

# A Snapshot of IPF Care in Europe



An EU-IPFF benchmarking report on access to  
Idiopathic Pulmonary Fibrosis (IPF) care in Europe

# Foreword

## from the EU-IPFF president



National IPF patient organisations have capitalised on this growing political focus, joining hands to drive policy change together.

The European Federation on Idiopathic Pulmonary Fibrosis & Related Disorders Federation (EU-IPFF) was established in 2016 to improve the care and the quality of life of IPF patients across the EU. Already we have developed the first European IPF Patient Charter and successfully encouraged the adoption of a Written Declaration by the European Parliament.

This 2018 EU-IPFF Benchmarking Report on Access to IPF Care in Europe is another important accomplishment for our community. The comparison of care standards identifies best practices to be encouraged and gaps to be filled, and also proposed concrete solutions to improve patients' quality of life. The resulting conclusions will propel policy asks to ensure a high level of quality care across Member States. Ultimately, we hope that this Report can inform decision-making at every level, to eliminate the inequalities in access to specialised care that people with idiopathic pulmonary fibrosis still experience today.

**Carlos Lines Millán**  
EU-IPFF President  
November 2018

Idiopathic Pulmonary Fibrosis (IPF) is a rare, long-term, progressive disease that affects the lungs. Most people have never heard of it. But for those affected, the symptoms are debilitating: a gradual decline in lung function leads to reduced oxygenation of the blood, brain and other vital organs. Without treatment, many patients only survive two to five years after diagnosis.

This makes recent pharmaceutical investment in this area a game-changer. IPF patients have a choice of treatment options. It has been enabled by the emergence of a European legislative framework supporting work on rare diseases. This began in 1999 with a European Regulation on orphan medicines that incentivised manufacturers to develop drugs. It has grown to include Council Conclusions released in 2009 that encouraged Member States to adopt a national plan or strategy for rare diseases, as well as the 2011 Directive on patients' rights in cross-border healthcare that established the European Reference Networks for rare diseases.

The content of this Benchmarking Report represents the views of the authors only and it is their sole responsibility.

This Report is not intended as an exhaustive or scientific review of the care and management of IPF in Europe. The interviews on which this Report is based have provided a useful insight into some issues affecting a selection of IPF patients and their families, as well as identifying some discrepancies in IPF care within and among some European countries.

This Report is a snapshot of the final Benchmarking Report. It has been developed in the context of an EU-IPFF event taking place at the European Parliament on 20 November 2018. A final report will be made available at a later stage.

Boeringher Ingelheim and F. Hoffmann-La Roche LTD financially supported the Benchmarking Report.

Recognising that this Benchmarking Report only represents a snapshot of the IPF landscape in thirteen EU countries, the EU-IPFF welcomes feedback. For more information or to share any concerns or comments you may have, please contact: [secretariat@eu-ipff.org](mailto:secretariat@eu-ipff.org)

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# Rationale

With a view to driving evidence-based policies, the European Idiopathic Pulmonary Fibrosis & Related Disorders Federation (EU-IPFF) has commissioned this Benchmarking Report to measure how those European countries represented by its members are performing on different areas of IPF care and management. The Report highlights best practices and identifies gaps where urgent policy action is needed.

The Benchmarking Report aims to:

- **Collect quality information about IPF patient care in EU-IPFF member countries in order to compare the situation of patients between countries;**
- **Identify gaps in IPF care across EU-IPFF member countries;**
- **Identify best practices in IPF care across Europe;**
- **Make recommendations for solutions that could improve IPF care and the overall quality of life of IPF patients**



# Methodology




A qualitative study was designed to collect data from 16 patient organisations from 13 Member States.<sup>1</sup> A structured questionnaire developed in collaboration with medical experts and patient representatives was used for phone interviews and included both closed and open-ended questions focused on the following areas:

- **Information about the disease;**
- **Diagnosis and access to specialised care;**
- **Access to pharmacological and non-pharmacological treatment;**
- **Access to palliative care and end-of-life care.**

EU-IPFF member organisations and partners were invited to take part in phone interviews pending written consent. Each EU-IPFF member organisation had the possibility to identify the most suitable representative for the 60-90 minute interview.<sup>2</sup>

The results of the interview fed into a scorecard illustrating country performances according to specific indicators. The results have been analysed using a points-based system: each answer has been assigned a colour code based on the level of progress and implementation. A detailed matrix was developed to support the codification process.

**The colours represent:**

-  **No existence of policy or development;**
-  **Policy or development exists but implementation has not started yet;**
-  **Policy or development exists and is fully implemented;**
-  **No information available.**

The codified answers were shared with interviewees and medical experts for approval and final validation. The findings of each interview have been used to develop a European scorecard that visually compares country performances against specific indicators.

**Acronyms used in the snapshot:**

**Idiopathic Pulmonary Fibrosis (IPF):** a rare, progressive and ultimately fatal pulmonary disease that affects the fragile tissue in the lungs. The cause of IPF is unknown and there is no cure.

**Interstitial Lung Diseases (ILDs):** a group of disorders characterised by progressive scarring of the lung tissue between and within the air sacs. IPF is an ILD.

**ILD Specialised Centres or Centres of Expertise:** centres for the management and care of rare disease patients, designated at a national level by each EU Member State. ILD/IPF centres of expertise specialise in ILDs and they aim to provide IPF patients (among others) with the highest standards of care around timely diagnosis, appropriate treatment, and follow-up.

<sup>1</sup>Austria, Belgium, Bulgaria, France, Germany, Greece, Ireland, Italy, The Netherlands, Poland, Spain, United Kingdom and Hungary. The questionnaire was translated by a translation agency in the following languages: German, Spanish, French and Italian.

<sup>2</sup>The majority of the interviews were conducted in English and four interviews were conducted in the native language spoken by some patient representatives (Italian, French and Spanish). Four interviewees preferred to respond to the questionnaire in writing.

# Highlights

The Benchmarking Report outlines the current state of IPF care and management in Europe, identifying best-performing countries along with challenges that demand greater political attention and an immediate response.



International guidelines on IPF<sup>3</sup>, validated by the relevant international respiratory medical societies, including the European Respiratory Society, are available. Only a handful of countries have developed or are developing national guidelines, or are on track to implement such guidelines<sup>4</sup>.



IPF patients lack access to reliable information. In most countries, information and self-management materials are either limited or not fully integrated into the care process. Newly diagnosed IPF patients do not always receive any supporting information from specialised centres; in the majority of the cases, it is up to patient support groups to provide these.



Across all countries, respondents reported that prompt diagnosis is challenging. Patient representatives noted slow referral periods, with extended gaps between the initial suspicion of IPF and a confirmed diagnosis. Delayed diagnosis or misdiagnosis due to unclear signs and symptoms are major obstacles within the diagnostic process.



EMA-approved pharmacological treatments for IPF are available and reimbursed with no out-of-pocket costs for patients in all thirteen countries surveyed. However, timely referral to specialised centres, a prerequisite for receiving a prescription for treatment, remains a major challenge. Many respondents deemed the 'wait-and-watch' approach to treatment to be a barrier.



A number of interviewees in different countries also reported access to non-pharmacological treatment (including oxygen therapy, pulmonary rehabilitation and lung transplantation) as being either restrictively available or, to some extent, unavailable. When available, it is not always fully covered or reimbursed, resulting in out-of-pocket expenses for patients.



Access to palliative care and end-of-life care is extremely fragmented. Some countries have established palliative care centres and teams, while others are only beginning to provide this kind of support.

“As an IPF patient, I was invited to join a team of expert healthcare professionals to review the German Guidelines on IPF. I strongly felt that I could contribute to this, providing input based on my personal experience. I am particularly satisfied because the concepts of timely access to treatment upon diagnosis, exceptional use of biopsy upon joint doctor-patient decision, and timely referral to a specialised ILD centre were included into the guidelines. I am glad that the patient’s voice was heard during such a process. Patients, alongside with medical experts, are the ones who know best what they need.”

**A patient from Germany**

<sup>3</sup> Available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5450933/>

<sup>4</sup> The following countries have developed national guidelines: Germany, United Kingdom, Ireland. The following countries are in the process of developing national guidelines: Poland, Austria.

# Diagnosis and access to specialised care



## Key challenge

Early diagnosis remains the main challenge across all countries surveyed.

International guidelines on the diagnosis of IPF<sup>5</sup> were updated in 2018. But they have not been fully implemented in all countries surveyed. Diagnostic procedures are generally standardised; however, the majority of countries surveyed do not have nationwide IPF diagnostic and care pathways. Instead, these are often established by each expert centre and can therefore vary from region to region.

General practitioners have a limited knowledge of or training in recognising IPF. The symptoms are therefore sometimes confused with those of other lung diseases. Additionally, genetic testing is not widely performed, not even when another family member has IPF. This further complicates the diagnostic process.

Timely access to specialised centres and multidisciplinary care has been flagged as a factor that can make a real difference for patients. Countries where patients have access to multidisciplinary teams perform better in the diagnostic process, resulting in a better experience for patients. Yet the composition of multidisciplinary teams varies greatly. Many

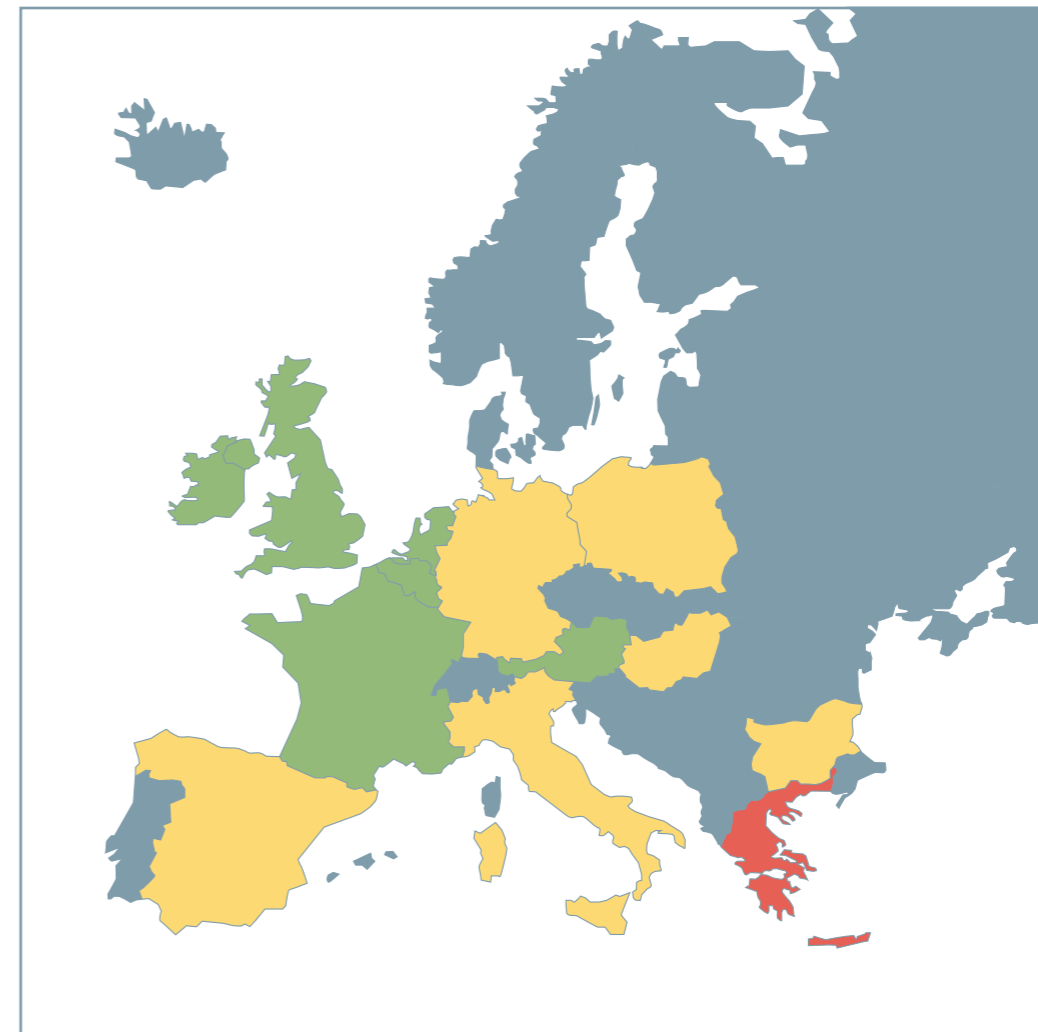
countries, such as Bulgaria, Italy and Spain, report shortages or a lack of recognition for specialist lung nurses, who play a crucial role in supporting patients and carers. By contrast, when specialist nurses are available to accompany patients in dealing with their disease every day, as is the case in the UK, positive effects are reported.

“Much remains to be done to improve IPF diagnosis in France. While I was diagnosed fairly quickly, the same cannot be said of my brother. He was misdiagnosed for years, not knowing what his condition was. It is only when I found out that I had IPF and after he shared this information with his doctor that he finally received an accurate diagnosis. We have to do more to ensure that people can be diagnosed in a more timely manner.”

*A patient from France*

“Communication with the respiratory physician and with members of the multidisciplinary team is essential in order to get quality information about how to manage IPF in everyday life. After my husband received his IPF diagnosis, we were really worried about what to do next and I did not know how best to support him. In those cases, it has been really essential to interact with the multidisciplinary team and to exchange information with fellow patients in the support group.”

*A carer from Austria*



<sup>5</sup> Available at: <https://www.atsjournals.org/doi/abs/10.1164/rccm.201807-1255ST>

# Access to pharmacological treatment



## Key challenge

Access to treatment in a timely manner following diagnosis is a priority for IPF patients.

There are currently no curative pharmacological treatments for people living with IPF. However, two antifibrotic drugs that can slow down disease progression have been approved by the European Medicines Agency. Reimbursement criteria for these drugs differ between countries, but none of the thirteen countries surveyed reported out-of-pocket costs for patients. However, this is not representative of the wider situation across the EU, since access to and reimbursement of EMA-approved drugs remains a barrier in countries not represented in the EU-IPFF (e.g. Malta).

Despite the theoretical availability of EMA-approved treatments, they are sometimes delayed in practice. This can be due to delayed diagnosis, clinical inertia (“wait-and-watch”), national prescription rules, or point-of-care treatment dispensation practices. Overcoming these challenges is vital, since timely access to treatment increases the ability to slow disease progression.

Even when IPF has been initially diagnosed, the “wait-and-watch” attitude is still reported. Some respiratory physicians prefer to monitor

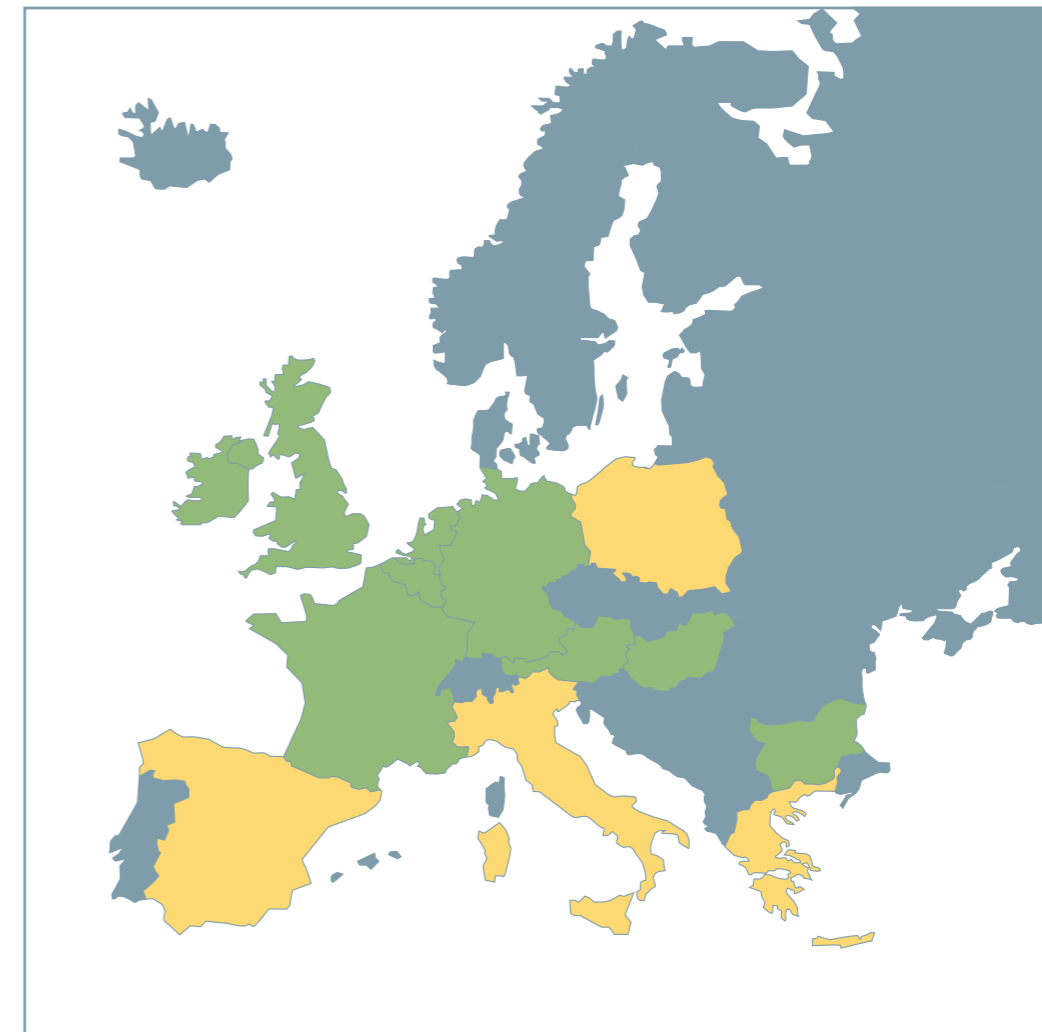
the evolution of the disease, postponing treatment. However, the unpredictable nature of IPF means that a patient’s condition can worsen rapidly: something that early adoption of antifibrotic treatment could mitigate.

Prescription rules are another significant hurdle. In most countries surveyed the prescription of pharmacological treatment is restricted to specialised ILD centres. However, in Austria, France, Germany, Ireland and Spain respiratory physicians can also prescribe treatment. Only in Ireland and Germany can general practitioners (GPs) prescribe antifibrotic treatments (with the renewal of prescriptions made by a respiratory physician).

Finally, treatment dispensation and the geographical distribution of centres present additional obstacles. In some countries (Belgium, Italy, Poland and Spain), treatment is only provided through hospital pharmacies or specialised centres. In Greece, only state pharmacies are allowed to dispense pharmacological treatment – but frequent shortages can result in long wait times for patients.

In other countries (Austria, Bulgaria, France, Germany, Hungary, Ireland, and The Netherlands), treatment can be dispensed by community pharmacies. This should make it easier to access treatment; however, not all community pharmacies have on-site availability of antifibrotic drugs, meaning patients have to order their treatment first before they can collect it. In the UK, community pharmacies offer home delivery, which speeds up access to prescribed treatment.

While, in principle, patients in all EU-IPFF member countries have access to and are reimbursed for antifibrotic treatments, it is clear that there are lingering disparities in the prescription and distribution processes between and within countries. To ensure equal access to treatment, these must be addressed.



# Access to non-pharmacological treatment



## Key challenge

Access to non-pharmacological treatment options is not homogeneous across Europe.

Non-pharmacological treatment options, such as lung transplantation, pulmonary rehabilitation, oxygen therapy and psychological support, are essential for holistic IPF care. Lung transplantation is currently the only curative form of treatment but it is far from ideal; access is limited, there are intrinsic risks associated with the procedure, and of course, there is a limited availability of organs. Oxygen therapy and pulmonary rehabilitation play an essential role in managing IPF but major inequalities persist as regards to patient access. Psychological support is often seen as a 'nice-to-have', with few hospitals or centres of expertise able to provide such support.

Lung transplantation is the only curative treatment available but it is only a viable option for a small number of IPF patients. There are many barriers to transplantation, such as the patient's health condition and age, the limited availability of viable organs, and long waiting times. There are specific limitations in some countries, such as in Poland, where there are a limited number of transplantation centres, or in Bulgaria and in Greece, which both lack lung transplantation centres – meaning patients must travel abroad for transplants.

Oxygen therapy at home or in hospital is a common therapeutic option for IPF patients. However, disparities exist between EU-IPFF Member States. These include: limited access (in Greece, it is only available in the hospital); delayed access; reimbursement issues (in Bulgaria and Poland, oxygen therapy at home is only partially reimbursed or not at all); or regional differences (in Ireland reimbursement is not standardised and depends on regional health budgets; in Italy, different regions provide different supply valves for the oxygen concentrators, affecting patients' in-country mobility).

As far as pulmonary rehabilitation is concerned, many respondents reported limited availability and reimbursement. In some countries, pulmonary rehabilitation programmes are not specifically dedicated to IPF patients. In Greece, for instance, IPF patients do not have access to such programmes – or if available, they are only reimbursed when administered in hospital. Both Bulgaria and Spain mentioned time limitations as their main barrier – in Spain rehabilitation is provided for four months, but it is only provided for ten days in Bulgaria.

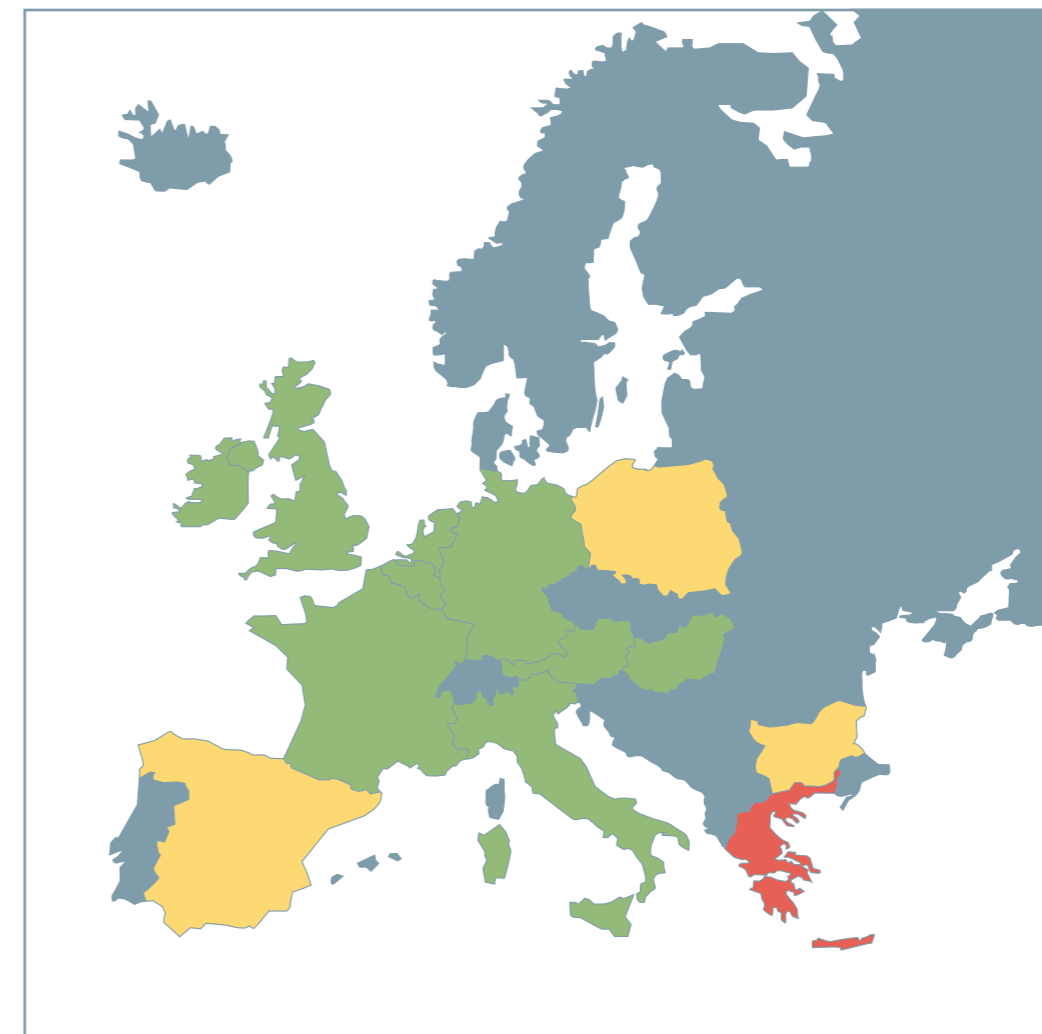
Only some countries (Belgium, France,

Germany, Ireland, UK) provide pulmonary rehabilitation at an ambulatory level, with very few countries having pulmonary rehabilitation centres either in-hospital or outside hospital at patients' disposal.

The majority of IPF patients reported a need for access to psychological and emotional support for themselves, for their families and for their carers. Access to psychological support is currently only available at a local level, through patient support groups. However, this is not systematically available and patients do not always know how to find help.

“The Spanish healthcare system greatly supports transplant programmes. In fact, in the last few years Spain has been recognised as a world leader in lung transplantation, and IPF is the most frequent reason for lung transplant.”

*A healthcare professional from Spain*





# Conclusions

Many people living with a rare disease face significant challenges, from diagnostic delays and lack of available treatments, to difficulty in accessing appropriate health services. Patients and their families feel isolated, unsupported and economically curtailed.

This Report reviewed best practices across thirteen EU countries, identifying existing gaps in the care and management of IPF. Although the results may not reflect the wider European situation, they do provide important insights into health inequalities and areas for improvement.

The findings show an alarming variation in access to specialised care across countries. Not one of the countries surveyed was excelling on all indicators. However, some countries did display best practices that could be replicated elsewhere.

To enable transformation in IPF care and management, action must be taken in all countries, starting with the implementation of existing guidelines to help standardise processes and address health inequalities.

Greater awareness of IPF signs and symptoms among general practitioners is needed to address delays in diagnosis and increase referral to specialist care. Rapid referral can improve diagnosis and timely access to

treatment, which can slow disease progression. Addressing the disconnect between primary and secondary care, implementing more efficient treatment dispensing practices and ensuring that available treatments are delivered to the right patient in a timely manner could significantly improve the patient experience. Increasing access to multidisciplinary teams, including specialist nurses, is vital to challenge clinical inertia and improve patients' quality of life.

The Report showed that too many barriers exist in access to non-pharmacological treatment including lung transplantation, supplemental oxygen, pulmonary rehabilitation, and palliative care. Long waiting lists and lack of donor organ availability represent some of the main hindrances to lung transplantation. Oxygen therapy and pulmonary rehabilitation can make a positive impact but action must be taken to make it more available, accessible and affordable. Similarly, palliative care should be destigmatised and better embedded into IPF treatment plans. Finally, for patients living with IPF, access to psychological support is fundamental and must be offered systematically and holistically.

*"A rare disease like IPF has been unnoticed for years, but this Benchmarking Report represents a good opportunity to shed light on such a forgotten disease. The burden of the disease is not only on the patient himself, but also on the family and the society as a whole. The indirect costs of IPF and its implications on quality of life are significant and cannot be ignored."*

*A patient representative from Italy*



# Call to action

Across the countries surveyed, there is a clear need to improve the diagnostic, treatment and care pathway for IPF patients and to address fragmentation of IPF care, which is creating huge health inequalities between and within countries. To support evidence-based policy-making, the EU-IPFF have identified recommendations that address the main barriers previously outlined in the Report.

While healthcare delivery remains a Member State competence, there is a role for the EU to play in sharing best practices and pooling resources, to the benefit of all European IPF patients. The European Reference Networks, in particular, represent an important avenue for the improvement of all areas mentioned by this Report.

The upcoming 2019-2024 European parliamentary term represents an opportunity for future EU leaders to promote radical policy change that can improve healthcare services and outcomes. We call upon current and future European policy-makers to ensure that:



Rare diseases remain a priority in the future European Commission Agenda.



Funding is earmarked for rare diseases in the future Horizon Europe framework, in order to reach the ambitious target of developing 1.000 new therapies for rare diseases by 2027, including a cure for IPF.<sup>6</sup>



Greater support is given to the integration and sustainability of established European Reference Networks for screening at-risk groups, expediting diagnosis and encouraging standardisation of rare disease care (including access to non-pharmacological treatment).



Opportunities for rare disease patient groups to collaborate and capacity-build are encouraged through future funding programmes, such as the European Social Fund Plus and the European Joint Programme on Rare Diseases.

## At a national level, national and regional governments can improve the delivery of healthcare services by focusing on:



Raising awareness of IPF amongst healthcare professionals and primary care practitioners to improve the recognition of early signs and symptoms.



Ensuring the implementation of IPF guidelines within the country.



Supporting collaboration with relevant European Reference Networks and networking excellence at national level, to better connect primary and secondary care and foster early diagnosis and timely access to treatment.



Promoting multi-disciplinary care and recognition of specialised nurses at national level.



Recognising the burden and financial impact of IPF on patients and their families, and ensure access to non-pharmacological treatment, especially oxygen therapy.



Providing access to palliative care to all IPF patients.



Encouraging the development of local support groups, given their role in providing patients with information and peer support.

The EU-IPFF is committed to working with all stakeholders to ensure that action on rare diseases remains a priority area at European and national level and support exchange of knowledge to guarantee that people with IPF have access to fair, equal and continuous quality care regardless of where they live in Europe.

<sup>6</sup> As set by the International Rare Diseases Research Consortium (IRDiRC) - <http://www.irdirc.org/about-us/vision-goals/>

# The European Scorecard

INDICATORS	COUNTRIES												
	Austria	Belgium	Bulgaria	France	Germany	Greece	Hungary	Ireland	Italy	The Netherlands	Poland	Spain	United Kingdom
GUIDELINES													
Availability of IPF guidelines (national and international)	Green	Green	Yellow	Green	Green	Red	Green	Green	Yellow	Green	Green	Yellow	Green
Implementation of IPF guidelines	Green	Green	Yellow	Yellow	Green	Red	Green	Green	Yellow	Green	Green	Red	Yellow
Assessment of IPF care pathways	Red	Yellow	Green	Grey	Red	Red	Green	Green	Yellow	Grey	Red	Red	Red
DIAGNOSIS AND ACCESS TO SPECIALISED CARE													
Assessment of diagnostic procedure	Green	Green	Green	Green	Green	Green	Green	Green	Yellow	Green	Green	Yellow	Green
Assessment of standardisation of IPF diagnosis	Green	Green	Grey	Grey	Green	Red	Yellow	Grey	Yellow	Green	Grey	Yellow	Green
Availability of information materials	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow
Assessment of self-management education tools	Red	Red	Yellow	Yellow	Yellow	Red	Red	Green	Yellow	Yellow	Yellow	Red	Yellow
Assessment of distribution and activities of specialised centres	Green	Green	Yellow	Green	Yellow	Yellow	Grey	Green	Yellow	Green	Yellow	Yellow	Green
Availability of and access to multidisciplinary team	Green	Green	Yellow	Green	Green	Red	Grey	Green	Green	Green	Yellow	Red	Green
ACCESS TO PHARMACOLOGICAL TREATMENT													
Availability of pharmacological treatment	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green
Reimbursement of pharmacological treatment	Green	Green	Green	Green	Green	Green	Green	Yellow	Green	Green	Green	Green	Green
Assessment of distribution of prescription centres	Green	Yellow	Green	Green	Green	Yellow	Green	Yellow	Yellow	Green	Yellow	Yellow	Yellow
Assessment of distribution of dispensation centres	Green	Green	Green	Green	Green	Yellow	Green	Yellow	Green	Green	Yellow	Yellow	Green
ACCESS TO NON PHARMACOLOGICAL TREATMENT													
Availability of and access to oxygen therapy in the hospital	Green	Green	Yellow	Green	Green	Yellow	Green	Green	Green	Green	Yellow	Green	Green
Reimbursement of oxygen therapy in the hospital	Green	Green	Green	Green	Green	Yellow	Green	Yellow	Green	Green	Green	Green	Green
Availability of and access to oxygen therapy at home	Green	Green	Green	Green	Green	Red	Green	Green	Green	Green	Yellow	Green	Green
Reimbursement of oxygen therapy at home	Green	Green	Red	Green	Green	Red	Yellow	Yellow	Green	Green	Red	Green	Green
Availability of and access to pulmonary rehabilitation programmes	Green	Green	Yellow	Green	Green	Red	Green	Green	Green	Green	Green	Yellow	Green
Coverage of pulmonary rehabilitation programme	Green	Yellow	Green	Green	Green	Red	Green	Green	Green	Green	Green	Yellow	Green
Availability of lung transplants	Green	Green	Red	Green	Green	Red	Green	Green	Green	Green	Yellow	Green	Green
Availability of and accessibility to information on clinical trials	Green	Green	Green	Green	Green	Red	Green	Green	Yellow	Green	Green	Green	Green
ACCESS TO PALLIATIVE CARE AND END-OF-LIFE CARE													
Availability of and access to palliative care	Green	Green	Green	Green	Green	Red	Red	Green	Yellow	Green	Yellow	Yellow	Green
Coverage of palliative care	Green	Green	Red	Green	Green	Red	Grey	Green	Green	Green	Green	Green	Green
Availability of palliative care centres and mobile teams	Green	Green	Grey	Green	Green	Red	Grey	Green	Red	Green	Green	Yellow	Green
Inclusivity of decision-making process for patients and families in palliative care	Green	Green	Grey	Green	Green	Red	Grey	Green	Yellow	Green	Green	Yellow	Yellow
Availability of and access to home hospice	Yellow	Yellow	Yellow	Yellow	Green	Red	Red	Yellow	Red	Green	Red	Yellow	Yellow

# Acknowledgements

The EU-IPFF would like to thank all the patients, carers and healthcare professionals who contributed to this Report by sharing their professional and personal experiences. In particular, we would like to thank the following patient organisations:

LOT Austria (AT)

Lungenfibrose Forum Austria (AT)

Association Belge contre la Fibrose Pulmonaire Idiopathique (BE)

Belgische vereniging voor longfibrose (BE)

IPF Bulgaria (BG)

Association Fibrose Pulmonaire Idiopathique Pierre Enjalran (FR)

Lungenfibrose e.V. (DE)

Hellenic Pulmonary Fibrosis Association (GR)

Magyar Tüdőfibrozis Egyesület (HU)

Irish Lung Fibrosis Association (IE)

AMA Fuori dal Buio (IT)

FIMARP (IT)

Longfibrose Patiëntenvereniging (NL)

IPF Polish Society (PL)

Asociación de Familiares y Enfermos de Fibrosis Pulmonar Idiopática (ES)

Action for Pulmonary Fibrosis (UK)

British Lung Foundation (UK)

Pulmonary Fibrosis Trust (UK)

The EU-IPFF also wants to thank all its members and the members of the Scientific Advisory Board for their help in contributing to this Benchmarking Report and for their invaluable comments on earlier drafts.

The EU-IPFF is also grateful to Boeringher Ingelheim and F. Hoffmann-La Roche LTD who have financially supported the development of this Benchmarking Report.

# Limitations

## For the purpose of this Benchmarking Report:

- No differentiation was made between the severity of IPF (moderate, mild and severe cases);
- The sample of the study represents an inherent bias since it was limited to the EU-IPFF member countries (Austria, Belgium, Bulgaria, France, Germany, Greece, Ireland, Italy, The Netherlands, Poland, Spain, United Kingdom plus Hungary).
- Perceptions from patient groups located in countries not represented by the EU-IPFF are not covered by this Report;
- The responses provided by patient groups are appropriate to the best of their knowledge, however they might be stemming from personal experiences or from experiences of other patients in each association;
- Some questions that were asked during the interviews have not been included in this short Report as not enough information on certain indicators was provided by the interviewees or responses varied too broadly and did not allow for comparison;
- Some patient representatives participated in phone interviews; for health-related reasons or for language-related reasons, some patient representatives filled in a written questionnaire instead;
- The replies were validated by the members of the EU-IPFF Scientific Advisory Board; however, the majority of them works in specialised ILD centres, which could affect their perception of IPF care in their country;
- The answers to the phone interviews were codified by interviewers; an interview guide was developed to minimise the personal bias but cannot fully eliminate it;
- When possible, the interviews were conducted in the native language of the respondent and then translated into English;
- The same colour code used to assess different countries does not necessarily mirror the same level of progression.



The European Idiopathic Pulmonary Fibrosis and Related Disorders Federation (EU-IPFF) brings together seventeen European national patient associations from twelve European countries. Its mission is to serve as the trusted resource for the IPF community by raising awareness, providing disease education, advancing care, and funding research. EU-IPFF collaborates with physicians, medical organisations, people with IPF, caregivers and policy-makers throughout Europe.

For further information, please visit [www.eu-ipff.org](http://www.eu-ipff.org).