EU-IPFF
EUROPEAN IDIOPATHIC PULMONARY FIBROSIS
& RELATED DISORDERS FEDERATION

Your experience of living with Idiopathic Pulmonary Fibrosis (IPF) or another form of Pulmonary Fibrosis (PF)

Thank you for agreeing to take part in this survey about living with IPF or PF. You can fill in the questionnaire yourself of your carer can do it for you. It will take about half an hour. The information you share will give EU-IPFF, the patients' European federation, a better understanding of the needs of IPF and PF patients and may help to improve services in the future. Your name will not be requested to complete this questionnaire.

- English plain review
- Translated in DE/FR/EL/ES/BG/IT/NL/PT/PL
- Time to complete: 25 minutes
- Online distribution
- Consent form requested before questionnaire is completed

General information about you	

I am a patient / carer. (If you are a carer or family member, please answer on behalf of the person you care for).	Relationship to the disease
I have IPF or another type of PF	Specific disease
I am male / female	Gender distribution
My age	Age distribution
Country I live in	Geographical distribution
Information about your IPF or PF	
Is there a history of IPF or PF in your family?	Family history of the disease
In which year were you diagnosed with IPF?	Age at diagnosis
Some countries have a national registry which collects health information from patients and uses it to improve knowledge and treatment of the disease. Do you know if there is an IPF (not PF) registry in your country? Yes / No / I don't know	Awareness of existence of IPF registry at Country Level
Do you know if there is a registry for PF (not IPF) in your country? Yes / No / I don't know	Awareness of existence of PF registry at Country Level
Do you contribute to the collection of registry data? Yes / No	Involvement in IPF/PF registry
Your experience of interacting with doctors	

Did your doctor give you information on your disease when you were diagnosed?	Assessment of availability of information for patients
If yes, what type of information did you receive?	Assessment of type of information provided to patients
Did you understand the information you were given?	Assessment of accessibility of information for patients
Did you have enough time to discuss your diagnosis with your doctor? Yes/ No	Assessment of time availability for information on diagnosis
How would you describe your experience of discussing your diagnosis with your doctor? (scale 1 to 5: 1= strong positive; 2=positive; 3=neutral; 4=negative; 5=strong negative)	Assessment of quality of exchanges on diagnosis
Besides your family doctor, did you have access to any other healthcare professionals to discuss your diagnosis? Yes / no	Availability of members of multidisciplinary team for information on diagnosis
If yes, please say which of the following you spoke with : • respiratory (lung) doctor (also known as a pulmonologist) • radiologist • specialist respiratory nurse • physiotherapist • rheumatologist • psychologist • thoracic (chest) surgeon	Access to multidisciplinary team

• other, please specify	
Did you get training or educational activities from your treating centre? Yes / No	Existence of dedicated training for IPF and PF patients
How could health care staff work more effectively with you and your carers? Please give us your suggestions and recommendations	Recommendations
Genetic screening	
Did you have a genetic test? This is a test to examine your genes to find out how likely you are to get IPF or PF. Yes / No	Access to genetic testing
If yes, did you get enough information about this test?	Quality of information on genetic testing for IPF/PF patients
Your referral	
How much time passed before your family doctor referred you to a respiratory doctor? • Less than a month • Between one and two months • Between two and six months	Delay in access to respiratory physician

• Between six and twelve months • More than a year	
How much time passed between the first consultation with your family doctor and your referral to a specialist lung centre? • Less than a month • Between one and two months • Between two and six months • Between six and twelve months • More than a year	Delay in access to specialist care
Did you get a wrong diagnosis before you were diagnosed with IPF or PF? Yes / No	Delay in access to accurate diagnosis
If yes, how much time passed between your first (wrong) diagnosis and your diagnosis with IPF or PF? • Less than a month • Between one and two months • Between two and six months • Between six and twelve months	Delay in access to accurate diagnosis

• More than a year	
In your country, how it easy is it to get a referral to a specialist lung centre? 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
How far is your centre from your home? • Less than 10 km (about 6 miles) • Between 10 km and 30 km (between about 6 miles and 18 miles) • Between 30 km and 50 km (between about 18 miles and 31 miles) • Between 50 km 100 km (between about 31 miles and 62 miles) • More than 100 km (more than 62 miles)	Distance between home and centre
Do you have access to a multidisciplinary team? Yes / No	Access to multidisciplinary team
Do you have access to a specialist lung nurse? Yes / No	Access to specialist nurse
Which healthcare professional has been monitoring your IPF or PF since your diagnosis?	Access to specialised care

• Respiratory doctor (pulmonologist) from the specialist lung centre • Family doctor • Specialist nurse • Physiotherapist • Palliative care doctor or nurse • Other, please specify	
On average, how often do you meet your multidisciplinary team to discuss your condition? • Once a month • Every 3 months • Every 6 months • Every 12 months • Other (please specify)	Frequency at which the IPF/PF patient meets with the multidisciplinary team
Following your diagnosis, did you get a treatment plan for your disease? Yes / No	Availability of treatment plan
Was your treatment plan explained clearly to you? Yes / No If no, please tell us more.	Understanding of treatment plan

Were you involved at any stage in the development of your treatment plan? Yes / No If yes, how were you involved (please describe)?	Understanding of involvement of patients in treatment plan decisions
Were you given different options for your treatment? Yes / No If yes, please say which options.	Understanding of patient's choice for treatment
Do you feel you got enough support from your doctors and healthcare team? Yes / No If no, please tell us what support you would have liked to get.	Access to satisfactory support throughout the care pathway
Access to medicines (only for IPF patients)	
Are you being treated with medicines for your IPF? Yes / No If no, were you treated with any medicines in the past? Yes / No	Information on individual pharmacological treatment
In what year did you start taking medicines for your IPF?	Information on individual pharmacological treatment
Did you have to change your medicines at any point? Yes / No If yes, please say why you had to change.	Information on individual pharmacological treatment
Overall, how long did you have to wait from diagnosis to receiving treatment? • Less than a month • Between one and two months	Assessment of delay in access to treatment

• Between two and six months • Between six and twelve months • More than a year	
In case you started late taking medicines, what are the main reasons? • Late diagnosis • Not referred in time to a specialist lung centre • Treatment not available for sale in your country • Treatment is not paid for • Treatment is only partially paid for • Treatment is not reimbursed for your type of IPF • Treatment is not prescribed by your centre • Other, please explain	Referral to pharmacological treatment
Are you fully (100%) covered for the costs of medicines by health insurance or the health service in your country? Yes / No	Coverage of pharmacological treatment: reimbursement
If no, how much do you have to pay for medicines out of your own pocket each year? • Less than €200	Out-of-pocket costs

• Between €200 and €500 • Between €500 and €1,000 • Between €1,000 and €2,000 • Between €2,000 and €5,000 • More than €5,000	
In your opinion, what would help increase the use of medicines for treating IPF? Please choose all that apply. • Making the prescription of medicines easier for doctors • Encouraging family doctors to refer more patients to specialist lung centres • Making the procedures for reimbursement easier • Cheaper medicines • Other, please explain	Accessibility of pharmacological treatment: opportunities for improvement
Access to other treatments	
Has your doctor prescribed portable oxygen therapy for you? Yes / No	Availability of ambulatory oxygen therapy

Is the cost of portable oxygen paid for by your health insurance or the health service in your country? - Yes, fully (100%) - Yes, in part - No	Availability of ambulatory oxygen therapy
What do you have to do to be fully or partially reimbursed? Please describe.	Access to ambulatory oxygen therapy
Has your doctor prescribed oxygen therapy for you to use at home? Yes / No	Availability of oxygen therapy at home
Is the cost of oxygen at home paid for by your health insurance or the health service in your country? - Yes, fully (100%) - Yes, in part - No	Coverage of oxygen therapy at home
What do you have to do to be fully or partially reimbursed for home oxygen therapy? Please describe.	Access to oxygen therapy at home
What are the main difficulties you face in accessing portable and home oxygen therapy? Please choose all that apply.	Access to oxygen therapy

• High cost • No availability of liquid oxygen portables • No availability of portable oxygen concentrators • Oxygen therapy was not prescribed • Other (please specify)	
Do you have access to a pulmonary (lung) rehabilitation programme? • Yes, out-patient • Yes, in-patient • No, none at all	Availability of pulmonary rehabilitation programmes
Is the cost of the pulmonary rehabilitation programme paid for by your health insurance or the health service in your country? • Yes, fully (100%) • Yes, in part • No	Coverage of pulmonary rehabilitation programme
What do you have to do to be fully or partially reimbursed for pulmonary rehabilitation? Please describe.	Access to pulmonary rehabilitation programmes

Do you have access to palliative care? Yes / No	Availability of palliative care/ symptom relief
Is palliative care paid for by your health insurance or the health service in your country? • Yes, fully (100%) • Yes, in part • No	Coverage of palliative care
What do you have to do to be fully or partially reimbursed for palliative care? Please describe.	Access to palliative care
Are you and your family involved in decisions about palliative care?	Inclusivity of decision-making process for patients and families in palliative care
Who supported you during your treatment (whatever type of treatment you had)? Please choose all that apply. • respiratory doctor (pulmonologist) • radiologist • pathologist • specialist nurse • multidisciplinary team coordinator • physiotherapist • rheumatologist	Access to support structures

• immunologist • thoracic surgeon • interventional pulmonologist (who uses minimally invasive endoscopic techniques) • psychologist • patient organisation or peer group • other, please indicate	
Do you have access to a patient organisation to support you during your treatment? Yes / No	Access to support structures
How would you describe your overall experience with the healthcare system in relation to your IPF or PF? Please choose from the following scale where 1= excellent; 2=good; 3=neither good nor bad; 4=bad; 5=very bad.	Assessment of patient's journey
Research	
Are you aware of any ongoing clinical trials? Yes / No	Availability/ accessibility of information on clinical trials

Were you ever asked to be involved in a clinical trial? Yes / No	Availability of information on clinical trials for patients
Have you ever taken part in a clinical trial? Yes / No	Availability of information on clinical trials for patients
Your suggestions	
Please tell us how you feel the experience of patients and carers could be improved at different stages of the disease.	General recommendations

Thank you for completing this survey.