



**The EU-IPFF Training on
the Benchmarking Report
2021**

The EU-IPFF Benchmarking Report Training Sessions

With a view to driving evidence-based policies, the European Idiopathic Pulmonary Fibrosis & Related Disorders Federation (EU-IPFF) commissioned a first edition of the Benchmarking Report in 2018. Its goal was to measure how European countries, where EU-IPFF members are based, were performing against a number of criteria related to IPF care and management. A [new edition](#) of the report (2020) is now available and includes four additional countries. The Report highlights best practices and identifies gaps where urgent policy action is needed.

The EU-IPFF Secretariat organised a series of training events associated with the publication of the second edition of the EU-IPFF Benchmarking Report and Country Reports in January and February 2021.

The purpose of the training and discussion sessions was to ensure that the participants, members of EU-IPFF through their respective country organisations, understand and can deploy the Benchmarking Report and the respective Country Reports in their local policy work. The Benchmarking Report and the associated toolkit provide information and recommendations for evidence-based advocacy work both in scientific research and health policy.

Seen as the countries most in need, three country member groups were invited to the training program:

- Greece
- Bulgaria
- Hungary

Unfortunately, and due to the disruption in the healthcare systems and the organisation caused by the COVID-19 pandemic, the group from Hungary stepped back from the program.

The sessions were organised according to the following schedule:

Date	Country group	Topic
13.01.2021	Bulgaria	Why are we patient advocates? History of patient advocacy Evidence-based advocacy The Benchmarking Reports
27.01.2021	Bulgaria	General principles of universal healthcare Healthcare and the civil society in low- and middle-income countries Country specific issues Discussion
11.02.2021	Greece	Why are we patient advocates? History of patient advocacy Evidence-based advocacy The Benchmarking Reports
24.02.2021	Greece	General principles of universal healthcare Healthcare and the civil society in low- and middle-income countries Country specific issues Discussion

Each online meeting lasted app. 90 minutes and were moderated by Alba Ubide from the EU-IPFF Secretariat and Dr Tamás Bereczky from Patvocates. Simultaneous translation services were provided for all groups as not all participants were sufficiently fluent in English. For each second session on universal healthcare and the role of the civil society, Prof. Dr Zoltán Kaló from the Budapest Semmelweis Medical University and Syreon Consulting was included as guest speaker. A lively discussion accompanied all sessions.

The country groups included in this project have some common features that emerged from the Benchmarking Report research exercise and common knowledge across the patient communities:

- Resource-limited settings in low- and middle-income countries
- Difficulties when accessing treatment options (e.g. lung transplantation)
- Low level of organisation of the patient community
- Funding difficulties of the patient groups/organisations
- Difficult environment for patient advocacy

Additional challenges were discovered in the course of the discussions during the training sessions:

- The pandemic has posed great organisational challenges to the patient communities
- The strain on healthcare systems has increased with the pandemic
- Language issues remain important from the perspective of international cooperation
- Cooperation with other patient groups across Europe would be essential

These points will need to be addressed with some intensity in the future in order to allow these patient groups to make progress towards their advocacy objectives.

Training topics

Common topics of the training sessions included the following.

Why are we patient advocates?

This module of the training explained the basics of patient advocacy and the importance of organised and systematic work for the achievement of key patient advocacy objectives.

Why are we patient advocates? - We want impact for the patients' good

- **Support patients** and their families affected by a challenging disease to make the right choices
- **Help clinicians** to be able to provide the best possible services to their patients, and avert bad and outdated practices
- **Influence regulators and payors** to make sure they are basing their decisions on patient preferences and needs
- **Tell policy-makers to do policy for patients**, not just about patients
- **Educate** ourselves and fellow patients about better health and science



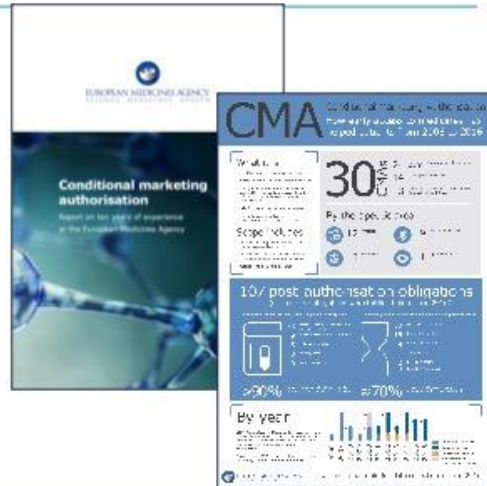
History of patient advocacy

The short introduction to the history of patient advocacy and activism helped the participants understand and contextualise the work and achievements of patient advocacy that started and has become increasingly important since the earlier nineteen-eighties.

Patient engagement is powerful

Success Stories from patient engagement

- ❖ New **criteria for conditional approval (EMA, 2006)** (Gilead first to apply, access 12 months accelerated)
- ❖ Lazarus effect on dying patients & HIV cohort studies in place to **proof cost-effectiveness of expensive treatment**
- ❖ Cross-Atlantic **lobbying for pivotal trial including 2 New Chemical Entities**, ending exposure to monotherapies & multidrug resistance 2007
- ❖ **Single tablet regimens** for convenience and adherence, while having single compounds to control toxicities, resistance and adapt drug levels, FDA: 27 NCE & 14 combos 1987-2017
- ❖ **Tiered pricing & voluntary licences** supporting global access (2000-present)



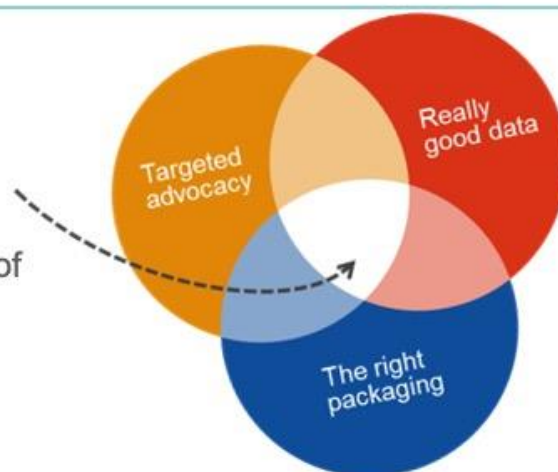
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https://www.ema.europa.eu/en/documents/other/conditional-marketing-authorisation-how-early-access-medicines-has-helped-patients-2006-2016_en.pdf

Evidence-based advocacy

The module of evidence-based patient advocacy highlighted not only the key principles of collecting, organising and deploying evidence, but also showcased some important examples for evidence-based advocacy projects by other patient groups.

Evidence-based advocacy

Advocating in a targeted, evidence-based, well-educated and professional manner, and measure impact and outcomes of what we do.



The Benchmarking Reports

Building on the examples for evidence-based advocacy projects, the case of the Benchmarking Reports was introduced as another relevant example for building an evidence base for more effective advocacy work.

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	Red	Yellow	Green	Yellow	Red	Red	Green	Green	Yellow	Green	Red	Red	Green
Assessment of IPF care pathways	Red	Yellow	Green	Grey	Red	Red	Green	Green	Yellow	Green	Red	Red	Green
DIAGNOSIS AND ACCESS TO SPECIALISED CARE													
Assessment of diagnostic procedure	Green	Green	Green	Green	Green	Red	Green	Green	Yellow	Green	Green	Yellow	Green
Assessment of standardisation of IPF diagnosis	Green	Green	Grey	Green	Green	Red	Green	Green	Yellow	Green	Green	Yellow	Green
Availability of information materials	Yellow	Green	Green	Green	Green	Red	Green	Green	Yellow	Green	Green	Yellow	Green
Assessment of self-management education tools	Red	Red	Green	Green	Green	Red	Red	Green	Yellow	Green	Green	Red	Green
Assessment of distribution and activities of specialised centres	Green	Green	Green	Green	Green	Red	Green	Green	Yellow	Green	Green	Red	Green
Availability of and access to multidisciplinary team	Green	Green	Yellow	Green	Green	Red	Green	Green	Yellow	Green	Green	Red	Green
ACCESS TO PHARMACOLOGICAL TREATMENT													
Availability of pharmacological treatment	Green	Green	Green	Green	Green	Green	Green	Green	Yellow	Green	Green	Green	Green
Reimbursement of pharmacological treatment	Green	Green	Green	Green	Green	Green	Green	Green	Yellow	Green	Green	Green	Green
Assessment of distribution of prescription centres	Green	Yellow	Green	Green	Green	Green	Green	Green	Yellow	Green	Green	Green	Green
Assessment of distribution of dispensation centres	Green	Green	Green	Green	Green	Green	Green	Green	Yellow	Green	Green	Green	Green
ACCESS TO NON PHARMACOLOGICAL TREATMENT													
Availability of and access to oxygen therapy in the hospital	Green	Green	Yellow	Green	Green	Red	Green	Green	Yellow	Green	Green	Yellow	Green
Reimbursement of oxygen therapy in the hospital	Green	Green	Green	Green	Green	Red	Green	Green	Yellow	Green	Green	Yellow	Green
Availability of and access to oxygen therapy at home	Green	Green	Green	Green	Green	Red	Green	Green	Yellow	Green	Green	Yellow	Green
Reimbursement of oxygen therapy at home	Green	Green	Red	Green	Green	Red	Green	Green	Yellow	Green	Green	Red	Green
Availability of and access to pulmonary rehabilitation programmes	Green	Green	Yellow	Green	Green	Red	Green	Green	Yellow	Green	Green	Yellow	Green
Coverage of pulmonary rehabilitation programme	Green	Yellow	Green	Green	Green	Red	Green	Green	Yellow	Green	Green	Yellow	Green
Availability of lung transplants	Green	Green	Red	Green	Green	Red	Green	Green	Yellow	Green	Green	Yellow	Green
Availability of and accessibility to information on clinical trials	Green	Green	Green	Green	Green	Red	Green	Green	Yellow	Green	Green	Yellow	Green
ACCESS TO PALLIATIVE CARE AND END-OF-LIFE CARE													
Availability of and access to palliative care	Green	Green	Red	Green	Green	Red	Green	Green	Yellow	Green	Green	Yellow	Green
Coverage of palliative care	Green	Green	Red	Green	Green	Red	Green	Green	Yellow	Green	Green	Yellow	Green
Availability of palliative care centres and mobile teams	Green	Green	Grey	Green	Green	Red	Green	Green	Yellow	Green	Green	Yellow	Green
Industry of decision-making process for patients and families in palliative care	Green	Green	Green	Green	Green	Red	Green	Green	Yellow	Green	Green	Yellow	Green
Availability of and access to home hospices	Green	Green	Green	Green	Green	Red	Green	Green	Yellow	Green	Green	Yellow	Green

General principles of universal healthcare

Patient advocacy is embedded in a border context of global efforts to ensure universal healthcare, equity and fairness in the access to healthcare services.

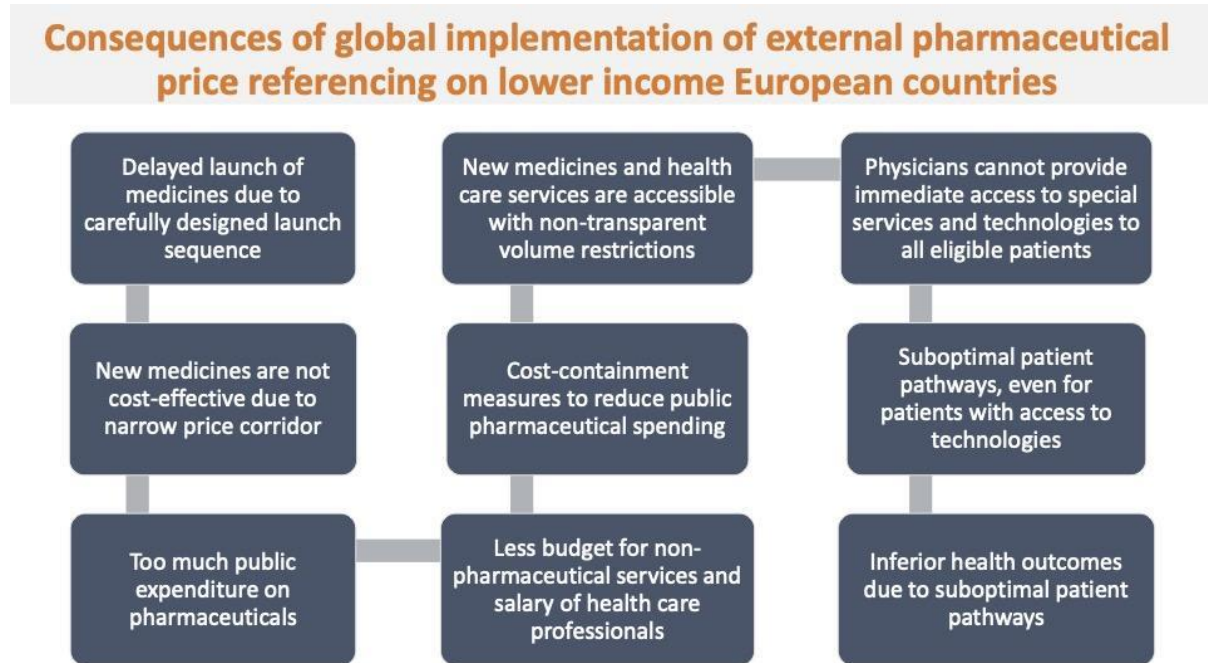
Universal Health Coverage and Access

- Universal health coverage is the goal that all people obtain the health services they need **without risking financial hardship** from unaffordable out-of-pocket payments
- **Universal health coverage** is attained when people obtain the health services they need and benefit from financial risk protection.
- **Access**, on the other hand, is the opportunity or ability to do both things. Hence, universal health coverage is not possible without universal access, but the two are not the same.



Healthcare and the civil society in low- and middle-income countries

Prof. Kaló's presentation introduced some common features of low- and middle-income countries that are particularly challenged when it comes to the development and sustainability of their healthcare systems.



Country specific issues

Based on the Benchmarking Reports and scorecards, each country's situation was analysed separately.

Discussion

The participants were allowed ample time to raise questions and discussion points. Possible reactions to the changed and more difficult situation due to the pandemic stood out.

Bulgaria



Bulgaria IPF Scorecard

<p>General introduction and guidelines</p> <p>The ATS/ERS/JRS/ALAT international IPF guidelines are available in Bulgaria, however, they are not always correctly implemented in the Bulgarian centres. No national IPF guidelines are available.</p> <p>IPF is included in the list of rare diseases. However, the disease file including information about the course of disease and its prognosis is still under development.</p>	<p>Access to non-pharmacological treatment</p>  <p>Key challenge: There are currently no clinics in Bulgaria that can perform lung transplantation. However, the Bulgarian Ministry of Health has recently signed an agreement with a foreign clinic that can perform lung transplantation for Bulgarian patients. Access to pulmonary rehabilitation remains too limited.</p> <p>Non-pharmacological treatment options are available to IPF patients in Bulgaria but the costs associated with these treatments are not always fully reimbursed. Oxygen therapy is available in hospital and at home but is only reimbursed in the case of the former.</p> <p>Pulmonary rehabilitation programmes for patients with chronic lung diseases are available in hospital but no specific IPF programmes have been developed. The costs are covered only for a period of 10 days per year and any additional days are at the expense of the patient.</p> <p>Lung transplantations are not performed in Bulgaria. IPF patients in Bulgaria have access to clinical trials.</p>
<p>Diagnosis and access to specialised care</p>  <p>Key challenge: Delayed diagnosis and lack of communication between the general practitioner and the respiratory physician have been reported as the main challenges in Bulgaria. Timely referral to a respiratory specialist would ensure accurate diagnosis and faster access to treatment.</p> <p>In Bulgaria there are no specialised ILD centres but there are 6 hospitals specialised in lung diseases, which do not operate fully as specialised centers (the University Hospital of respiratory diseases "St. Sofia" - Sofia Medical University; the pulmonary department of the Military Hospital Sofia - Medical Faculty of Sofia University; the Acibadem City Clinic Tokuda Hospital in Sofia; the University Hospital "St. George" - Plovdiv Medical University; the University Hospital "St. Marina" - Medical University Varna; the University Hospital "G. Stranski" - Medical University Pleven).</p> <p>IPF guidelines are only partially implemented in these hospitals. Although multidisciplinary teams (MDTs) MDTs are becoming more common in Bulgarian hospitals, MDTs for IPF care are available and fully in place in only one centre. There are no ILD nurses who can support patients in their daily lives. Upon diagnosis, information materials are available to patients, mainly provided by the local patient support groups.</p>	<p>Access to palliative care and end-of-life care</p>  <p>Key challenge: Palliative care costs are not reimbursed for IPF patients.</p> <p>Palliative care is available to IPF patients in Bulgaria but it is not reimbursed by the national healthcare system. Only private hospices provide this type of care and the costs can be high.</p> <p>In the overall patient journey, the families and local support groups are the ones providing relevant support to IPF patients.</p>
<p>Access to pharmacological treatment</p>  <p>Key challenge: Although both EMA-approved pharmacological treatments for IPF are approved and reimbursed, patients still experience some delays in access to treatment as the therapy is not started immediately after diagnosis.</p> <p>EMA-approved pharmacological treatments for IPF are available and reimbursed with no out-of-pocket costs for Bulgarian patients. The pharmacological treatments can be prescribed by five of the clinics specialised in lung diseases and they are dispensed by community pharmacies.</p> <p>The current prescription rules might represent a barrier to access to pharmacological treatment; it has been reported that allowing general practitioners or respiratory physicians to prescribe treatment has the potential to improve the issue.</p>	<p>Patient representative statement</p> <p><i>"Delayed diagnosis is a big issue in Bulgaria and it is mainly due to lack of knowledge of the disease at primary care level and late referrals to respiratory physicians. In addition, the lack of communication between specialised centres and the National Health Insurance Fund, which reimburses the treatment, causes further delays in access to pharmacological treatments. We at IPF Bulgaria, hope that this situation will improve soon so that access to pharmacological treatments for IPF patients will not be delayed unnecessarily."</i></p> <p>Todor Mangarov, IPF Bulgaria</p>

The main issue defined for Bulgaria is that there are delays in the diagnosis of IPF exacerbated by a delay in communication between the general practitioner and the lung specialist. Another important issue is the lack of access to lung transplantation as a treatment option. Palliative care options are not reimbursed for IPF patients, creating an additional barrier for end-of-life treatment.

The participants confirmed the following challenges:

- Late diagnosis
- Late or no referrals
- Issues with prescribing
- Lack of lung transplant capacities
- Cost of non-pharmaceutical treatment not always reimbursed
- No reimbursement for palliative care

They also added some more comments that have an influence on the treatment and wellbeing of IPF patients, notably:

- Lack of awareness of IPF
- The impact of the pandemic
- Lack of organisation in the healthcare system
- Corruption
- Lack of resources


They also had some specific questions that were successfully discussed with recommendation and the sharing of experience by the trainers.

- Working with other stakeholders in the healthcare system
- Working with other patient groups internationally
- Cooperation with German and Hungarian patient group(s) as lung transplantation is

- mostly done in Germany and Hungary
- Psychosocial support for the patients organised by the patient group
- Exploiting synergies between IPF and COVID-19 infection

Following extensive and very engaging discussions, the training was concluded with a rudimentary plan by the patient group to start building a communications plan. This should not only target the healthcare system in the country but also the patients, and ultimately also the international patient community. The purpose should be ensuring a better flow of information and coordination along joint interests. The EU-IPFF Secretariat could play a key role in making sure that cooperation across patient groups can be facilitated internationally.

Greece



<p>General introduction and guidelines</p> <p>The ATS/ERS/URSLAT 2018 international IPF guidelines are not always correctly implemented in Greece. The Hellenic Thoracic Society and the Scientific Society for Rare Diseases & Orphan Drugs organise a number of scientific activities for physicians throughout the year that help address some of the implementation issues.</p> <p>The Greek Alliance of Rare Diseases refers to the ORPHANET's list of rare diseases among which IPF is included. However, an official list is not available.</p>	<p>Access to non-pharmacological treatment</p> <p>Key challenge: Access to non-pharmacological treatments is very poor in Greece, in particular lung transplantation which is virtually not an option for Greek patients as there is no lung transplantation centre in the country.</p> <p>Non-pharmacological treatment options are not always available and fully reimbursed for IPF patients in Greece. For example, to have access to liquid oxygen, patients need to pay 25% of the cost.</p> <p>IPF patients do not have easy access to pulmonary rehabilitation programmes, since only a few hospitals provide this service. At the moment, there is no lung transplantation centre in Greece. Greek patients have to go to a lung transplantation centre abroad (usually in Austria). Given that there are not enough lung donors from Greece the majority of Greek candidates cannot receive a transplant, even abroad.</p> <p>There are a few Greek centres participating in clinical trials but access to these trials seems to be problematic for patients.</p>
<p>Diagnosis and access to specialised care</p> <p>Key challenge: Getting a correct and timely diagnosis is very challenging as general practitioners are not always aware of the disease.</p> <p>There are a few specialised centres in major Greek cities; however, there are no IPF patient pathways in place. Misdiagnosis and late diagnosis are very common in the country a multidisciplinary teams are not available to patients.</p> <p>Upon diagnosis, information materials are available for patients; they are provided by the existing patient support group and the specialised centres.</p>	<p>Access to palliative care and end-of-life care</p> <p>Key challenge: Patients have limited access to palliative care.</p> <p>Palliative care is offered only in a few hospitals in the country. Home hospice is not a viable option for patients.</p> <p>Families and respiratory physicians are the ones providing relevant support to IPF patients. IPF has a huge impact on family members acting as the patient carer; there is a significant loss in terms of productivity at work for these relatives who would need to quit their job to take care of the patients.</p>
<p>Access to pharmacological treatment</p> <p>Key challenge: Only state pharmacies are allowed to dispense pharmacological treatment, pending the approval of doctor's application by a government appointed committee, creating unnecessary delays in patient access.</p> <p>EMA-approved pharmacological treatments for IPF are available and reimbursed with no out-of-pocket costs for patients. The pharmacological treatments can only be prescribed by physicians working in state or private hospitals. These physicians need to submit an application - including all the necessary examinations - to a government-approved committee and it might take up to 10-15 days in order to get an approval (due to the treatment's high cost). This can result in long waiting times for patients. There are also issues with point-of-care dispensing as the pharmacological treatment can only be dispensed by the national health scheme pharmacies.</p> <p>Access to pharmacological treatments also differs from one city to another. In fact, in smaller cities, the distribution system is more efficient and less exhausting for the patient, who receives the pharmacological treatment at home by post. On the contrary, in larger cities patients experience long waiting times in order to get the treatment.</p>	<p>Patient statement</p> <p><i>"In addition to proper and effective medical and professional help, patients need the support of family, friends and patient organisations at both national and European level, to give us hope, and belief in a better future for IPF patients."</i></p> <p>Anthony Antoniou, Hellenic Pulmonary Fibrosis Association</p>

Key challenges in Greece include:

- Timely and correct diagnosis
- Administrative barriers delay access to treatment
- Very limited capacities for lung transplantation
- Limited access to palliative care

Additional points were also uncovered during the discussions:

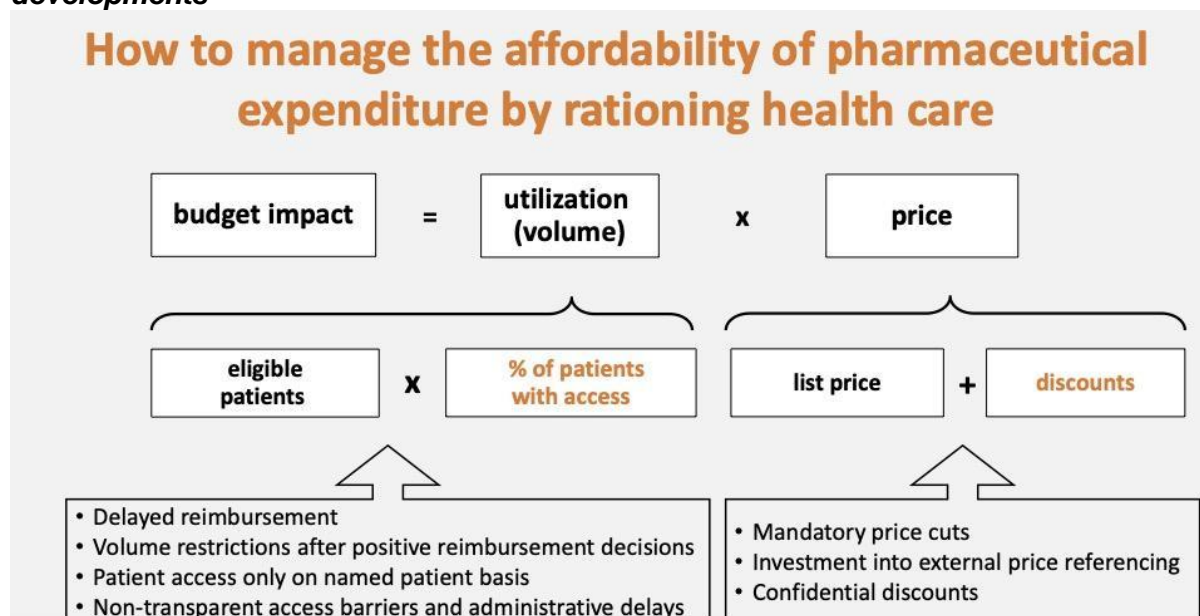
- The impact of the pandemic
- Lack of awareness of IPF
- Lack of organisation in the healthcare system
- Corruption
- Lack of resources
- Disarray in healthcare due to the general political and economic situation
- Cooperation with German and Hungarian patient group(s) as lung transplantation is mostly done in Germany and Hungary

Some of the key issues overlap with Bulgaria (and also Hungary). These make it even more reasonable and desirable for the countries' patient groups to work together and develop a joint advocacy strategy with the involvement of additional partners from inside and outside the IPF communities to leverage on skills and experiences.

The way forward

A few easier targets for further work (together with the EU-IPFF Secretariat) could be identified in the course of the training sessions and discussions. It is advisable to keep the patient group in Hungary included in the work and communication flow as we expect the burden of the pandemic to ease, which will free up resources and capacities on the patients' side to work together with the EU-IPFF Secretariat and other stakeholders.

Critical analysis of the current situation and its relationship with global trends and developments



As certain features of the three countries overlap and are determined by external factors such as their economic and political situation, it makes sense to perform a joint analysis of the similarities and differences in the challenges and possibilities. This exercise could deepen the findings of the Benchmarking Reports and the scorecards, and operationalise the findings for coordinated advocacy action.

Improving access to certain medical technologies, especially lung transplantation

There is a limited number of clinics that perform lung transplantation in Europe. Germany and Hungary were mentioned as examples for countries where this service may also be available to patients from other countries. Therefore, it may make sense to establish coordinated and regular exchanges with patient groups and organisations in these countries, and also to establish contacts with the healthcare providers and institutions involved.

Assessing and coping with the impact of the COVID-19 pandemic

The impact of the pandemic was a recurring theme during the training sessions and the discussion rounds. It seemed that the pandemic itself, the associated isolation and insecurity, the resulting disarray have caused much distress in the communities of patients already living with a difficult lung condition.

The need for psychosocial support was mentioned in both groups several times. Specific questions were raised about how the patient community can organise its own psychosocial support structures, and how such a service can be funded. It may make sense to develop a project at EU-IPFF that looks at the impact of the pandemic and how patients can be helped with coping with it.

Psychosocial support to the IPF community

- Self-organising
 - Designing a support service
 - Setting up a support service
 - Fundraising for support service
- Recruiting friendly psychologists
 - Volunteers
 - Paid professionals
- Reaching out to other patient organisations
 - They may have a similar service already
 - You may be able to split the costs
- Developing a specific project for fundraising

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Keeping IPF on the agenda

The lack of attention and awareness of IPF appeared as a general issue in all conversations. The patient community thinks that one of the reasons why there are few treatment options and limited access to them is that neither the general public nor healthcare providers are aware of or sufficiently familiar with IPF. Several questions in the discussion rounds were aimed at wanting to know how better communications and awareness campaigns could be built to improve the situation.

Communication about IPF (and keeping it on the agenda)

- Developing a consistent communication plan
 - Ask for help from EU-IPFF
 - Map your volunteers' skills and capacities
 - Use professional approaches
- Implementing the communication plan
 - You must act NOW so that there is an effect LATER
 - While there is a lot of noise around COVID-19, your claims are not less valid
 - Focus on a professional working method
 - Remain patient and don't panic
- Look for examples and cooperate

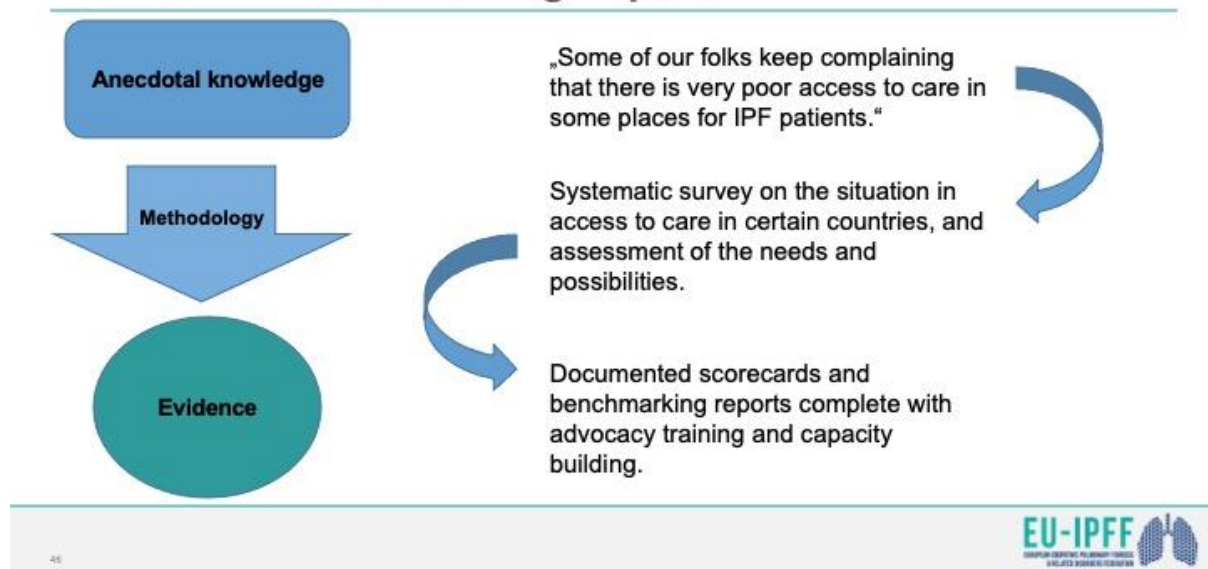
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The EU-IPFF Secretariat is well positioned to help the patient groups in these countries with the development of a relevant communication strategy and an awareness campaign. If possible, these could also extend to other countries, with the secondary objective of improving the cohesion within the IPF patient community across Europe.

Continued use of the Benchmark Reports and the scorecards as advocacy tools

In addition to the use of the Benchmark Report findings for the three countries included in this project, it may make sense to continue and extend the use of the Reports and the scorecards as advocacy tools.

The EUIPFF Benchmarking Reports



It may make sense for the EU-IPFF Secretariat to explore further possibilities for the clustering of countries with similar problems and challenges, and to motivate their patient groups for additional joint work in the different problematic areas.

As general findings from this training project, we have found that attention and active outreach are much appreciated by the patient communities concerned. We also assume that even better results can be achieved once the pandemic is over or more under control. There are some areas that offer themselves as general targets in addition to the specific problems on a country level. These include:

- Awareness of IPF
- General diagnostic and treatment knowledge
- Cooperation across patient groups
- Active and assertive advocacy towards decision makers



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