

Questionnaire for healthcare professionals on the patient’s journey through Idiopathic Pulmonary Fibrosis (IPF) and other forms of Pulmonary Fibrosis (PF)

Time to complete: 30 minutes

- English only
- Online distribution

General information	
Indicators	Outcomes
I am a doctor / nurse	Relationship with the patient
Your organisation’s name and location	Location of organisation (country)
Your country of residence	Geographical distribution
Is your organisation a recognised Centre of Expertise specialising in interstitial lung diseases (ILDs)? Yes / No	Differentiation of answers between centres for expertise specialising in ILDs and other healthcare providers
Is your organisation a member of ERN-LUNG? Yes / No	Understanding of similarities between ERN-LUNG centres relative to other healthcare providers

Epidemiological data	
Indicators	Outcomes
How many patients with Idiopathic Pulmonary Fibrosis (IPF) are managed in your centre each year?	Prevalence of IPF patients in each centre
How many patients with Pulmonary Fibrosis (PF), but excluding IPF, are managed in your centre each year?	Prevalence of PF patients in each centre
How many new patients were diagnosed with IPF within the past 12 months at your centre?	Incidence of IPF patients in each centre
How many new patients have been diagnosed with other forms of PF within the past 12 months at your centre?	Incidence of PF patients in each centre
Is there a national registry for IPF in your country? Yes / No	Presence of IPF registry at country level
Is there a registry for IPF in your centre? Yes / No	Presence of IPF registry at centre level
Is there a national registry for other forms of PF in your country? Yes / No	Presence of PF registry at country level
Is there a registry for PF in your centre? Yes / No	Presence of PF registry at centre level
Do you contribute to the collection of registry data? Yes / No	Involvement in IPF registry
Interactions between doctors and patients	
Indicators	Outcomes

<p>Have you received training to effectively communicate information on diagnosis and treatment to IPF and PF patients and carers? Yes / No If yes, please specify the training.</p>	<p>Understanding of existence or lack of specific training for interactions with patients</p>
<p>Do you feel equipped to give clear and easy-to-understand information to IPF and PF patients and carers? (Please choose from the following scale where 1=strongly agree; 2=agree; 3=neither agree nor disagree; 4=disagree; 5=strongly disagree)</p>	<p>Understanding of personal opinion on ability to interact with patients</p>
<p>Do you feel you have enough time to discuss their diagnosis with patients? (Please choose from the following scale where 1=strongly agree; 2=agree; 3=neither agree nor disagree; 4=disagree; 5=strongly disagree)</p>	<p>Assessment of time availability for diagnosis</p>
<p>Do you feel you have enough time to discuss their treatment with patients? (Please choose from the following scale where 1=strongly agree; 2=agree; 3=neither agree nor disagree; 4=disagree; 5=strongly disagree)</p>	<p>Assessment of time availability for treatment</p>
<p>Does your centre offer training or educational activities to IPF and PF patients? Yes / No If yes, please specify.</p>	<p>Existence of dedicated training for IPF and PF patients</p>

How do you think interactions with patients could be improved?	Recommendations
Screening	
Indicators	Outcomes
Does your centre have access to genetic testing to diagnose IPF and PF? Yes / No	Availability of genetic testing to diagnose IPF and PF
If yes, is the test provided to IPF and PF patients in your centre or in another centre? <ul style="list-style-type: none"> • In my centre • In another centre 	Access to molecular testing for IPF and PF patients
Does your centre have access to genetic counselling? Yes / No. Please specify for both answers.	Availability of genetic counselling
If yes, is it provided to IPF and PF patients?	Access to genetic counselling for IPF and PF patients
Referral pathway	
Indicators	Outcomes
In your country, how easy is it to identify a centre of expertise specialising in ILDs for IPF and PF patients? (Please choose from the following scale where 1=very easy; 2=easy; 3=neither easy nor difficult; 4=difficult; 5=very difficult).	Assessment of access to specialist care

<p>Do IPF and PF patients have access to a multidisciplinary? Yes / No</p>	<p>Access to multidisciplinary team</p>
<p>Do IPF and PF patients have access to a specialist ILD nurse? Yes / No</p>	<p>Access to specialist ILD nurse</p>
<p>Which of the following professionals is part of the multidisciplinary team or supportive interdisciplinary team? (Please tick all that apply)</p> <ul style="list-style-type: none"> • consultant respiratory physician or pulmonologist • consultant thoracic radiologist • consultant pathologist • interstitial lung disease specialist nurse • multidisciplinary team coordinator • physiotherapist • rheumatologist • immunologist • thoracic surgeon • pharmacist • other (please describe) 	<p>Understanding of composition of multidisciplinary teams</p>

<p>On average, how often do you or the multidisciplinary team review an IPF or PF patient's case?</p> <ul style="list-style-type: none"> • Once a week • Twice a month • Once a month • Every 3 months • Every 6 months • Every 12 months • Other (please specify) 	<p>Frequency of MDT review of single cases</p>
<p>On average, how often do you or the multidisciplinary team invite the IPF or PF patient to the clinic to discuss their case?</p> <ul style="list-style-type: none"> • Once a month • Every 3 months • Every 6 months • Every 12 months • Other (please specify) 	
<p>Are IPF and PF patients involved in developing their treatment plan? Yes / No</p>	<p>Understanding of involvement of patients in treatment plan decisions</p>

If yes, how?										
Do you provide different treatment and support options to your IPF and PF patient? Yes / No	Understanding of patient's choice for treatment									
How are IPF and PF patients referred to you? Please indicate the top-two options that apply: <ul style="list-style-type: none"> • General practitioner • Pulmonologist • Other pulmonologist • Self-referral • Other (please specify) 	Understanding of the referral circuit									
Access to pharmacological treatment (specific to IPF)										
Indicators	Outcomes									
The following treatments for IPF are approved by the European Medicines Agency (EMA). Please indicate if they are prescribed in your country <table style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="text-align: left; width: 30%;">Active substance</th> <th style="text-align: center; width: 30%;">Available</th> <th style="text-align: center; width: 30%;">Not available</th> </tr> </thead> <tbody> <tr> <td>• Pirfenidone</td> <td></td> <td></td> </tr> <tr> <td>• Nintedanib</td> <td></td> <td></td> </tr> </tbody> </table>	Active substance	Available	Not available	• Pirfenidone			• Nintedanib			Availability of specific pharmacological treatment for IPF patients in your country
Active substance	Available	Not available								
• Pirfenidone										
• Nintedanib										

<p>Please indicate if the following EMA-approved treatments for IPF are available for prescription in your centre</p> <table border="0" style="width: 100%;"> <thead> <tr> <th style="text-align: left;">Active substance</th> <th style="text-align: center;">Available</th> <th style="text-align: center;">Not available</th> </tr> </thead> <tbody> <tr> <td>• Pirfenidone</td> <td></td> <td></td> </tr> <tr> <td>• Nintedanib</td> <td></td> <td></td> </tr> </tbody> </table>	Active substance	Available	Not available	• Pirfenidone			• Nintedanib			<p>Availability of pharmacological treatment for IPF patients in your centre</p>
Active substance	Available	Not available								
• Pirfenidone										
• Nintedanib										
<p>Please indicate if the following EMA-approved treatments for IPF are fully (100%) reimbursed or not in your country</p> <ul style="list-style-type: none"> • Pirfenidone Yes / No • Nintedanib Yes / No <p>If no, please elaborate.</p>	<p>Reimbursement of pharmacological treatment for IPF patients</p>									
<p>Are there any inclusion or exclusion criteria when administering the following treatments:</p> <ul style="list-style-type: none"> • Pirfenidone Yes / No • Nintedanib Yes / No <p>If yes, please specify.</p>	<p>Criteria for administering EMA-approved treatment</p>									
<p>Are there any barriers to prescribing EMA-approved IPF treatments in your centre? Please select all that apply</p> <ul style="list-style-type: none"> • Severity of disease (mild, moderate, severe) 	<p>Limitation to prescription of IPF pharmacological treatments</p>									

<ul style="list-style-type: none"> • Disease progress • Patient clinical status • Age • Other, please explain 	
<p>What is the average time from suspected diagnosis to starting treatment with Nintedanib or Pirfenidone?</p> <ul style="list-style-type: none"> • Less than a month • Between 1 month and 6 months • Between 6 months and 1 year • More than a year 	<p>Delay in access to pharmacological treatment from suspected diagnosis</p>
<p>If IPF patients in your centre experience delays in accessing treatment, what are the main reasons for the delay? Please select all that apply</p> <ul style="list-style-type: none"> • Wrong recognition of symptoms and signs • Time from suspected diagnosis to confirmed diagnosis • Delays in referral to a centre specialising in ILDs • Treatment not available for sale in your country • Treatment not reimbursed 	<p>Reasons for delay in access to treatment</p>

<ul style="list-style-type: none"> • Treatment only partially reimbursed • Treatment not reimbursed for all types of IPF or PF • Treatment not prescribed by your centre • Other, please explain 	
<p>Do you have patients who might benefit from access to pharmacological treatment but who are not eligible?</p> <ul style="list-style-type: none"> • No • Less than 10% • Less than 30% • More than 30% 	<p>Barriers to accessing pharmacological treatment</p>
<p>In your opinion, what would improve access to treatment for IPF patients?</p> <ul style="list-style-type: none"> • No limitations for prescription • Reimbursement • Timely referral to specialist ILD centre • Better pricing policies • Other, please explain 	<p>Opportunities to improve access to pharmacological treatment</p>
<p>Access to non-pharmacological treatment</p>	

Indicators	Outcomes
Does your centre prescribe ambulatory oxygen for IPF and PF patients? Yes / No	Availability of ambulatory oxygen therapy
Is ambulatory oxygen reimbursed? Yes / No / Partially	Access to ambulatory oxygen therapy
Can your centre prescribe oxygen for IPF and PF patients to use at home? Yes / No	Availability of oxygen for use at home
Is oxygen for use at home reimbursed? Yes / No / Partially	Access to oxygen for use at home
Can your centre prescribe pulmonary rehabilitation for IPF and PF patients? Yes / No	Availability of rehabilitation programmes
Is pulmonary rehabilitation reimbursed? Yes / No / Partially	Access to rehabilitation programmes
Can your centre prescribe medication for palliative care or symptom relief for IPF and PF patients? Yes / No	Availability of palliative care and symptom relief
When do you start palliative care or symptom relief for IPF and PF patients? Please specify according to the stage of progression of the disease.	Meaning of palliative care in IPF and PF for doctors
Is end-of-life care discussed with IPF and PF patients and their families? Yes / No	Inclusivity of decision-making process for patients and families
In your country, what are the eligibility criteria for a lung transplant? Please select all the criteria that apply.	

<ul style="list-style-type: none"> • Age, please specify • General health condition • Likelihood of developing risks associated with transplant (for example, infections, rejection of new lung) • Severity of IPF or PF • Progression of IPF or PF • Availability of organs • Surgical procedure not available • Other, please specify 	
<p>In patients eligible for lung transplantation, do you refer these patients for a lung transplant? Yes / No</p>	<p>Availability of lung transplantations</p>
<p>Do patients in your centre have access to psychological support such as counselling? Yes / No. If yes, please specify if psychological support is reimbursed: Yes / No / Partially</p>	<p>Access to psychological support</p>
<p>Do patients in your centre have access to educational materials on IPF and PF?</p>	<p>Access to educational materials</p>
<p>Research</p>	

Indicators	Outcomes
Are you aware of current IPF and PF clinical trials? Yes / No If yes, please state which trials.	Availability of information on clinical trials in general
Do you tell IPF and PF patients that they could take part in clinical trials? Yes / No If yes, please specify if: <ul style="list-style-type: none"> • your centre participates in trials • your centre refers patients for trials to another centre • you refer to the patient association 	Availability of information on clinical trials for patients
General recommendations	
Please share your suggestions for improving the patient's experience of the IPF or PF journey.	General recommendations

Thank you for completing this survey.