

EFA BOOK ON

Minimum Standards of Care for COPD Patients in Europe



European Federation of
Allergy and Airways Diseases
Patients Associations



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By addressing the existing care for COPD patients, we hope to reveal the best practices which can help identify ways to lower costs and move healthcare systems towards greater sustainability.

Breda Flood, EFA President

Foreword by Breda Flood

EFA President



By addressing the existing care for COPD patients, we hope to reveal the best practices which can help identify ways to lower costs and move healthcare systems towards greater sustainability.

As EFA President, I have witnessed the tremendous efforts of patients, researchers and healthcare professionals to increase the awareness of chronic obstructive pulmonary disease (COPD) in recent years. There has definitely been a positive change. COPD awareness is at an all-time high among policymakers and physicians, although still not the lay public. EFA is inviting stakeholders now to capitalise on this momentum to achieve even greater recognition of the burdens the disease can cause for patients and society alike.

For as many positive developments as there have been in recent years for COPD, EFA's newest publication takes steps to highlight certain aspects which are in need of major improvement. For instance, it is widely agreed that rehabilitation is beneficial for all COPD patients as it improves their quality of life and decreases their risk for an exacerbation. Nevertheless, within some of the European countries surveyed, I am shocked to see rehabilitation is only available for COPD patients who are employed! For EFA, this is inexcusable and we believe rehabilitation is a service which should be available to all COPD patients in need regardless of their employment situation.

In addition, free health check-ups once per year, which already exist in some European countries, should be standardised for all Europeans to better identify chronic diseases as early as possible and should also include spirometry testing. For all smokers and ex-smokers over 35 years old, spirometry testing should be administered by primary care physicians during annual check-ups. This would also require adequate education for these physicians to interpret spirometry results.

In the long run the cost savings for an earlier diagnosis would be of mutual benefit to the patient and society, as it will decrease the number of COPD patients retiring from the workplace at an earlier age. In a recently published article written by the former President of the International Primary Care Respiratory Group (IPCRG), Miguel Román Rodríguez, which compares the quality of life of employed and unemployed patients, the findings clearly showed employed COPD patients had less exacerbations and less incidence of co-morbidities, including anxiety and depression [1].

Another aspect of COPD in need of urgent improvement is the common perception of it being a 'self-inflicted disease,' as the reality is far from indicating that this is the truth. Anyone alive 30-40 years ago can recall obvious product placement of cigarettes on TV and in movies building the common perception of tobacco products being trendy across European societies. Even today we still find tobacco companies continuing to market products like 'slim' cigarettes to broaden their trendiness and appeal to a younger generation.

As a consequence, it is unfair to accuse COPD patients of having brought their suffering upon themselves as the guilt cannot be placed so simply upon the individual. Smoking is addictive. Many are not aware that some COPD patients have developed their conditions from passive smoking or poor air quality at work. Continuing to view COPD as a self-inflicted disease restricts the level of commitment policymakers are willing to make in addressing the disease. The responsibility of meeting patient needs lies with the individual national healthcare system, and as a result, patients are dependent upon policymakers to support efforts to maintain and improve COPD care.

It is my hope that, with EFA's newest book, COPD can not only receive the attention it deserves, but also gain recognition as a neglected disease with unacceptable variations in care across Europe. By addressing the existing care for COPD patients we hope to reveal the best practices which can help identify ways to lower costs and move healthcare systems towards greater sustainability.

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The publication of this book should not be viewed exclusively as an aid to patient advocacy, but rather it presents healthcare professionals with a powerful tool which helps to shed light on a tremendous opportunity to change the status quo.

Jørgen Vestbo, Medical Advisor for the EFA COPD Project

Foreword by Jørgen Vestbo

Medical Advisor for the EFA COPD Project



It is my great pleasure to welcome EFA's newest publication on COPD, which appropriately points towards the creation of minimum standards for care across Europe.

This timely publication complements the recently released ERS White Book by specifically focusing on

COPD from the patient's perspective while drawing upon the most recently released evidence. My role as the chair of the scientific committee for the Global Initiative for Chronic Obstructive Lung Disease (GOLD) allows me to confirm with confidence that the publication successfully outlines patient-centred approaches to COPD care which will be warmly received by healthcare professionals across Europe.

I am very pleased to see nearly all the countries surveyed in this publication either have their own national adaptation of GOLD guidelines or use the GOLD document directly for diagnosis, assessment and management of COPD in patients [2]. Awareness in recent years has improved and healthcare professionals, now more than ever before, recognise there is a necessity to attend to the needs of COPD patients. However, the existence of guidelines does not necessarily mean they are being complied with universally.

While the EFA book acknowledges positive developments over recent years, it still points to areas where improvement is still desperately needed. One example would be the improvement of diagnosis and the use of spirometry testing, without which healthcare systems will continue to see costs soar with aging populations in most European countries. It is astonishing to see the variability of how differently COPD diagnosis and

management is performed across Europe and this variance could very well be an indicator of poor care for patients. This also points to the obvious need for earlier diagnosis.

As a healthcare professional, I aspire to assure patients the best quality of life possible based on evidence and I can continue to achieve this in the future only with more efficiency and pragmatism. Identifying specific strengths and weaknesses of European healthcare systems is of great utility, as this book shows how to improve access to both prevention and care, which can ultimately empower patients in the successful self-management of COPD. The creation of patient-driven minimum standards of care for Europe would be an important step in making this a reality, aligning the needs of patients with the aspirations of healthcare professionals. Indeed, the needs of healthcare professionals in being able to do their jobs successfully are closely tied to those of the patient. Where a patient may have no access to proper rehabilitation, the risk thus increases for that patient's condition to deteriorate. Rehabilitation is quite simply the most successful preventative step against the reoccurrence of exacerbations.

The publication of this book should not be viewed exclusively as an aid to patient advocacy, but rather it presents healthcare professionals with a powerful tool which helps to shed light on a tremendous opportunity to change the status quo. Across much of Europe we still must strive to tighten connections between general practitioners (GPs), pulmonologists and emergency centres to streamline the treatment of COPD patients. In addition, we must aim to comply with the national guidelines and the GOLD strategy for COPD and I welcome EFA's efforts to try to create minimum standards for COPD care in Europe in order to push for these much needed changes to healthcare systems.

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Care of people with COPD and other obstructive diseases is not evenly distributed within the European countries.

Michael Wilken, Chair of the EFA COPD Working Group

Foreword by Michael Wilken

Chair of the EFA COPD Working Group



I never thought we would get this far!

For years, specialist publications in medical literature and publications of patient organizations have pointed to the significant growth of COPD and other obstructive respiratory diseases. Not only rising prevalence figures and health-care costs are mentioned in these publications, but also the enormous economic consequences. These efforts to create and raise awareness of this issue have not had their desired and essential success yet. Outside of a circle of medical experts and the knowledge of those concerned, the general public is largely unaware of this topic. It seems to take a long time with continuous efforts in order to make information and knowledge effective enough so that the awareness of the general public can be increased.

In addition to that, several recent studies have shown that the inpatient and outpatient care of people with COPD and other obstructive diseases is not evenly distributed within the European countries, nor is it distributed according to requirements. We therefore have to assume that there are big differences in the availability and quality of healthcare. These important concerns raised a question during the workshop of EFA's COPD working group:

What are the minimum standards of care which have to be available, from the patient's perspective, in order to be able to recognise it as sufficient medical care?

We were aware of the fact that, from a patient's point of view, no reliable figures existed on the number and quality of pulmonary care in Europe. There are certainly people who think this is reckless; yet, in fall 2012, we (as patients) took the decision to collect a base of information on our own initiative. This decision was based on the experience that political goals are not achieved unless they are supported by data and facts – regardless

of how useful outcomes might be even for those not directly affected by the disease.

You will find our questionnaire as an appendix on page 57.

Now I will comment on a very important issue here separately, namely co-morbidities and one specifically which we will have to pay increasing attention to in the future: the devastating consequences of depression and anxiety accompanying COPD. The existing data is still confusing and shows enormous fluctuations. Yet, it is certain depression occurs much more frequently among COPD patients than people who are not affected by the disease. Recent large-scale studies have come to the quite plausible conclusion that about 40% of COPD patients also suffer from depression [3]. Similar figures are also found for anxiety and panic disorders, whereby there is no correlation with the stage of disease [4].

It has been proven depression and anxiety disorders have a strong influence on the course of the disease. However, the detection and treatment rates of mental disorders seem to be very low. From the patient's point of view, it can be concluded that a comprehensive treatment must pay much more attention to psychosocial aspects, especially to psychiatric co-morbidities.

When we decided to tackle this project in the above-mentioned face-to-face meeting in Brussels, I was not certain that we would succeed. All the greater is the joy that we now hold the book in our hands and I wish to express my thanks to all those who contributed to its success:

Antje-H. Fink Wagner, who was the project coordinator and organized the project in a proven and effective way; Scientific Communication srl and Daniela Finizio as representative of the entire team, who helped to design the questionnaire with plenty of experience, organized the online data collection, and made available the data report and all graphs; all representatives of the 16 participating EFA member organizations and partner organizations from Austria, Belgium,

Bulgaria, the Czech Republic, Finland, France, Germany, Italy, Poland, Portugal, Serbia, Spain, Sweden, Switzerland, the Netherlands and the UK, which took over the painstaking research in their countries that sometimes meant several weeks of work; and David Brennan, who compiled a readable text from the data.

We would like to cordially thank our Medical Advisor of this project Jørgen Vestbo for volunteering his precious time and generously answering

even our most trivial questions out of goodwill. We deeply appreciate Professor Vestbo's patience. My thanks also goes to all members of the EFA Board, in particular to our president Breda Flood, who was involved in the entire project. We hope – and I can certainly speak for all members of the COPD working group – this book serves a strong foundation to provide stakeholders influencing the COPD healthcare networks in Europe with even better arguments for improving the medical and psychosocial care of patients.

A photograph of a woman with short, wavy white hair and glasses, looking upwards and blowing bubbles. She is holding a blue bubble wand in her right hand. The background is a lush green foliage, slightly out of focus. The overall mood is peaceful and joyful.

Executive Summary

Europe currently faces a time of austerity where healthcare and social programmes are under threat and calls for investment are met with increasing reluctance. Within this context, many European countries are witnessing a demographic change where their aging populations are approaching retirement and will incur increasing costs from healthcare systems. As a disease which predominantly affects people over the age of 35 years old, chronic obstructive pulmonary disease (COPD) is a chronic disease recognised as a major burden to societies globally. However, in Europe, it is a concern because of not only the changing age demographics, but also because most European countries have the means available to implement measures and reduce its prevalence in societies. If prevalence increases, the economic impact of COPD in European countries will be significant as the disease will become the third leading cause of death among chronic diseases in the world [2].

COPD, as defined by GOLD, is “a common preventable and treatable disease” known for persistent and usually progressive deterioration of a person’s lung capacity, or ability to breathe,

which can be triggered by noxious particles or gases ultimately leading to exacerbations [2]. The affected patients can experience varying degrees of severity depending upon the frequency of their exacerbations and comorbidities, which can result in emergency hospital visits and even death. EFA stresses the “preventable” and “treatable” nature of the disease as a signal for increased action because COPD is a chronic disease with negative effects that can be halted. The cause of COPD in Europe is primarily the result of tobacco smoke; other causes are predominantly the result of consistent exposure to poor air quality, both indoors and outdoors. Within the European Union, it is estimated that respiratory diseases comprise as much as 6% of total national healthcare budget costs with COPD alone accounting for more than half of that cost in each European country [2].

EFA acknowledges the care situation and awareness of chronic obstructive pulmonary disease (COPD) has improved for COPD patients over the past four years. Nevertheless, progress does not mean consistency of the care exists across all of Europe or that the situations for all

*"COPD is preventable
and treatable."
GOLD Guidelines*

COPD patients have improved. The results collected in 2013 from EFA members uncover significant areas for improvement. EFA will seek to highlight for the development of minimum standards of care for COPD patients in Europe. This publication is presented with the goal of making a case for the creation of patient-centred minimum standard guidelines for COPD care in Europe with the real needs of COPD patients serving as the starting point.

The idea for minimum standards was originally conceived by EFA's COPD Working Group, which brings together several European patient associations representing COPD patients, who compiled a list of issues related to care within their own national contexts together. The list was comprehensive and specific needs were highlighted as especially important to compare across the continent since initial discussions pointed towards differences experienced by COPD patients. Then, based upon the list and discussions, EFA, in the framework of our COPD project, produced an extensive and unique questionnaire capable of measuring patient needs, confirming the status quo in many European countries and incorporating epidemiological information to satisfy and evidence the trends being uncovered by the responses of the patient associations representing people with COPD.

The primary areas for analysis based upon issues identified by EFA's COPD Working Group members in this publication concern four key areas: I) **Prevention**; II) **Diagnosis**; III) **Management and Therapy**; and IV) **Rehabilitation**. First, **prevention** addresses ways to keep healthy people from becoming COPD patients (e.g. strict measures against tobacco) and helping COPD patients to reduce their disease progression. Second, **diagnosis** concerns spirometry testing as the best

means possible to identify COPD patients and measures to ensure the earliest diagnosis possible, including the training of general practitioners (GPs) to perform the tests and interpret the results. Third, **management** and **therapy** discuss the COPD patient's treatment process along with existing problems in ensuring follow-ups, actions to reduce exacerbations and the communications between GPs, specialists and hospitals. Lastly, **rehabilitation** provides arguments confirming pulmonary rehabilitation which emphasises physical exercise is extremely successful and should be made available for all patients in need. An additional section is included on the status of care for patients with the genetic predisposition, alpha-1 antitrypsin deficiency (AATD) in Europe as EFA recognises that sometimes COPD patients are also Alpha-1 patients and the symptoms of Alpha-1 can lead to COPD (however, not exclusively).

Appearing in this same order listed prior, each section will link different aspects of COPD patient care within the countries surveyed to the *needs and actions* required for the improvement of European healthcare systems on a whole. Best practices deserving consideration are highlighted where possible and appeal for recommended actions to be considered where they have not already been taken. Using the support of the most updated publications from the scientific community, such as the ERS White Book and the updated GOLD guidelines, EFA presents evidence to accompany the patient centred recommendations made in the book. Among the benefits of presenting a publication with a patient centred approach are the quick identification of similarities in patient needs across Europe, an acknowledgement of strengths in various healthcare systems which can be duplicated in other national contexts and the provision of valuable insights for healthcare professionals and policymakers on the best means to increase efficiency and reduce costs in healthcare systems.



Request for Minimum Standards of Care for COPD Patients

The *EFA Book on Minimum Standards of Care for COPD Patients in Europe* follows up where *EFA's Book on COPD in Europe: Sharing and Caring* left off in 2009. *EFA's Book on COPD* was a first of its kind in surveying patient associations for revealing the status quo of COPD patient care in Europe. This newest publication is the compilation of answers from a follow-up questionnaire that was sent to EFA Members and other patient organisations across Europe over the course of the spring and summer months of 2013. EFA is pleased to see significant progress made between 2009 and 2013, with guidelines recommended for use in all countries surveyed. Improved awareness of COPD has undoubtedly helped to increase diagnosis and patient referrals to pulmonary specialists for proper treatment of the disease. EFA members participating in EFA's COPD Working Group first recognised the need to follow up on the 2009 publication in the autumn of 2012, when they brainstormed a list of specific aspects of COPD care which require further improvement. Additionally, the EFA COPD Working Group members compared their national contexts for these aspects and quickly discovered significant variation between

standards of care. As a result, it was decided by the EFA COPD working group members that a new questionnaire could be created from the list of aspects, which would seek to provide the foundation for a minimum standard of COPD care in Europe. National guidelines already exist in each country surveyed, which are often based upon the GOLD guidelines; however, this does not mean these guidelines are strictly followed.

National programmes or strategies on COPD appear to currently exist in many countries. Nevertheless, certain countries like Austria, Belgium, Germany and Poland appear to have no national COPD programmes and survey responses did not indicate any plans for the government to begin one. Of those programmes or existing strategies, most are funded by a public authority while in other countries a coalition of healthcare professional associations, patient associations and industry provide funding in collaboration with the national governments. In connection of the European Union's reflection process on chronic diseases, launched in 2010, EFA promotes an EU strategy and programme on chronic diseases to be inclusive of disease specific chapters, such

as COPD, and share best practices on national disease programmes across Europe [27] [28]. EFA aspires to see national COPD programmes or strategies implemented across all European countries, as it has proven to be an extremely successful method of reducing the costs of the disease to society.

For instance, in Finland between 1998 and 2007, a ten year national COPD programme demonstrated significant benefits to investment in public awareness and treatment of the disease. There were five major aims for the programme which included (1) reductions in COPD prevalence, (2) improvements in COPD diagnosis – especially by GPs, (3) reductions in the number of moderate and severe cases of COPD, (4) minimisation of COPD related hospitalisations and (5) cuts in treatment costs [5]. There were extensive efforts to involve a wide spectrum of stakeholders, including patient associations and pharmacies, to help advertise the use of disease prevention methods, like smoking cessation services. EFA aims to improve prevention and treatment of COPD across all European societies and among patients as the Finnish COPD Programme has done. EFA also uses its survey to move forward with specifically identified issues which are reoccurring across Europe to draw attention to, and similarly call for, the improvement of patients' quality of life while avoiding high costs of maintaining the status quo.

Minimum standards of care for COPD patients implies that Europeans are offered every opportunity to avoid becoming a COPD patient through effective prevention, or are provided with as early a diagnosis as possible so as to receive adequate care to mitigate the disease's progression. An assurance would be to have an inclusive national programme or strategy which brings together a wide spectrum of stakeholders. EFA believes that the existing guidelines do not necessarily reflect the status quo in each country as healthcare professionals are not necessarily consistently compliant with their own recommendations. Thus, EFA requests the establishment of *patient centred* minimum standards of care for COPD patients in Europe. Strategies across Europe may be able to offer an equitable standard of care to all European COPD patients. EFA's survey reflects the awareness of patients to available services and speaks to the experience of patients in their respective systems, confirming

widespread compliance to or disregard of existing guidelines.

As a result of the questionnaire responses, EFA requests the following as minimum standards of care for COPD patients in Europe:

1. Ensure early diagnosis of COPD by using spirometry testing in primary care for current and ex-smokers older than 35 years old;

For many COPD patients, diagnosis comes much too late. In order to guarantee the best quality of life possible for patients, a prerequisite is an accurate diagnosis and support to prevent the diseases from progressing further. If the patient is still smoking tobacco, they should be encouraged to utilise, and be provided with, smoking cessation services as well as follow-ups to reduce the risk of their disease progressing to a more severe stage. The sooner these steps can be undertaken, the more likely a patient can preserve their quality of life and remain independent in their disease management in the future.

EFA asks European countries to standardise the use of spirometry testing for both current and ex-smokers older than 35 years old to better identify undiagnosed COPD patients, prevent COPD progression to severe stages and preserve the best quality of life possible for COPD patients.

2. All general practitioners should be adequately educated to administer spirometry testing and interpret the results so as to assure early and accurate diagnosis;

In order to better implement the wider utilisation of spirometry testing in Europe for the identification of undiagnosed COPD patients, the testing must be made available at the first line of defence for most of the European population: among general practitioners (GPs). GPs require sufficient training on how to use spirometry testing and then interpret the results accurately for patients. A risk of poor training could be the misinterpretation of results leading to a misdiagnosis or confusion between respiratory diseases. Spirometry testing should be a reimbursable procedure for GPs to encourage its utilisation and new COPD patients should always be referred to pulmonary specialists following a diagnosis.

EFA asks European countries to encourage GPs to administer spirometry testing to their

patients at risk for COPD, provide the necessary training for them to interpret the results and reimburse them for the time they require for testing their patients so as to provide the necessary incentive to build an adequate system for COPD diagnosis and prevention.

3. Coordination should be increased between primary care, specialists and hospitals to increase efficiency of treatment and quality of life for patients;

EFA's survey evidences that a communication gap exists in many European healthcare systems between primary care, pulmonary specialists and emergency care in hospitals. By failing to link these healthcare professionals together, COPD patients may not have the attention required to ensure compliance to their treatment plans, receive adequate care and undergo pulmonary rehabilitation when it may be necessary. Follow-ups with patients to make sure they are taking appropriate steps and receiving adequate assistance in managing their disease are critical to halt the disease's progression, avoid unnecessary exacerbations and lower the number of costly hospital visits.

EFA recommends European countries to improve means for collaboration between different medical professionals caring for COPD patients. By increasing this cooperation, results include an improved quality of life for patients, a more effective use of time for medical professionals and a decreased consumption of healthcare system resources by COPD patients, who are better informed on how to cope with their disease independently.

4. Smoking cessation services and pulmonary rehabilitation should be made available for all COPD patients in need, regardless of their employment status;

Prohibitive legal barriers for COPD patients, such as the requirement to be employed, are unnecessary impediments preventing equitable access to care and services in European countries. The restriction of any smokers from access to smoking cessation services, particularly those already diagnosed with COPD, keeps individuals from seeking and receiving the support they require for fighting their addiction and changing their habits. The prevention of COPD patients from accessing pulmonary rehabilitation is unacceptable as it is verifiably among the most cost

effective means for healthcare systems to assist patients improve their quality of life and avoid future exacerbations.

EFA argues for European countries to provide access to smoking cessation services and pulmonary rehabilitation for all COPD patients to guarantee equal opportunities and access to COPD care services. These services are of fundamental importance in improving the quality of life for COPD patients and the prevention of the disease's progression.

5. Increase the number of centres for COPD care and rehabilitation and ensure there are systematic plans in place for how to avoid exacerbations, consistent follow-ups with patients and intensive up-to-date training on the self-management of the condition;

At the present many COPD patients across Europe do not have the access they need for medical centres specialising in COPD care and rehabilitation. This can be attributable to their concentration in urban areas or due to the limited number which exist in the first place. Increasing access to these facilities for COPD patients could provide a tremendous boost to future cost savings since they would provide opportunities for educating patients on self-management strategies. The training of patients to overcome the limitations of their disease with pulmonary rehabilitation is imperative to keeping them active and preserving a higher quality of life. Medical professionals should encourage COPD patients to use such centres where they already exist to help ensure patients consistency with follow-ups.

EFA encourages European countries to improve the availability of centres for COPD care and rehabilitation to help empower patients towards self-management. Healthcare professionals may also benefit from increasing the services and roles of such centres in patient care since they could help offer consistent follow-ups and assistance for patients.

6. Promote a multidisciplinary approach for the rehabilitation of COPD patients to involve all necessary medical professionals who can help improve their quality of life with comorbidity assessments so as to efficiently treat all COPD patients;

The availability of pulmonary rehabilitation for COPD patients alone cannot offer an

improvement in their quality of life. The presence of comorbidities and individualised patient needs require the availability of a multidisciplinary team of specialists and medical professionals. While a pulmonary specialist can aid with addressing certain aspects of COPD care, a psychologist should be considered of seminal importance in providing services which may help COPD patients retain self-esteem and avoid succumbing to depression. Physiotherapists, nurses and nutritionists can all play a role in providing a personalised approach to rehabilitation for patients.

EFA encourages European countries to endorse multidisciplinary approaches towards pulmonary rehabilitation for COPD patients. This can help address obstacles common comorbidities, such as depression, and lead to more personalised approaches which can in turn increase the likelihood of patients succeeding in improving their quality of life.

7. The participation of COPD patients should be legally embedded in all government decisions or processes directly affecting COPD patient care;

The European Union has consistently emphasised the involvement of patients in decision-making processes. The example of the European Medicines Agency (EMA) can be presented as a best practice with a model featuring (i) the inclusion of patient representatives in decision-making bodies, (ii) a dedicated body for patients and consumers for input, (iii) a clear framework for patient involvement and (iv) a plan for training and capacity-building for patient representatives [29] [30] [31]. Other pieces of legislation, currently under review, such as the new regulations for clinical trials and medical devices, follow this path and require patients' involvement in decisions influencing their health. National governments should make parallel efforts to embed COPD patient representatives into all decisions, initiatives or processes which may result in direct or indirect impacts to their health. By legally inserting patients into a role within government plans affecting COPD care, the opportunity arises for COPD patients to help

integrate real needs for patient centred affordable care that creates value, provide recommendations and help other stakeholders to avoid potential oversights which could be obvious more to the patients themselves than other parties involved.

EFA urges European countries to embed the involvement of patients in any government measures which could result in changes to COPD patient care so as to assure all COPD patient needs are considered and understood. Governments should emphasise the inclusion of patient representatives by following the lead of the EU to ensure all stakeholders are involved to ensure future healthcare system developments move in the right direction.

8. Alpha-1 Antitrypsin Deficiency (AATD) testing should be available for infants and pregnant women at risk and augmentation therapy (AT) should be available in all European countries with the possibility for reimbursement;

The number of COPD patients and costs to European healthcare systems can be reduced with the quicker identification of AATD patients as these individuals can be educated to avoid risk factors, like tobacco smoke, which can lead to a worsening of their condition. Those AATD patients whom already exhibit symptoms of COPD should be eligible to receive AT and have it reimbursed to them, as is already the case in several European countries. The disease progression can be addressed pre-emptively if pregnant women have an AATD testing should they have a family history of risk factors and infants could also be tested during the first year of their life through blood testing.

EFA, alongside its counterpart Alpha Europe Federation, promotes AT as the best treatment presently available for AATD patients in Europe and urges European countries to make it available to all patients in need. AATD testing should be available for pregnant women with a medical history prone to the development of the predisposition as well as infants within the first year after their birth.



1 The Increasingly Significant Economic Burden of COPD

Before addressing specific steps required to establish minimum standards of care in Europe for COPD in prevention, diagnosis, management/therapy and rehabilitation, it is necessary to look at the big picture. More specifically, why should COPD receive consideration as a major problem for Europe societies in general? If COPD is a disease affecting mostly people who smoke, or have smoked in the past, at least in Europe, why should non-smokers have an interest in helping COPD patients?

While the answers to these questions are not straightforward, there is a major factor which incentivizes the mobilization of efforts to counteract the increasing prevalence of the disease. The **economic burden** of COPD is acknowledged as *increasing* and therefore adding to the pre-existing financial strains which already hinder the development of European healthcare systems. Since COPD is also most prevalent among older populations in societies, the demographic trend in Europe, which shows that in most countries populations are getting older, is a cause for concern because the needs for adequate diagnosis, disease management, therapy and rehabilitation services will grow.

As a result, while effective prevention will be a key factor in helping to reduce the economic burden of COPD in the future, it is vital to recognize both the direct and indirect costs COPD places upon European societies. Direct costs relate to hospital care (including emergency room stays and consultations with specialists), primary care visits and treatment (e.g. drugs, including oxygen therapy). In contrast, indirect costs correspond with decreasing productivity caused by work absences, early retirement and assistance from nursing services. However, beyond direct and indirect costs, are also additional expenses imposed by disability and loss of life-years, which is calculated at a monetary value using the notion of disability-adjusted life-years, commonly referred to as DALYs.

The economic burden of COPD is increasing.

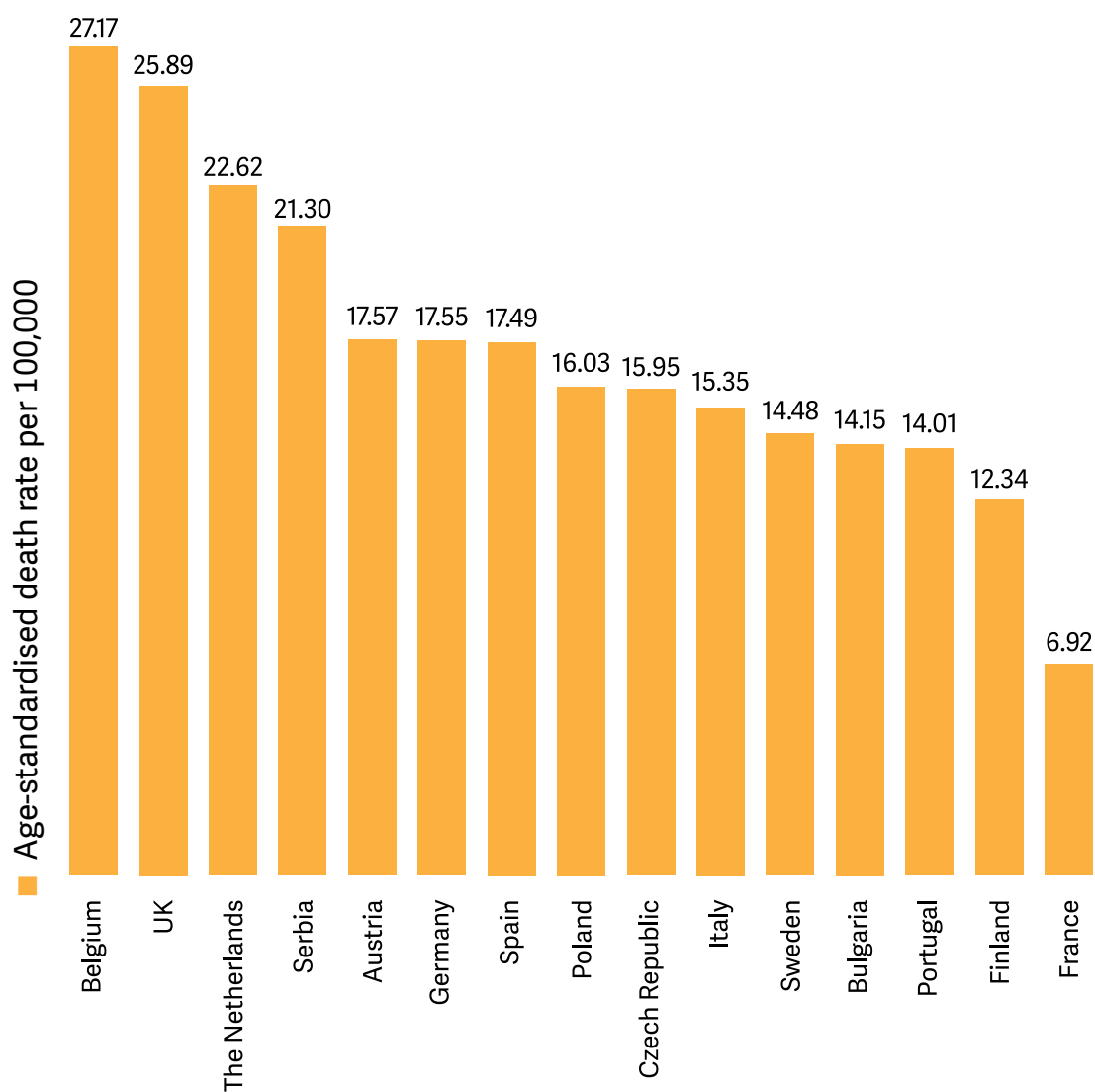
As a starting point to offer an overall glimpse of COPD's potential cost, the average age standardized mortality rate per 100,000 people across the countries surveyed is approximately 17.25, which is consistent with the average cited by the ERS White Book of 18; the highest being Belgium at 27.17 and lowest France at 6.92, where the French Ministry of Health estimates that on

average 16,000 people die of COPD annually. In most of the countries surveyed, there is a higher prevalence of COPD among men than women with estimates that, throughout Europe, 5-10% of adults over 40 years old have COPD [6]. The prevalence rates of COPD across the countries surveyed ranges from as low as 4.4% to as high as 14.2% with a trend of steadily increasing prevalence with older age. Most countries surveyed confirm COPD patients have a public insurance or free access to public healthcare. Within these

countries, free services include specialist visits, oxygen therapy, ambulatory care, an annual health check-up, hospital care and rehabilitation services. Nevertheless, in Belgium, as in several other countries, patients do have to pay a certain amount for access to their healthcare. In Finland a specialist visit is not free for patients and is reimbursed up to 65%.

The most recent estimate by the ERS White Book (2013) indicates COPD accounts for €48.4 billion

Yearly mortality for COPD



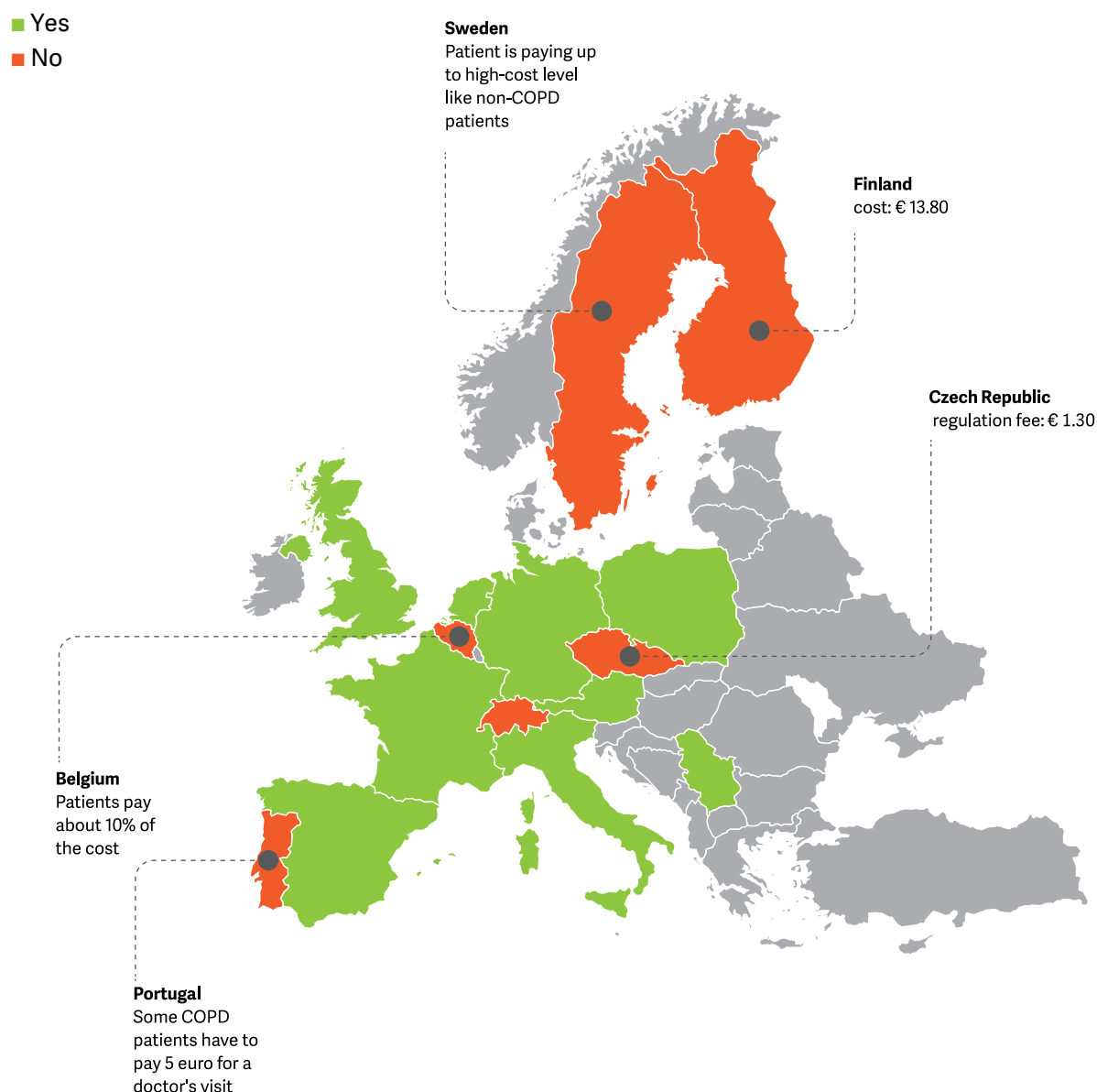
Source: ERS White Book 2013

in direct and indirect costs combined. Direct costs can be anywhere from €1,200 per year to more than €5,000 per year for COPD patients depending upon the country concerned and the access to healthcare available. When considering the number of COPD patients existing within each national context, it is clear the combined costs are staggering. Unfortunately, EFA can confirm that limited information is readily available on direct costs based on the severity of the disease, though it is nevertheless estimated exacerbations are

among the largest direct costs for the treatment of COPD. The major costs associated to exacerbations are hospitalisations, which is then followed by the cost of medications, representing 58% and 32.2% of the total costs respectively [7].

The indirect costs of COPD to patients are also difficult to estimate; however, a recent study including data from both the US and the EU concluded that “COPD results in significant indirect costs in terms of impaired productivity and

Is a doctor's visit free for COPD patients?



lost productivity due to early retirement in the working age population” [8]. An example of this has been calculated in the Netherlands where, according to the Dutch National Institute for Public Health and the Environment, the average cost of sick leave due to COPD was €1,900 per employee while the annual mean cost due to the lost productivity resulting from early retirement was estimated at €1,200. Sick leave and disability were the most prevalent among older employees with COPD and those patients older than 55 had higher costs of production losses than healthcare costs, or in other words, higher indirect costs than direct costs [9].

An additional concern arises as a consequence of COPD patients who remain undiagnosed. It is estimated that just 21-25% of people identified as having COPD during screening already had a prior diagnosis of the condition [6]. This implies ‘hidden costs’ to society because a large number of undiagnosed COPD could cause a gross underestimation of the indirect costs to societies. Among the greatest challenges COPD poses to European societies is the significant loss of productivity to employers. Estimates show significant projections in disability-adjusted life-years (DALYs) for COPD, where the monetised value of DALYs lost totals approximately €93 billion across Europe [6].

Cardiovascular disease is the most frequent comorbidity associated with COPD as roughly 30% of COPD patients will have heart failure [10].

Hypertension and osteoporosis are also frequent comorbidities which have received increasing attention [11]. Comorbidities are especially concerning for COPD patients due to the age demographic affected, since older people are more vulnerable to develop other conditions or other chronic diseases as well. Studies on comorbidities have been conducted, but there is unfortunately a scarcity of data available at the national level. While it is unfortunate national data is unavailable for comorbidities, EFA believes the relationship between COPD and these other diseases cannot be ignored. Such relationships should receive much needed attention in the future while medical professionals should continue to acknowledge patients with comorbidities cannot be adequately treated if each disease is attended to in isolation.

Psychological conditions which develop in COPD patients can also be considered major comorbidities because both anxiety and depression are associated with a poor prognosis [12]. Indeed, as emphasised by EFA’s COPD Working Group Chair, Michael Wilken, who is a psychologist by profession “the mental fragility of many COPD patients is a major concern because it can prevent them from receiving proper treatment and rehabilitation. The absence of sufficient moral support from peers, family and professionals to improve their self-management of the disease can lead to increasing direct costs to society as these patients are more likely to remain in poor health and see very little improvement in their situation.”

Needs and Actions

Systematic assessments of comorbidities and COPD patients should be included in national guidelines and programmes

Minimum standards of COPD care are necessary to cut future costs while maintaining a sufficient level of care for patients

EFA believes this overview of the different costs to European healthcare systems and COPD patients offers a vital starting point for discussing specific aspects of COPD care and services as it contextualises the *reasons why, from a societal*

point of view, change is needed. The cost estimations provided point to clear research gaps and practical areas for improvement. EFA strongly encourages a systematic assessment of comorbidities be included in national guidelines and

programmes so as to treat all COPD patients as efficiently as possible.

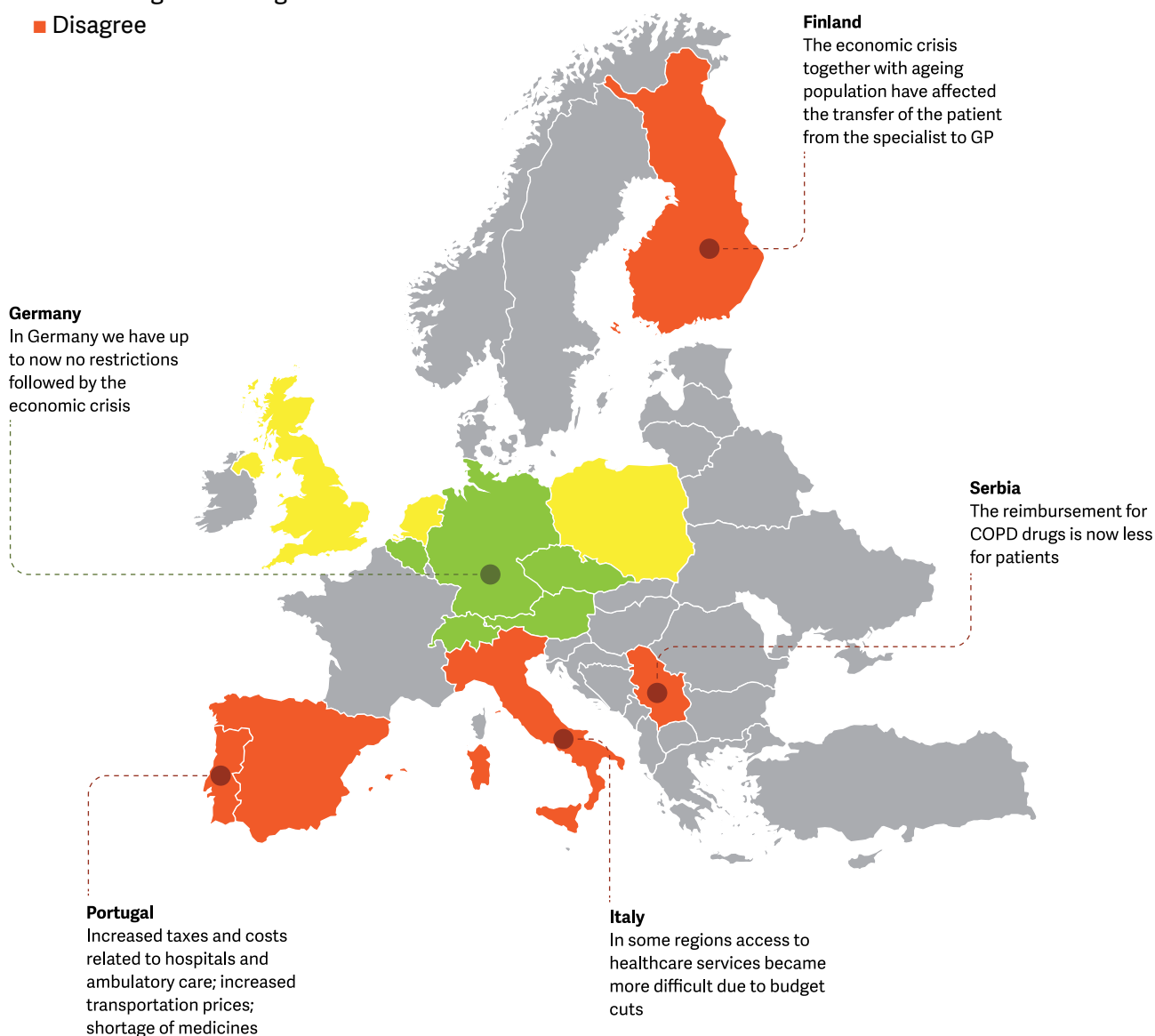
Although many of the countries surveyed indicated the economic crisis had not impacted COPD care, others like Portugal, indicated a deterioration where increasing taxes as well as healthcare and transportation costs paired with

a shortage of medicines has strongly impacted the quality of life for COPD patients. In order to prevent these problems from spreading to even more European countries, the development of minimum standards of care can assist in providing necessary guidance to cut costs in the long run and assure patients do not witness deterioration in their care services.

The effects of the economic crisis on COPD care

Question: Do you agree with the following statement? "The economic crisis in Europe has not affected COPD care"

- Agree
- Neither agree or disagree
- Disagree





Taking the Right Steps Forward in Prevention

Arguably one of the most important areas in improving care for European COPD patients are efforts for **prevention**, which can be viewed in two ways. First, primary prevention is critical for decreasing the number of people with a COPD diagnosis in the future, as it concerns all activities and initiatives used to keep a society healthy. Secondary prevention concerns ways in which people previously diagnosed with COPD can remain 'stable,' through limiting the progression of the disease and thus diminishing the direct and indirect costs to healthcare systems. Together, the prevention of COPD specifically from becoming more prevalent across Europe could yield significant returns for governments, increasing available funds while decreasing the demand for healthcare professionals' time and the unnecessary use of expensive emergency room visits.

As a starting point, general prevention has made significant strides in many countries through measures to curb the popularity of smoking. By prohibiting smoking inside public spaces,

Patients associations are active in improving empowerment and health literacy for COPD patients.

restaurants and other venues, European governments have begun a positive trend, which can effectively deter passive smoking, also known as second-hand smoke. The European institutions in Brussels have recently made significant strides in pushing this trend forwards through the European Parliament's vote of the European Commission's proposal for the Tobacco Product Directive in Strasbourg on October 2013. The main provisions of the legislation which were approved are (1) health warnings covering 65% of tobacco product packages at the top, front and back of cartons; (2) positive list of additives with a ban of menthols within the next 10 years; (3) banning of slim/fancy packaging with less than 20 cigarettes; and (4) pictorial warnings are now compulsory [13].

EFA also strived for plain packaging for tobacco products, where brand could only be written as text and this measure is still possible and is left as a decision to be made by member states. Ireland has already decided to make this change to plain packaging, leading the way for the rest of the EU to follow. However, these results do fall short of meeting all of EFA's desired outcomes

because slim cigarettes were not banned outright and e-cigarettes are not to be regulated as medicinal products unless their producers claim health benefits. Together with our partners, EFA also would have preferred to see health warnings cover 75% of tobacco product packages. Nevertheless, tobacco industry requests were not supported on every measure and there remains a possibility the Council of the EU, whose approval is also required, will still enforce certain measures, such as the regulation of e-cigarettes as medicinal products.

Since smoking is among the leading causes of COPD in European patients, the availability of cessation services for smokers and adequate measures to reduce the availability of tobacco products to minors are crucial, as it targets both current smokers and reducing the number of smokers in future generations. Although EFA's survey reveals many European countries have cessation services available, such cessation services are not available in every national context, as is the case in Poland. A wider variety of healthcare professionals were available for smoking cessation services only in Portugal, the Netherlands and Switzerland, which regularly can involve general practitioners, nurses or psychologists. Physicians should not be alone in counselling their patients as others can further help to successfully encourage smokers to quit.

In addition, quality indicators should exist for cessation services; this is to say proof should be available demonstrating the services provided are sufficient to help smokers who seek help to quit and overcome their addiction. Potential quality indicators include the successful reimbursement of treatments, such as medication, and utilisation of free access to smoking cessation services. However, it must be acknowledged that the availability of such services does not mean smokers have easy access to them. For instance, in Austria while there is a hotline which is very easy to reach, it is still very difficult to find a general practitioner who offers smoking cessation services. For example, in Sweden, a survey from EFA's member on smoke cessation clinics in 2010 confirmed only 43% of clinics offered qualified smoke cessation by educated healthcare professionals. Within these countries, as well as Italy, the UK and Finland, the services are usually concentrated in major urban areas, thus leading to uneven distribution and less access among

certain populations.

A surprising number of countries do not provide smoking cessation services free of charge.

In Belgium, France, Germany, the Netherlands, Poland, Spain, Sweden and Switzerland, smoking cessation services may be paid by the patient, partially refunded or free for high risk populations (such as pregnant women or COPD patients) and in specific facilities. For instance, in France smoking cessation services are only free in hospitals and in Germany it is variable among the different health insurances. The answers EFA received concerning the reimbursement for smoking cessation therapy reveal significant variability. Only in Finland, Italy, the Netherlands, Sweden and the UK does the national government reimburse smoking cessation therapy, while in Belgium and France, it is just partially reimbursed by health insurance, sometimes for a fixed fee. In the rest of the countries surveyed, the patient is receiving therapy at their own expense.

Although smoking cessation is vital for prevention, parallel efforts through education and health literacy are necessary to better inform patients of COPD and help prevent the worsening of their health. It is encouraging to note that all countries who answered the EFA questionnaire confirmed efforts are being made to improve patient education; however, there is great variation in the sourcing of the presently available information to patients. In the UK and the Netherlands, both national and local patients' organisations as well as national healthcare systems and physicians' associations all have information available to COPD patients. In other countries, a diverse range and combination of these groups provide information. Some EFA members organise information sessions and materials themselves, such as Bulgaria and Italy, while individual specialists and doctors will make information, whether produced by patient organisations or not, widely available to patients elsewhere. Only in Serbia does it appear that no role whatsoever exists for national or local patients organisations in increasing health literacy among COPD patients.

*"The National Healthcare System does not fund smoking cessation services."
Poland*

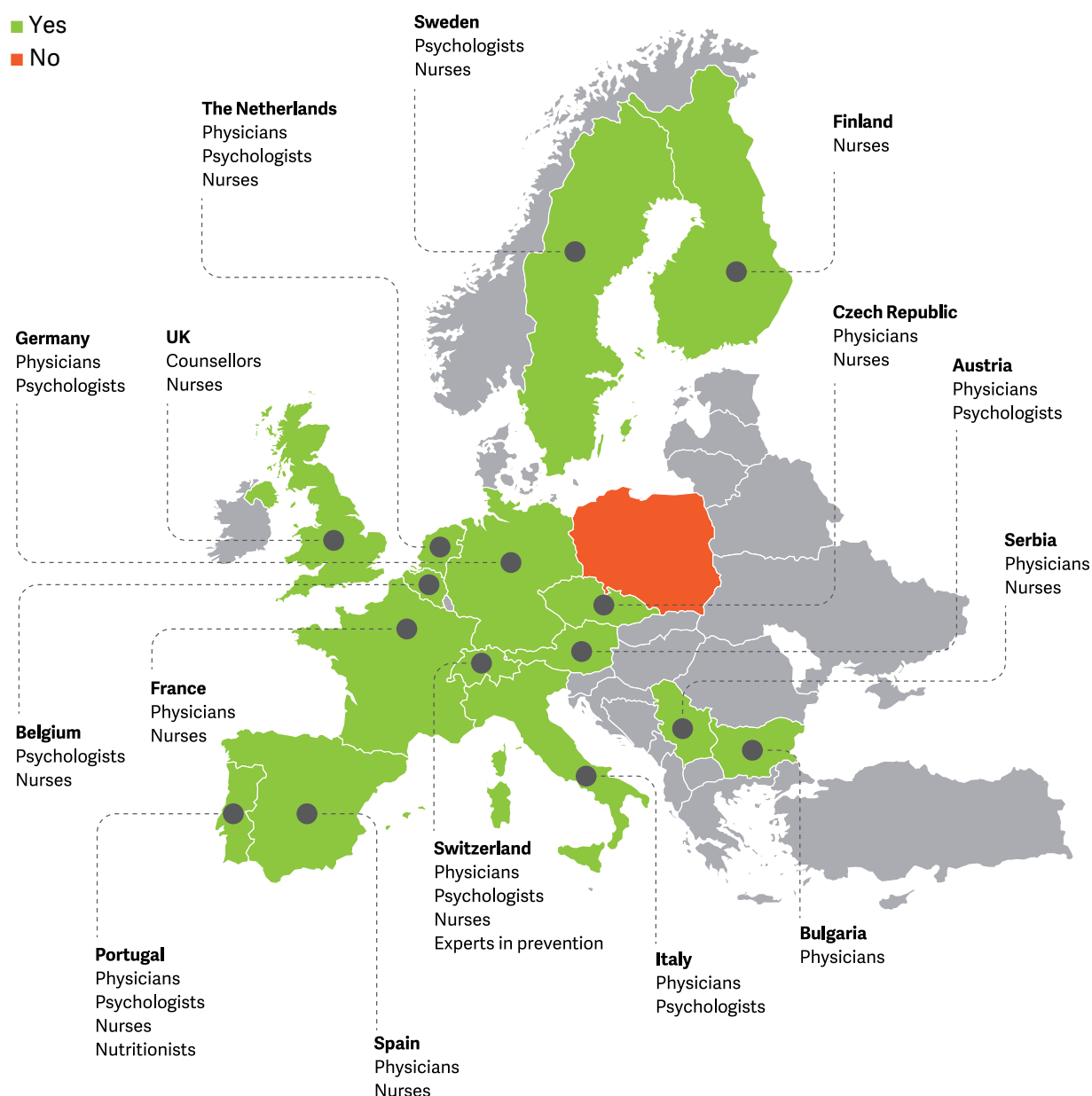
In many countries smoking cessation services are only partially refunded or are free only for at-risk population (e.g., pregnant women or COPD patients).

A wide variety of tools are available to increase health literacy and therefore patient empowerment. All of EFA's members representing COPD patients offer at least a website and brochures as a bare minimum, which is a starting point for an informed patient. Interestingly, in Austria, there is even COPD training organised by the national patient association. This occurs in 4 separate sessions lasting 105 minutes each and once per year there is an event held at the Vienna Town Hall for the 'Day of the Lung' to encourage early diagnosis of COPD. In Finland, the COPD patient group organises rehabilitation as a service for the official healthcare system. A majority of the countries also confirmed the availability of sport/

exercise groups organised for COPD patients, although unfortunately in the Czech Republic, Italy, Poland, Portugal, Serbia and Spain no such activities are available. However, several different providers ranging from patient associations to hospitals promote activities like Nordic walking to help keep COPD patients active.

The role of COPD self-help groups is prominent in a majority of the countries surveyed by EFA. The organisation of these groups through national or local patients' associations as well as hospitals is the most common. However, it is possible the groups are underutilised, as is the case in Italy, which confirmed there are not many patients

Are smoking cessation services available? And who is involved in these services?



who take advantage of the service when offered. Social or special assistance at home is also available for COPD patients in all countries surveyed, with the exception of Serbia, although the conditions for eligibility to receive home assistance differ across national contexts. In Portugal, the service is free depending upon the socioeconomic status of a given COPD patient, while in Belgium the patients have to apply for home services and in Finland they are only available for €30 per session. The key benefits of social or special assistance are that by enabling severe COPD patients to stay at home longer, their quality of life improves and costs of hospital stays to patients and the healthcare system are reduced.

There is no question most patient associations, whether local or national, are involved in improving empowerment and health literacy for European COPD patients. The degree to which patient associations are actively involved in advising on the needs of patients varies considerably. In Austria and Germany, patients do not appear to be well integrated in making decisions regarding the management of their disease, in healthcare decision-making in the government, in the national medicines authority or in the preparation of national guidelines. In fact, the only countries where patients appear to be universally involved in all these areas would be Finland and France,

while in other countries patients are considered to be actively involved in anywhere between one and three of these areas. Additionally, only in Finland and Switzerland are effective measures in place to help COPD patients remain at home as long as possible and motivate them to remain active.

EFA considers the legal embedment of patient organisations - a necessity in all governmental and central initiatives - such as national disease programmes, disease management plans, guidelines and ethics committees. The European Medicines Agency (EMA) involves patients more and more at all levels of its activities [29] [30] [31]. The same level of involvement should be promoted at the national level in all decisions taken by authorities that directly or indirectly affect the health of patients. The EU has already promoted the embedment of patients' participation in some legislation currently under revision, such as the regulations on clinical trials and for medical devices. However, the EU could go beyond and recommend EU member states follow the EMA's lead. In addition, it is important patients should be involved with *both* healthcare professionals and national healthcare systems, as this will help both parties have patient focused insights to serve real needs and increase their knowledge base to understand how to improve patients' quality of life.

Needs and Actions

European countries should take steps towards reducing tobacco smoke in public and work places while the EU should place strict requirements on tobacco products

The availability and reimbursement of smoking cessation services to patients, ideally with a multidisciplinary approach, should be standardised in all European countries

The participation of patient organisations should be legally embedded into all government initiatives which may impact COPD care

EFA identifies improvement of prevention, both in general and specifically for keeping COPD patients 'stable,' as the first step in assisting to relieve the burden of COPD in Europe. The survey reveals a generally positive outlook for the development

of COPD prevention overall in Europe. Nevertheless, since smoking is still permitted indoors within many European countries and with the degree to which EU Tobacco Products Directive will be strengthened remaining uncertain, there

are still steps in general prevention to be taken. EFA is hopeful the European countries still needing to take general prevention steps to decrease the exposure of the public to passive smoking will quickly follow the best practices already in place in many other countries. The Tobacco Products Directive provides major aid with the eventual mandatory labelling requirements along with the ban on menthol cigarettes.

In several countries measures and services are currently in place which can help to diminish the risk of COPD patients' conditions from worsening further. Where it is not already the case, EFA strongly encourages the standardisation of specific practices which can best help: (1) the reimbursement of smoking cessation services as a common practice for smokers in all European countries; (2) secondly, the participation of patient organisations should be legally embedded in all governmental decisions or processes which will directly or indirectly impact COPD patient care.

EFA believes the significance of the variability in the accessibility of smoking cessation services and the reimbursement of these services cannot be underestimated. Smoking cessation is easily the most cost effective step for prevention and treatment for COPD patients who are still smokers. All smoking cessation programmes should ideally involve counsellors, rather than only a physician, and there is also a need for quality

indicators for the smoking cessation programmes offered. Where smoking cessation services are not free, a strong case can be made that this is unreasonable. Such services are clearly shown to be an effective means for prevention in which investment can offset future costs of COPD care. By not making such services available to all smokers, European countries do not offer equal opportunities for people who want to quit, as some may not be able to afford the costs required or have the strength to look and access available support. Additionally, it is unjustifiable to make the claim cessation programmes are less effective for COPD patients than others as no evidence suggests this is in fact the case.

The widespread differences in European countries between the degrees of involvement patients have should be improved upon. While in some contexts patients are seemingly well involved in decisions affecting their health, this should be the case in all European countries. EFA believes urging COPD patients to remain active and help them retain independence is crucial, and thus encourages steps to consistently address these points. As EFA is committed to see patients integrated in all decisions affecting their health, their involvement integrated in making decisions regarding the management of their disease, in healthcare decision-making in the government, in the national medicines authority or in the preparation of national guidelines should be a future priority for stakeholders involved.



Promoting Early Diagnosis

The diagnosis of COPD is an important area for discussion because it is commonly recognised to be a disease which is diagnosed much too late, and the consequence of this is that the disease brings 'hidden costs' to society. There are commonly three different symptoms seen as indicative of COPD, particularly among the adults over 35 years old: (1) dyspnea – a persistent shortness of breath, (2) chronic cough and/or sputum production and (3) a history of exposure to risk factors (e.g. current or ex-smoker, work environment with exposure to toxic emissions, etc.) [2]. GOLD indicates adults over 40 years old with any combinations of the above symptoms should undergo spirometry testing to receive a proper diagnosis and to assess their potential risk [2]. The Danish National Board of Health recognised an earlier detection of COPD can be of tremendous value, and as a consequence, currently recommends "individuals with tobacco/occupational exposure, and at least 1 respiratory symptom" to undergo spirometry testing [14].

Since COPD is a progressive disease, studies have shown spirometry is the best means of monitoring the illness and annual declines are frequently

reported when testing results are compared over a fixed period of time [6]. EFA's questionnaire confirms spirometry is a key test for the diagnosis of COPD in all European countries; however, the access to spirometry and specific healthcare professionals performing or analysing the test for at risk patients differs depending upon their country of residence. It is clear GPs play a role in the diagnosis of COPD in the countries surveyed, and should play a more important role in early diagnosis. GPs may suspect a patient has COPD based upon their symptoms but generally the final diagnosis and therapy is decided by the specialist after a referral. While EFA understands the important role of pulmonary specialists, EFA asks, in the interest of achieving early diagnosis, that primary care physicians in each European country integrate spirometry testing into their routine health check-ups of current smokers, former smokers and all adults above the age of 35.

In the Czech Republic, Italy, Poland and Portugal general practitioners (GPs) are not performing spirometry tests, but the testing is rather performed exclusively by pulmonary specialists or

“Diagnosis is generally made too late.” Austria

hospital physicians. Only in the Netherlands and United Kingdom are all GPs capable of performing spirometry testing, while in the rest of the countries surveyed, only a select number of GPs are able to perform the test. A convincing study from Denmark concludes “early detection of COPD appears to be feasible through offering spirometry to adults with tobacco/occupational exposure to pollutants and at least 1 respiratory symptom” after a sample of 3095 adults revealed one-third of them had airway obstruction [14].

The experience of the health professionals issuing the test ranges from general practitioners (GPs) to pulmonary specialists and even nationally unique professionals, such as ‘longifunctie analisten’ or ‘lung analysts’ in the Netherlands. In some countries, like Spain and Sweden, COPD nurses administer spirometry tests, while in other countries, specifically Poland and Portugal, it is unclear if GPs are responsible for performing spirometry tests. It is important

“Spirometry is not part of the check-up, which is paid once a year.” Austria

to note that although spirometry may be readily available for GPs in some European countries, it is not known if they have been adequately trained to interpret the test results.

In just five countries, Belgium, the Czech Republic, Poland, Spain and the Netherlands, is spirometry testing included as a part of routine check-ups and this is only the case for patients with asthma, chronic bronchitis or rare lung diseases.

Surprisingly, only in Spain are smokers considered for spirometry testing in routine check-ups. In many countries such as Austria, GPs may not perform spirometry testing with their patients coming for health check-ups because they are not paid to include this test. It was noted in Finland and a few other countries GPs are taking more initiative in making the diagnosis with spirometry testing and then referring their patients to a pulmonary specialist.

The EFA members confirm there are not many COPD centres, and they do not routinely follow-up with patients. This is partly due to very low coordination between GPs and COPD centres but also a result of the general unwillingness or inability of COPD patients to travel long distances for a routine follow-up. Where COPD centres do currently exist, most are placed in an urban area which means an uneven national distribution of centres and limited access for COPD patients living in more rural locations or distant suburbs of large cities. The numbers of COPD centres will need to increase in the future to keep up with the disease prevalence so all patients have adequate access. This astonishing variability across the surveyed countries could be indicative of levels of care in the locations where follow-ups are unavailable. EFA thus asserts in countries where follow-ups are unavailable, the care provided to COPD patients may indicate poor levels of quality. While healthcare systems in Europe must be tailored to each setting, it is important to note the important roles for GPs in diagnosis of COPD and the need for them to coordinate effectively with pulmonary specialists and COPD centres where they are available.

Needs and Actions

Annual visits and free of charge routine health check-ups with GPs for adults over 35 years old, who are smokers, ex-smokers or show signs of respiratory illness, should undergo spirometry testing

GPs must be properly trained to administer and assess spirometry test results

GPs should be reimbursed for their time spent administering spirometry testing

COPD patients should always be referred to a specialist after a confirmed diagnosis

EFA believes the variability of how COPD diagnosis is undertaken across Europe to be astonishing and thus notes several key areas for improvement across all European countries based upon the survey results. Firstly, annual visits and routine health check-ups with GPs for adults who are over 35, are smokers or have specific respiratory symptoms should include spirometry testing. When the test results show signs of respiratory illness, GPs should help to arrange an appointment with a specialist for a detailed diagnosis and treatment plan.

Next, in order to standardise spirometry testing in primary care, GPs across Europe must be in a better position to perform and interpret the test results. This implies GPs should be paid or reimbursed for spirometry testing, which is not the case in all countries. Diagnosis should be tailored to each setting but if a GP cannot make use of spirometry, diagnosis will continue to occur much too late. Most GPs know how to provide spirometry testing but not all know how to interpret the results and many underutilise the test because they are not paid to perform it.

Therefore, the training and payment of GPs for spirometry should become an immediate priority so it can become a common practice within all European countries. Spirometry is acknowledged to be the best tool available to diagnose COPD

and therefore should to be utilized for assuring a correct COPD diagnosis. EFA strongly believes training of GPs on how to read spirometry test results is essential to increase diagnosis of COPD in all European countries. From EFA's point of view, it is vital to note there is no systematic routine follow-up in the COPD centres among the countries surveyed. Another area requiring action is to increase coordination between GPs, specialists and COPD centres so as to help keep patients healthy and assure their COPD remains in a 'stable' condition for as long as possible. Frequent and systematic follow-ups at COPD centers, which should be distributed proportionally within European countries, can help COPD patients avoid costly exacerbations and prevent unnecessary hospitalizations.

Lastly, while national guidelines already exist as reference points for COPD care in many places and implementation has been consistently recommended, it remains the case that they are not followed closely by health professionals and spirometry remains underutilised. The importance of using spirometry as a tool for the prevention of COPD remains underappreciated across European countries EFA surveyed. COPD guidelines only serve well if they are utilised; therefore, physicians must be trained on their national COPD guidelines to ensure they are adequately used.



Caring for Patients: Management and Therapy

An initial diagnosis of a patient with COPD leads to questions concerning management and therapy but the specific answers will depend upon whether or not the patient's condition is considered 'stable' or 'unstable.' According to GOLD, the management of 'stable' COPD patients should attempt to reduce and relieve symptoms, improve the ability to exercise and health status, prevent future risks - including disease progression - and reduce mortality. These goals should be pursued with few side effects from treatment [2]. Unfortunately, this is a complex task because many COPD patients have comorbidities, making it even more challenging to effectively treat patients as their other conditions similarly require very close attention.

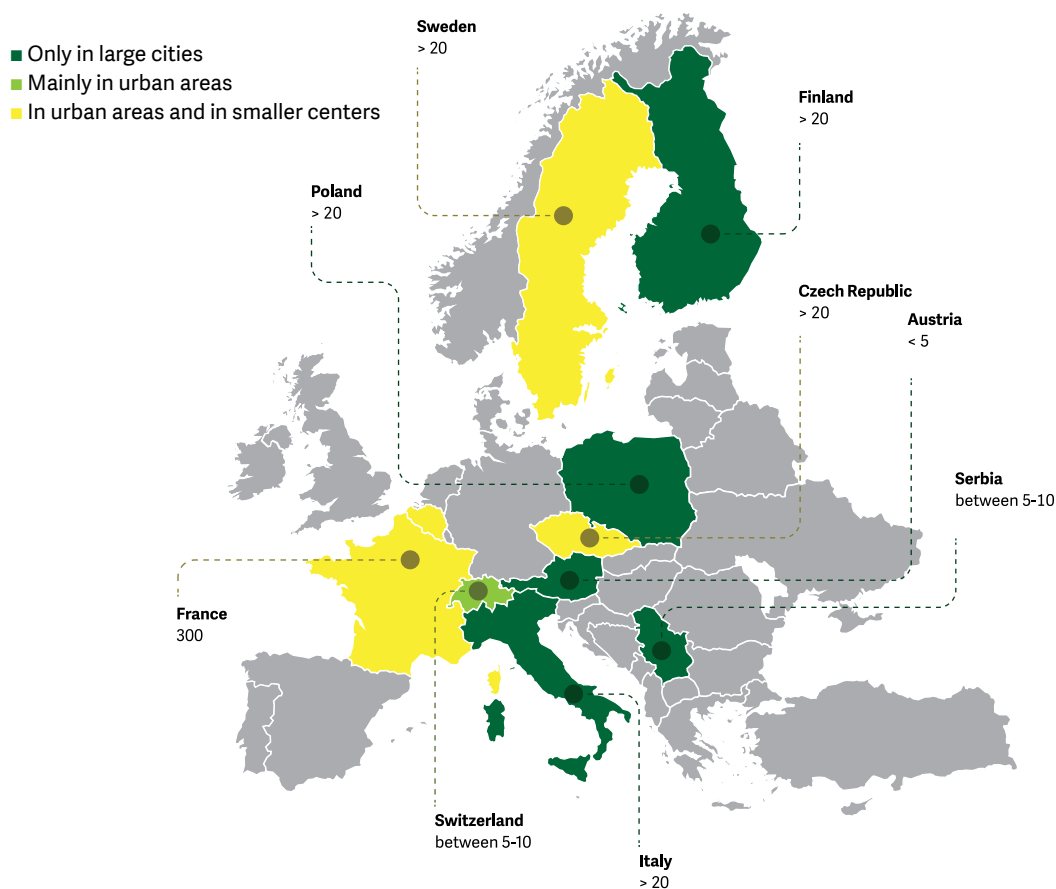
The amount of attention a patient receives tends to depend on the severity of their disease, which is common practice. In most cases, those with 'stable' COPD are seeing GPs while those with 'unstable' COPD will be seen by specialists; however, across all the countries surveyed there are almost no systematic follow-up plans and many patients will only see their doctor on an 'as needed' basis, most likely in the event of an exacerbation. This is crucial and requires

a more systematic approach. Not many COPD centres exist and in the countries where they do, like Austria and the UK, patients rarely have follow-ups within these facilities.

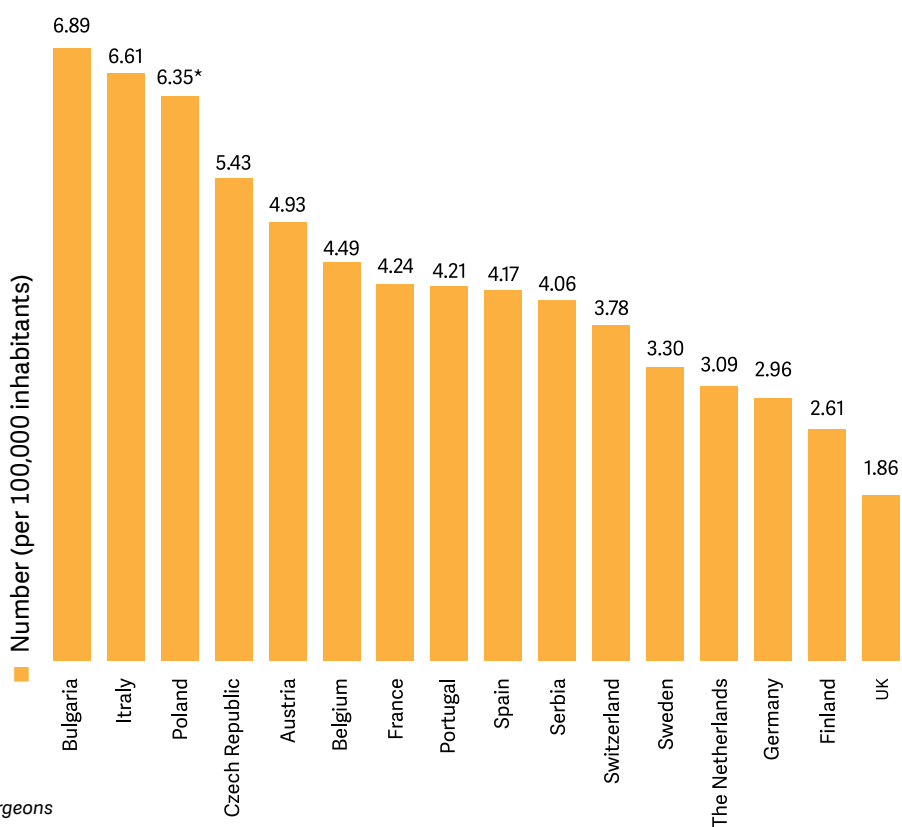
Most replies from surveyed countries reveal GPs are usually involved in the management process of stable patients. Patients will visit GPs at a minimum of once per year depending on the stability of their COPD condition. As pointed out by the EFA member from Switzerland, GPs are more involved with COPD patients because they regularly must co-manage their COPD along with multiple other comorbidities. Based upon EFA's survey answers, the most robust care system for COPD management appears to be in the Netherlands, where guidelines are strictly followed, and a patient may see a healthcare professional as often as every two months if their condition requires such attention. In Serbia, COPD patients usually visit pulmonologists once or twice per year but they must see a GP on a monthly basis for prescriptions in order to receive their medications for COPD treatment from the pharmacy.

In numerous countries surveyed by EFA, healthcare professionals do not need to undergo specific

Centres specialized in respiratory diseases



Number of respiratory specialists



*physicians and surgeons
Source: ERS White Book 2013

“Severe cases are followed up in COPD centres, but they are located mostly in large cities.” Czech Republic

training to manage COPD patients; only a continuous medical education (CME) programme covering all medical content is mandatory in Germany, Spain and the Netherlands. In the Netherlands, specific training becomes an important indicator of good quality care, according to the COPD & Asthma Practitioners Advisory Group (CAHAG), and is often required by health insurance organisations.

An important aspect of disease management is also to properly inform COPD patients how to avoid exacerbations, as severe episodes can cause progression of the disease which is not reversible. In the cases where patients have an exacerbation, in nearly all countries pulmonary specialists are available to treat patients, while GPs are also available to treat patients in most cases. In Germany, it is estimated 50% patients who have mild exacerbations manage these themselves, while more severe exacerbations are treated by a GP, specialist or hospital depending upon the seriousness of the episode [15]. In general, treatment for exacerbations will depend upon the severity of the patient's condition with GPs normally treating patients first and then sending patients to specialists or the hospital if there are no signs of improvement. It appears that only in Sweden exacerbations are treated exclusively by specialists. However, the approach taken to exacerbation management depends on the geographic location of patients with respect to services and whether or not national guidelines are used as a basis for providing care.

Patients with COPD are at high risk for infections and need education from health professionals involved in their disease management. Patients must be instructed to avoid situations where they may be at risk to contract an infection, which is the most frequent starting point for exacerbations. Examples of such situations include inappropriate clothing for wet or cold weather and attendance to gatherings of a number of people, particularly during flu season. An important strategy is to have GPs and healthcare

“All patients can reach a good hospital within 20 minutes.” Belgium

professionals administer (or prescribe if necessary) patients flu and pneumococcus vaccinations.

It is extremely important for patients to see their GP at the first sign of an exacerbation and they must receive early treatment against infection. Many COPD patients attempt to self-manage an exacerbation, only for it to become severe; as a result, patients must be properly informed of the importance to seek medical help with early signs of exacerbation as part of a self-guided management plan. The importance of exacerbations cannot be understated as they can result in unnecessary hospital visits to the emergency room, which is one of the reasons COPD has such a high cost to European societies. Increasing the quantity and accessibility of COPD centres in Europe is an additional step which can help direct COPD patients requiring help to the right place and decrease trips to the hospital.

As a part of disease management for some patients with COPD, oxygen therapy may be necessary to help a patient maintain an acceptable quality of life. EFA's survey reveals prescriptions for oxygen therapy can be issued by pulmonary specialists in all countries, by GPs in only three countries (Belgium, Italy and Portugal) and by hospital physicians in five countries (Austria, Belgium, France, Germany and Portugal). The significant differences between reimbursement policies for oxygen are important to note. While Bulgaria and Poland are the only countries of those surveyed which do not offer reimbursement of any kind for oxygen therapy, in other countries, partial reimbursement is commonly dependent on the severity of the disease, which is useful to assure the people who are in the highest need receive the therapy they require (e.g. Finland, Portugal and Sweden).

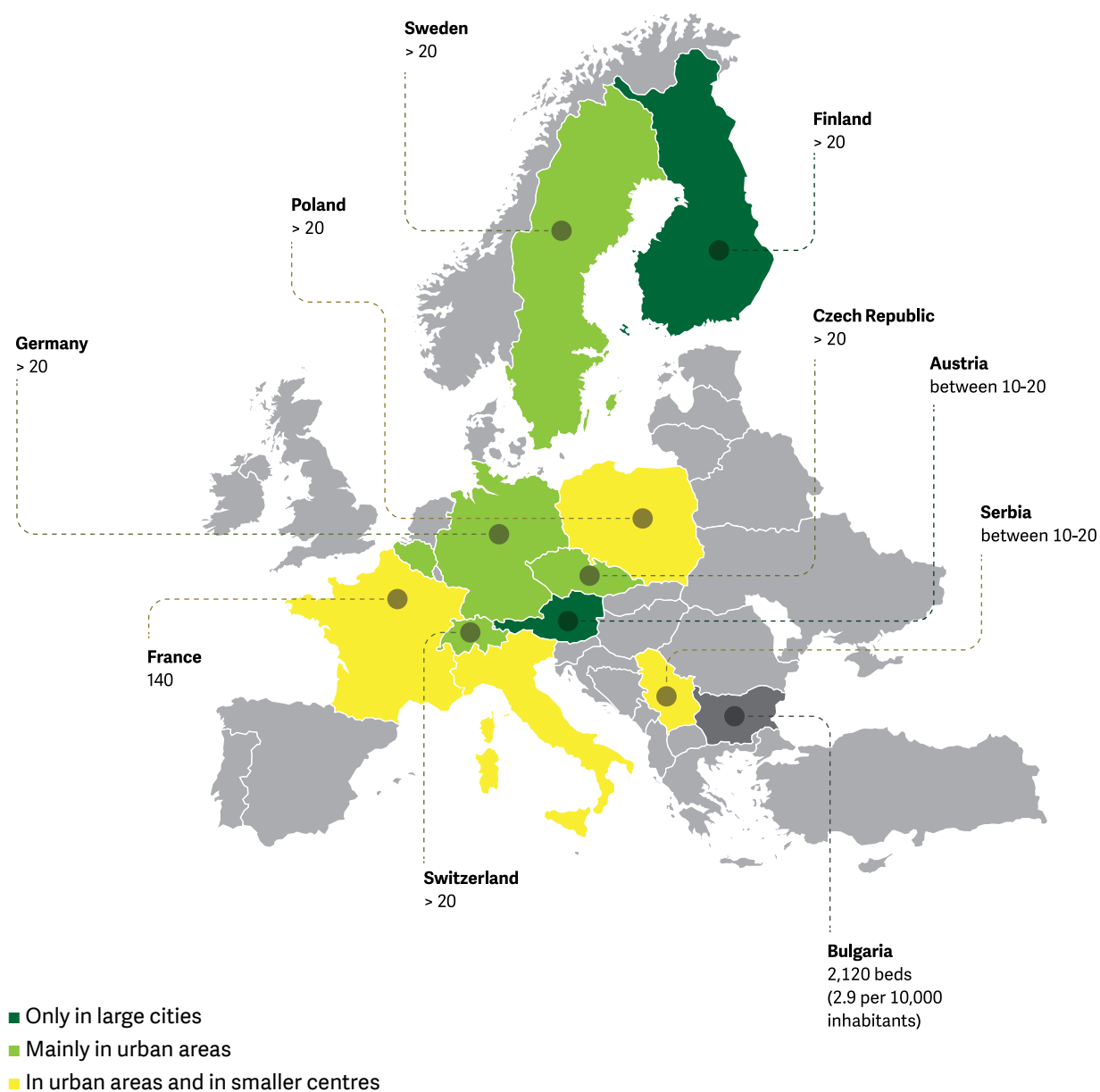
Easy access and reimbursement of oxygen therapy for COPD patients when they travel appears to be feasible and very important for the patients as easy access and reimbursement can allow patients to conduct a normal life. Lifting limitations for COPD patients requiring oxygen therapy when they travel can assist to promote psychological well-being as well because the inability or high cost to travel with oxygen can lead to depression, especially if it prevents them from seeing family members or implies consequences at work. The healthcare systems in many countries appear to support reimbursement of oxygen therapy during travel, but there are important particularities across most of the countries. These range from the

limited availability of liquid oxygen to once per year in Serbia to the restrictions of local budgets in Italy. Such differences reveal that even among countries offering reimbursement there still exist various contrasting approaches by European healthcare systems to oxygen therapy.

The replies in the survey demonstrate mixed levels of satisfaction with oxygen therapy, with the most approval in Austria, France, Switzerland and Portugal, while the lowest satisfaction is notable in Poland, Serbia and the Netherlands.

Overall oxygen supply services are satisfactory, but these services appear to be less organised for patients when they travel long distances either within the same country or internationally. The organisations provided a range of comments which further indicate inconsistencies across healthcare systems on issues such as compatibility of strollers and complexities in arranging for oxygen therapy when traveling. Shockingly, in Poland the cost of portable oxygen concentrators (POCs) are equivalent to ten times the national minimal monthly income, with less expensive

Respiratory units in hospitals



immobile oxygen concentrators only available in specific COPD centres. The cross-border healthcare directive from the EU that entered into force in October 2013 may provide a legal basis for helping patients requiring the use of oxygen when traveling in another EU member state because it calls for governments to guarantee equal treatment as patients in that country. If they are entitled to the same care at home, the home country can reimburse provided that patients asked for permission from their healthcare system [26].

There is a limited amount of information available on weaning centres in Europe. These are where patients undergo ventilator weaning, which “is the process of slowly, carefully and

safely removing someone from mechanical ventilation in order for him or her to breathe without help from a machine” [16]. Weaning centres are especially important in the care of patients with severe exacerbations when they may require frequent ventilation to significantly improve their condition followed by careful ‘weaning’ enabling them to breathe by themselves again. EFA’s survey results appear to show there is a very low number of weaning centres in Europe; however, those confirmed to exist are usually in large cities and within pulmonary departments or resuscitation units of public or university hospitals. EFA acknowledges many weaning centre patients do not have COPD and this could be a significant reason for the limitations on information provided.

Comments on satisfaction with oxygen therapy supply

Austria: Travelling abroad: It depends on the supplier and varies very much from region to region. Sometimes it is very difficult to get oxygen and is often costly. Travelling abroad needs very exact and early planning.

Germany: 1) Liquid oxygen supply is satisfactory, concentrator 70%; 2) Oxygen supply covers the whole country, but there are regional differences; 3) Most patients get no tank for their car; 4) Travelling aboard is difficult and complicated.

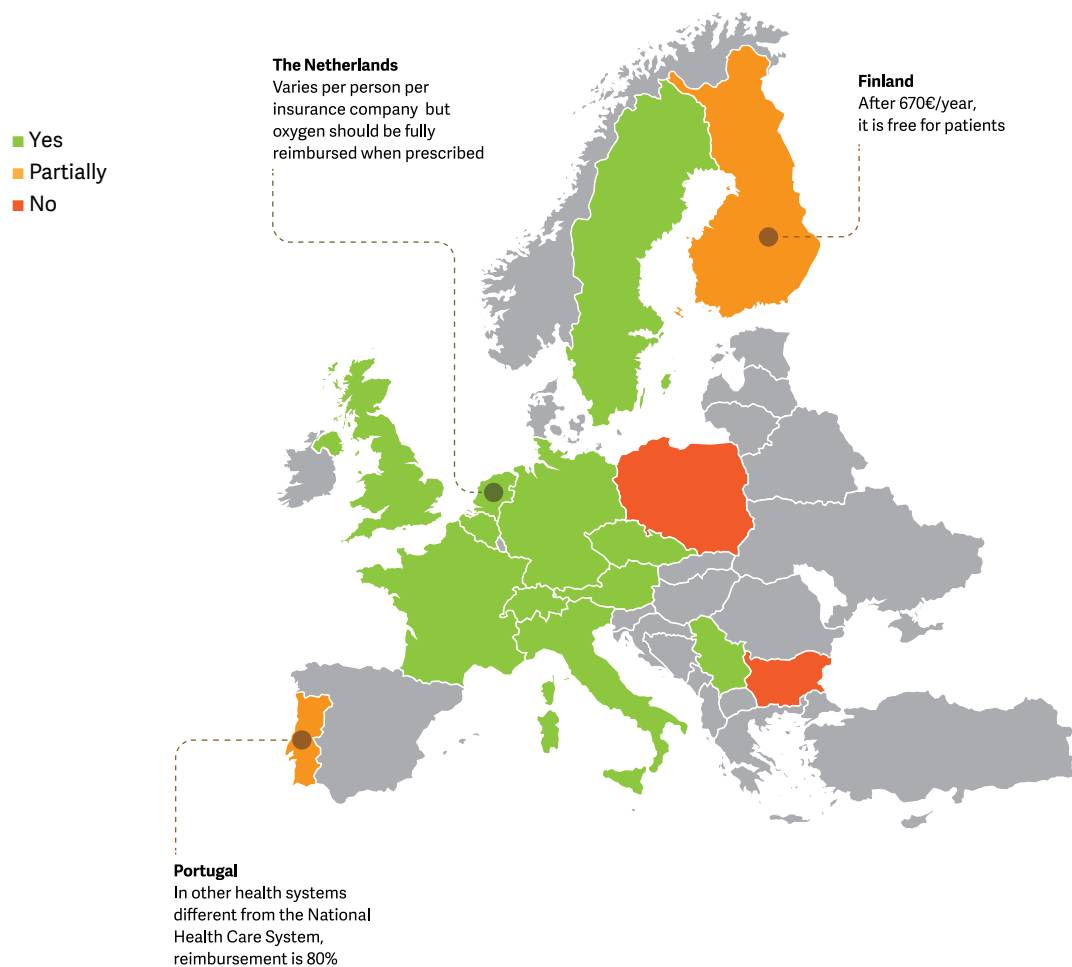
Italy: Supply depends on the company. Bureaucracy is a barrier. In Italy every 4 years the Regional Healthcare System selects the supplier via a tender. Patients should be involved in the decision-making phase in order to have what is really needed. For example, the strollers are

important. More information on supply centers would also improve patients social life. Stroller systems should be universal or compatible so patients can recharge with no difficulties. When travelling it may be not easy to find information.

Poland: We have centres for home oxygen therapy in all country but the waiting list usually is about one month; in our service we have only oxygen concentrators, without any possibility to move with the equipment; the cost of mobile device is about 10x of minimal monthly income.

The Netherlands: Oxygen is now topic of a workgroup of the Lung Alliance Netherlands to enhance the quality of delivery, information and reimbursement.

Reimbursement of liquid oxygen and concentrators



Reimbursement policies for oxygen therapy (including the cost of electricity to operate oxygen concentrators, oxygen supply when travelling for holidays, etc.)

Austria: Oxygen therapy is reimbursed. For liquid oxygen the patient has to pay € 5.30 per tank refill. Electricity for concentrators is not reimbursed. Oxygen is also reimbursed for holidays within the country.

Belgium: The cost of electricity is reimbursed; oxygen on holiday is reimbursed but with restrictions.

Czech Republic: The cost of electricity is reimbursed on special request only.

France: Oxygen therapy is reimbursed when sick and continues to be while patients travel or are on vacation.

Germany: Employed persons get both methods, if they can demonstrate that it will be necessary. Electricity is not fully reimbursed for concentrators. For holidays reimbursement is given once a year.

Italy: Sometimes, depending on local budgets, concentrators are not given free of charge.

Portugal: Reimbursed in the National Health System.

Serbia: Only oxygen concentrator is reimbursed. The patients have to pay for liquid oxygen which became available in Serbia for less than one year ago.

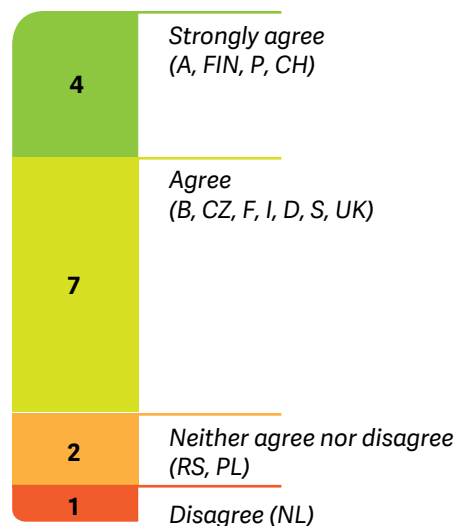
Sweden: The cost of electricity is not reimbursed.

Switzerland: Oxygen while travelling is reimbursed. The cost of electricity is not reimbursed.

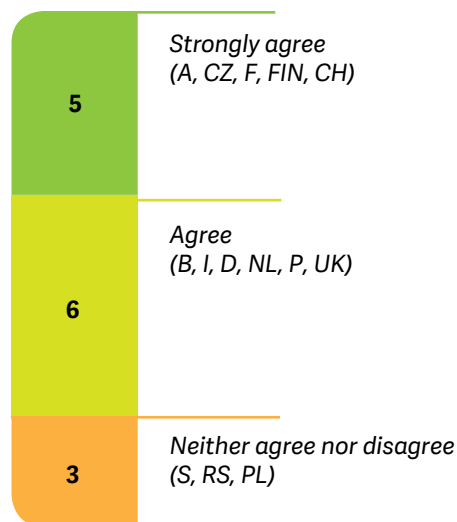
The Netherlands: Oxygen therapy is reimbursed, but details vary per health insurance company, per year, regarding costs of electricity, holiday travel and mobile devices.

Perceived satisfaction regarding oxygen therapy supply

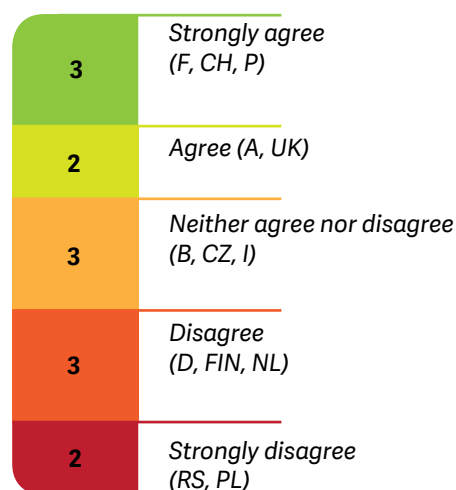
The oxygen supply service is satisfactory



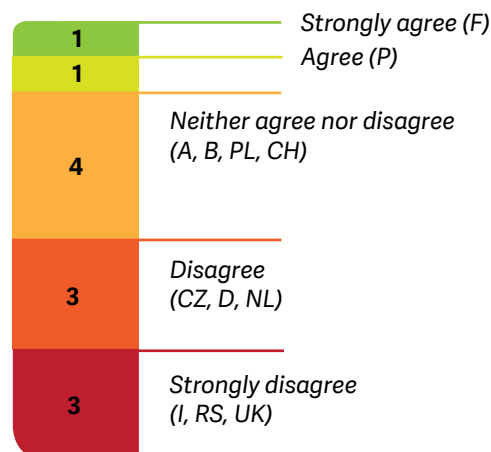
The oxygen supply service covers the whole country



The patients can easily find an oxygen supply when travelling within their country



Patients can easily find an oxygen supply when travelling abroad



Abbreviations: A, Austria; B, Belgium; CZ, Czech Republic; FIN, Finland; F, France; I, Italy; D, Germany; PL, Poland; P, Portugal; RS, Serbia; S, Sweden; CH, Switzerland; NL, The Netherlands; UK, United Kingdom

Needs and Actions

All healthcare professionals involved in the care of COPD patients should closely cooperate to ensure a patient has consistent follow ups and their disease management plan is effective and appropriate for the severity of their condition

Reimbursement and access to oxygen therapy should be harmonised for traveling long distances in Europe

Stronger links should be created between pulmonary and resuscitation units within hospitals to ensure COPD patients in emergency care are evaluated by pulmonary specialists

The EFA survey's results reveal there is no routine follow-up in the COPD centers/clinics in many European countries, which is a serious problem. Patients should have an adequate understanding of their condition, which can only happen if they are following up with medical professionals. They must clearly understand the necessity of avoiding risk factors and all situations which could trigger a severe exacerbation, such as exposure to cigarette smoke. All COPD patients should be ushered to smoking cessation services with follow ups if they are smokers themselves and should be vaccinated (against flu and pneumococcus disease) in due time before picking up infections during the colder seasons.

EFA emphasises the necessity for healthcare professionals to increase their collaboration and improve communications, specifically between GPs and specialists since management of the patient's condition is dependent on severity. On the one hand, the professionals have a responsibility to communicate in lay friendly language necessary steps and instructions to patients so as to ensure they understand and can use the advice as written self-management plans are imperative. On the other hand, a patient must be assured appropriate care so the healthcare professionals have an obligation to confer and confirm the care required. Without specific follow-up plans in place, a lack of communication between these two sides can lead to inefficient care for COPD patients. Such inefficiencies make patients more prone to exacerbations and a progression of the disease to more severe stages.

While only a few countries have GPs able to prescribe oxygen, this is still encouraging as these countries appear to be following previously established COPD care guidelines. However, reimbursement of oxygen therapy when patients are traveling is extremely important. For example, some patients have both a permanent address and secondary address for seasonal residency, and as a result, having two addresses can be a practical problem for oxygen therapy use. Travel by airplane was also identified by EFA as a major concern as there are no harmonized regulations for oxygen use on European airlines. EFA's recent booklet *Enabling Air Travel with Oxygen in Europe* clearly demonstrates ongoing discrimination against passengers requiring oxygen therapy during air travel, as they are commonly charged several times the price of normal airfare [17]. The ongoing practice of exploiting patients with chronic respiratory diseases is especially unfortunate because these patients benefit from staying in warmer regions during the winter and is a potential way to avoid exacerbations.

Where weaning centres may be located within resuscitation units of hospitals, a link must be developed with pulmonary units as they are normally not in close proximity or collaboration. With an aging population in most European countries, the future will require a firmer link between acute and chronic care. COPD patients who undergo emergency treatment should always be assessed by a pulmonary specialist as a heart attack victim would be assessed by a cardiologist.



5 Staying Active and Improving Rehabilitation

The use of *pulmonary rehabilitation* in this publication specifically refers to “an evidence-based, multidisciplinary, and comprehensive intervention for patients with chronic respiratory diseases who are symptomatic and often have decreased daily life activities” [18]. Rehabilitation is known to be a critical step in the process of disease management for COPD patients because it is tailored for individual patients and leads to improvement of their lives in many respects. Following an acute exacerbation, patients often achieve stability of their disease after they undergo pulmonary rehabilitation. COPD patients require the treatment when normal activities and movements become increasingly difficult to perform, which would indicate the onset of reduced mobility and a deteriorating quality of life.

“Not all patients can access rehabilitation due to mobility difficulties. Moreover, there are long waiting lists.” Italy

It is possible to have pulmonary rehabilitation available on an outpatient basis or in a patient’s own home, but this practice is less common than in hospitals or specialised

centres. Rehabilitation meets patient needs because it simultaneously combats the progression of the disease and targets reducing symptoms. Most importantly, it promotes an increase in physical activity, which “is the strongest predictor of all-cause mortality in COPD patients, and increased activity is associated with better prognosis, physical and cognitive status” [6], in short, a better and longer life. Studies confirm beneficial outcomes for patients, including improvement in breathlessness, exercise tolerance and health-related quality of life; other potential outcomes include reducing consumption of healthcare resources, improved function of respiratory muscles and survival, but these two latter potential outcomes still require further evidence [6] [19]. Continuation and repetition of the rehabilitation permits patients to profit further as “the benefits from pulmonary rehabilitation persist to some degree for a year [and] repeating pulmonary rehabilitation after a period of one year provides benefits in exercise capacity and quality of life” [20].

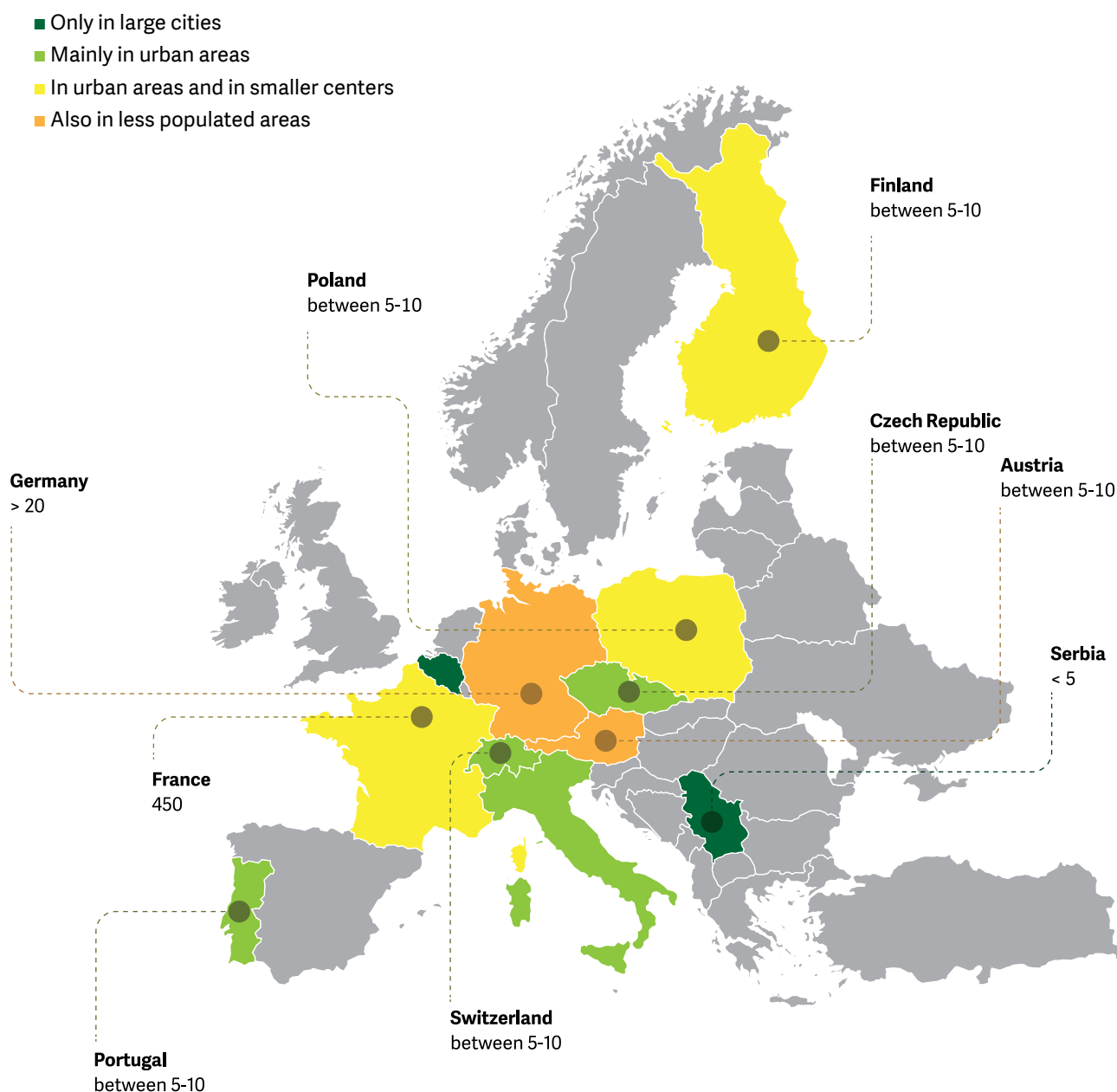
Overall, in the countries surveyed by EFA, there is a need for more rehabilitation centres/programmes for COPD patients. In some countries,

there are no regular programmes, and patients can undergo rehabilitation “only occasionally” like in Austria, Finland, France, Germany, Poland, Serbia and the UK. In Austria, it is also the case reimbursement is paid for and rehabilitation is accessible to *only the working population*, with few exceptions dependent upon the insurance provider. EFA notes the example of Austria is an *especially negative practice* as rehabilitation improves the quality of life for *all* patients, regardless of whether or not they are employed. The UK only allows rehabilitation for ambulant patients

and the Netherlands makes pulmonary rehabilitation available exclusively by referral from a pulmonologist.

Unfortunately, pulmonary rehabilitation is not available for outpatients in many countries. In the case of Austria, patients have to go to fitness centres for rehabilitation and neither the national healthcare or insurance pay for rehabilitation in an outpatient setting. In Bulgaria, separate pulmonary rehabilitation hospitals for patients with respiratory diseases exist. Belgium appears to be

Respiratory rehabilitation centres



“Patients must seek access to rehabilitation themselves. There is no systematic approach.”

France

services for patients. It appears many rehabilitation centres in Europe which do exist have limited reimbursement available for COPD patients using their services.

Rehabilitation enables people to manage their condition better no matter what the level of severity. Outpatient rehabilitation is particularly important because it can lead to an improved quality of life for patients and can empower patients to become increasingly independent. For instance, a recent study of COPD patients in India demonstrates twelve weeks of yoga classes yielded significant improvement in patient's quality of life and a reduction in their dyspnea symptom severity [19]. The success of using yoga as a rehabilitation method was due to the patients' ability to learn the exercises and continue to perform them regularly in their own homes. For the initial four weeks of the study, patients were at the hospital for their yoga rehabilitation sessions twice a week, whereas for the last eight weeks patients were encouraged to do exercises at home and only came for classes once a week. Arguably, the success of the model used was the encouragement of patients to use yoga as a rehabilitation method in their own homes. This increased independence and empowered the study subjects to improve their wellbeing, thus making

the only country with pulmonary rehabilitation available exclusively in the hospital setting and only four have reimbursable ser-

vice available to patients who previously had very poor access to such services, while successfully improving their breathing [19].

EFA's survey results overview how access to pulmonary rehabilitation has been organized in each country, if rehabilitation is available for all patients who meet the necessary criterion or is only accessible when patients are just in the acute phase. Moreover, since the intervention should be multidisciplinary, members were also asked which healthcare professionals are involved. According to the ERS COPD audit, only 30% of eligible patients receive pulmonary rehabilitation while the same percentage of hospitals are able to offer both hospital-based and home-based rehabilitation [6]. Bearing this in mind, the information collected by EFA can be quite revealing with respect to specific background details which may indicate reasons why more COPD patients do not receive pulmonary rehabilitation.

Results show GPs are very rarely involved in rehabilitation programmes, but in some cases, they are involved within programmes of specialized centres (Germany, Sweden and the Netherlands). In both Sweden and the UK, GPs are also involved in outpatient care, but these are exceptions among the countries surveyed. Nurses also carry out rehabilitation in just a few countries and, interestingly, pulmonary physiotherapists are often available but only for rehabilitation in hospitals. Other professionals like internal medicine specialists, psychologists and occupational therapists are included in some cases.

Needs and Actions

Pulmonary rehabilitation should be available to all COPD patients who are identified as requiring such services

Centres offering pulmonary rehabilitation for COPD patients should be increased as it is a cost-effective means to prevent future exacerbations and hospital trips

COPD patients who are discharged from the hospital should engage in pulmonary rehabilitation as soon as possible to regain normality in their everyday lives

Multidisciplinary approaches to pulmonary rehabilitation should be utilised as often as possible so as to appropriately address comorbidities and personalise patient care

COPD patients must be encouraged to actively engage in rehabilitation so they do not become passive with their conditions thereby permitting regressions

Pulmonary rehabilitation must be available to all eligible COPD patients who are capable of benefiting from such a service. Benefits of rehabilitation have been clearly outlined this year by GOLD, the British Thoracic Society and the ERS, all of which agree it can make a significant positive impact in the lives of COPD patients. In addition, placing emphasis upon increasing the accessibility of pulmonary rehabilitation to patients can yield long-term benefits to society as a whole since it primarily involves guided and supervised *physical exercise*. This should *not* be limited to a specific demographic (e.g. patients with work) but rather should be *as inclusive as possible*.

By organising and creating more rehabilitation centres and programmes, opportunities for more COPD patients to benefit from both inpatient and outpatient rehabilitation can result in healthcare systems avoiding the high costs of future hospital visits and allow for reallocation of resources. Since physical exercise is emphasised in particular, national ministries of both health and education can collaborate to introduce even more extensive programmes to help patients avoid debilitating episodes of exacerbations and prevent extended disability. As an additional bonus, rehabilitation does not involve heavy dependency on expensive products but instead employs the consistent commitment of patients to self-improvement and the human resources to guide and supervise activities to ensure patients

can receive the maximum benefits from their sessions.

For COPD patients who are discharged from the hospital, it is vital they can commence with rehabilitation very soon afterwards to regain an acceptable quality life and re-engage in everyday activities both physically and psychologically. EFA recognises COPD patients are often most vulnerable to psychological co-morbidities following an exacerbation and inadequate care can lead to social anxieties and depression. With an individualised approach, patients can benefit more from the attention provided during rehabilitation since customised advice can help focus their treatment to specific aspects of their life requiring more attention.

Pulmonary rehabilitation should be able to serve as a multidisciplinary approach, which includes diverse medical professionals, including psychologists and physiotherapists, to counteract a wide range of potential problems. The rehabilitation process, when correctly utilised by patients, should succeed in providing motivation and adequate support to help patients build confidence in resuming a normal life and stalling the progression of the disease. Only with consistent availability of pulmonary rehabilitation services can COPD patients realistically come closer to the necessary control of their disease and provide the incentive necessary to overcome the temptation to passively manage their condition.



6 The Special Case of Alpha-1 Patients

Alpha Europe Federation's aim is to provide a European information and resources network for patient support groups and linked associations, health professionals, institutions and industry who wish to improve and extend their knowledge of Alpha-1 Antitrypsin Deficiency. We aim to use and create services and tools in order to share this knowledge and those skills available to provide a much improved understanding of the condition, health care, social and psychological support for patients and families affected. EFA is excited to collaborate with Alpha Europe to provide this information in the *EFA COPD Book for Minimum Standards of Patient Care* because of their work in parallel on this very issue, to create quality standards of care for alpha-1 antitrypsin deficiency (AATD) patients in Europe.

Within the questionnaire sent to EFA members, specific inquiries were also included for patients with alpha-1 antitrypsin deficiency (AATD), which can be viewed in Annex I. However, unfortunately, there was not a significant amount of verifiable recent epidemiological data available in many of the countries surveyed to gauge prevalence rates. As a result, EFA reached out to

its existing counterpart in Europe for AATD, the Alpha Europe Federation, for further assistance in acquiring the most accurate and detailed information available for this section. Nevertheless the information provided still cannot be described as comprehensive. Despite this situation, EFA was still determined to make the information it was able to acquire regarding AATD patients available in its COPD book because these patients require similar minimal standards of care as EFA requests on the behalf of European COPD patients. The low public awareness and knowledge of AATD, even within COPD patient associations, makes it imperative for EFA to include information concerning these patients.

Minimum Standards for Alpha-1 Patients in Europe

AATD is a genetic disorder which is defined by low levels of the 'alpha-1-antitrypsin' protein in the bloodstream. The protein is necessary to counterbalance enzyme activity which can result in damage to the lungs. When concentration of the protein is at 10-20% of normal levels, a person can be considered to have the AATD condition [20].

While it is possible for symptoms to appear early in life, AATD non-smokers can expect to lead a normal life; however, some may experience worsening lung, skin or liver conditions with age. If a patient is a smoker, their condition is much more likely to deteriorate rapidly and increase probability of developing COPD. Although AATD patients do not represent a vast proportion of Europeans, EFA nevertheless believes clarifying standards of care to be a necessity since their needs are very similar to those of patients with COPD.

The calculation of the condition's prevalence firstly depends on how AATD patients are defined. For this book, they will be defined as having PiSS, PiSZ and PiZZ genotypes. The most easily accessible and credible prevalence data available to EFA is from 2007, showing significant prevalence of these genotypes among the European population when compared to the rest of the world with countries like Spain, Portugal and Latvia showing a much higher prevalence for at least one of these genotypes than other nations [21]. In Austria there are only 171 patients with PiZZ genotype and 5 with PiSZ genotype in the registry. The international incidence is close to 1 in 3000 people, which would imply more than 2500 AATD patients should exist in Austria [22]. The data available for AATD prevalence distribution by gender is unknown in most European countries with the exception of Austria, whose EFA member confirmed a prevalence distribution of 61.9% among males and 38.1% among females according to a study with 139 AATD patients [22].

Although AATD is a genetic disease, implying no variation with age, the associated diseases do tend to vary with age as the onset of AATD-related COPD is earlier than COPD which is caused by other factors. The total percentage of COPD patients tested for the condition is unknown, but according to the most recent studies, the prevalence for Alpha-1 deficiency is higher than formerly believed and yet is rarely diagnosed in a timely manner [23]. Since AATD patients already are more vulnerable to develop chronic respiratory disease than others, it is especially important to clearly outline the means to diagnose AATD as early as possible in the patients' lives, as the condition is always present from birth. If COPD patients as a whole require earlier diagnosis to save costs and offer better quality of life for individuals in the early stage of the disease, then this is similarly true and needed for AATD patients

since many do not have a correct diagnosis.

EFA calls for systematic AATD tests for all infants in the first year of their life through blood testing. Pregnant women could also have their medical history evaluated for risk factors which could indicate the high possibility for their child to have AATD. While EFA realises an achievement of such standardised testing could be challenging due to the diagnosis costs with relation to the condition's incidence, diagnosing AATD earlier in the life of patients is extremely important to prevent the unnecessary loss in their quality of life, particularly those who already have a COPD diagnosis before the age of 45. Fortunately, AATD diagnostic testing is available in all European countries, which further incentivises its use as requested.

There is low public awareness and knowledge on Alpha-1 and on such patients needs.

Specific guidelines are known to exist for AATD patient care from the American Thoracic Society (ATS), European Respiratory Society (ERS) and World Health Organisation (WHO). Additionally, a working group hosted by the European Parliament has brought together Alpha-1 experts, who together provided recommendations which establish a reliable basis for European guidelines in AATD diagnosis and care. The Alpha-1 experts recommended genetic testing and early detection for the identification of patients requiring augmentation therapy (AT) in a timely fashion to both reduce costs and optimise health outcomes.¹ Adults with symptoms of emphysema, COPD or asthma are considered to be a main target group of patients with respiratory disease for testing. Countries with populations known to have higher prevalence of AATD should be encouraged to utilise genetic testing, particularly among people with unexplained liver disease, persisting difficulties in lung function with clear risk factors (like cigarette smoke or occupational hazards) and relatives of diagnosed AATD patients.²

Many countries surveyed by EFA already have national guidelines existing; for example, in Germany all patients with COPD along with their relatives receive blood tests with additional guidelines to recommend further measures forthcoming. National registries for the condition also exist in many of the countries, which helps to confirm and track the AATD patients and thus

1. Alpha-1 in the European Union Expert Recommendations, Recommendations of the Alpha-1 Expert Group, European Parliament. Accessed 22 October 2013. <http://www.alpha-federation.org/expertrecommendations.htm>

2. *Ibid.*

Diagnosis of Alpha 1 deficiency in early life is important to prevent unnecessary quality of life loss.

provide a reliable basis for prevalence measurement. The International Alpha-1 Registry (www.aatregistry.org) is also known to collect data from many European countries, which someday could also contribute to a broader continental and or regional calculation of AATD prevalence.

According to EFA's questionnaire results, the primary contacts among medical professionals for AATD patients are usually, and almost exclusively, pulmonary specialists. The pattern of medical management of AATD patients varies widely across the European member states. Germany is one country where both GPs and specialists are the main points of contact. Additionally, in each German state there are Alpha-1 centres for adults and in most states there are centres for children. In most European countries, patients have an annual or bi-annual visit to an AATD specialist, but subsequent care will be performed by primary care, pulmonary rehabilitation specialists, respiratory nurses or others. EFA also acknowledges that like all COPD patients, people with AATD require personalised and comprehensive disease management plans ensuring high quality information and educational material is available for people with the condition, including its different stages and levels of severity. Similarly, AATD patients who are smokers should also receive regular encouragement to utilise the full range of available smoking cessation support. Those with long-term oxygen therapy should also have annual check-ups to ensure no changes are required in their treatment due to the status of their disease's symptoms.

One major surprise for EFA, when reviewing responses from its members, was the lack of

availability for AATD patients to receive AT in about half of the countries surveyed. Access to AT is extremely important because studies indicate it can reduce mortality by 33% and can prevent the further loss of lung tissue by 33-50%.³ In evaluating information received from Alpha Europe and the EFA members' survey replies, AT is only available in Austria, Belgium, France, Germany, Italy, Spain, Switzerland and Portugal, although certain limitations can exist in these countries. Countries where AT is not available include Denmark, Ireland, the Netherlands, Norway, Poland, Serbia and Sweden, where sometimes it is the case that AT is licensed but not authorised or reimbursed. Improved access to AT in Europe would mean a better quality of life as well as equity for AATD patients, as the national practices barring AT from reimbursement puts specific national populations at higher risk for life-threatening consequences. EFA strongly encourages AT being available to patients in *all European countries* along with the possibility for its reimbursement.

The existence of the Alpha Europe Federation is an encouraging indicator of increasing mobilisation of AATD patients across European countries. Cross-border collaboration can encourage and facilitate the harmonisation of coordinated actions to help in promoting awareness for AATD in Europe and assist in promoting better practices for ensuring the quality of life for patients. AATD national associations exist in many European countries, but unfortunately, not in all of them. There are presently twelve countries with patient associations identifiable by EFA's own members and the membership composition of Alpha Europe Federation. EFA encourages the mobilisation of AATD patients in countries where this has not yet occurred and endorses efforts by existing associations to continue the promotion of earlier diagnosis for AATD patients and free access to augmentation therapy in all European countries.



7 Conclusion

EFA encourages the creation of minimum standards of care for COPD patients in Europe in order to promote cost-effective solutions and raise awareness to one of Europe's most neglected healthcare burdens. Without identifying specific measures to overcome the multitudes of problems confronting healthcare systems, it is uncertain whether or not the status quo can be maintained for future generations. As a result, minimum standards of care for COPD patients aim to provide national healthcare systems with best practice goals they can aspire to incorporate into their approaches to mitigate the disease's impact on their societies. While the European Union may play a role in promoting such practices, ultimately the member states must create the opportunities to enforce acceptable standards of care for COPD patients in their countries.

As a first step, national healthcare systems in Europe should strive for the strongest possible measures for the prevention of COPD. Enforcing smoke-free areas in public places and further restricting sales of tobacco products as well as smoking prevention activities in schools (targeting children of the ages 7-10) is a starting point,

but establishing free smoking cessation services should be a priority, as they may ultimately lead to long-term cost savings for healthcare. All smokers require consistent encouragement to quit and should be offered the full range of cessation services should they wish to utilise them. In addition, preventing progression of COPD into more serious stages can be accomplished through cessation services and educational materials detailing how to avoid risk factors and improve quality of life.

Secondly, European healthcare systems must improve COPD diagnosis through emphasising the utilisation of spirometry testing by GPs in annual health check-ups for their patients who are over 35 years old, are current or ex-smokers and exhibit potential symptoms of the disease. By identifying higher numbers of COPD patients in the earlier stages of their disease's progression, more opportunities exist for these individuals to adapt their lifestyles and learn to self-manage their disease. GPs must also be trained on how to administer and read the results of spirometry testing and should be reimbursed for their time spent testing patients.

“Policy makers should involve the patients in the decision-making phase, in order to understand our real needs” Italy

A third step concerns the management and therapy of COPD patients through collaboration between GPs, specialists and hospitals or other medical centres. This is critical to ensuring patients the quality care and consistent follow-ups they require. In addition, when COPD patients have an exacerbation and are admitted to resuscitation units, there should be an opportunity to be evaluated by a pulmonary specialist to determine the best means to decrease the risk of future exacerbations. Ideally a follow up should occur within the first few weeks following an exacerbation. Oxygen therapy should be available to patients in need with as few restrictions as possible for both reimbursement and travel throughout the European continent.

The final step concerns the assurance of pulmonary rehabilitation to all COPD patients who

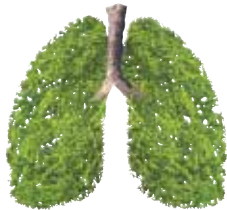
may benefit from such services, regardless of their employment status. Strong evidence shows the effectiveness of rehabilitation to improve a patient's quality of life and reduce the likelihood of disease progression. By increasing the number of centres specialising in COPD care and pulmonary rehabilitation, patients can be directed to the most qualified medical professionals and specified access points for assistance in their rehabilitation. Outpatient rehabilitation is proven to be cost effective.

These four steps are crucial for the implementation of the EFA's minimum standards of care for European countries. Should European countries incorporate these recommendations into national strategies or programmes for COPD prevention and care, it could provide much needed relief for healthcare systems in the future. By keeping the perspective that short-term actions can reap long-term benefits, the way in which COPD patients receive their healthcare can improve considerably across the continent.

Your Partners the Patients: Patients' Associations Best- Practices and Descriptions of the Participating EFA Members

AUSTRIA - Österreichische Lungenunion (Austrian Lung Union)

www.lungenunion.at



**ÖSTERREICHISCHE
LUNGENUNION**

The Austrian Lung Union is a patient organisation for people suffering from allergies, asthma, COPD, lung cancer and atopic eczema with about 5000 members.

“We are here to listen to you – We are here to talk to you – We can offer you this kind of assistance”

- Explanation of and information about your illness
- Information and educational lectures and discussions about relevant topics with experts in the field
- Functional breath and vocal production training
- Consultations for the parents of children with respiratory diseases
- Information pamphlets on a wide range of topics for patients
- Free advice and answers
- Educational center for people suffering from respiratory and pulmonary diseases

BELGIUM - Astma- en Allergiekoepelvzw (Dutch-speakers association)

www.astma-en-allergiekoepel.be



We provide information about COPD, asthma and allergy to patients and healthcare workers. We try to raise awareness for our people to society and government. We do this through our leaflets, by speaking at info moments and by taking part in different organisations. We have a website and a free phone number. We put information stands up at places where a lot of people pass like fairs for infants or seniors etc. We have a three monthly magazine for our members but we also send it to doctors.

BULGARIA - Association of Bulgarians with Bronchial Asthma, Allergy and COPD (ABBA)

www.asthma-bg.com



ABBA was established in 2002 consequent to an increasing crisis in health-care, an unequal position of asthmatic patients versus other patients, lack of information about asthma for the general public, and the alarming fact that asthma is the most common chronic disease among children. ABBA works for an accurate diagnosis, treatment and prevention for patients. Its goal is to promote training and qualification of doctors in order to improve the control and treatment of respiratory diseases, namely asthma, chronic obstructive pulmonary disease (COPD).

CZECH REPUBLIC - Czech Civil Association Against COPD

www.copn.cz



Priorities of the organisation include:

- 1) Education of pneumologists, internists, practitioners and other medical care professionals within GOLD.
- 2) Providing the medical care sector organizers and general public with information on the burden of COPD.
- 3) Organization, stimulation and support of projects dealing with the topic of COPD.
- 4) Publishing materials on COPD for the professional community as well as the general public.

FINLAND - The Organisation for Respiratory Health in Finland

www.hengityслиitto.fi



The Organisation for Respiratory Health in Finland seeks to promote respiratory health and the quality of life of people with pulmonary diseases. Good ambient air quality promotes respiratory health, and everyone is entitled to clean, smoke-free indoor air. All sufferers from respiratory illness deserve a good standard of care with equitable and high quality health services that safeguard their quality of life. Rehabilitation remains an integral part of the care system. Over the last seven decades the Pulmonary Association has grown into a powerful and prestigious stakeholder in the field of health and social affairs, a lobbyist for sufferers from respiratory illness, and a guardian of welfare and health that commands public attention. The organisation also provides a wide range of rehabilitation, training and employment services.

FRANCE - Fédération Française des Associations et Amicales de malades, insuffisants ou handicapés respiratoires (FFAAIR)

www.ffaair.org



FFAAIR works to:

- Improve the future of patients with respiratory insufficiency and related disabilities as regards medical and social aspects.
- Promote a real social policy by addressing psychological and social problems and encouraging hobbies, outdoor activities, travel and vacations.
- Organize vacations especially adapted to respiratory patients and their families, in cooperation with ANTADIR (a medical-technical service).
- Propose education for patients to simplify their 'integration' into everyday life: patients as partners and educators of newcomers.
- Identify the conditions for a better understanding among interested persons by placing the patient at the centre of the care system, from research and medical practice in pulmonology to home care, involving manufacturers and providers of materials, equipment and medicines.

GERMANY – Patientenliga Atemwegserkrankungen e.V.

www.patientenliga-atemwegserkrankungen.de



The patient organisation “Patientenliga Atemwegserkrankungen e.V.” was founded in 1986. Now it is organized into 30 chapters that provide information presentations by specialists and giving social and emotional support for their members. Information about asthma, COPD and emphysema are given on the website of the organization, twice a year a magazine called “Luftpost” where new information is published. Another patient organization affiliate is “COPD-Deutschland e.V.” (www.copd-deutschland.de). 58 self-help groups meet once a month, giving information for patients and giving them emotional support. There is a large informative web portal for patients (www.lungenemphysem-copd.de) with a mailing list including more than 2,700 participants, founded by Jens Lingemann, who also organizes a patient congress each year. The lectures are published in DVD. There is a special patient organization for patients undergoing oxygen therapy: “Deutsche Sauerstoffliga LOT e.V.” (www.sauerstoffliga.de) with 62 self-help groups and informational support especially concerning oxygen therapy. There are also patient organizations for “Alpha-1” and “fibrosis”.

ITALY – Associazione Italiana Pazienti BPCO

www.pazientibpco.it



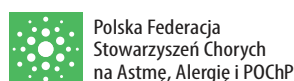
The Italian Association of COPD patients was founded on 24 June 2001 with the aim of improving the health conditions and quality of life of COPD patients. It is a member of EFA and of the ICC–International COPD Coalition.

Its main objectives are:

- To provide COPD patients, their families and carers with information, and educational and cultural services aimed at improving their health conditions.
- To increase awareness of the social impact of respiratory diseases.
- To promote information and prevention campaigns directed at the public at-large about reducing the risks of developing COPD (tobacco smoke, air pollution, lifestyle, etc.).
- To promote initiatives aimed at improving the quality of life of COPD patients.
- To promote and support scientific research.

POLAND – Polish Federation of Asthma, Allergy and COPD Patients Organizations

www.astma-alergia-pochp.pl



The Polish Federation of Asthma, Allergy and COPD Patients’ Organization is a nationwide organization linking organizations of patients with asthma, allergy and/or COPD. One of the member organisations of the Federation is the Society of Friends of Asthma Patients as well 10 other organizations with a total population of about 1000 members.

The activities of the Polish Federation of Asthma, Allergy and COPD Patients’ Organization:

- Participation in the organization of World Spirometry Day (2012) and Polish Spirometry Day (2011 and 2013);
- Organization of the Asthma Week in April 2013 through the mass-media activities (radio, TV, newspapers, etc.);
- Organization of the World COPD Day by organization of pulmonary function tests, press conference and events combined with the actions popularizing not to smoke;
- Continuous cooperation with the Polish Society of Allergology and Polish Society of Lung Diseases;
- Active participation (as the Federation) in conferences organized by the Polish Society of Allergology (4 instances) and Polish Society of Lung Diseases (2 instances);
- Leading and coordinating training for patients with asthma and COPD;
- Participation in the public consultation on access to treatment among patients with obstructive lung diseases;
- Cooperation with the National Health Fund in the project: “Each breath counts” and with the Minister of Health in the ministerial initiative entitled “The Dialogue on Health”.

PORTUGAL – RESPIRA

www.respira.pt



RESPIRA is a Portuguese national association for people with COPD and other respiratory diseases, registered as a non-profit organization in 2007 with around 400 members. The Board of Directors is the highest governing body, and our source of income are membership fees (5%) and private sponsors (95%). Our Mission is to set patterns for the awareness, prevention and healthcare of people with COPD and other respiratory diseases.

Our main goals and objectives are:

- Support health respiratory promotion and tobacco prevention.
- Promote awareness of COPD and other respiratory diseases.
- Work with health professionals, public authorities, schools and general public in order to motivate the utilization of best practices in healthcare delivery and the research in the respiratory disease area.
- Help and support our members with their rights, obligations and privileges.
- To struggle for achieving the recognition of the disease and for the adequate access to medicines and oxygen therapy.
- To share news, reports and information, increase membership and partnership.

In our daily work, we cooperate with health authorities, members of parliament and private partners, in working groups and public meetings, spirometry testing, celebration of World Days (No tobacco, Spirometry, COPD, etc.). We also publish a quarterly newsletter, brochures about COPD, translated EFA's Book on COPD in Europe and distributed them for free. We have a regular presence in media with interviews and newspaper articles.

SERBIA – Association for Asthma and COPD in Serbia

www.udah.org.rs



The Association for asthma and COPD in Serbia was founded in 2000. The members are physicians, nurses, patients and the patient's family members. The goals and tasks of the association and its members' operations are educating health-care workers and patients to improve the treatment of asthma and COPD. This includes the education of health-care workers who through their work and professional activity will contribute to the development of treatment and improve the quality of life of patients. The association organizes, alone or in cooperation with other organizations, professional meetings, conferences, seminars and other forms of education in the prevention of chronic respiratory disease and treatment of patients with asthma and chronic obstructive pulmonary disease. It also translates the international asthma and COPD guidelines, publishes books and other publications related to the prevention of chronic respiratory diseases, treatment of asthma and COPD. Also, the association organizes continued medical education courses, COPD Day, World Asthma Day and Spirometry Day 2012.

SPAIN – National Federation of Respiratory Disease Associations

www.fenaer.es



The National Federation of Respiratory Disease Associations, FENAER, is a non-profit organisation which has as its primary purpose to promote all actions and subsequent health-related or scientific activities aimed towards improving the quality of life for people affected by respiratory diseases. Such actions and activities are coordinated by its federation members and carried out under the direction of the secretariat and in agreed programmes. FENAER was formed by the various Spanish associations for allergy, asthma, COPD, alpha-1, sleep apnoea and pulmonary fibrosis situated in Málaga, Grenada, Jaén, Madrid, Salamanca, Galicia and Barcelona. Since its foundation at the end of 2007, by four associations from Grenada, Jaén, Barcelona and Madrid, it has grown a lot with a lot of associations expressing interest in joining the federation and currently has 11 members.

SWEDEN – The Swedish Heart and Lung Association

www.hjart-lung.se



The Swedish Heart and Lung Association is a member's/patient's organisation offering support to our members to increase their quality of life through actions such as its program for lifestyle activities, such as physical activity adjusted for either heart or lung patients, smoke cessation, lectures, cooking classes and more. Local organisations are meeting points for social interaction and sharing of experiences. We also try to put pressure on decision makers in health care and welfare systems and interact with partners. We also promote and support clinical research.

SWITZERLAND – Swiss Lung Association

www.lungenliga.ch/de - www.pneumo.ch



The Swiss Lung Association advises and takes care of patients with lung diseases and respiratory impediments, and helps them to live as free and autonomously as possible and thus to reach a higher quality of living. The Swiss Lung Association is member of a strong network of experts to support patients. The organisation is also committed to tobacco prevention and less air pollution to prevent more and more people from getting lung and respiratory diseases. The 300 members of the Swiss Respiratory Society (SGP/SSP) are lung specialists working as scientists, clinicians in private practice or in hospitals, or in other associated academic fields. The steering committee consists of 18 members, representing these different areas. The SGP/SSP runs 19 commissions and working groups (e.g. pulmonary rehabilitation, sleep apnoea, mechanical home ventilation).

THE NETHERLANDS – Longfonds

www.longfonds.nl



Our lungs are indispensable. The Lung Foundation Netherlands fights for healthy lungs and against incurable lung diseases. We make a stand for your lungs, whether they are sick or healthy. The Netherlands count over a million people suffering from a chronic lung disease, like asthma, COPD, and rare chronic lung diseases. The Lung Foundation of the Netherlands stands up for those people, because lungs are a matter of life and death. We fight for healthy lungs and against chronic lung diseases. Scientific research has made The Lung Foundation Netherlands determined to prevent asthma in children and to treat severe asthma more effectively. We would really want to see incurable lung diseases cured, and it would be even better if we could mend damaged lungs some day. The Lung Foundation of the Netherlands aims to improve medical care for people with an incurable lung disease and try to improve their way of life. We do this in cooperation with, for example, doctors, insurance companies, and patients themselves. The Lung Foundation of the Netherlands strives for clean air for everyone, inside and outside. This is something we would like to achieve together with specialists and patients. Political lobbying is part of what we do. As a patients' association, the Lung Foundation of the Netherlands promotes the interests of people with a chronic lung disease through the entire country. We provide information, advice, and experiences.

THE UNITED KINGDOM – The British Lung Foundation

www.blf.org.uk



We support people affected by lung disease, so that no one has to face it alone. We promote greater understanding of lung disease and we campaign for change in the nation's lung health. We reach out to people who are frightened and debilitated by lung disease, from mild asthma to lung cancer. We have more than 230 Breathe Easy support groups across the UK. These are local groups where people can meet other people affected by

lung disease and find out more about conditions. Our groups also work together to campaign for change. We have a pen-pals scheme people can join to get in touch with people in a similar situation. BLF nurses provide specialist care at home and in community clinics. This can mean people have the choice to stay at home, during treatment rather than go into hospital, or to be discharged earlier. The specialist team of nurses and advisers on our helpline are dedicated to answering patients questions. People call the helpline to find out about more than 40 lung conditions, to ask questions about your rights, or simply to talk to someone who cares. We fund vital research so that new treatments and cures can help to save lives. Excellent research is key to finding new treatments for lung disease – saving and prolonging lives. We invest more than £1 million a year in research projects to fight lung disease.

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Annex I: Questionnaire

Below we report the questionnaire used to collect data from the National Associations

The aims of this questionnaire are: to document the situation in Europe and to develop a patient centred consensus about minimal standards of care for COPD patients.

Part 1: About your Association

1. Your Association

Name of Association
Association website
Country

2. Some information about you

Name and surname
E-mail address
Tel
Role in the Association
Your profession

3. Tell us about your association! Your initiatives, your members, your activities (max 300 words). We will include this information in the book based on the questionnaire. If you prefer you can write your Association's profile in your own language, EEA will translate it.

Part 2: Diagnosis and Management in Your Country

4. In your country who usually performs spirometry tests for diagnostic purposes?

All GPs
Some GPs
Pulmonary specialists
Internal medicine specialists
Other specialists (e.g., cardiologists, ENTs, geriatricians)
Hospital physicians
Other (please specify)

5. Is spirometry testing included in routine check-ups (e.g. in yearly check-ups)?

Yes
No (please go directly to question 7)
There are no routine check-ups (please go directly to question 7)

6. (Only if you replied "Yes" to Question 5) If spirometry testing is included in routine check-ups, please indicate in which of the following groups:

The entire adult population (> 20 years old)
All people above 40 years of age
Smokers
Patients with asthma or chronic bronchitis
People with comorbidities (e.g., cardiovascular diseases)
Other (please specify)

7. Please briefly describe the diagnostic procedure for COPD (Who makes the diagnosis? What happens after diagnosis? Do patients typically see a specialist for diagnosis?)

8. Please briefly describe the management of stable COPD (How often do patients see a doctor? Is COPD managed by a specialist? By the GP? Are patients with stable COPD routinely followed up in COPD centres?)

9. Please indicate the number of respiratory specialists; if possible, per 100,000 inhabitants.

10. Please indicate the number and geographical distribution of the facilities listed below (indicate number and distribution)

Centres specialized in respiratory diseases
Respiratory units in hospitals
Respiratory intensive care units
Respiratory rehabilitation centres
Ventilator weaning centres*

Comment on strengths and weaknesses:
*Ventilator weaning is the process of slowly, carefully and safely removing someone from mechanical ventilation in order for him or her to breathe without help from a machine. Source: <http://www.reshealth.org/pdfs/HF318%20FAQ.pdf>

11. In which hospital departments are ventilator weaning centres generally located?

Resuscitation units
Pulmonary/respiratory departments
Other (please specify)

12. Who is allowed to prescribe oxygen therapy in your country?

- GPs
- Specialists
- Hospital physicians
- All doctors

13. Are liquid oxygen and concentrators reimbursed in your country?

- Yes
- Not fully reimbursed (go directly to question 15)
- No (go directly to question 16)

14. (Only if you replied "Yes" to Question 13) Is oxygen therapy fully reimbursed (for example, is the cost of electricity to operate oxygen concentrators also reimbursed, is oxygen supply reimbursed also when travelling for holidays, etc.)?

15. (Only if you replied "Not fully reimbursed" to Question 13) What percentage is reimbursed?

16. How much do you agree with the following statements regarding oxygen supply services?

- Reply options: *Strongly agree, Agree, Neither agree nor disagree, Disagree, Strongly disagree or Not applicable*
- The oxygen supply service is satisfactory
 - The oxygen supply service covers the whole country
 - Patients can easily find an oxygen supply when travelling in our country
 - Patients can easily find an oxygen supply when travelling abroad
 - Comment:

Part 3: Pulmonary rehabilitation in your country

Definition: Pulmonary rehabilitation is an evidence based, multidisciplinary, and comprehensive intervention for patients with chronic respiratory diseases who are symptomatic and often have decreased daily life activities. (American Thoracic Society/European Respiratory Society statement on pulmonary rehabilitation. Am J Respir Crit Care Med. Jun 15 2006 173(12):1390413.)

17. Where can patients access pulmonary rehabilitation and what healthcare professionals are involved? Please select as appropriate.

- Reply options: *GPs, Pulmonary specialists, Internal medicine specialists, Physiotherapists or Nurses*
- In hospital (acute rehabilitation)
 - In specialized centres
 - Outpatients care
 - Other (please describe)

18. What COPD patients that meet the criteria defined above are entitled to pulmonary rehabilitation?

- All patients
- Ambulant patients
- Housebound patients
- Only the working population
- Other (please specify)

19. Patients have access to pulmonary rehabilitation (please indicate one of the following options):

- Just once
- Only occasionally
- Regular programmes of rehabilitation exist
- There are no rehabilitation programmes

20. Please describe briefly the strengths and weaknesses of access to pulmonary rehabilitation for COPD patients.

Part 4: Access to care in case of exacerbation in your country

According to GOLD Definition: An exacerbation is an acute event characterized by worsening of the patient's respiratory symptoms that is beyond day-to-day variations and that leads to changes in medication. GOLD updated 2013, Chapter 5, p 40. http://www.goldcopd.org/uploads/users/files/GOLD_Report_2013_Feb20.pdf

21. Are the criteria for COPD exacerbations in your country in line with the GOLD definition (see above)?

- Yes
- No
- No studies available
- Comment:

22. Who usually treats patients with exacerbations?

- GPs
- Pulmonary specialists
- Other (please specify)

23. What proportion of patients is seen by a specialist when admitted with an exacerbation?

- Less than 10%
- Between 10-30%
- Nearly 50%
- Between 60-80%
- Virtually all patients are admitted
- No studies available
- Comment:

24. Please briefly describe how COPD exacerbations are managed (Are they managed by the specialist? By the GP/primary care physician? By COPD centres?)

25. How many lung transplantations are performed each year?

Number of lung transplantations
If possible, give separate figures for Alpha1 patients
Reference (if available):

Part 5: Minimum standard of care foreseen by your healthcare authority for COPD patients

26. Do COPD patients have free access to the following doctors?

Reply options: *Yes, No, Partially*
GPs
Pulmonary specialists
Other specialists

27. Is a doctor's visit free for COPD patients?

Yes
No
If no, what percentage of the cost must they pay?

28. Are medications 100% reimbursed for COPD patients?

Yes
No
If no, what percentage of the cost is reimbursed?

National programmes, guidelines and quality measures in your country

29. Are there guidelines to diagnose and treat COPD patients?

Yes, we have national guidelines
No, we follow the GOLD Guidelines (no translation available)
No, we follow the GOLD Guidelines (translated into our language)
We don't follow specific guidelines
Please provide reference:

30. Do you have a national COPD programme/strategy (or similar initiative)?

Yes
No
If there is no National programme go directly to question 34.

31. If you have a national programme for COPD, please indicate:

Name of the programme/strategy (or similar initiative):
Issuing body (Government, Scientific Society, etc):
Website/Contact:

32. By whom it is funded?

Public authority
Private body
Mixed (please specify):

33. Who is involved?

Ministry of Health
Pulmonary specialists association
GPs/primary care physicians associations
Nurses associations
Patients associations
Other (please specify):

34. Is a disease management plan for COPD in place in your country?

Yes
No
Reference/website:

35. Does your national healthcare system foresee quality indicators for the diagnosis and clinical management of COPD?

Yes
No
Reference/website:

36. Must GPs/primary care physicians fulfil specific education and training requirements in order to manage their COPD patients?

Certification by a national authority
Certification by a scientific society
Mandatory continuous medical education programme
No specific education and training is required
Other (please specify):

Cooperation between healthcare professionals in the management of COPD patients in your country

37. Are there medical associations/scientific societies in which GPs /primary care physicians and pulmonary specialists cooperate regarding:

COPD
All respiratory disorders
Respiratory disorders other than COPD
No associations in my country
Other (please specify):

38. Are there national/governmental boards in which GPs/primary care physicians and specialists cooperate to develop guidelines for COPD diagnosis and management?

Yes
No
Don't know
Comment:

39. Is there an association of GPs/primary care physicians specialized in respiratory diseases?

Yes

No

Please provide name of the association:

40. Do GPs/primary care physicians and specialists organize joint meetings/public initiatives (e.g., World Respiratory Day)?

Yes

No

If yes, please briefly describe:

41. Do patients take an active part in such events?

Yes, as equal members of the programme committee

Yes, in the entire programme

Yes, with a specific patients session

Yes, as invited speakers/chairs

Yes, with a booth

No

42. Are best practices in place regarding collaboration between GPs/primary care physicians and specialists?

Yes

No

If yes, please describe briefly or give reference/website:

Part 6: Prevention of COPD and support services for patients in your country

Smoking cessation services in your country

43. Are smoking cessation services available? If so, who is involved in these services:

Physicians

Psychologists

Nurses

Other (please specify):

44. Are smoking cessation services easy to access?

Yes

No

If no, please explain the difficulties in accessing such services:

45. Are smoking cessation services evenly distributed throughout the country?

Yes

No

Comment:

46. Are smoking cessation services free?

Yes, for everyone

Yes, for the at risk population

Yes, for COPD patients

They are not free (please specify the average cost)

47. Is smoking cessation therapy (medication) paid for by:

The government

Insurance/sick funds

It is not free

Other (please specify):

Support services for COPD patients and patient empowerment in your country

48. Do patient self-help groups exist?

Yes

No

49. If yes, who organizes them?

National patients' associations

Local patients' organizations

Hospitals

Other (please specify):

50. Are there support groups for Alpha-1 patients?

Yes

No

If yes, please briefly describe (include contact details if available):

51. Are there support groups for pulmonary fibrosis patients?

Yes

No

If yes, please briefly describe (include contact details if available):

52. Are there support groups for patients who need long-term oxygen therapy?

Yes

No

If yes, please briefly describe (include contact details if available):

53. Who provides patient education?

National patients' associations

Local patients' organizations

National healthcare system

Physicians' associations

Other (please specify):

54. Please describe briefly the main educational tools available (e.g., an action plan distributed to COPD patients, websites, brochures, meetings, etc.):

55. Are sport exercise groups organized for COPD patients?

Yes

No

If yes, please describe or provide a reference or web-link:

56. Do you agree with the following statements:

Reply options: *Strongly agree, Agree, Neither agree nor disagree, Disagree, Strongly disagree*

The patient's point of view is always taken into account in making decisions regarding the management of their disease

Patients' associations are actively involved in healthcare decision making

Patients' associations are involved in the national medicines agency/authority

Patients' associations are actively involved in the preparation of national guidelines

Effective measures are in place to help patients remain at home as long as possible (e.g., ground floor accommodation)

Measures are taken to motivate COPD patients to be active

57. Is there a systematic approach to involve employers in keeping COPD patients employed and in the work process?

Yes

No

If yes, please briefly describe it:

58. Is social assistance available at home for COPD patients?

Yes

No

If yes, please briefly describe the assistance and indicate if patients must pay for it:

59. Is psychiatric and psychological support (in case of depression and anxiety) available for COPD patients?

Yes

No

If yes, please describe the support and indicate if patients must pay for it:

Epidemiology

60. Please provide the most recent prevalence data on the epidemiology of Alpha-1.

Prevalence:

Reference (if no study is available, please state "no study"):

61. Please provide the most recent prevalence data on epidemiology for Alpha-1 according to gender.

Prevalence:

Reference (if no study is available, please state "no study"):

62. Please provide the most recent prevalence data on epidemiology for Alpha-1 according to age?

Prevalence:

Reference (if no study is available, please state "no study"):

63. What percentage of COPD patients are tested for Alpha-1 deficiency?

Percentage:

Reference (if no study is available, please state "no study"):

64. Who is the main contact for continuous care of Alpha-1 patients?

GPs/Primary Care Physicians

Specialists

Other (please specify):

65. Are there specific guidelines about who should be screened for Alpha-1?

Yes

No

If yes, please describe briefly or give reference:

66. Is there a national registry of Alpha-1 patients?

Yes

No

If yes, please describe briefly or give reference/website:

67. Is the diagnostic test for Alpha-1 available in your country?

Yes

No

Comment:

68. Is augmentation therapy available?

Yes

No

Comment:

Part 7: Alpha-1 antitrypsin deficiency in your country

In this section we ask you to provide some information related to Alpha-1 patients, including screening, diagnosis and access to appropriate therapy.

69. Is augmentation therapy free?

Yes

No

Comment:

70. Is there an Alpha-1 patient organization?

Yes

No

Please provide reference:

*** Indirect costs are costs associated to the disease from the perspective of society as a whole, not directly deriving from the medical management, such as costs for loss of workdays for the patients and his/her caregivers.*

76. The economic crisis in Europe has not affected COPD-care

Reply options: Strongly agree, Agree, Neither agree nor disagree, Disagree or Strongly disagree

Comment:

Part 8: Economic burden and epidemiology of COPD in your country

In this section we ask for data on the economic and social burden of COPD in your country. Such data may not be easily available to you, so please provide only the information you have access to.

71. Do patients have to pay for access to the public health-care system?

Public healthcare is free for everyone

Public healthcare is free for selected patients

Patients must always pay a certain amount

Patients have a public (or similar) insurance

Patients have private insurance

Other (please specify):

72. Please select which services are free for COPD patients?

Specialist visit

Oxygen therapy

Other medicines

Ambulatory care/annual check-up

Hospital care

Rehabilitation services

73. What is the annual direct cost* for COPD in your country?

74. What are the annual direct costs* according to the GOLD classifications of disease severity?

(Indicate cost for each)

Mild/Moderate

Severe

Very severe

**Direct costs are costs directly associated to medical management of the disease, including costs for hospitalization, therapies, medical visits, etc.*

75. What is the annual indirect cost for COPD in your country?**

(Indicate cost for each)

For the patient

For society

77. Please provide the most recent epidemiological data on the prevalence of COPD in the general population of your country.

Prevalence:

Reference:

78. Please provide the most recent epidemiological data on the prevalence of COPD in your country according to gender.

Prevalence:

Reference:

79. Please provide the most recent epidemiological data on the prevalence of COPD in your country according to age.

Prevalence:

Reference:

80. Are there any recent data on hospital admissions due to COPD?

Yes

No

Reference:

81. Please provide data on yearly mortality for COPD

Data:

Reference:

82. Are there any data about comorbidities (e.g., cardiac disease, diabetes mellitus, hypertension, osteoporosis, and psychological disorders) in COPD patients?

Yes

No

Reference:

EFA Manifesto for 2014

European Parliament Elections

400,000 EFA patients
=
400,000 votes



Three priority areas and fourteen actions to improve the health and quality of life of people with asthma, allergy and chronic obstructive pulmonary disease in Europe.

We are calling on you to commit yourselves to the following priorities in the area of health:

1. Develop an EU strategy on chronic diseases with disease specific chapters

As an outcome of the EU reflection process on chronic diseases, dating back to 2010, an EU strategy with disease specific chapters should be developed. The strategy would enable us to effectively tackle incidence and risk factors, while helping us deal with negative consequences for the health of affected people, their families and the economies of the EU and its Member States.

2. Invest in prevention – tackle health determinants

- 2.1. Reduce tobacco consumption through a stricter tobacco products directive
- 2.2. Implement the smoke free Europe recommendations
- 2.3. Introduce a better strategy on outdoor air pollution with limit values in line with WHO recommended levels
- 2.4. Adopt a strategy on indoor air quality that includes the home and the workplace
- 2.5. Include pollen monitoring under the Clean Air Programme for Europe
- 2.6. Reduce exposure to chemicals in everyday life
- 2.7. Introduce labelling of all ingredients in the ingredients list of food products and in the long-term perspective, abolish the “may contain” labelling for allergens

Bearing in mind the principle of health in all policies, all EU activities should take into account their impact on public health. The objective of improving the health of European citizens should be overarching all EU decisions.

3. Help ensuring equal access to care for each patient

- 3.1. Eliminate discrimination of patients based upon their disease or condition
- 3.2. Reduce health inequalities as regards access to care and quality of treatment within and between Member States

- 3.3. Initiate or boost patients' participation in decision-making in all areas relating to their health and wellbeing, particularly concerning the placement of medicinal products and medical devices on the market and their reimbursement, priority setting for studies, trials and research, through promotion, facilitation and support of programmes in Member States, ensuring funding for patients' organisations
- 3.4. Strengthen patients' safety
- 3.5. Improve accuracy and quality of information to patients and boost health literacy
- 3.6. Ensure early and accurate diagnosis of allergies and chronic respiratory diseases, such as asthma and COPD, through increased training for healthcare professionals, development of national programmes, set up of registers and spirometry testing
- 3.7. Ensure that more funds are allocated for EU health policy and programmes and prioritise investments in research of allergic and respiratory diseases

Better treatment and healthcare contribute to the long-term objective of the EU to guarantee healthy ageing for all citizens and make the healthcare systems more sustainable.

Ahead of the European Parliament elections in 2014, patients with allergy, asthma and COPD in Europe ask you to take these concerns into account and to make these actions a priority in your political agenda. Help us make Europe a place where patients have the right to best quality of care and safe environment, live uncompromised lives and are actively involved in all decisions influencing their health.



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