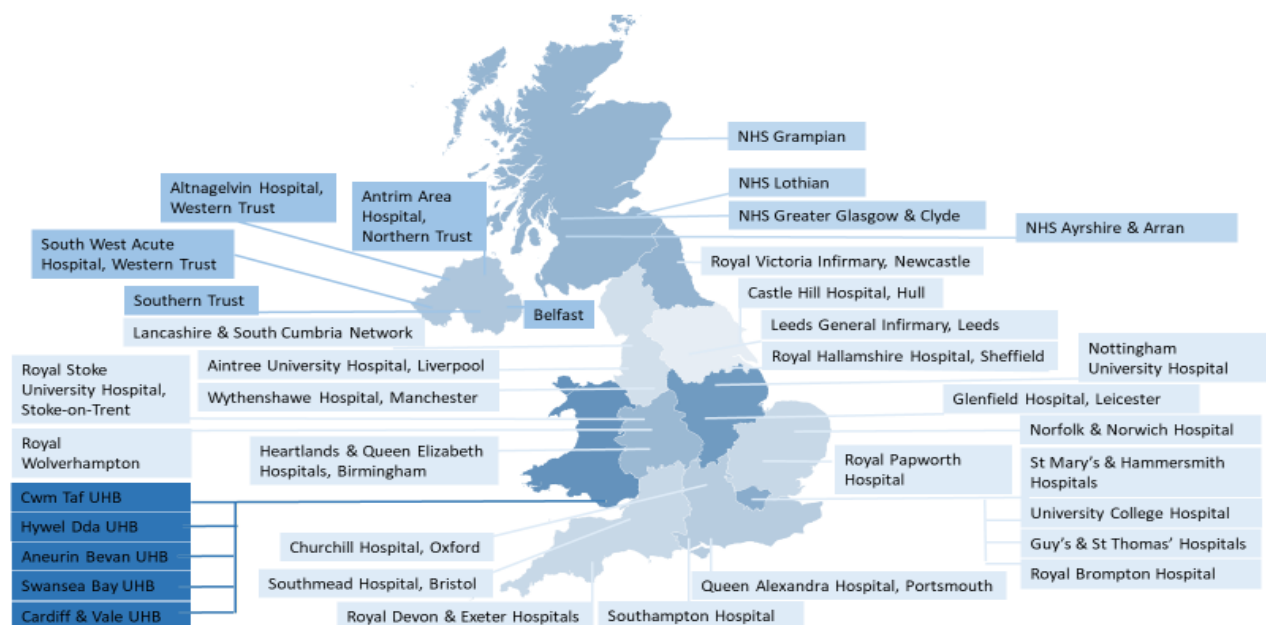


Figure 1. Map of ILD specialist centres in England and respiratory services that provide care for people with ILD in Scotland, Wales and Northern Ireland that were identified to contribute to this project.



England

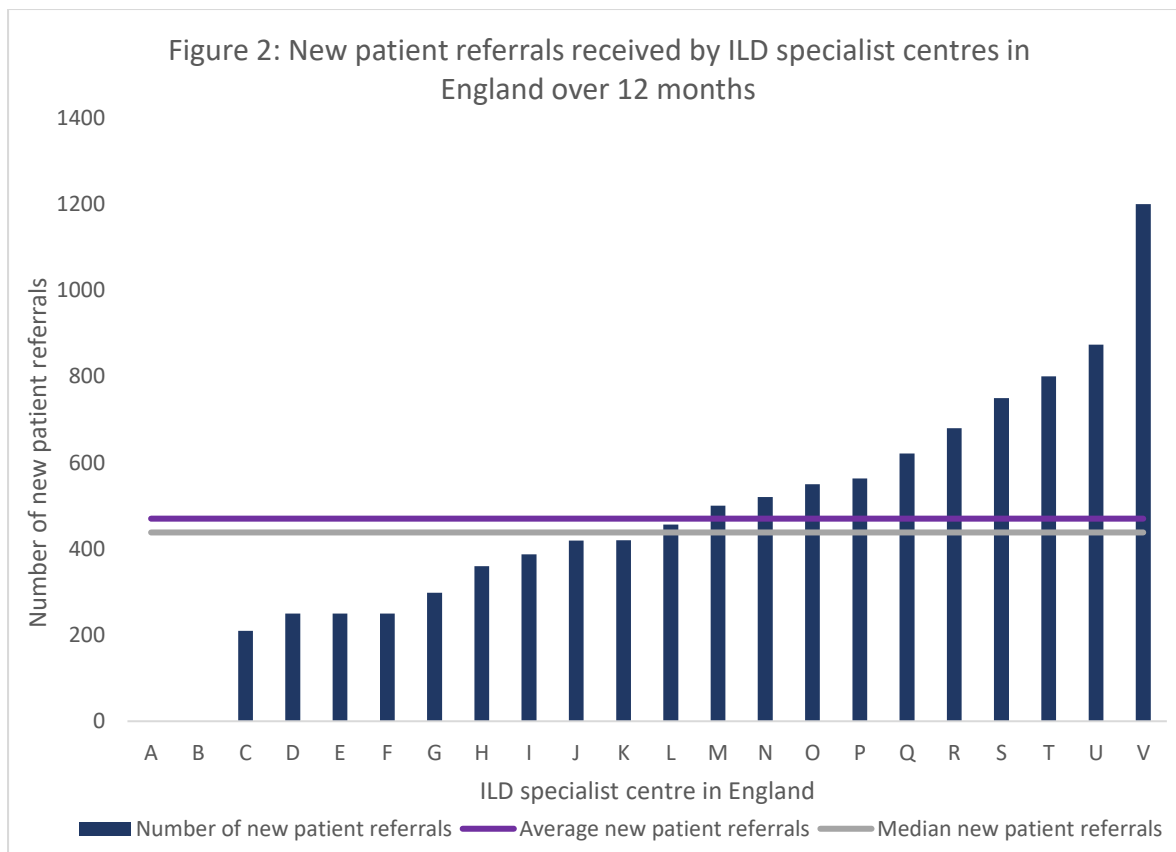
Twenty-two responses, out of a possible 23, were received from ILD specialist centres in England. Data was retrospectively collected for a 12-month period from January to December 2022.

New patient referrals received by ILD specialist centres over 12 months

10,358 new patient referrals to ILD specialist centres	470 average (438 median) number of new patient referrals per ILD specialist service	ILD specialist centres received between 210 and 1200 new patient referrals
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ILD specialist centres differ in the number of new patient referrals received and the composition of ILD patient cohorts they diagnose.

Twenty ILD specialist centres reported receiving 10,358 new patient referrals. Figure 2 demonstrates the variance in new patient referrals received by 20 ILD specialist centres, ranging between 210 and 1200. Two services did not provide this data. ILD specialist centres in England reported new patient referrals have increased by more than **2-5 times** since the NHS England ILD service specification was published in 2017.



Not all patients with ILD are referred to specialist centres and thus the number of new patient referrals reflects a percentage of the national cases that are complex and where diagnostic uncertainty exists and those that require access to specialist medicines; it does not reflect national incidence. New patient referrals are increasing; this may be due to increased incidence, earlier identification of disease and wider indications for antifibrotic prescribing, including progressive pulmonary fibrosis (PPF) and idiopathic pulmonary fibrosis (IPF) with forced vital capacity (FVC) above 80% predicted. It is thought that targeted lung health checks may also be contributing to increased new patient referrals to ILD specialist centres.

Recommendation 1: Commissioning of ILD services should reflect the increasing number of new patient referrals to specialist centres

This could be achieved by:

- reviewing how we collect and share data on incidence of all ILDs, service provision and workforce dedicated to people with ILD
- commissioners providing adequate resource and time for service management and maintaining data on patient numbers and ILD diagnoses
- commissioners providing adequate resource to all healthcare providers involved in the patient care pathway to enhance capacity for the increasing number of new patient referrals

New prescriptions for antifibrotic and immunosuppressant medicines in ILD specialist centres over 12 months



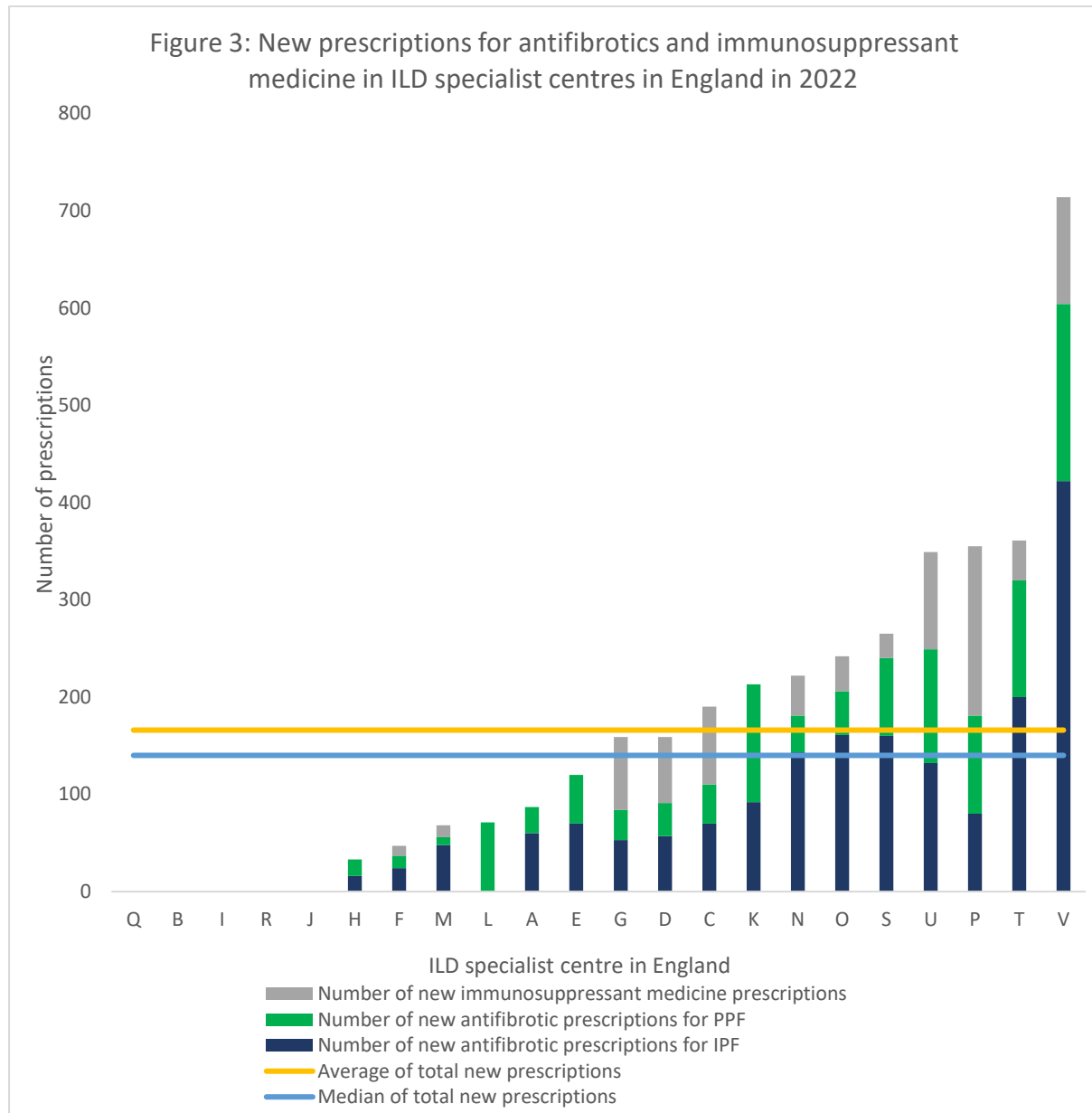
In England, prescribing of antifibrotic medicines for the treatment of IPF and PPF are currently limited to ILD specialist centres. The National Institute for Health and Care Excellence (NICE) recommends pirfenidone as an option for treating IPF, if FVC is between 50 and 80% predicted.⁵ NICE also recommends nintedanib as an option for treating IPF when FVC is 50% predicted or above, and for treating PPF.⁷⁻⁹ Seventeen ILD specialist centres in England reported 2883 new antifibrotic and 772 new immunosuppressant medicine prescriptions were issued in 2022 (excluding corticosteroid prescribing). 82% of ILD specialist centres supply medicines through a Homecare service. Table 1 details antifibrotic and immunosuppressant medicine prescribing in ILD specialist centres in the 12-month period. Two thirds of antifibrotic prescriptions were for IPF and one third for PPF.

Table 1: Prescribing in ILD specialist centres

Antifibrotic medicines	New	Total
IPF	1788	3786
PPF	1095	1273
Immunosuppressant medicines (excluding corticosteroids)	New	Total
ILD	772	1256
Total	3655	6315



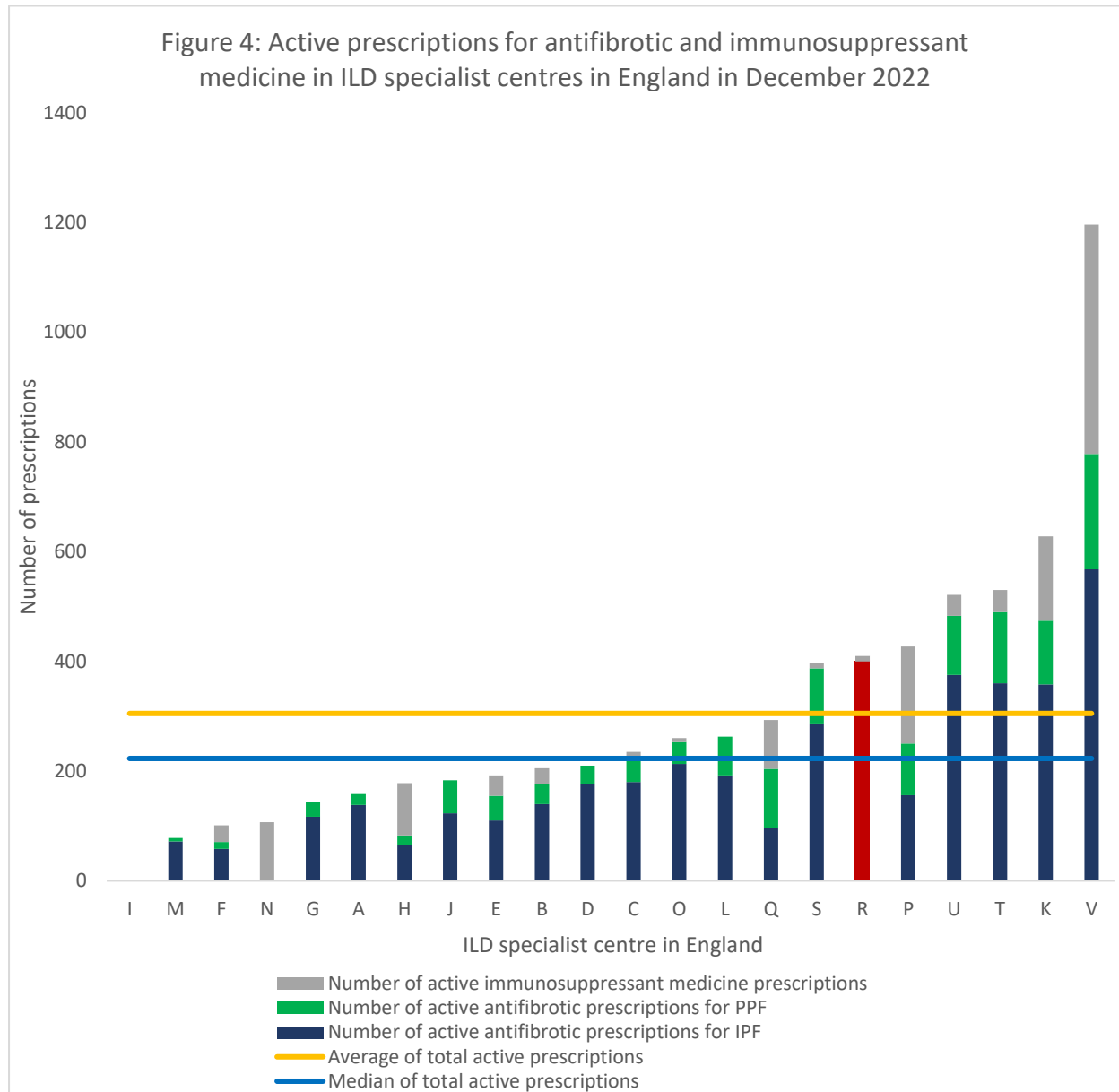
Figure 3 demonstrates the variance in number of new prescriptions for antifibrotic and immunosuppressant medicine per ILD specialist centre, which ranged from 33 to 714. The proportion of prescriptions for antifibrotics to treat IPF and PPF and immunosuppressants differed in each service. For example, services A and M predominantly prescribed antifibrotics for IPF and for services K and P antifibrotic prescribing for PPF exceeded that of IPF. Approximately 50% of the services prescribed immunosuppressant medicines and service P prescribed significantly more immunosuppressant medicines than the other services. Five centres did not provide data.



Some of this variance can be attributed to the size of the ILD service and/or different patient cohorts, for example, some services may have a significant CTD-ILD population and therefore prescribe more immunosuppressant medicines. Variance may also be attributed to shared management and prescribing by respiratory teams in local care settings and/or other specialties, such as rheumatology. The number of new prescriptions is likely to increase with increased incidence, earlier identification of disease and wider indications for antifibrotic prescribing.



Figure 4 demonstrates the variance in total number of active prescriptions for antifibrotic and immunosuppressant medicines per ILD specialist centre. Twenty-one ILD specialist centres reported there were 5059 active antifibrotic and 1256 immunosuppressant medicine prescriptions in December 2022. On average, 40% of people initiated on immunosuppressant medicines were moved to shared care. One service did not provide this data.



Note: the red bar indicates a service that provided total number of prescriptions only and did not provide separate data for IPF and PPF.

Recommendation 2: Services should be adequately resourced to manage the prescribing and monitoring of antifibrotic and immunosuppressant therapy

This could be achieved by:

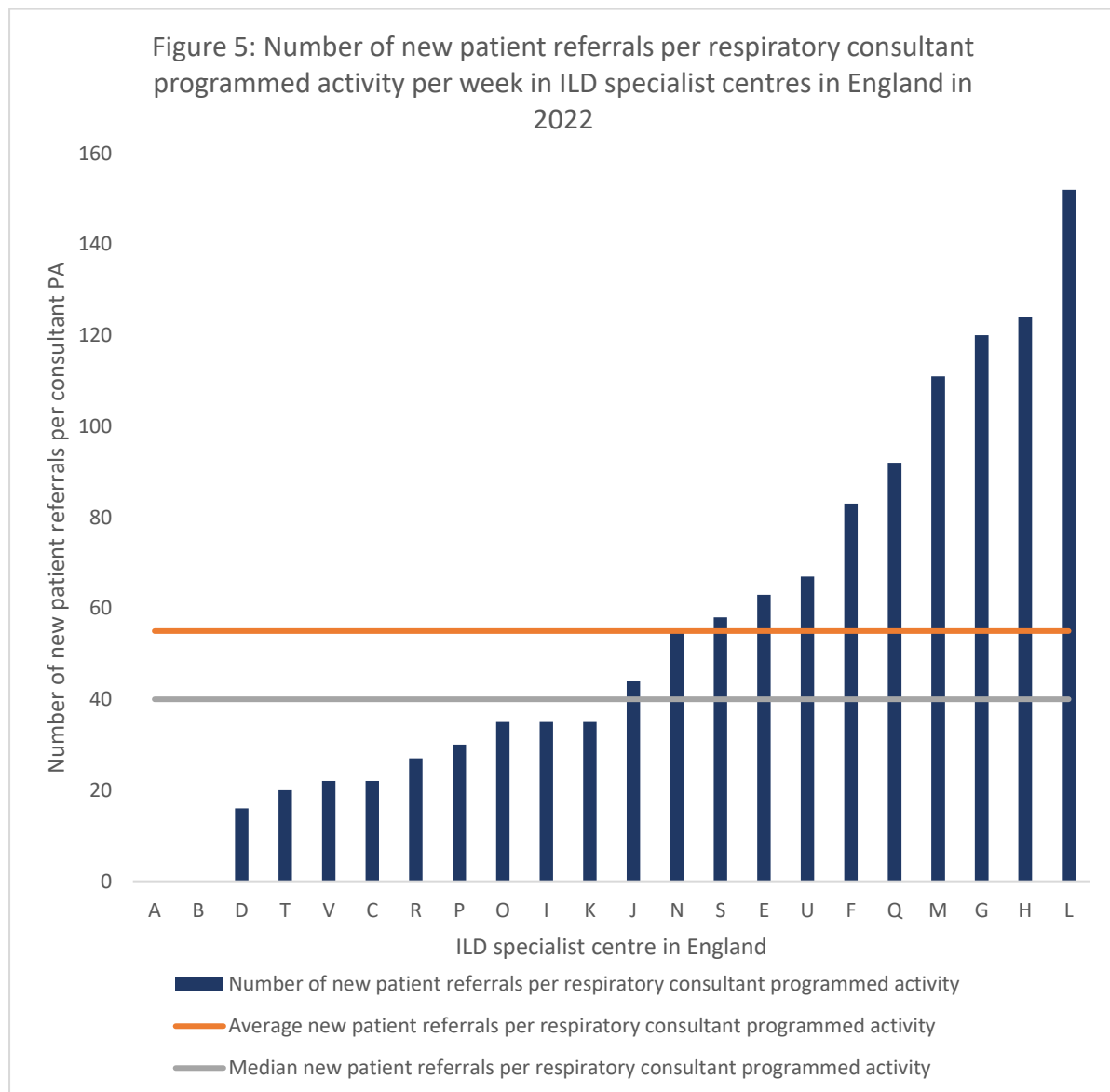
- ensuring minimum number of pharmacy and nursing staff per new and active prescriptions for antifibrotic and immunosuppressant medicines
- greater use of formalised shared care agreements between care providers
- including antifibrotic medication in national shared care policies and guidelines

Workforce in ILD Specialist Centres in England

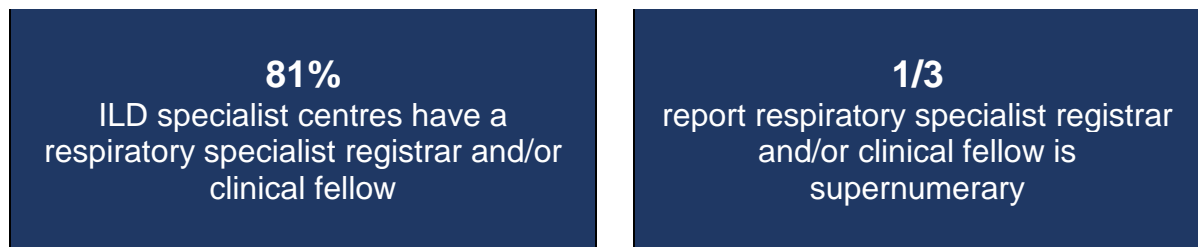
Respiratory and Rheumatology Consultants

All ILD specialist centres have dedicated respiratory consultants but numbers can vary from 1 to 6 with total programmed activity (PA) dedicated to ILD varying from 1 to 55 per week. One PA is equivalent to 4 hours. Figure 5 demonstrates the variance in new patient referrals per respiratory consultant PA per week dedicated to ILD. Greater respiratory consultant PAs dedicated to ILD does not always correlate with number of new patient referrals.

Most ILD specialist centres reported less than 1 rheumatology consultant PA dedicated to ILD per week. Only 1 ILD specialist service had significant rheumatology input from 3 rheumatology consultants, dedicating 7.5 PAs per week in total to ILD. One of the ILD specialist centres reported semi-formal arrangements for rheumatology opinion and a desire to develop structured collaborative working but limitations due to lack of resource. Rheumatology consultant representation in the ILD multidisciplinary team is essential for appropriate diagnosis and management of people with connective tissue disease related ILD.

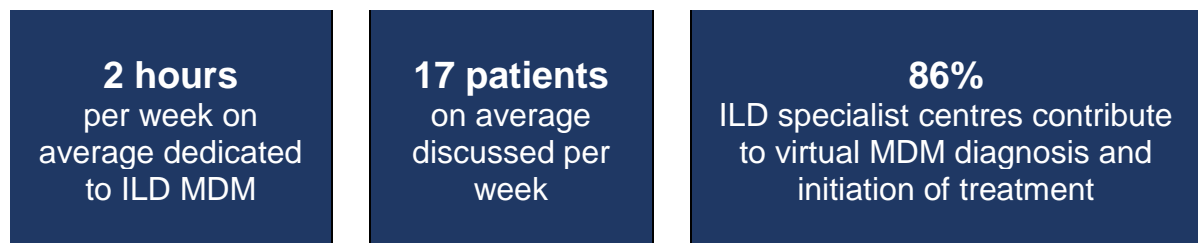


Respiratory Specialist Registrar or Clinical Fellow



81% of ILD specialist centres have at least 1 respiratory specialist registrar and/or clinical fellow which suggests provision of training for future ILD specialists. Some services report excess workload which may lead to erosion of training time. Specialist registrar and clinical fellow input will often, at least in part, be supernumerary.

Radiology



ILD specialist centres report they dedicate 2 hours per week on average (1 hour and 45 minutes median) to ILD multidisciplinary meetings (MDM), ranging from 0.5 to 3.5 hours. An average of 17 patients are discussed per week (median 15). The majority of services contribute to virtual MDM diagnosis and initiation of treatment. Below is a quote from ILD specialist service O which demonstrates how a specialist centre utilises virtual MDM to diagnose and support local physicians to manage people with ILD.

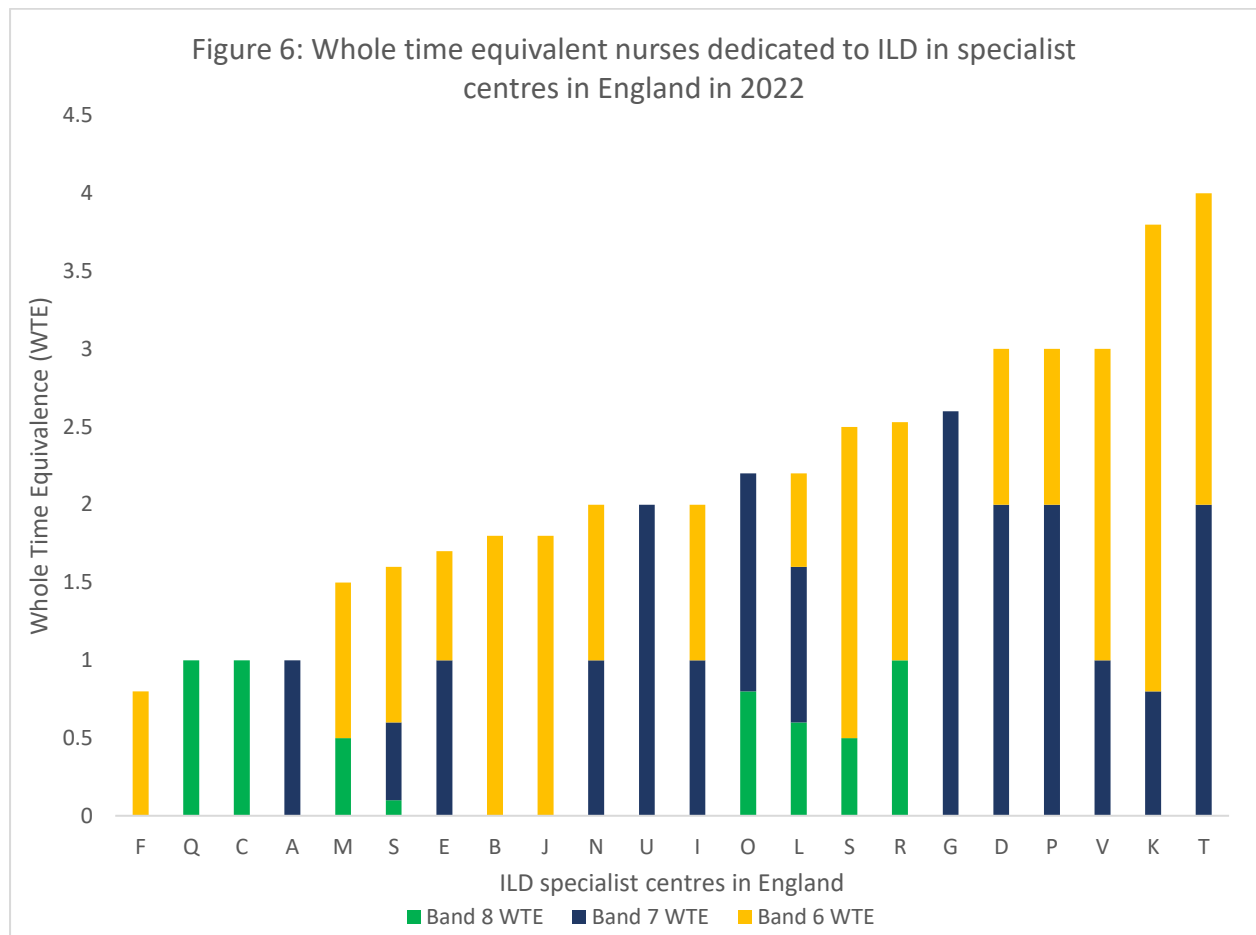
“We receive approximately 550 new referrals per year but importantly we review a third in virtual ILD MDM only. A detailed ILD MDM outcome letter with diagnosis and management plan is returned to the referrer. This engages local physicians to manage ILD with our support where they can, and avoids patient travel.”

Multidisciplinary Team



Nurses

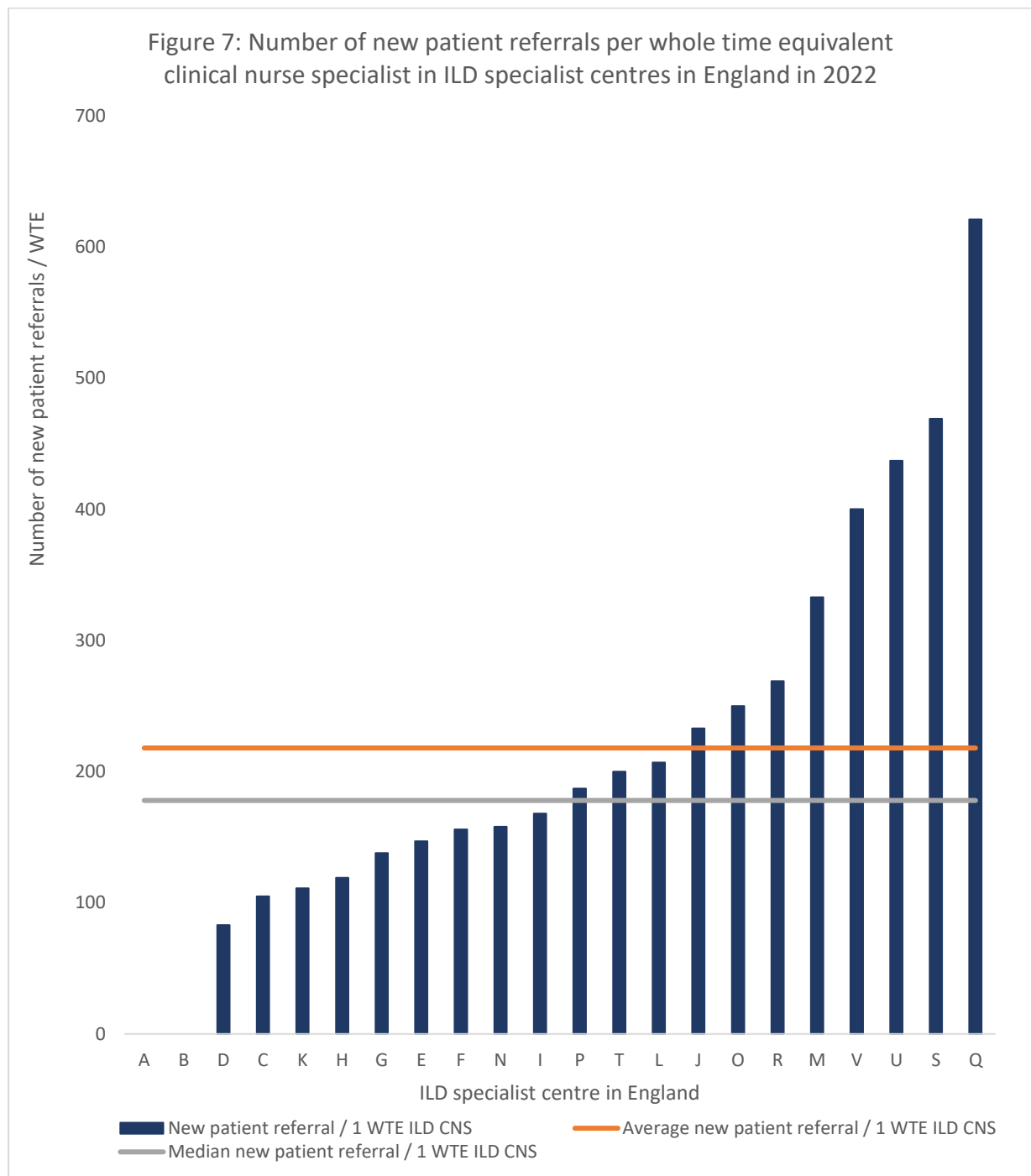
ILD nurses play a key role in patient and carer education and support, managing adverse reactions to medicines, pulmonary rehabilitation assessment and referral, oxygen therapy and palliative care/symptom management. They can also support the prescribing and monitoring of medicines to treat ILD. All the ILD specialist centres fulfil the NHS England service specification requirement and have dedicated ILD clinical nurse specialist (CNS) support. The level of support varies in whole time equivalence (WTE) and Agenda for Change pay bands, as demonstrated in figure 6.



The number of nurses in ILD specialist centres ranged from 1 to 4, with 1.5 to 3.3 WTE. Just under half of the ILD CNS workforce was on the Agenda for Change pay band 6, with the remaining workforce band 7 to 8. Three of the ILD specialist centres had band 6 ILD CNS with no senior support. ILD nurses have highly developed clinical skills in ILD and nursing, relevant diagnostic skills, the confidence to work in a rapidly changing environment with complex needs management, specialist knowledge of disease specific guidelines, and leadership skills to promote service development. The British Thoracic Society (BTS) professional development framework for respiratory nursing suggests these competencies fulfil the requirement of nurses practising at band 7.¹¹ Below is a quote from ILD specialist service T, which demonstrates the leadership demonstrated by the ILD CNS workforce.

“We lead networks of teams to manage patients who travel long distances. This is a model that continues to expand and is supported by ILD nurses and pharmacists who are non-medical prescribers.”

Figure 7 demonstrates number of new patient referrals (as an indicator for patient caseload) per one whole-time equivalent ILD CNS. There is variance across England and given the increasing new patient referrals and complex needs of people with ILD, most ILD specialist centres have inadequate ILD CNS resource, in number of WTE dedicated to ILD and Agenda for Change pay bands. This can lead to delays in accessing treatments. In some cases, services have well established shared management arrangements with local care providers who support people with ILD with ongoing management and supportive care after diagnosis. There should be adequate CNS workforce resource in all healthcare settings to enable the safe and effective shared management of people with ILD.



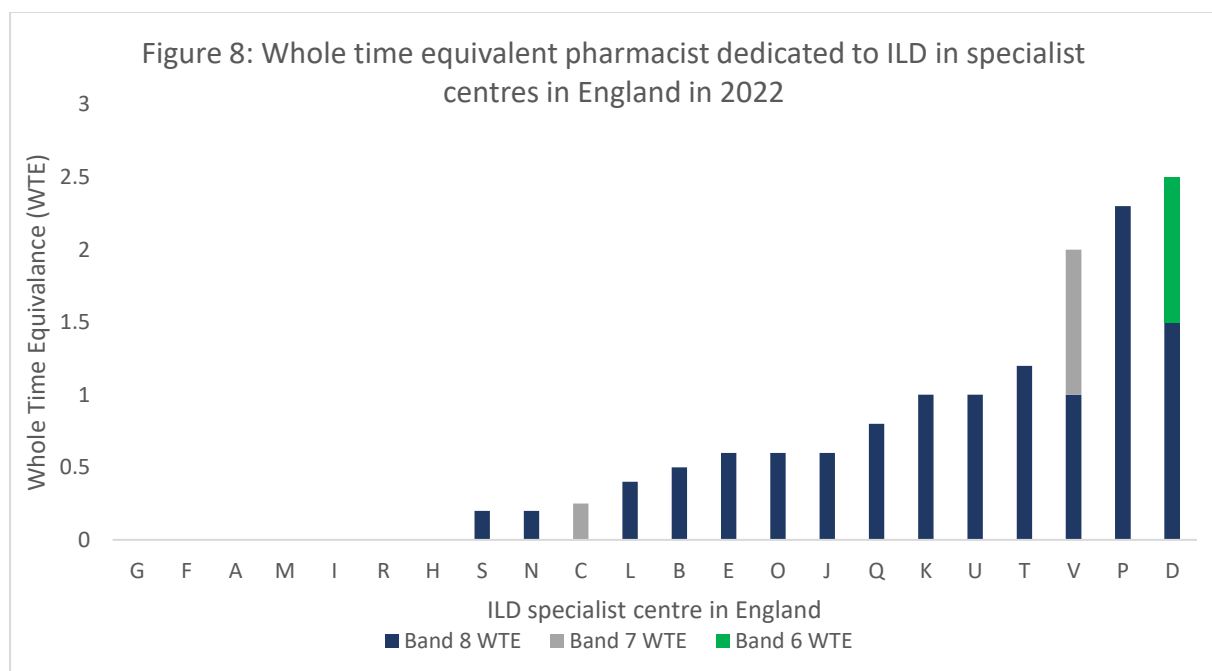
WTE – whole time equivalent; CNS – clinical nurse specialist



Pharmacists

Pharmacists are instrumental in the provision of medicines management, patient and carer education, prescribing and monitoring of high risk and/or high cost medicines and managing related adverse reactions. Two thirds of the ILD specialist services reported dedicated ILD pharmacy support, ranging from 0 to 4 pharmacists with 0 to 2.5 WTE across ILD specialist centres, as demonstrated in figure 8. Although the number of pharmacists WTE dedicated to ILD has been increasing, most ILD specialist centres have inadequate ILD pharmacist resource which can lead to delays in accessing treatments. The majority of the pharmacists were on the Agenda for Change pay band 8 (80%) with some band 6-7 support (20%). New prescriptions for antifibrotic and immunosuppressant medicines do not always correlate with pharmacy WTE. Below is a quote from ILD specialist service M who would benefit from pharmacy resource dedicated to ILD.

“Having a pharmacist as part of our ILD service would transform the way we work, improve efficiency of prescription management and free up nursing time”



WTE – whole time equivalent

Allied Healthcare Professionals

NICE recommends access to pulmonary rehabilitation, assessment and management of psychosocial needs and palliation of symptoms for people with IPF.⁵ Only 4 ILD specialist services (out of 22; 18%) reported dedicated allied healthcare professional resource which includes clinical psychology, physiotherapy and occupational therapy. These healthcare professionals are underrepresented in ILD specialist centres.

ILD Co-ordinator

86% of ILD specialist services have access to a dedicated co-ordinator; on average, 1 full-time member on the Agenda for Change pay band 4. The ILD service specification details a fully constituted MDM should consist of a respiratory physician with specialist training in ILD, a thoracic radiologist with expertise in ILD, a specialist ILD nurse and an MDM co-ordinator. All services should have access to a co-ordinator for MDM.³ The lack of appropriate service administrators leads to huge inefficiencies in services.



ILD Workforce Summary

There is variance in the ILD workforce, which is highlighted further when compared to new patient referrals and new prescriptions for antifibrotic and immunosuppressant medicines. Some ILD specialist centres have considerably less new patient referrals per respiratory consultant PAs per week when compared to the national average. Most ILD specialist centres reported less than 1 rheumatology consultant PA dedicated to ILD per week. All ILD specialist centres have dedicated nurse support for people with ILD. The level of support varies in WTE and Agenda for Change pay bands. Some professions are underrepresented despite the need for their expertise and NICE recommendations, for example, people with pulmonary fibrosis should have access to pulmonary rehabilitation tailored to their needs, oxygen therapy and palliative care. There are no ILD specific competencies for nurses, pharmacists or allied healthcare professionals. Some services do not have an ILD co-ordinator as recommended in the NHS England ILD service specification. Overall, there is insufficient multidisciplinary ILD workforce resource in ILD specialist centres. As demonstrated in figure 9, for every 500 new patient referrals, there are on average 13 respiratory consultants PAs per week, 1 full-time specialist registrar or clinical fellow, 1.4 WTE clinical nurse specialists and 0.7 WTE pharmacists dedicated to ILD.

Figure 9: Average workforce per 500 new patient referrals in ILD specialist centres in England

For every 500 new patient referrals to an ILD specialist centre in England, there are on average:

13 respiratory consultant PAs per week

1 FT specialist registrar or clinical fellow

1.4 WTE clinical nurse specialists

0.7 WTE pharmacist

PAs - programmed activities; 1 PA = 4 hours of work; FT – full-time; WTE - whole time equivalent; specialist registrar and clinical fellow input will often, at least in part, be supernumerary

Recommendation 3: People with ILD should receive care by appropriately trained multidisciplinary healthcare professionals at each stage of their care pathway

This could be achieved by:

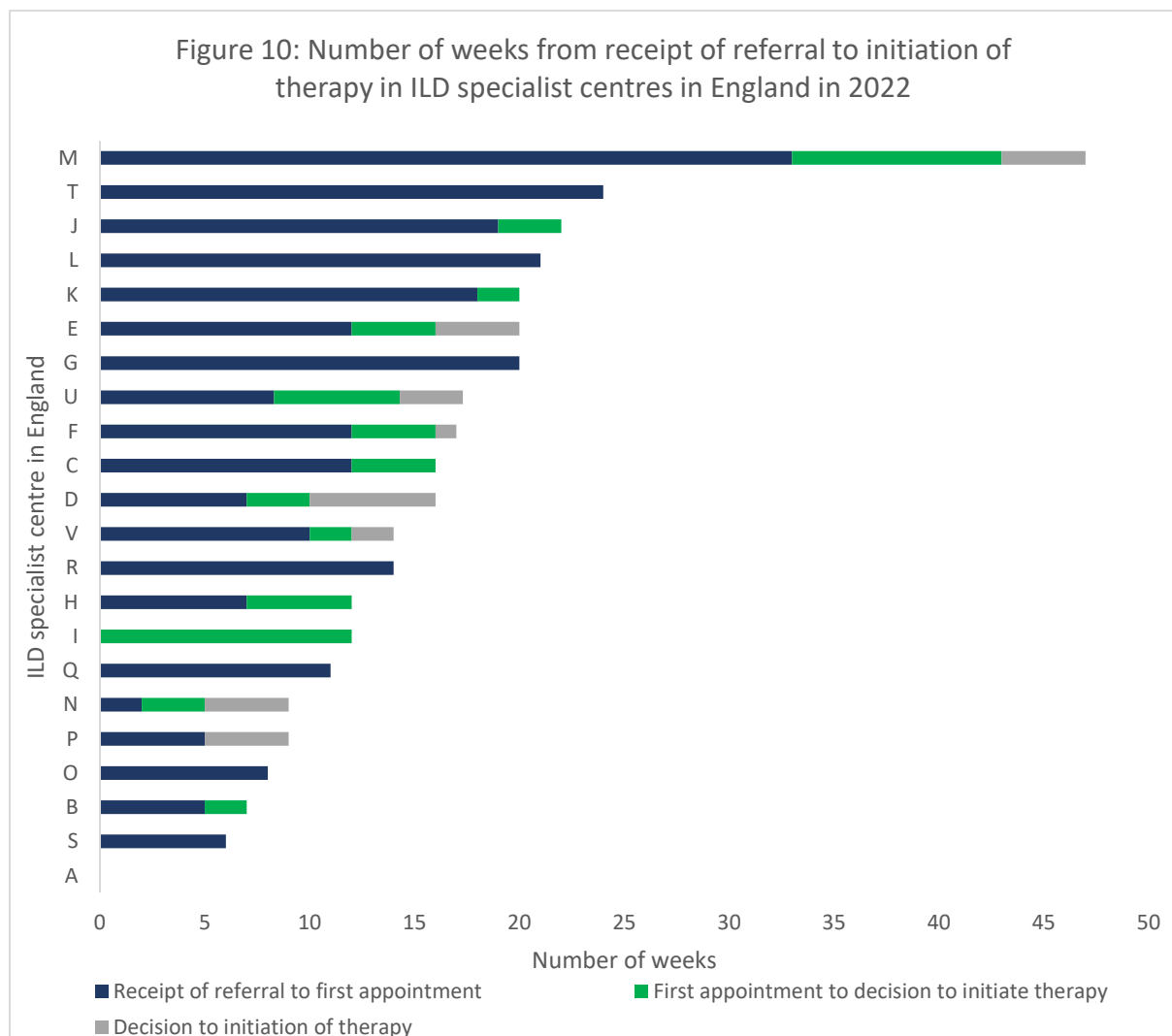
- commissioners reviewing the ILD service specification with a view to reflecting wider membership of ILD multidisciplinary healthcare professionals involved in patient care, including respiratory and rheumatology consultants, specialist nurses, pharmacist, allied healthcare professionals and administrative support
- ensuring multidisciplinary representation in ILD teams, including ILD specialist nurses, pharmacists and allied healthcare professionals, are trained and fulfil defined competencies to deliver ILD specialist role and/or manage patients with ILD
- ensuring nursing, pharmacy and allied healthcare professional workforce is on the appropriate Agenda for Change pay band that reflects the complexity of their roles in ILD



New and follow-up ILD service provision

There is unwarranted variation in waiting times for new patients to be reviewed in ILD specialist centres, ranging from <5 to 33 weeks from receipt of referral, as demonstrated in figure 10. NHS England recommends new patient referrals to an ILD specialist centre should be reviewed within 8 weeks; most services are unable to meet this due to rising demand and insufficient workforce resource. For example, ILD specialist centre M has one of the highest numbers of new patient referrals per respiratory consultant PAs per week dedicated to ILD and this is reflected in the highest waiting time for new patient referrals to be reviewed in this service. Waiting time to initiate therapy varies but most services are able to initiate treatment within 4 weeks of the decision to treat. The average time between receipt of new patient referrals and initiation of therapy is 15 weeks.

For many people with ILD, the waiting time between the ILD specialist centre receiving the new patient referral and initiation of therapy is additional to any delays they may have experienced in primary and secondary care settings. If timely access to ILD specialist review, diagnosis, specialist medication and supportive care does not occur, patients may experience disease progression and ongoing and/or increasingly debilitating symptoms with reduced quality of life. This can lead to greater demands for urgent healthcare with patients seeking help from GPs or emergency departments, leading to greater pressures on the healthcare system.

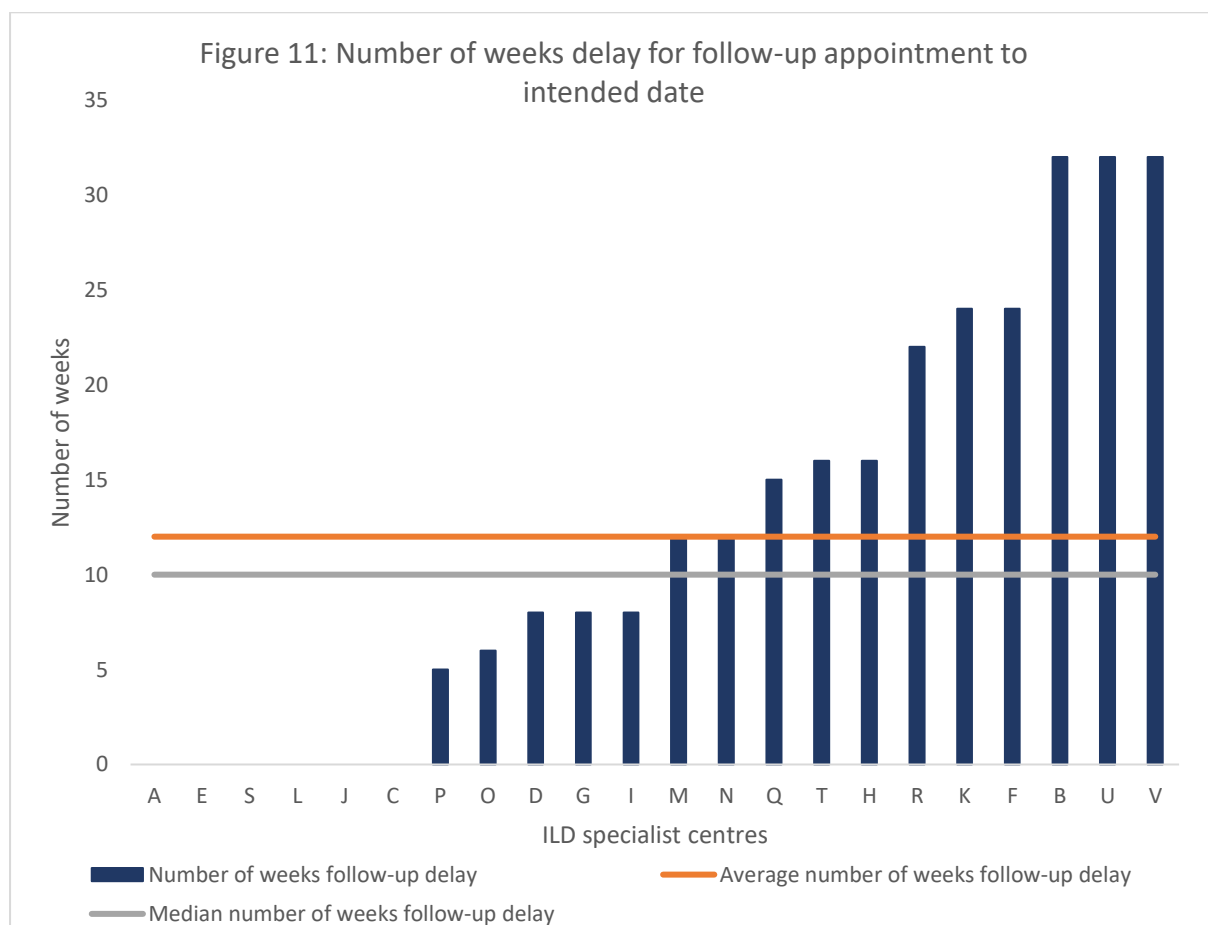


The new to follow-up ratio, median DNA rate and average follow-up delay to intended follow up date reported is better than suggested in the Getting It Right First Time (GIRFT) report. For example, ILD specialist centres reported median DNA rate of 4% compared to the national median DNA rate of 12%. There is variance in the follow-up delay to intended follow up date as demonstrated in figure 11, with an average of 12 weeks (10 weeks median).

1:3
average new to follow-up ratio

4%
median DNA rate

12 weeks
average follow-up delay



Some ILD specialist centres, such as F, have less than the average respiratory consultant PAs per week dedicated to ILD. This results in longer waiting times for first appointment and follow-up as demand for service exceeds workforce capacity. Other ILD specialist centres, such as V, have a high number of new patient referrals and reflected respiratory consultant PAs per week dedicated to ILD. However, they also have greater delays for follow-up. This may suggest that demand for service exceeds workforce capacity but also highlights the need for shared management with local care providers to improve the patient care pathway and reduce delays to follow-up. Early access to local management and support for people with ILD may also reduce the need for urgent healthcare. Adequate respiratory multidisciplinary workforce resource dedicated to ILD in local care settings is required to enable efficiency and maximise the impact of specialist services.



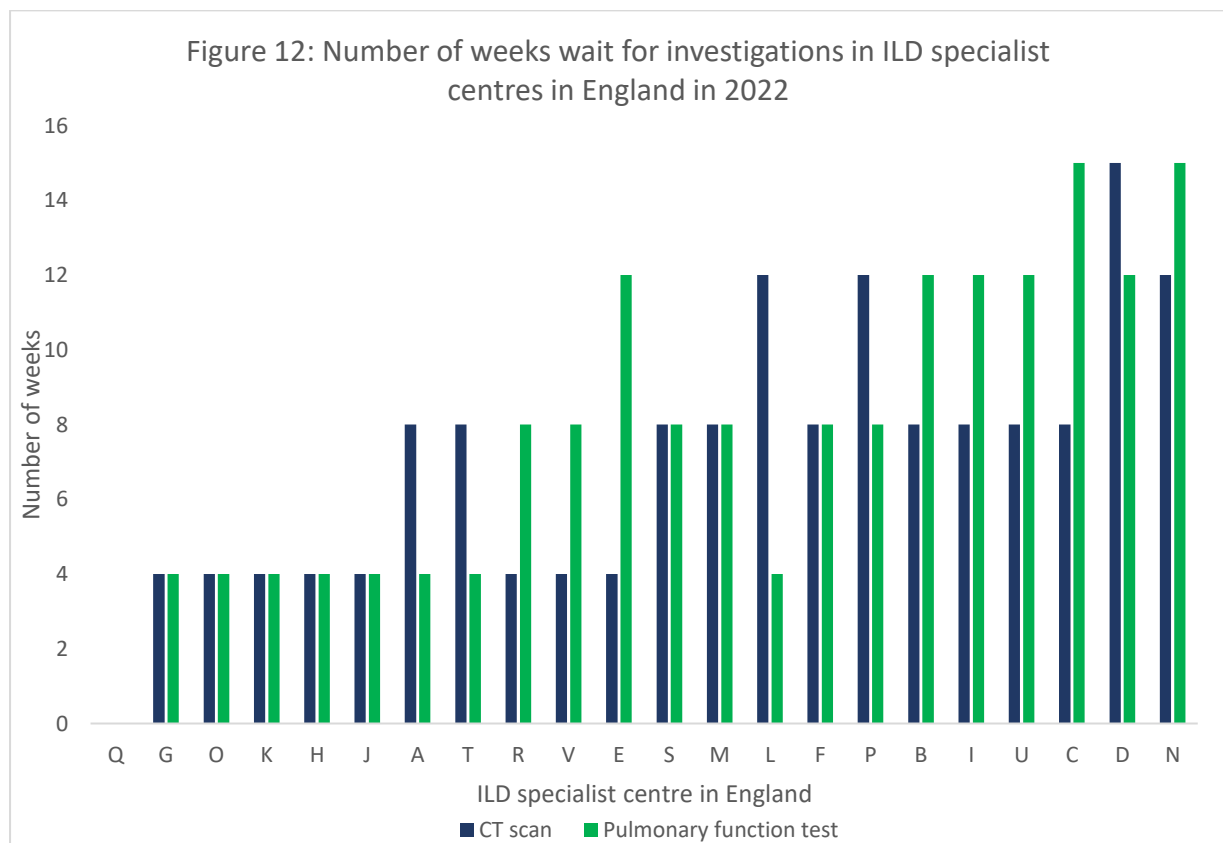
Recommendation 4: People with ILD should receive an accurate diagnosis and access to specialist medicines and supportive care, closer to home where possible, in a timely manner

This could be achieved by:

- ILD specialist centres identifying resource required to meet NHS England recommendations for new patient referrals to be reviewed within 8 weeks
- commissioners making a recommendation on the desired number of weeks between receipt of new patient referral and initiation of therapy
- ensuring multidisciplinary representation in ILD teams, including specialist nurses, pharmacists and allied health professionals so people with ILD are offered the most appropriate treatments at the right time
- adequate respiratory multidisciplinary workforce resource dedicated to ILD in local care settings for improved shared management and reduced ILD specialist centre follow-up
- commissioners enabling local hospitals to oversee the prescribing and monitoring of antifibrotic therapy with the support of nurses and pharmacists with ILD expertise in these care settings

Average wait for investigations

CT scans and pulmonary function tests (PFTs) are required for the diagnosis and monitoring of ILD. There is variation in number of weeks wait for CT scans and PFTs, ranging from under 4 weeks to over 12 weeks. Figure 12 shows this variation per ILD specialist centre. Services that have long waiting times for investigations may also have long waiting times for first appointment and/or follow-up appointments.

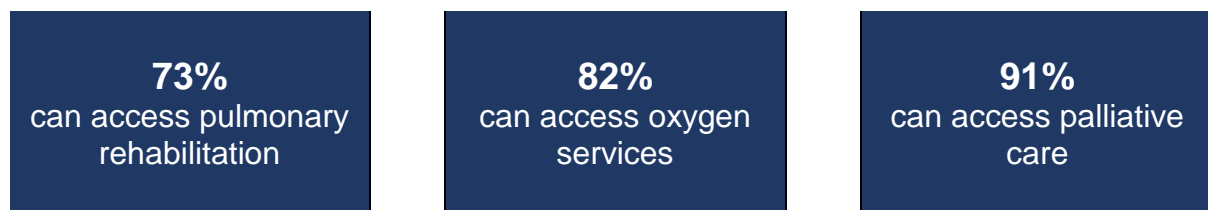


Recommendation 5: Local care providers should undertake investigations locally and ensure ILD specialist centres have access to the full results when new patients are referred and where follow-up is required

This can be achieved by:

- streamlining the new patient referral to ILD specialist centres with referral criteria, to include results of completed investigations
- All ILD specialist centres having adequate ILD co-ordinator input to liaise with referrers to ensure any results of local investigations are forwarded to avoid unnecessary duplication

Supportive care services



The majority of ILD specialist centres reported people with ILD could access pulmonary rehabilitation, oxygen therapy and palliative care. However, many of the services reported challenges, such as lack of local commissioning for people with ILD, lack of support tailored to people with ILD and long waiting times; these are detailed in table 2.

Table 2: Challenges with supportive care services	
Pulmonary rehabilitation	Long waiting times Not commissioned for people with ILD Limited to people with IPF and COVID Not tailored to the needs of people with ILD
Oxygen	Not commissioned for ILD Difficulty organising oxygen outside catchment area Some areas do not offer (HOSAR) oxygen services which impacts patients, hospital services and waiting times
Palliative care	Some services provide in-house palliative care Variable provision until patients access hospice support. Occasional misunderstanding of the reason for referral to palliative care, e.g. breathlessness management vs end stage disease with severe symptoms No formal pathways resulting in delays in referring to the team best placed to support

Pulmonary rehabilitation is a key intervention for managing people with ILD and should be available and accessible for all patient groups that would benefit. However, a quarter of ILD specialist centres reported difficulties in accessing pulmonary rehabilitation for their patients. We received a number of examples where local services had insufficient capacity to cope with referrals and as a result there were long waiting times and exclusion of people with ILD. In addition, a number of services reported the pulmonary rehabilitation programmes were not tailored to people with ILD.



Oxygen assessment and therapy should be considered for all patients with severe resting or exertional hypoxaemia and breathlessness. However, a fifth of ILD specialist services reported difficulties in accessing local oxygen services due to lack of commissioning for ILD. This is likely to impact patients and ILD specialist centres who may oversee the assessment and provision of oxygen for patients who cannot access it locally. Local care providers should be involved to ensure adequate provision of oxygen assessment and therapy closer to home.

Palliative care referrals should be considered from the first appointment and diagnosis to manage symptoms such as breathlessness and anxiety. A relatively small number of services, 9%, reported difficulties accessing palliative care support for people with ILD. Some of the challenges included variable provision of palliative care until patients access hospice support and lack of formal pathways resulting in delays. As a result, ILD specialist centres may be involved in provision of palliative care for those who cannot access it locally.

91% services organise support groups for people with ILD.

Recommendation 6: All patients with ILD should have access to personalised pulmonary rehabilitation, oxygen services and palliative care services, as required

This could be achieved by:

- ensuring multidisciplinary representation in ILD teams, including physiotherapists, occupational therapists and clinical psychologists
- commissioners providing adequate resource for services providing pulmonary rehabilitation, oxygen services and palliative care to enhance capacity and support timely enrolment
- commissioners ensuring protected time for pulmonary rehabilitation, oxygen and palliative care services to provide specific support to people with ILD
- agreeing formal referral pathways to pulmonary rehabilitation, oxygen services and palliative care to reduce delays and ensure people with ILD can access the support they need

Recommendation 7: To strive towards agreed national standards around workforce dedicated to people with ILD across all health settings

This could be achieved by:

- ILD specialist centres benchmarking their workforce and services with other ILD specialist centres and reviewing whether any improvements could be made to improve the patient journey
- ILD specialist centres understanding local service and workforce provision in their region to plan and deliver services which meet the needs of the community as Integrated Care Systems



Scotland, Wales and Northern Ireland

The model of care is different in Scotland, Wales and Northern Ireland where people with ILD are diagnosed and managed in respiratory specialist teams across all hospitals. We received responses from 3 services in Scotland, 3 services in Wales and 4 services in Northern Ireland. We did not capture all services managing people with ILD in the devolved nations as this is shared across respiratory teams in all hospitals. There were a number of gaps in the data which suggest that services do not collect this data as routine.

Over the 12-month period, services reported an average of 506 new patient referrals and 72 new antifibrotic prescriptions per hospital in Scotland, 91 new patient referrals and 45 new antifibrotic prescriptions per hospital in Wales, and 128 new patient referrals and 25 new antifibrotic prescriptions per hospital in Northern Ireland. As there are a greater number of respiratory specialist teams diagnosing and managing ILD, the number of new patients and new antifibrotic prescriptions per service are lower than ILD specialist centres in England.

Similarly, the workforce resource dedicated to ILD is significantly lower than in ILD specialist centres in England. For example, there were on average 6, 4 and 5 respiratory consultant PAs per week dedicated to ILD per hospital in Scotland, Wales and Northern Ireland, respectively. Many of the services reported lack of workforce resource which impacts on waiting times. The services reported a greater new to follow-up ratio with 11 to 18 weeks wait for first appointment and 8 to 20 weeks follow-up delay. One service reported they did not have access to a local radiologist with ILD interest so they joined a virtual ILD MDM hosted by another health board to discuss patients with IPF or PPF.

The services mostly reported oxygen and palliative care services are accessible but as in England, there is a lack of dedicated pulmonary rehabilitation services and long waiting times for people with ILD. Although a small number of services submitted data, there are similarities with many of the challenges demonstrated by the ILD specialist centres in England. The workforce dedicated to ILD does not meet the rising demand and more resources are required to ensure people with ILD can access the care they need.

Summary

The diagnosis of ILD is often complex. Accurate and early diagnosis, regular monitoring of disease progression and identification of comorbidities ensures people with ILD are offered the most appropriate treatments at the right time. Management of ILD requires a holistic and multidisciplinary approach which includes patient education, supportive care, prescribing and monitoring of high risk and/or high cost medicines and managing related adverse reactions.

NHS England commissions ILD services from 23 specialist respiratory centres in England for diagnosis and treatment planning as well as treatment administration and disease monitoring, where necessary. ILD specialist centres in England reported new patient referrals have increased by more than 2-5 times since the NHS England ILD service specification was published in 2017. The number of new prescriptions to manage ILD is likely to increase further with increased incidence, earlier identification of disease and wider indications for antifibrotic prescribing.

There is variation in the ILD specialist centre workforce in England with some services under resourced. On average, for every 500 new patient referrals, there are 13 respiratory consultants PAs per week, 1 full-time specialist registrar or clinical fellow, 1.4 WTE clinical nurse specialists and 0.7 WTE pharmacists dedicated to ILD. This does not reflect how stretched services and staff are and the lack of workforce resource impacts waiting times for first appointment, initiation of therapy and follow-up. Supportive care services in England



vary and the main challenges include lack of commissioning, services not tailored to meet patient needs and long waiting times for people with ILD. Although the model of care in the devolved nations is different and people with ILD are diagnosed and managed in respiratory specialist teams across all hospitals, the services report similar challenges with workforce resource and lack of supportive care services commissioned for people with ILD.

This service evaluation has enabled us to measure ILD service provision and workforce across the United Kingdom from January to December 2022. We have made key recommendations to support the NHS Long Term Plan to minimise variation and enable the delivery of equitable, high-quality and timely care by multidisciplinary healthcare professionals regardless of where people with ILD live, their background and personal circumstances.

To find out more about ILD-IN visit: [Interstitial Lung Disease Interdisciplinary Network | ILD-IN](#)

This report was produced by: Marium Naqvi, ILD-IN Co-chair

With support from the ILD-IN committee: Rosie Boorsma, Joshua Burrough, Joanne Dallas, Laura Fabbri, Janine Hood, Jenny Lynch-Wilson, Carmel McInerney, Kerry Mills, Sarah Mulholland, Geeta Vekaria

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