



EFA BOOK ON
CHRONIC OBSTRUCTIVE
PULMONARY DISEASE
IN EUROPE.
SHARING AND CARING

Edited by Mariadelaide Franchi



European Federation of
Allergy and Airways Diseases
Patients Associations

EFA
European Federation of
Allergy and Airways Diseases
Patients Associations
EFA Central Office
35 Rue du Congrès
1000 Brussels, Belgium
Tel. +32 (0)2 227 2712
Fax. +32 (0)2 218 3141
info@efanet.org
www.efanet.org

Edited by Mariadelaide Franchi

Project coordination

Data collection, writing assistance and production

Daniela Finizio, Jean Ann Gilder

 Scientific Communication srl

Via G. Quagliariello 35/E, 80131 Naples, Italy - Tel. +39 081 2296460

Fax. +39 081 0072045 - info@jeangilder.it - www.jeangilder.it

Statistical analysis

Felice Addeo, Department of Communication, University of Salerno, Italy

EFA Book on Chronic Obstructive Pulmonary Disease in Europe. *Sharing and Caring*

Edited by Mariadelaide Franchi



Contents

Preface	1
Introduction	3
What is COPD?	8
1. Epidemiology, Economic Burden and Social Impact of COPD	9
The prevalence of COPD in Europe	9
Mortality and death rate	12
Patients with severe COPD undergoing long-term oxygen therapy	14
Risk factors	16
The economic burden of COPD	16
Social impact of COPD in the patients' own words	18
2. Access to Care for COPD Patients and their Families	21
COPD: A disease unknown to the general public	21
Access to preventive measures	22
Access to an early diagnosis	23
Access to spirometry/lung function tests	25
Access to information for COPD patients	26
Access to treatment	27
<i>Access to the treatment options available</i>	
<i>Access to vaccination</i>	
<i>Access to free treatment</i>	
<i>Access to rehabilitation</i>	
<i>Access to educational programmes</i>	
<i>Access to oxygen therapy</i>	
<i>Access to non-invasive mechanical ventilation</i>	
<i>Access to home care</i>	
<i>Access to telemedicine monitoring</i>	
Access to support services for patients and carers	37
Specific national successes and national problems regarding quality of care	39
Take home messages	41
3. The Role of Healthcare Professionals in the Management of COPD	42
The role of the general practitioner	42
The role of the pulmonary specialist	46
<i>Access to specialists other than pulmonary specialists</i>	
The role of COPD nurses, respiratory therapists and lung function technicians	50
Take home messages	53

4. Studies on Quality of Life of Patients, their Families and Carers.	54
The Patient's Perspective	54
Take home messages	55
5. National COPD Programmes	56
Take home messages	57
6. National COPD Guidelines	59
Take home messages	60
7. National Legislation for Healthy Air Quality	61
Take home messages	61
8. Sharing: Best Practices for Smoking Cessation	62
Access to help stop smoking	62
Smoking cessation campaigns and initiatives	64
Take home messages	66
9. 'Speak up for the Patient': Advocacy, Educational Programmes and Other Activities	67
Taking action for policy making	67
Taking action in establishing guidelines and standards for treatment	70
Taking action in educational programmes	71
10. Sharing the Care: Material and Campaigns Produced by the Patients Associations	74
Education, information and support tools produced by the patients associations	75
11. COPD in Europe: Summing-up	92
Access to prevention, early diagnosis and treatment	92
COPD patients have the right to a safe environment	95
Sharing and caring: the role of patients associations	95
How Europe is doing	96
References	98
Appendix 1. Methodology	101
Appendix 2. National studies on quality of life of COPD patients in the countries surveyed	103
Appendix 3. National COPD guidelines in the countries surveyed	104
Appendix 4. Legislation for healthy air quality in the countries surveyed	106
Appendix 5. Antismoking laws in the countries surveyed	107
Appendix 6. Smoking cessation campaigns and initiatives carried out in the last 3 years in the countries surveyed	108
EFA Sofia Declaration	110
What is EFA?	111
EFA members	113

Preface

Chronic respiratory diseases, including chronic obstructive pulmonary disease (COPD), place a heavy burden on societies as a whole and on individuals and their families. In fact, 210 million people throughout the world suffer from COPD. Unfortunately, according to WHO estimates, these figures are destined to increase. In 2030, COPD will be the third cause of death worldwide.

Many old and new problems are implicated in the increased prevalence of COPD. Tobacco smoking, which is the most important risk factor for COPD, is still high. It is increasing among women and young people in some countries, and it is also increasing in developing countries. In addition, COPD remains largely underdiagnosed and it is not assessed as part of chronic systemic disease surveillance (which often includes cardiovascular diseases, cancer and metabolic disorders).

A comprehensive, integrated approach is needed to address these problems, as well as others related to the prevention of COPD, its diagnosis and treatment, the quality of life of patients and the social burden of the disease. The Global Alliance against Chronic Respiratory Diseases (GARD) was created with the aim of initiating such an approach. GARD recognizes the importance of a strong alliance between doctors and patients in order to identify specific needs and improve the quality of treatment and the management of patients and, ultimately, their quality of life. In this context, during the GARD General Assembly held in Rome in June 2009, a session was devoted to patients needs.

EFA is a very active member of GARD, and over the years has made important contributions towards improving conditions for patients with respiratory diseases. Now, EFA and its member associations are to be applauded for this book, which contains the results of the first systematic evaluation of the needs of COPD patients in Europe.

The 'EFA Book on COPD in Europe' gives an insightful panorama on the state-of-the-art of COPD in Europe as regards information, prevention, early diagnosis,

treatment, quality of life and services for COPD patients. The main result of the survey is that, despite some progresses made in recent decades, much still remains to be done. EFA shows that European countries share several problems with respect to access to information, treatment and services for COPD patients and their families. These issues may benefit from a European approach. Interestingly, this book also reports the strategies and best practices that have been successfully adopted in various countries. These strategies, applied at other local levels, might contribute to harmonize the level of care and services for all COPD patients in Europe.

I believe that EFA's effort is an important step towards 'A world where all people breathe freely'.

Jean Bousquet, MD, PhD
Chairman of WHO GARD

Introduction

Chronic obstructive pulmonary disease (COPD) is a preventable and treatable disease characterized by airflow limitation that is not fully reversible and is usually progressive. Every hour, COPD is estimated to kill over 250 people worldwide [1]. According to World Health Organization (WHO) estimates, currently 210 million people have COPD and 3 million people died of COPD in 2005 [2]. The WHO predicts that COPD will become the third leading cause of death worldwide by 2030 [3], and that COPD-related disability will go from the ninth to the fifth place in terms of disability-adjusted life years (DALYs) in 2020.

It was the WHO that, in the 1990s, first raised the alarm about the increase in the prevalence and mortality of COPD. In 1997, to address this issue, the WHO, in collaboration with the US National Heart, Lung and Blood Institute, formed the Global Initiative for Chronic Obstructive Lung Disease (GOLD). GOLD works with healthcare professionals and public health officials around the world to raise awareness of COPD and to improve its prevention and treatment also through the development of evidence-based guidelines for COPD management. The first GOLD document, entitled 'Global Strategy for the Diagnosis, Management, and Prevention of COPD', was published in 2001 and the most recent update appeared in November 2008 [4]. Moreover, since 2002, GOLD has organized the World COPD Day. This event, which takes place on the third Wednesday of November each year, has become one of the world's most important COPD awareness and educational events.

A major step forward in the fight against COPD came in 2006 when the WHO established the Global Alliance against Chronic Respiratory Diseases (GARD) as part of the global work to prevent and control chronic diseases. GARD is a voluntary alliance of national and international organizations, institutions and agencies working towards a common goal of improving global lung health, particularly in low and middle income countries and vulnerable populations. EFA is a founding member of GARD. Implementation of the GARD Action Plan for 2008-2013 is expected to have an impact at global and local level.

Around the same time, the European Commission, also in response to appeals of the scientific community and volunteer organizations, included respiratory diseases among the major diseases targeted for translational research in the 7th Framework Programme (2007–2013). This has given an enormous impulse to research in respiratory diseases.

From a scientific viewpoint, at the end of 2003 the European Respiratory Society (ERS) in conjunction with the European Lung Foundation published the ‘European Lung White Book’, which is the first comprehensive survey ever made on respiratory health in Europe [5]. One year later the ERS together with the American Thoracic Society (ATS) produced an updated position paper on ‘Standards for the diagnosis and treatment of patients with COPD’. The blueprints for the position paper were earlier ATS and ERS standards (1995), and the GOLD initiative that appeared in 2001.

With the dismal WHO statistics, also patients associations became increasingly active in the field of respiratory diseases. In 2002, the European Federation of Asthma and Allergy Patients Associations (EFA) incorporated ‘COPD’ in their mission, hence becoming the European Federation of Allergy and Airways Diseases Patients Associations. In the same year, the European Network of COPD Patients Associations (ENCPA), which was part of EFA, issued the **European COPD Patient Manifesto ‘A Vision for Change’**. The Manifesto made a seven-point call for: 1) Improvement in diagnostic strategies and optimum care at every level; 2) Reduction of risk factors; 3) Programmes for training, education, empowerment and rehabilitation; 4) Safeguard of COPD patients rights; 5) Patient unity; 6) Financial and social support for patients and their families; and 7) Commitment to research.

In June 2009, EFA joined with the International COPD Coalition (ICC), which is constituted by COPD patients organizations worldwide, to organize the First World Conference of COPD Patients in Rome, Italy. The conference approved the **COPD Patients Bill of Rights**, which are: 1) The right to receive an early and accurate diagnosis; 2) The right for information and education about COPD; 3) The right for support and understanding; 4) The right to receive care and treatment that will benefit them; 5) The right to their fair share of society’s involvement and investment in their welfare and care; 6) The right to advocate with other COPD

patients and supporters for improved COPD care and COPD prevention; and 7) The right to safe air and to a safe environment.

Despite the major advances indicated above, evidence shows that COPD remains scarcely known, underdiagnosed and undertreated. Millions of Europeans are affected by COPD. Millions of patients, in particular elderly patients with advanced disease, have to cope daily with its debilitating consequences; they feel frustrated about the lack of effective treatment and despair at the lack of hope. Even in its early stages, COPD exerts a negative impact on the patients quality of life and begins to irreversibly damage the lungs.

In this scenario, EFA was prompted to try to bring COPD out of the shadows by collecting information about the disease from patients associations. Indeed, it is the patients associations that have direct experience of the main problems of COPD and of the barriers to the effective translation of scientific advances into the reality of the patient's daily life. Our aim was to find out how patients perceive and evaluate access to education and information, preventive measures and care.

This book is based on the results of a questionnaire that was sent to COPD patients associations in Europe. All the associations taking part in this survey dealt masterly with the wide spectrum of topics covered in this project, which go from statistical aspects to economic and social aspects, from health policy to the patient's real needs.

It clearly emerges from this project that the more severely affected patients have greater difficulty in accessing essential programmes and treatment. While most national authorities, with the help of associations of doctors and patients, have made progress in education, prevention and access to treatment, areas such as rehabilitation, support services and home care need to be improved in some countries. Similarly, it appears that more should be done in some countries to ensure the same level of care in urban and non-urban areas, and to encourage an effective patient/doctor dialogue so as to improve the management of COPD.

Another conclusion arising from this project is that the epidemiological and social impact of COPD must be effectively recognized now. And, rather than dispersing initiatives, this is best done through a *coordinated* and *comprehensive strategy* on

COPD at European and national level, taking into consideration local situations, and involving EU and national policy makers, healthcare professionals and all other stakeholders including patients associations.

The prevalence and mortality of COPD would not be so high had there been earlier interventions at institutional and political level. Now, we must strive to:

- Improve the care and management of diagnosed COPD patients.
- Increase the awareness of the public-at-large about COPD, its symptoms and risk factors in order to prevent the disease and to encourage an early diagnosis.
- Safeguard the respiratory health of future generations.

To achieve these aims, it is essential to *promote alliances* with professional and patients organizations and health institutions, and to *participate actively* in the definition and development of guidelines and strategy documents.

The last part of the ‘EFA Book on COPD in Europe’ highlights the importance of the *role of patients associations* in safeguarding the rights and the point of view of the patients, their families and carers in European countries. Each association has developed a series of operative models aimed at improving awareness of COPD, at mobilizing resources and at interacting at various institutional levels on behalf of patients. These best practices – projects that have been successful at local level – may be candidates for development in other countries.

We hope that this book will be a concrete tool for advocacy for EFA, its members and all COPD patients organizations, that it will inform policy makers (EU and national) about COPD thereby prompting action where necessary, that it will encourage healthcare professionals to collaborate with patients organizations, and finally that it will raise the media’s awareness about this disabling disease. This book is EFA’s challenge to you. Take it and be part of a positive outlook for the future to tackle COPD.

We wish to thank the Board of EFA for their enthusiastic support in relation to this initiative, to Jean Ann Gilder, Daniela Finizio and Paola Caruso for collecting the

data and for help in producing the book, and to Felice Addeo for data analysis. Special thanks are due to Boehringer Ingelheim and GlaxoSmithKline for supporting EFA in this project with an unrestricted educational grant. Above all, we would like to thank the COPD patients associations that took part in this project for their invaluable contribution in providing the information and particularly for sharing their activities in favour of COPD patients.

Mariadelaide Franchi
EFA COPD Advisor

Marianella Salapatas
EFA President

What is COPD?

Chronic means it is persistent – the disease won't go away

Obstructive means the airways are partly blocked

Pulmonary means in the lungs

Disease means sickness

The term COPD is unknown to the majority of people. In the past, COPD was called by many different names:

- Emphysema
- Chronic bronchitis
- Chronic obstructive bronchitis
- Chronic airflow limitation
- Chronic airflow obstruction
- Chronic airways obstruction
- Chronic obstructive airways disease
- Chronic obstructive lung disease
- Non-reversible obstructive airways disease

The most common symptoms of COPD are breathlessness, an increased effort to breathe, heaviness or a 'need for air', excessive mucus, and a chronic cough. Some people feel they are gasping for breath. These symptoms get worse when exercising, in case of a respiratory infection or during an exacerbation – periods of time when there is a sudden increase in symptoms and the disease is worse.

COPD affects the ability to breathe. It is a progressive disease, which means that COPD gets worse over time. This means that the ability to breathe is affected, and because of this, daily activities may become more difficult as the disease worsens.

COPD is a complex, progressive, debilitating and possibly life-threatening disease. Not everyone has all of the symptoms, and some people have different combinations of symptoms to other people.

Adapted from EFA's website (http://www.efanet.org/copd/what_is_copd.html)

Epidemiology, Economic Burden and Social Impact of COPD

1

According to the World Health Statistics released by the WHO in 2008, COPD is predicted to be the third leading cause of death in 2030 [3]. Much of the increase in COPD is associated with projected increases in tobacco use [2]. This section focuses on the epidemiology of COPD in Europe, and in particular in the countries that participated in this survey. Also reported is information about the economic burden and social impact of COPD.

The data in this section derive mainly from official sources and published information, and were collected by the associations taking part in the project. An interesting finding to emerge from this project is the lack of standardisation in epidemiological surveys as regards both the definition of COPD and the methodology used to compile statistics.

The prevalence of COPD in Europe

Figure 1 shows the prevalence of COPD in Europe reported by the Organization for Economic Co-operation and Development.

Based on the data provided by the patients associations that participated in the EFA survey, the prevalence of COPD varies from an estimated 2% (the Netherlands) to more than 10% (Austria and Germany) (Table 1). This variation may reflect differences in social, economic and environmental conditions. However, medical and methodological issues may also explain the differences in COPD prevalence among the countries surveyed. Indeed, COPD is widely underdiagnosed [6-10], which means that many cases elude the official statistics. In addition, based on the spirometric classification of disease severity, COPD seems to be underdiagnosed in young people and overdiagnosed in the elderly [11-13]. This misclassification

‘COPD is predicted to be the third leading cause of death in 2030.’ *WHO*

The prevalence of COPD varies from an estimated 2% (the Netherlands) to more than 10% (Austria and Germany).

may also contribute to the misquantification of the real dimension of the disease.

To compound the confusion surrounding COPD epidemiology, the definition of relevant indicators is not consistent among surveys. For example, COPD prevalence values (Table 1) are calculated with different reference populations: some surveys use the adult population (over 18 years) or a 'total population', whereas others use the middle-age population (over 40 years). Consequently, COPD epidemiology data are not easily comparable.

The lack of uniformity in data collection standards may contribute to the misquantification of COPD.

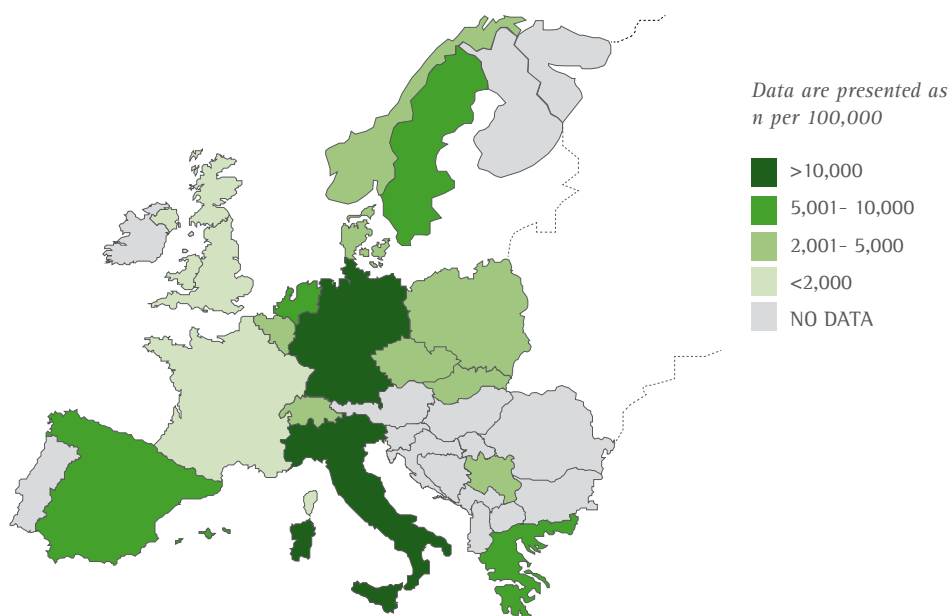


Figure 1. Prevalence of COPD in Europe according to the Organization for Economic Co-operation and Development (www.oecd.org).

Table 1. Prevalence of COPD in the countries surveyed

Country	COPD Prevalence	Reference Population	Data Source	Year
Austria ^a	4.6%	Sample	Statistik Austria [14]	2007
Belgium	5.3%	Middle-aged population	Ministry of Health. Health for All Database	2004
Czech Republic ^b	2.4%	Adult population	Institute of Health Information and Statistics [15]	2007
Finland ^c	Over 5% of the population suffers from COPD; a further 5% may suffer from latent COPD.	Total population	The National Finnish COPD Programme	2007
France	From 6% to 8%	Adult population	Ministère de la Santé et des Solidarités [16]	2005
Germany ^d	13.2%	Adult population	Geldmacher et al. (BOLD study) [17]	2008
Ireland	7.3%	Adult population	The Irish Thoracic Society	2008
Italy	4.5%	Total population	ISTAT [18]	2007
Netherlands	2%	Estimated	The National Institute for Public Health and the Environment [19]	2006
Portugal	4.6%	Adult population	National Observatory of Respiratory Disease	2008
Serbia	6.0%	Adult population	Institute of Public Health of Belgrade	2007
UK ^e	1.5%	Population > 40 years	Stang et al. [20]	2000

^aIn 2007, Firlie et al. reported (within the BOLD framework) a prevalence of 10.7% of GOLD stage 1-IV. The reference population was above 40 years of age [21]. More recently, results from the Austrian BOLD study show a prevalence of 13%.

^bVondra et al. (1993) found a prevalence of 7.7% in an adult population in the Czech Republic [22].

^cKotaniemi et al. (2006) found a prevalence from 5.4% (BTS) to 9.4% (GOLD) in a mid-age population in Finland [23].

^dDeutsche Lungenstiftung e.V. According to 2005 data, the prevalence of chronic bronchitis was 10-15% among adults. Data for emphysema and COPD are not available.

^eThere are an estimated 3.7 million people with COPD in the UK, although only an estimated 900,000 (1.5% of the population) are correctly diagnosed [20].

Regarding socioeconomic factors, the analysis of the data on the prevalence of COPD revealed that:

- Men are more likely to suffer from COPD than women; however, according to the WHO, the number of women affected by COPD is expected to grow because more and more women are taking up smoking.
- Severe COPD mainly affects the elderly. However, the disease starts damaging lungs and impacting lives much earlier.
- There appears to be a link between COPD and social status as evaluated by level of education.

Few countries have statistics on the national prevalence of COPD in relation to education. However, in Italy, 58% of COPD patients have no formal education or at most have completed primary school, 26% have completed secondary school, and 15% have a high-school diploma or a university degree. Similarly, data on the prevalence of COPD among young people are scarce. According to a study by De Marco et al. [24] on data from the European Community Respiratory Health Survey (conducted in the early 1990s), the prevalence of COPD in the population between 20-45 years old is 3.6%.

The number of women affected by COPD is expected to grow because more women are taking-up smoking.

Mortality and death rate

Misclassification of COPD and different COPD definitions impact also on the consistency of COPD mortality data, especially in a comparative perspective. A step towards standardisation of terminology came with the 9th and 10th revisions of the WHO International Classification of Diseases (ICD) in which COPD and chronic airway obstruction are classified under 'COPD and similar conditions' (codes 490-496 of ICD-9 and codes J42-46 of ICD-10). However, COPD still remains unrecognized and underestimated. Although COPD may be the primary cause

'Misclassification of COPD and different COPD definitions impact also on the consistency of COPD mortality data.'

of death, it is often recorded as a contributing cause or it is omitted from the death certificate, and death is attributed to another disease. Table 2 shows the COPD mortality and death rates emerging from the EFA survey. Besides non-standard terminology and under-recognition of COPD, the data of different countries should be compared with caution because the statistics were calculated with different methods.

Table 2. Annual COPD mortality and death rate per country

Country	Mortality	Death Rate (per persons)	Reference	Year
Austria	2,680	0.322 per 1,000	Statistik Austria [25]	2008
Belgium	4,425	0.463 per 1,000	Centre for Operational Research in Public Health [26]	2004
Czech Republic	2,059	0.24 per 1,000 men 0.09 per 1,000 women	Institute of Health Information and Statistics of the Czech Republic [27]	2007
Finland	1,109	0.209 per 1,000	Statistics Finland [28]	2007
France	16,000	0.253 per 1,000	Ministère de la Santé et des Solidarités [16]	2005
Germany	23,051	0.280 per 1,000	Statistisches Bundesamt [29]	2007
Ireland	1,289	0.304 per 1,000	Inhale Report, 2nd Edition [30]	2006
Italy	12,678	0.214 per 1,000	ISTAT [31]	2006
Netherlands	5,662	0.350 per 1,000	National Institute for Public Health and the Environment [32]	2004
Portugal	2,622	0.260 per 1000	Peto et al. [33]	2000
Serbia	567 (Belgrade)	0.347 per 1,000	Institute of Public Health of Belgrade	2007
UK	23,735	----	Online National Statistics [34]	2007

Patients with severe COPD undergoing long-term oxygen therapy

Long-term oxygen therapy (LTOT) for patients with severe COPD increases survival and has a beneficial impact on pulmonary haemodynamics, haematological characteristics, exercise capacity, lung mechanics and mental state [4]. The number of patients receiving LTOT is an indicator of the efficiency of national healthcare systems; it can also provide additional information about the presence of severe COPD cases in a given country. Table 3 shows the number of patients on LTOT in the countries surveyed. The difference in LTOT data among countries may depend on the different sources of data. It would be interesting to investigate if these findings correlate with the incidence of the severity of COPD, in particular with GOLD stage IV.

Table 3. Patients receiving long-term oxygen therapy

Country	Number of Patients	Source
Austria	8,000 (96 per 100,000)	Distributor
Czech Republic	2,520 (24 per 100,000)	Linde Company
France	100,000 (155 per 100,000)	Ministère de la Santé et des Solidarités
Ireland	195 per 100,000	National Respiratory (COPD) Framework [35]
Italy	62,000 (104 per 100,000)	Distributor
Portugal	24,360 (229 per 100,000)	RESPIRA Survey (estimated)
Serbia	250-300 in Belgrade. 100 in other towns	Estimated
UK	90,000 (in England and Wales)	Department of Health

GOLD COPD Stages

Stage I: Mild COPD – Mild airflow limitation ($FEV_1/FVC < 70\%$; $FEV_1 > 80\%$ predicted) and sometimes, but not always, chronic cough and sputum production.

- At this stage, the individual may not be aware that his/her lung function is abnormal.

Stage II: Moderate COPD – Worsening airflow limitation ($FEV_1/FVC < 70\%$; $FEV_1 50\% \leq 80\%$ predicted), with shortness of breath typically developing on exertion.

- This is the stage at which patients typically seek medical attention because of chronic respiratory symptoms or an exacerbation of their disease.

Stage III: Severe COPD – Further worsening of airflow limitation ($FEV_1/FVC < 70\%$; $FEV_1 30\% \leq FEV_1 < 50\%$ predicted), greater shortness of breath, reduced exercise capacity, and repeated exacerbations which have an impact on patients' quality of life.

Stage IV: Very severe COPD – Severe airflow limitation ($FEV_1/FVC < 70\%$; $FEV_1 < 30\%$ predicted or $FEV_1 < 50\%$ predicted plus chronic respiratory failure). Patients may have very severe (stage IV) COPD even if the FEV_1 is $> 30\%$ predicted, whenever this complication is present.

- At this stage, quality of life is very appreciably impaired and exacerbations may be life-threatening.

FEV_1 = the amount of air that can be forcefully exhaled in the first second.

FVC= the total amount of air that can be forcefully exhaled after taking a deep breath.

From the GOLD Guidelines [4]

Risk factors

The primary risk factor for developing COPD is tobacco smoking, including secondhand or passive exposure.

According to the WHO, more than 3 million people died of COPD in 2005 (5% of all deaths). The primary risk factor for developing COPD is tobacco smoking, including secondhand or passive exposure. Smoking cessation is the most effective preventive measure against COPD [4]. Other risk factors are indoor and outdoor air pollution, occupational pollution (dusts and chemicals), and severe hereditary alpha-1 antitrypsin deficiency which is a rare condition.

The economic burden of COPD

The total annual financial burden of lung disease in Europe amounts to nearly €102 billion. COPD accounts for almost one half of this figure [5]. The Confronting COPD International Survey [36] showed that COPD has a high economic impact on society. The total societal costs of COPD per patient range from €3,538 in Spain to €1,024 in the Netherlands. Lost productivity due to COPD accounted for 67% of overall costs in France, 50% in the Netherlands and 41% in the UK. The costs to the healthcare system per patient - mainly due to exacerbations and subsequent hospitalizations - range from €530 in France to €614 in the Netherlands and to €3,238 in Spain.

Table 4 contains the data on the direct and indirect COPD costs provided by the associations participating in the EFA survey. This information is in line with the outcome of the Confronting COPD International Survey [36].

Table 4. Direct and indirect COPD costs per country

Country	Direct Costs Euro	Reference	Indirect Costs Euro	Reference
Austria	69,545,445 ^a	Ministry of Health	163,000,000	Institut für Pharmaekonmische Forschung
Belgium	5,600 per patient	Centre fédéral d'expertise des soins de santé [37]	-----	-----
Czech Republic	-----	Data in press	-----	Data in press
Finland	108,000,000	Tynkkynen et al. Finnish Medical Journal 23/2009	194,000,000	Tynkkynen et al. Finnish Medical Journal 23/2009
France	530 per patient	Piperno et al. [38]	1,078 per patient	Piperno et al. [38]
Ireland	437,000,000	Inhale Report, 2nd Edition [30]	387,100,000	Inhale Report, 2nd Edition [30]
Italy	2,724 per patient	Social Costs of Asthma and COPD in Italy [39]	216.84 per patient	Social Costs of Asthma and COPD in Italy [39]
Netherlands	280,000,000	The National Institute for Public Health and the Environment	-----	-----
UK	GBP 500,000,000	National Institute of Clinical Evidence	-----	-----

^aJust costs of hospitalization without rehabilitation or outpatient treatment.

Social impact of COPD in the patients' own words

The associations seem to share the view that the prevalence of COPD is very high and that it is going to increase.

'COPD affects approximately 1 million Austrians, 400,000 of whom are in COPD stage II-IV. The very high number of adolescents who smoke will lead to a dramatic increase of COPD in the future.' *Austria*

'The prevalence of COPD is high in Italy and its impact in terms of disability very alarming – 21% of COPD patients are severely disabled.' *Italy*

'COPD is a major health problem; it is foreseeable that it will become one of the main causes of death at the end of the first decades of the 21st century.' *Portugal*

Many associations observed that one of the greatest problems is underdiagnosis of COPD.

'The seriousness of the situation with COPD is underestimated. In many cases, patients are diagnosed late, when they are already disabled.' *France*

'COPD is underdiagnosed, undertreated and neglected when compared with other major diseases e.g., heart disease or cancer.' *Ireland*

'COPD is underdiagnosed and undertreated.' *Serbia*

'COPD has been neglected by healthcare services, with misdiagnosis a common theme and those affected become isolated by the physical and emotional side effects of the disease as its severity increases. Most will eventually find themselves unable to work, will struggle to do everyday activities, and without proper treatment and care, they will be rushed into hospital fighting for breath time and time again which is terrifying for them.' *UK*

Based on their experience, the associations noted the implications that COPD has for society as a whole and the implications that it has for patients.

‘COPD results in limitation of physical and social activity, and loss of paid work.’ *Czech Republic*

‘While COPD-related ill health impacts on the health service, it also has a social dimension in terms of employment absenteeism, disability and poor quality of life for the person with COPD, their family and carers.’ *Ireland*

‘COPD is an important cause of death and loss of quality of life. The costs for COPD will increase to more than 1,000 million euro a year.’ *Netherlands*

All associations emphasized the psychological consequences of COPD. Anxiety and depression are very frequent comorbidities of this disease.

‘It appears that ensuring a better quality life for COPD patients, also by addressing psychological problems, is almost as important as curing the disease.’ *Italy*

‘Patients with COPD have more difficulties than the general population, also in the domain of psychological functioning. They often experience everyday life more negatively than the general population.’ *Finland*

‘Evaluation of quality of life is very important for COPD patients, but is often underestimated. It is necessary to evaluate each therapeutic intervention in the light of quality of life.’ *France*

‘Various psychological issues are associated with the disease, namely depression, anxiety and loss of independence. It is important that patients receive psychological support for quality of life issues.’ *Germany*

‘Patients with COPD have a worse quality of life than the general population. They are physically and socially limited. They have more problems with work and finances.’ *Netherlands*

Anxiety, depression and stress in COPD

Anxiety and depression are frequently associated with COPD and with acute and chronic respiratory diseases in general. Whereas anxiety may appear earlier than depression, the latter is related to the severity of COPD and to the degree of impaired functioning. Both conditions significantly affect COPD prognosis. Unfortunately, psychiatric disorders are not systematically evaluated and diagnosed in COPD patients, and consequently they are not always treated adequately. This negatively affects the evolution of the respiratory disease and the patient's quality of life; it also increases healthcare and social costs. Three issues are fundamental to the overall optimal management of patients affected by COPD:

- A patient's psychiatric disorder should be diagnosed as soon as possible. The impact of anxiety and/or depression on clinical parameters and on the patient's level of functioning (including quality of life of patients and carers) should be evaluated.
- Anxiety and depression should be treated adequately (drug therapy systematically associated with psychotherapy, and educational and counselling interventions) in parallel with the primary disease.
- Stress should be evaluated in carers.

Adapted from M. Nardini, World COPD Day 2006, Rome, Italy

Access to Care for COPD Patients and their Families

2

Access to care is crucially important for patients and their families because it can relieve them of much of the burden of COPD. In the European COPD Patient Manifesto ‘A Vision for Change’, EFA and its members call for:

- Optimum and safest care at every level, from primary care to specialist healthcare.
- Equal access to treatment, information, education, prevention and pulmonary rehabilitation programmes for all COPD patients and their families.

This section looks at how COPD patients and the associations view their access to preventive measures, early diagnosis, treatment, education, control and monitoring, and support services.

COPD: A disease unknown to the general public

COPD is vastly underrepresented as a social disease and very rarely attracts the attention of the mass media. As a consequence, information about COPD seldom reaches the general public. Patients tend to stay at home, and the general public simply doesn't see COPD patients. In this scenario, public campaigns like the World COPD Day are important in increasing awareness of COPD among the general public as well as among patients and their families and carers. However, more should be done to increase the awareness of the public about COPD, its symptoms, risk factors and the social-economic burden it has on patients, their families and carers. A communication strategy involving scientific societies, medical associations and patients associations would help to draw public attention to the key points of prevention and management of COPD.

‘The term COPD [BPCO] remains unknown to most people and is difficult to explain’.
France and Italy

‘The media should provide more information about COPD.’
Serbia

COPD self-assessment test

COPD is a very frequent disease. Many people have COPD without knowing it.

- | | | |
|--------------------------------------------------------------------|-----|----|
| 1. Do you often cough and bring up mucus? | Yes | No |
| 2. Do you have difficulty breathing compared with people your age? | Yes | No |
| 3. Does this limit your physical activities? | Yes | No |
| 4. Are you over the age of 40? | Yes | No |
| 5. Are you a smoker or an ex-smoker? | Yes | No |

If you answered yes to three or more of these questions you may have COPD. Ask your doctor if you should have a spirometry test. An early diagnosis of COPD is essential to prevent the disease worsening.

Visit your doctor for a diagnosis!

From www.goldcopd.it

Access to preventive measures

COPD is a preventable and treatable disease state characterized by airflow limitation that is not fully reversible. *GOLD Guidelines*

'... every effort should be made to prevent others from suffering from this disease.'
COPD Patients Bill of Rights

The words 'preventable and treatable' were incorporated in the definition of COPD subsequent to the American Thoracic Society/ European Respiratory Society recommendations to recognize the need to present a positive outlook for patients, to encourage the healthcare community to take a more active role in developing programmes for COPD prevention, and to stimulate effective management programmes to treat people with the disease [4]. The main risk factors of COPD are tobacco smoking, indoor and

Access to preventive measures was considered 'difficult' or 'very difficult' in 8 out of 10 countries.

outdoor pollution and occupational exposure to pollutants – all factors that concern the health of the public in general and not only patients.

In this survey, 8 out of the 10 participating associations that replied to this question, found that access to preventive measures was ‘difficult’ or ‘very difficult’. In most countries, there is a lack of awareness and of information about COPD prevention. Access to prevention was judged ‘normal’ in the Czech Republic and in Germany, in the latter country mainly because of easy access to smoking cessation programmes.

Access to an early diagnosis

The later the diagnosis, the more severe the disease. An early and accurate diagnosis of COPD means timely treatment and lifestyle changes that can prevent the progression of the disease and its associated premature morbidity and mortality [40]. Despite the well-recognized importance of an early diagnosis, all the associations surveyed reported that access to an early diagnosis of COPD is ‘difficult’ or ‘very difficult’ in their countries (Table 5). This seems to depend on two factors. Firstly, patients do not consult their doctor. They either underestimate their symptoms and do not realise they need help, or they fear a diagnosis of progressive disability. Some patients tend to adapt their lifestyle to their breathlessness and do not see a doctor until their condition is far advanced. Secondly, in most countries, spirometry is not routinely performed by GPs, who provide the first line of care for COPD patients.

A clinical diagnosis of COPD should be considered in any patient who has shortness of breath, chronic cough or sputum production, and/or a history of exposure to risk factors for the disease [4]. More information in the public domain might alert patients to contact their doctor before their condition deteriorates. Similarly, campaigns targeting GPs might heighten their awareness of COPD.

‘Diagnosis is generally made too late.’ *Germany*

‘Only 50% of COPD patients in Italy receive an early diagnosis.’ *Italy*

Table 5. Access to an early diagnosis

Country	Access to Early Diagnosis	Comment
Austria	Very difficult	Diagnosis is generally made too late. Spirometry is not part of the check-up, which is paid for once a year. Check-up doesn't focus on lung diseases.
Belgium	Difficult	People don't realize they need help.
Czech Republic	Difficult	The public is not sufficiently aware of COPD. People don't realize they need help.
France	Very difficult	The term COPD and the first symptoms remain unknown. The insidious development of the disease adds to the problem of diagnosis.
Germany	Difficult	Diagnosis is generally made too late.
Ireland	Difficult	Waiting time for examination.
Italy	Very difficult	Only 50% of people with COPD symptoms are diagnosed.
Netherlands	Difficult	(Early) diagnosis is becoming a more important issue in the education of caregivers and in the daily care of practitioners and pulmonary specialists.
Portugal	Very difficult	But in 2009, spirometry tests (by pulmonary specialists) began in Lisbon, Oporto and Espinho.
Serbia	Very difficult	Smokers think that they cough because they smoke and that they are short of breath because they are getting older and loose the capacity to tolerate efforts.
UK	Difficult	Spirometry testing is not offered as part of a national health check programme. BLF is campaigning for lung function testing for patients regardless of symptoms.

Access to spirometry/lung function tests

Spirometry can easily identify COPD before the appearance of significant symptoms. The GOLD Guidelines recommend that all patients with suspected COPD should undergo spirometry [4]. This simple, non-invasive test should be performed in the GP's surgery as well as in pulmonary/respiratory centres.

Based on the EFA survey, access to spirometry/lung function tests in Europe at GP level is perceived to be 'difficult' or 'very difficult'. This is mainly because many GPs lack the necessary equipment. For example, only over half the GPs in Ireland can provide spirometry. Similarly, in Serbia and Italy spirometry is not used sufficiently. In Italy 1 out of 2 patients diagnosed with COPD have never undergone spirometry [41]. In the UK, a survey of GPs conducted by the BLF showed that less than a quarter had received spirometry training [42].

Many patients associations have organized events, usually to coincide with World COPD Day, to raise awareness about early diagnosis and the importance of spirometry. In these events free spirometry tests are offered in public places.

'More spirometers are needed. Technicians and doctors should undergo training in spirometry and learn to interpret the results correctly.'
Serbia

'It's very difficult to get GPs to do spirometry.'
France



Spirometry testing in Austria

Despite clear evidence that proper diagnosis and management can improve quality of life and reduce mortality, many systems do not reimburse physicians for simple screening tests to rule out COPD. This is relevant because most patients with early stage disease, who could benefit the most from smoking cessation and therapeutic interventions, see primary care physicians on a regular basis. This is the most important place for identification and diagnosis to take place. Lung function testing should be a regular part of a physical examination. Many physicians recommend screening be done in all patients over 40 with a history of smoking or symptoms. Technologies are now available that make screening as easy and cost-effective as measuring blood pressure.

Access to information for COPD patients

Ideally, COPD patients and their families should have access to easy-to-understand information about COPD, its symptoms and risk factors, preventive measures, treatment options, and what they are entitled to under their health programmes. Information should be tailored to the patient and should also aim at building confidence and a positive outlook [43].

Most of the associations surveyed judged access to information on COPD as a disease to be 'normal'. Information is available in various forms (websites, print, events), and is produced by health authorities, scientific societies, medical associations and patients associations. The patients association in France stressed that information is available, but there is no coordination among the various healthcare professionals who produce this material.

'There's a lot of information, but it's not coordinated.'
France

'It is difficult to obtain adequate information from GPs.'
Italy

Given the variability of information on the web, patients, their families and carers should be warned that only information posted by health authorities, scientific societies, medical associations or patients associations and their scientific committees is reliable.

Access to treatment

Not only is COPD preventable, it is also treatable [4]. A wide variety of pharmacological and non-pharmacological treatments can be used to improve the patient's symptoms and/or complications and quality of life. It makes good economic and social sense to ensure that patients have access to the best evidence-based treatment available. Given the dismal predictions for COPD morbidity and mortality, the best management strategy is to provide optimum treatment tailored to each patient in their own environment, when possible.

Access to the treatment options available

Patients and healthcare professionals should be aware of the range of possible treatments, both pharmacological and non-pharmacological. According to B. R. Celli [44], patients should be encouraged to actively participate in the management of their disease. This may also help to improve self-reliance and self-esteem [43].

'Patients should be encouraged to actively participate in the management of their disease.'
Celli 2006

In some of the countries surveyed, information about treatment options is provided mainly by patients associations also through telephone helplines and support groups. Access to information about treatment options is considered 'normal' or 'easy' in seven countries (Belgium, Czech Republic, France, Germany, Ireland, the Netherlands and the UK) and 'difficult' or 'very difficult' in Austria, Italy, Portugal and Serbia. Although access to information is 'easy' in France, there is often a lack of coordination of the information deriving from different sources. In Italy, it is difficult to obtain information from GPs, also because the time they can devote to each patient is limited. Both Portugal and Serbia made a call for more education for healthcare professionals about treatment options. The Irish Thoracic Society noted that patients have difficulty in accessing demonstrations of the inhaler technique.

Access to vaccination

Vaccination against seasonal influenza has been shown to reduce serious illness for patients with COPD by as much as 50% [45]. The GOLD Guidelines recommend that all patients receive an annual influenza vaccination [4]. Pneumococcal vaccination every five years is also recommended for patients above 65 years and for younger patients with an FEV₁ < 40% predicted. This vaccine has been shown to reduce pneumococcal pneumonia in patients with COPD [46]. The WHO has declared H1N1 influenza a pandemic. COPD patients are an at-risk population for H1N1 influenza, and should consult their doctor for advice on vaccination.

According to a survey conducted in Ireland, 97.5% of GPs reported that it's easy/very easy to access flu and pneumococcal vaccination [28, 47]. A 'Prevention and lifestyle' study conducted by the Italian COPD Patients Association showed that one out of three patients did not have a regular annual influenza vaccination. The rate of pneumococcal vaccination was 31%. Interestingly, 27% of patients who had never received this vaccination did not know it existed.

Access to free treatment

COPD is a chronic disabling disease that places a considerable social and economic burden also on the patient's family. Access to and affordability of diagnostics and drugs are essential for optimal management of chronic respiratory diseases [48]. In turn, optimal management can reduce the number of exacerbations and hospitalizations, and improve quality of life and survival. Pharmacological and non-pharmacological treatments should be available not only in case of exacerbations, but patients should receive continuous optimal care based on the most recent evidence.

Seasonal influenza vaccination and pneumococcal vaccination are recommended for COPD patients.

Patients should receive continuous optimal care based on the most recent evidence.

From this survey, it appears that no country grants full free access to treatment and tests for COPD patients with the exception of Wales in the UK (Table 6).

Table 6. Access to treatment for COPD patients in the countries surveyed

Country	Access	Comment
Austria	Very easy	A fee of €4.9 is required for prescriptions up to a maximum of 2% of a patient's net wage.
Belgium	Difficult	Patients must always pay a part of the cost.
Czech Republic	Difficult	Insurance companies set cost limits to doctors for treatment. Patients must contribute to costs.
France	Easy	Some limitation due to reimbursement policies.
Ireland	Normal	The General Medical Service provides free treatment for persons 'who are unable without undue hardship to arrange general practitioner services for themselves.'
Italy	Very difficult	Patients must pay a 'ticket' for each treatment. The cost varies depending on the region. COPD is not recognized as a chronic disease.
Portugal	Easy	Treatment is partially reimbursed for chronic patients within the civil service subsystem and free for patients within National Health System based on family income.
Serbia	Very easy	Patients pay part of the costs of medicines.
UK	Difficult	In Wales, prescriptions are free of charge but in the other UK countries (England, Scotland and Northern Ireland) patients must pay for their prescriptions. Patients still have to pay for oxygen concentrators.

Measures that COPD patients can take to improve their condition

- Ask their doctor for more details and written information about their condition.
- Follow the treatment plan.
Take their medication exactly as prescribed in their health plan.
- Attend control visits regularly even if they feel well.
- Follow prescribed rehabilitation programmes.
- Have an influenza vaccination every year and a pneumococcal vaccination every 5 years.
- Try to avoid infections of the upper airways.
Avoid people with colds and flu, and crowds in the flu season.
- Smokers should try to stop smoking as soon as possible.
If necessary, they may ask their doctor for information about the help available.
- Avoid passive smoking.
If non-smoking laws are in force, insist they are respected.
- Avoid exposure to pollution, both indoor (fumes, dust, strong detergents etc.) and outdoor (airborne particles from traffic and industrial processes).
- If possible, spend time in a healthy environment (parks, in the mountains or by the sea), try to follow a healthy diet and exercise regularly.

The Italian COPD Patients Association

Access to rehabilitation

The main aims of pulmonary rehabilitation are to reduce symptoms, improve quality of life, and increase the patient's physical and emotional participation in everyday activities [4]. It has been shown that exercise training programmes can improve exercise tolerance and symptoms of dyspnea and fatigue in COPD patients at all stages of the disease.

In this survey, access to rehabilitation is judged 'difficult' or 'very difficult' in 8/11 countries (Figure 2). It appears that national healthcare services in Europe are not sufficiently aware of the importance of rehabilitation for the management of COPD. In Austria, only inpatients undergo rehabilitation and there is a long waiting list. In other countries, there are not enough centres offering rehabilitation (France, Italy, Serbia and the UK), and only a small portion of patients are sent to rehabilitation (Germany and Ireland). In Ireland, most people with COPD are diagnosed in primary care, yet only 8% of GPs can access pulmonary rehabilitation services for their patients. Nearly 40% of acute hospitals confirmed that they had a formal pulmonary rehabilitation programme. Referrals for pulmonary rehabilitation programmes were usually only accepted from hospital-based services. Only 20% accepted referrals from GPs [47]. A more optimistic picture emerges from Portugal, where access to rehabilitation is 'very easy'. Thanks to partnerships among patients associations, GOLD, pharmaceutical companies and local institutions, rehabilitation has been specifically promoted in events such as World COPD Day and the World No Tobacco Day.

It appears that national healthcare services in Europe are not sufficiently aware of the importance of rehabilitation for the management of COPD.

Exercise training programmes can improve exercise tolerance and symptoms of dyspnea and fatigue in COPD patients at all stages of the disease.

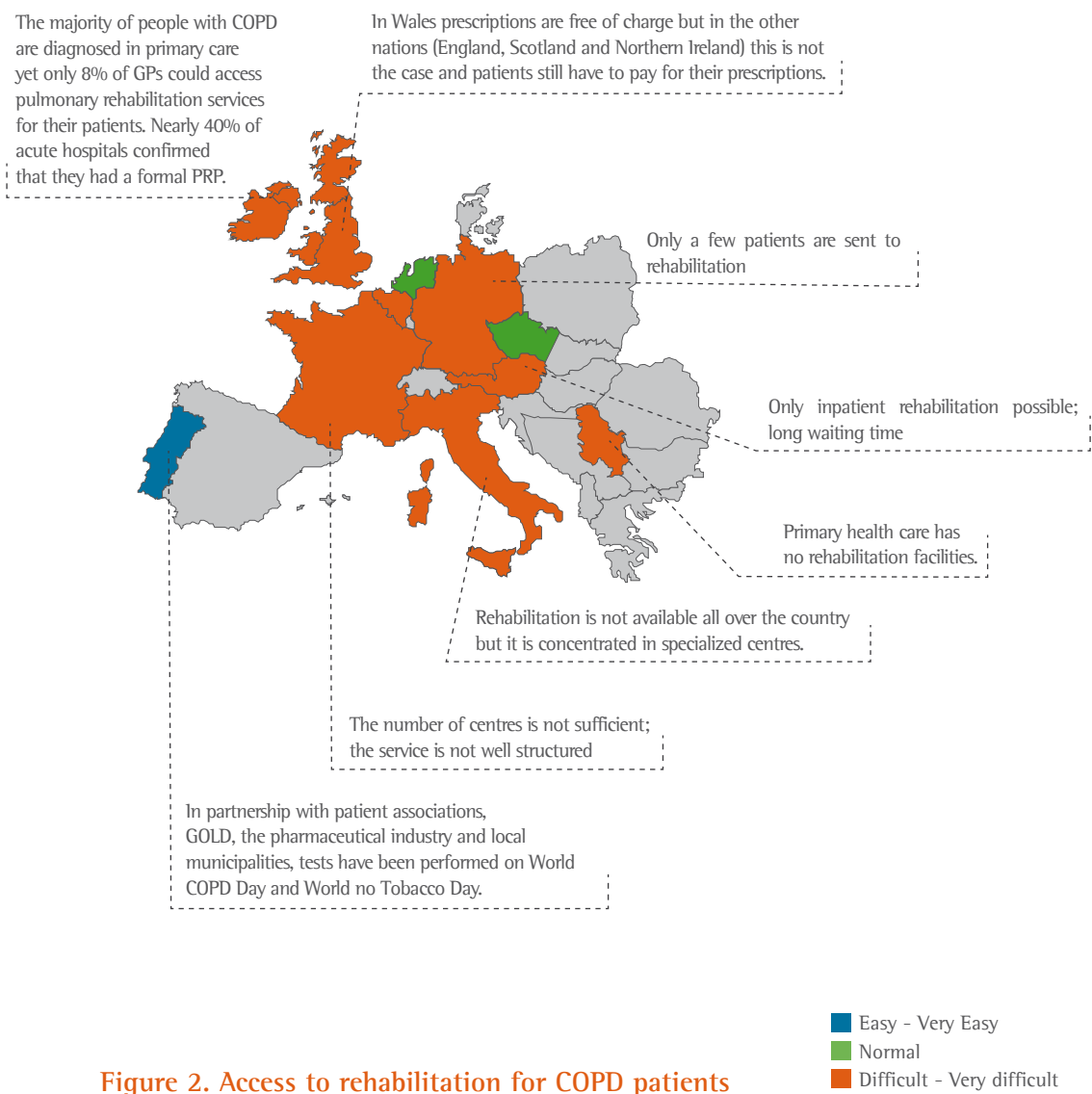


Figure 2. Access to rehabilitation for COPD patients

Access to educational programmes

Patients who are well informed about their condition can be effective partners of their doctor. Patient education can help to improve skills, the ability to cope with illness and health status, and should be tailored to the individual patient to address symptoms and improve quality of life [4].

As shown in Table 7, in this survey, the main issues concerning access to education and re-education programmes for COPD patients were:

- A lack of coordinated actions and programmes at national level (Austria, Czech Republic, France, the Netherlands and Serbia).
- Difficulty in finding or accessing educational programmes (Belgium, Ireland and Portugal).

Interestingly, in Germany some insurance companies have started Disease Management Programmes for COPD patients. This practice and the results warrant further investigation.

‘There is no coordinated action on patient education at national level and there is no consensus among the various healthcare professionals.’ *France*

Table 7. Access to educational programmes

Country	Access to Educational Programmes
Austria	No national programme. Education is only available through the patients organization and a few pulmonary specialists.
Belgium	Patients themselves must look for educational programmes.
Czech Republic	Difficult
France	There is no coordinated action at national level and no consensus among different healthcare professionals.
Germany	Some insurance companies have started Disease Management Programmes for COPD patients that include education.
Ireland	Patient education was easy to access in many GP practices, but 5% reported no access, with almost 30% of GPs finding it difficult/very difficult.*
Italy	There are no national or regional educational programmes. Education is provided by some pulmonary specialists and patients associations.
Netherlands	Access is not difficult, but not all hospitals have educational programmes.
Portugal	Available only in main urban areas. The patients association and the Portuguese Scientific Society of Pneumology have published educational material.
Serbia	Education is not organized on a regular basis.
UK	The Department of Health runs an Expert Patient Programme for people living with a long-term condition.

*GP survey carried out as part of the National Respiratory (COPD) Framework [47]

Access to oxygen therapy

In Europe, more than 500,000 people are under long-term oxygen therapy (> 15 hours per day). This intervention, which is generally prescribed for patients with very severe COPD, has been shown to increase survival in patients with chronic respiratory failure [49, 50].

Access to oxygen therapy in the countries surveyed is considered 'easy' or 'very easy' only in two countries (Austria and France). Oxygen therapy is reimbursed in Austria, France and the Netherlands, and is free in Italy and Serbia. However, several specific problems emerge from this survey. In Austria, the public health insurance system prefers to pay for O₂-concentrators, and in Germany, oxygen equipment does not always conform to the prescription. In the Czech Republic liquid oxygen is provided mostly for patients awaiting lung transplantation, liquid oxygen therapy is given only to patients who are mobile. In Ireland, patients have difficulty in accessing long-term therapy, and in Italy, bureaucratic barriers complicate access to oxygen therapy. In fact in an Italian survey that included 308 patients under oxygen therapy, 90% were satisfied with the service, but complained about the excessive bureaucracy. In Portugal, access to oxygen therapy is 'difficult' because of administrative practices in some regions, but may improve after the publication in 2009 of a public tender. In Serbia, oxygen therapy is based on well-defined criteria, and the social insurance system pays for oxygen concentrators. A pulmonary municipality service provides oxygen at home. Home oxygen service has recently improved greatly in the UK and patients now have access to home oxygen and cylinders, which makes it easier for them to get out.

'An effective well organized structure. Good reimbursement.'
France

'A major problem is the lack of places where patients can recharge their stroller when away from home.'
Italy

'Patients still have to pay for oxygen concentrators.'
UK

Access to non-invasive mechanical ventilation

Non-invasive mechanical ventilation in COPD exacerbations improves respiratory acidosis, increases pH, decreases the need for endotracheal intubation, and reduces the partial pressure of carbon dioxide (PaCO₂), respiratory rate, severity of breathlessness, length of hospital stay and mortality [4]. Patients continue non-invasive mechanical ventilation until their blood level of oxygen reaches an acceptable level.

Access to non-invasive mechanical ventilation is judged 'normal' or 'easy' in all the countries surveyed except Portugal and Serbia, in which it is considered 'very difficult'. It is noteworthy that this technology evolves rapidly and thus there is a need for continuous updating for healthcare providers.

Access to home care

Patients with severe COPD (GOLD stage IV) have great difficulty in carrying out day-to-day activities. In most cases, the patient is elderly, affected by other chronic conditions, alone or with a spouse who also may have health problems. Home care is essential for such patients also to ensure continuity of treatment, rehabilitation and education.

Home care should be provided by a network of health professionals that include the patient's GP, a respiratory specialist (and other specialists depending on comorbidities), a respiratory rehabilitation expert and nurses.

According to this survey, home care appears to be 'difficult' to access in European countries. In fact, it is limited in most of the countries surveyed. In Portugal, for example, home care is provided mainly by private organizations and charities. A rosier picture emerges from France, where home care is well organized and effective. Interestingly, the National Health

Service in Italy foresees three levels of home care that include medical, nursing and rehabilitation assistance depending on the severity of the patient's condition, however access to home care in Italy is judged 'very difficult'.

Access to telemedicine monitoring

Despite its potential for the home monitoring of COPD patients, telemedicine monitoring it is not yet widely practiced in the countries surveyed. Telemedicine is currently being piloted across the UK.

Access to support services for patients and carers

Support services for patients and their families can help to improve quality of life. Such services can address psychological problems such as depression and anxiety, as well as practical problems that patients encounter in their daily activities, for instance by providing transport. Unfortunately, as shown in Figure 3, access to support services is considered 'easy' only in Austria, where however it is difficult to obtain support for ventilated patients at home. In some countries, such as in the Netherlands there are support services for patients such as transport, meals-on-wheels, and support in home care. Room for improvement was highlighted by France where there is a discrepancy between cities and provinces in the services provided. In Italy support services are sporadic and mainly provided by volunteers.

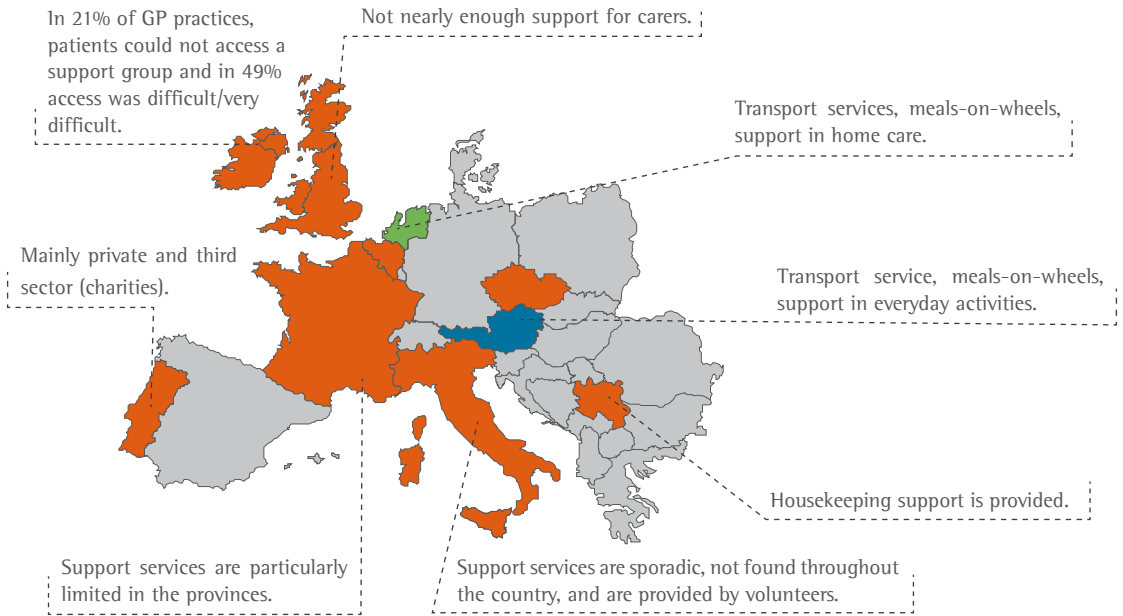


Figure 3. Access to support services

- Easy - Very Easy
- Normal
- Difficult - Very difficult

Travelling by air with oxygen therapy

People using oxygen therapy can travel by air provided their doctor agrees.

EC Regulation 1107/2006, which contains an updated Code of Practice regarding the carriage of disabled and reduced mobility passengers, requires airlines to provide the necessary assistance without any additional costs. However, regulations about oxygen use on planes differ from country to country and from airline to airline, and can be complicated. See the European Lung Foundation website for detailed information on the requirements of airlines operating in Europe (www.european-lung-foundation.org).

Specific national successes and national problems regarding quality of care

In this survey, the associations were requested to describe key successes and problems regarding the care of COPD patients in their countries. Identification of these features at national level may lead to improvements in the care of COPD patients at EU level.

Country	Specific National Successes
Austria	Respiratory intensive care units have been established, although more are needed.
France	The service of oxygen therapy is a real success of French healthcare. There is a well structured network. Thanks to full reimbursement by social security, the quality of care has improved.
Germany	Health insurance companies have started Disease Management Programmes for COPD.
Italy	A law to include COPD among chronic diseases is tabled for discussion by the Italian Parliament. The Italian COPD Patients Association was a member of the Working Group of the Italian Ministry of Labour, Health and Social Policies established to prepare a GARD-Italy Strategy document. The GARD-Italy Strategy was launched on 11 June 2009, and was endorsed by 50 organizations including the Italian COPD Patients Association.
Netherlands	The patients association is increasingly being consulted by health insurers to help them improve the quality of the contracts they make with caregivers.
Portugal	A multidisciplinary team consisting of doctors, nurses, therapists and nutritionists has been established in a hospital in Matosinhos. This multidisciplinary team provides a holistic approach to COPD patients and has resulted in much better health outcomes.
Serbia	<ul style="list-style-type: none"> • Respiratory intensive care units have been established in tertiary health institutions. • An oxygen therapy service is available in Belgrade. • Reimbursement for drugs has improved. • An antismoking strategy.
UK	<ul style="list-style-type: none"> • A ban on smoking in public places across the UK since July 2007. • The announcement of the National Clinical Strategy for COPD to standardise care across England for people affected by COPD (due to be published in 2010).

Country	Specific National Problems
Austria	No funding for patient education; no plan for the palliative care of COPD patients; no ambulatory rehabilitation.
Czech Republic	The total population is 10,380,000. 2.2 million (30-36%) of the population over the age of 15 smoke, and 250,000 individuals below the age of 18 smoke.
France	There is little time for patient communication.
Italy	The Italian COPD Patients Association has long advocated for the inclusion of COPD in the list of chronic and disabling diseases of the Ministry of Labour, Health and Social Policies. Asthma and respiratory failure are in the list, but not COPD. Recognition of COPD as a chronic condition means that patients will receive essential treatments for disease monitoring (spirometry testing, hemogas analysis etc.) free of charge. Unfortunately, the law has not yet been amended.
Netherlands	To finance chain care, insurers have to make contracts with many different caregivers, each of whom has their own financial requirements.
Portugal	Access to oxygen therapy (liquid oxygen) depends on where the patient lives and on the health subsystem he/she belongs to.
Serbia	Lack of awareness of COPD in the general population. There are not enough spirometers at primary care level.
UK	Awareness of COPD is very low in the UK. A national awareness survey commissioned by the BLF in 2008 found that 86% of people had not heard of COPD. This means that COPD is frequently under diagnosed (3.7 million are thought to have COPD in the UK but only 900,000 are currently diagnosed) and those who are diagnosed are frequently misdiagnosed with asthma.

Access to care – Take home messages

- COPD is a preventable and treatable disease characterized by airflow limitation that is not fully reversible and is usually progressive.
- Efforts should be made to reduce exposure to risk factors and in particular to avoid both active and passive tobacco smoking.
- COPD patients throughout Europe should have access to an early diagnosis, education, support services and the best treatments available regardless if they live in urban or non-urban areas. Despite the efforts made in several countries, more work must be done to fully achieve this goal.
- Patients should receive information about treatment options that are based on evidence-based guidelines.
- GPs should be more aware of COPD and play a greater role in the diagnosis, management and education of COPD patients. An alliance between patients, GPs and pulmonary specialists is needed to achieve this goal. Health institutions should provide measures to support an early diagnosis and adequate treatment.
- The management and education of COPD patients should be tailored to each individual's needs also taking comorbidities into consideration.

The Role of Healthcare Professionals in the Management of COPD

3

A chronic disease management programme for COPD patients that incorporates a variety of interventions, including pulmonary rehabilitation and implemented by primary care, has been shown to reduce admissions and hospital bed days [51]. Key elements were patient participation and information sharing among healthcare providers.

It is now becoming clear that the optimal management of COPD patients should be based on the coordinated action of the GP, the pulmonary specialist and other specialists, respiratory nurses, respiratory therapists and lung function technicians.

This section focuses on the role played by each of these healthcare professionals in the countries that completed the EFA questionnaire.

Poor patient/clinician communication may be one of the factors why many patients are not achieving the level of treatment success that may be possible [36, 52, 53]. Patients are not always supported to clearly explain their symptoms, and doctors often lack the time to collect a detailed 'history'. In this scenario, a short simple questionnaire (the COPD assessment test) has been developed for the assessment of the impact of COPD on health status with the aim of facilitating patient/physician communication [54].

The role of the general practitioner

It is estimated that GPs treat about 85% of all patients with asthma or COPD in the UK [55] and in the Netherlands [56]. GPs are in a good position to manage these chronic conditions because of their long-term continuous relationship with their patients [57].

'GPs treat about 85% of all patients with asthma or COPD.'

UK and Netherlands

General practitioners have a central role in the diagnosis and management of COPD patients. They are responsible for an early diagnosis, and they refer the patient to the pulmonary specialist. Importantly, most of the management could be done by GPs, especially in cases of mild or moderate COPD. The family doctor is in a unique position to reinforce messages about positive lifestyle changes, to evaluate the patient's personal risk as it mutates over the years particularly as regards cardiovascular and respiratory diseases, and to ensure continuity of care [58]. To enable them to be effective, GPs should also be actively involved in patient education and re-education programmes.

'The GP is in a unique position to reinforce messages about positive lifestyle changes, and to evaluate the patient's personal risk as it mutates over the years.'

From the EFA survey, it appears that GPs are responsible for early diagnosis, management of mild and moderate COPD and long-term follow-up. However, often GPs are not sufficiently aware of COPD or of the importance of an early diagnosis. Spirometry is not available for all patients attending primary care as shown by the replies to the survey.

Austria. Patients first see their GP, who refers patients to the pulmonologist who makes the diagnosis of COPD. After diagnosis, the GP manages the treatment recommended by the pulmonologist.

Belgium. Many patients are treated only by their GP. They see a pulmonary specialist in case of hospitalization. The GP starts home care and support services and gives information. Some GPs send their patients to a specialist and then follow-up the patients.

Czech Republic. The GP provides basic information about COPD management, inhalation technique, sends patients to a pneumologist for spirometry, and treats patients with stage I and II COPD in coordination with the pneumologist.

Finland. The GP is responsible for early diagnosis, long-term follow-up, medication if needed and assessment of pulmonary rehabilitation.

France. The GP is responsible for prevention and dissemination of information about COPD and for its diagnosis. The GP treats and monitors the patient in continuity. He/she collaborates with pulmonary specialists, nurses, respiratory therapists and technicians.

Germany. Many patients are treated only by their GP, but currently spirometry is not available to all patients. In general, there is a lack of awareness about COPD among many GPs and also among their patients. Recently, a small poll showed that only one of six patients knew what kind of disease he/she had when the doctor said: 'You have COPD'.

Ireland. Currently, spirometry is not readily available to all patients attending primary care, and where it is available the performance and interpretation are variable. Most GPs and their patients with COPD do not have rapid access to supports and respiratory expertise when required, and emergency department attendance/acute hospital admission may be the only option.

Italy. The GP is responsible for an early diagnosis and preventive measures. In many instances, there is a lack of awareness about COPD among GPs. A survey of 400 GPs showed that only 2.5% of a total of 617,280 patients had COPD. It appears that GPs usually prescribe treatment without the use of spirometry, and/or without taking the severity of airway obstruction into account. In fact, during a 10-year period, only 32% of COPD patients had a spirometry and only 30% saw a pulmonary specialist. In general, patients with COPD are undertreated and the level of management seems to fall short of recommended international guidelines [41].

Netherlands. The GP plays a central role in COPD. The GP makes the diagnosis, refers the patient to the pulmonary specialist, prescribes medicine, advises about lifestyle interventions, provides instruction about inhalation techniques, and is responsible for follow-up.

Portugal. The GP makes the initial diagnosis and prescribes further analyses. He/she monitors patients who have stabilized, provides support for the patient's family and refers the patient to a pulmonary specialist.

Serbia. Patients are seen by a specialist (usually a pulmonologist), who makes the diagnosis and the GP prescribes medications. However, GPs should be the first contact for diagnosis and for the management of COPD patients. Regular continual medical education is mandatory for GPs, and the GP should play a major role in deciding therapy prescription.

United Kingdom. A survey of 776 GPs from all over the UK carried out for the BLF in 2008 by Doctors.Net showed that most had difficulty differentiating between asthma or COPD, causing misdiagnosis and distress amongst patients. One key finding was that four-fifths of GPs (80%) find differentiating between asthma and COPD quite or very challenging. There is a need to establish clear care pathways for people diagnosed.

Patient from France

My COPD arrived suddenly

'My COPD arrived suddenly. I saw one hospital pneumologist in 5 years and I used only a bronchodilator. Later another pulmonologist measured my respiratory function (FEV₁ 24% of normal). He confirmed severe COPD and I was immediately hospitalized because I was close to asphyxia. I spent three weeks in the hospital under oxygen and 10 weeks in the respiratory rehabilitation centre. I felt better, my FEV₁ increased to 31%, but I shall need oxygen therapy for 15 hours a day for the rest of my life.

This makes everyday social life and arranging journeys difficult for me, my family, and others. But I have been able to overcome all the problems, which is not the case of everyone. I have been hospitalized three times in 4 years (once it was for heart-lung decompensation). I have been depressed at times because of my disability, but it is necessary to know how to create a good environment and to be strong.

Looking back, I am happy to live in France where all my care is provided for. I soon (after 18 months) received the status of a disabled person (80%). I can take care of my disease without having any financial problems. I hope that our healthcare system will continue like this for a long time.'

The role of the pulmonary specialist

Usually, the first healthcare professional that a patient with respiratory symptoms sees is the GP (see ‘The role of the general practitioner’). And it is the GP who will refer the patient to a specialist if necessary. Good coordination between the GP and the pulmonary specialist is a prerequisite for effective management of COPD patients.

Access to pulmonary specialists is very important for COPD patients, both for an accurate diagnosis and for the management of the disease. As shown in Figure 4, a dual picture emerges from the data collected in this survey. In some countries, access to pulmonary specialists is ‘easy/normal’, while in other countries access to specialists is considered ‘difficult’ especially in rural and non-urban areas. The difficulty in accessing a pulmonary specialist in non-urban areas may negatively affect the treatment and management of COPD in patients living in those areas. In some countries (France and Ireland), another problem is long waiting lists.

In most of the countries taking part in this survey, the pulmonary specialist is usually responsible for the management of patients, especially in case of severe and very severe COPD.

The difficulty in accessing a pulmonary specialist in non-urban areas may negatively affect the treatment and management of COPD.

‘COPD accounts for at least one-third of hospital respiratory activity, in terms of both hospitalizations and bed days used.’
Ireland

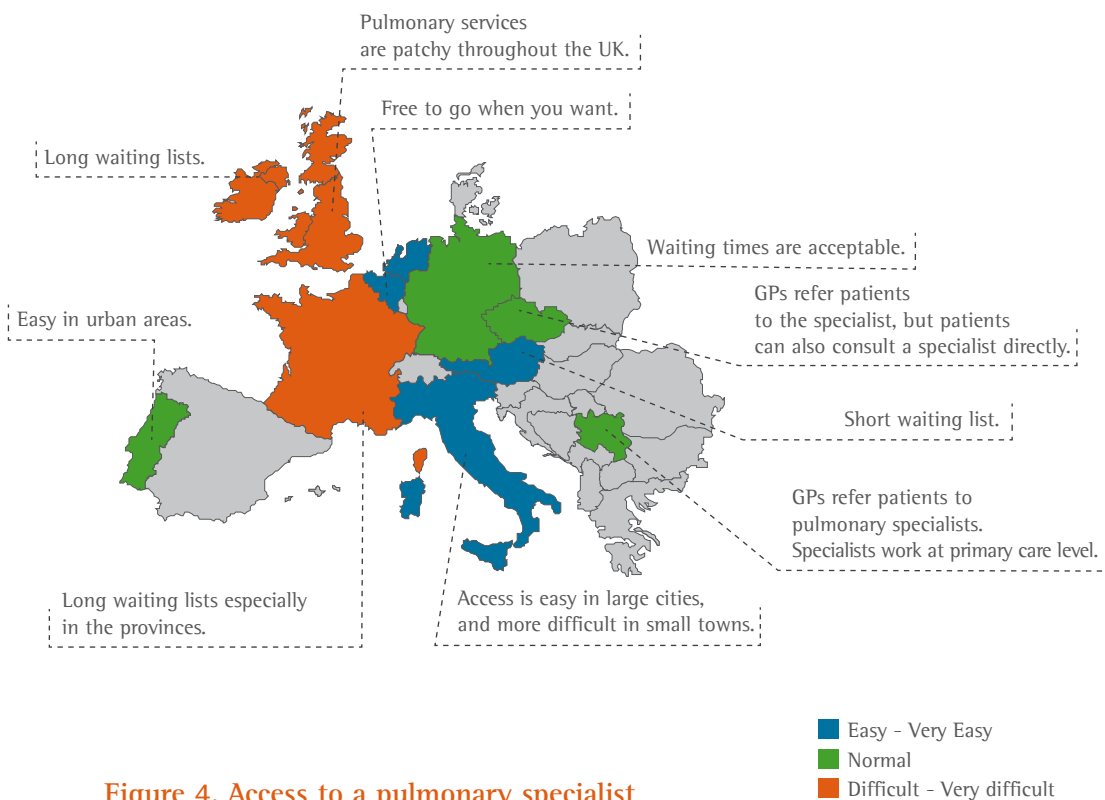


Figure 4. Access to a pulmonary specialist

The majority of associations affirm that pulmonary specialists in their country are highly qualified and their associations are active in national COPD programmes.

Austria. The pulmonologist makes the diagnosis, plans the therapy and carries out control examinations.

Belgium. Many patients go to the pulmonary specialist on their own initiative in their search for more information or better treatment. Treatment is not coordinated because patients go to the specialist without contacting their GP. Consequently, there is expensive specialist care without the support of the GP.

Czech Republic. The pulmonary specialist provides complete care for stage I-IV COPD and special care for stage III and IV COPD. This care includes early detection of COPD, training in the inhalation technique and rehabilitation. In addition, also through the association of professional specialists, they cooperate with GPs, smoking-cessation organizations, caregivers and the Ministry of Health.

Finland. The pulmonary specialist is responsible for the differential diagnosis and for the treatment and management of severe COPD.

France. The pulmonary specialist confirms the diagnosis, decides treatment and controls its efficacy. The pulmonary specialist organizes COPD training programmes for GPs. He/she works in collaboration with GPs, nurses, respiratory therapists and lung function technicians. Pulmonary specialists participate in the development of national programmes (also in collaboration with patients associations) and in conducting clinical research. Treatment compliance and partnership with the patient and family should be an important part of the specialist's activity.

Germany. The pulmonary specialist is normally responsible for the differential diagnosis and for the treatment and management of more severe cases of COPD.

Ireland. COPD accounts for at least one-third of hospital respiratory activity, in terms of both hospitalizations and bed days used. Timely access to pulmonary specialist expertise is essential for optimum patient care. The availability of such services can ensure that patients are cared for in the most appropriate setting, usually primary care, and receive the benefits of specialist advice that otherwise may necessitate hospital admission. Currently there are 35 whole time equivalent respiratory consultants (i.e. 1 per 120,000 population compared with the UK norm of 1 per 50,000 population). Almost half of Ireland's respiratory consultants are based in Dublin.

Italy. Pulmonary specialists may be public or private. There are pulmonary units in all main hospitals and university hospitals. Specialists and centres are highly qualified, both in the treatment of COPD exacerbations and in monitoring.

Netherlands. The pulmonary specialist diagnoses the patient when the GP is not able to do so based on anamnesis and spirometry, and treats patients with GOLD stage III-IV COPD.

Portugal. The pulmonary specialist confirms the initial diagnosis, refers the patient to hospital (if necessary), and is responsible for the treatment, training and education of patients and their families.

Serbia. All patients are easily referred to pulmonary specialists. Pulmonary specialists need continuing medical education on diseases other than tuberculosis.

Access to specialists other than pulmonary specialists

As COPD patients become older, they are frequently affected by other chronic health conditions that may need the attention of specialists other than a pulmonary specialist. Thus, it is important to coordinate the overall management of these patients. The GP with his/her knowledge of the patient and in view of comorbidities can play a key role in this context. According to Fabbri et al. [59], the comorbidities of COPD may be classified as:

1. Causal (diseases associated with such common risk factors as smoking and age).
2. Complicating (systemic effects of COPD).
3. Concurrent (co-existing chronic conditions without any known causal relationship with COPD).

Comorbidities associated with COPD

- Myocardial infarction
- Angina
- Hypertension
- Osteoporosis
- Bone fractures
- Respiratory infection
- Depression
- Diabetes
- Sleep disorders
- Anaemia
- Glaucoma
- Weight loss
- Nutritional abnormalities

The role of COPD nurses, respiratory therapists and lung function technicians

The role of respiratory nurses, therapists and technicians differs among the countries participating in this survey. In some countries (Czech Republic, France, Ireland, the Netherlands and the UK), respiratory nurses play an important role in home care and in the education of patients. However, in countries where there are respiratory nurses, they are often not sufficient. In other countries, respiratory nurses simply do not exist (Austria, Belgium, Italy and Serbia).

A more uniform pattern emerges with respect to respiratory therapists. In most cases they are active only in hospitals and in respiratory centres, and their number is generally perceived to be insufficient. Nevertheless, in some countries, such as Italy, respiratory therapists are not officially recognized.

Lung function technicians are a key to an accurate diagnosis. In Europe, they are located mainly in hospitals and in respiratory centres. In France, the role of respiratory technicians who provide oxygen therapy in home care is well defined by the Charter of Patients Receiving Home Care, elaborated by the FFAAIR Patients Association. But in some countries (Italy) respiratory technicians are not officially recognized, and generally, their number is not sufficient.

'The COPD nurse advises the patient about lifestyle adjustments, gives inhalation instructions, organizes oxygen deliveries, visits the patients at home and gives advice about sanitation, and takes care of the follow-up.'
Netherlands

'Patients are often unaware that a respiratory therapist can help them.'
Belgium

British Lung Foundation Nurses

The BLF Nurse Programme was launched in February 2006 to provide specialist care for people with respiratory conditions. There are currently 42 BLF Nurses with more posts in development.

Improving patient care

BLF Nurses play a key role improving the quality of care for patients by reducing unplanned hospital admissions, facilitating early discharge, providing nurse-led clinics in the community and improving patient self-management skills.



To ensure patients receive the most appropriate care, BLF Nurses work closely with health professionals and social care across the primary and secondary interface sharing skills, knowledge and expertise.

Specialist nurses who are able to provide advice to healthcare professionals and the public also answer the BLF helpline.

Education

BLF nurses have a major role in:

- Providing information to patients and carers about lung disease.
- Sharing expertise with health professionals through delivery of structured education programmes as a specialist resource.

Service models

The nurses are developing new ways of working to ensure respiratory patients receive the highest level of care in the community. The service models they provide include:

- Early Supported Discharge
- Hospital at Home
- Specialist respiratory assessment either in a clinic or home setting
- Peripatetic Community Pulmonary Rehabilitation
- Ongoing support and end of life care.

A story of love and rehabilitation

'It needed only a simple blood test (hemogas analysis) to identify my severe respiratory insufficiency. But when I went to my doctor, my breathlessness when walking even short distances was attributed to air pollution plus stress. This was not the case. Instead, I was suffering from bullous emphysema with severe primary pulmonary hypertension – a congenital problem.

It wasn't until two years later and after many visits to doctors that I was diagnosed by the specialists of a pulmonary centre. Unfortunately, by then my lungs were in a very poor condition. The sentence was: bilateral lung transplantation, for which I'm on the waiting list. I refuse to give in. I continue to go ahead with all my energy and with the support of my husband and three children united in a single sentiment: Love.

The specialists of the transplant centre told me that I mustn't let my ribcage become atrophied; they said that I should constantly exercise with respiratory therapy so that my body will be ready to receive the new lungs. Unfortunately, I had great difficulty in finding out where I could do rehabilitation. When I finally found a rehabilitation centre, I regained the joy of living and the will to go ahead. When I started rehabilitation, I weighed just over 38 kg, was pale and drawn, without appetite, and used high doses of oxygen. Today, although my disease has not regressed, its progress has slowed down. Now I weigh 45 kg, I look healthier and I've cut down the use of oxygen by half.

My improvement is due to my doctor and to my physiotherapist who take care of me with professionalism and affection; it is also due to the extraordinary support of my family. I'm still on the waiting list for a lung transplant but I'm neither anxious nor in a hurry.'

The role of healthcare professionals – Take home messages

- Different kinds of healthcare professionals (GPs, pneumologists, COPD nurses, respiratory therapists and lung function technicians) must be involved in the management of COPD patients.
- Coordination among healthcare professionals is essential for effective COPD management.
- GPs are responsible for an early diagnosis and, in the presence of certain conditions, they should be alert to the possibility of COPD.
- COPD nurses, respiratory therapists and lung function technicians are key in the management of COPD and their role should be recognized and their number increased.

Studies on Quality of Life of Patients, their Families and Carers.

The Patient's Perspective

4

COPD is a chronic, progressive disabling disease that may limit a patient's daily activity (doing housework, walking to the shops, climbing stairs and even dressing). This can negatively affect the psychological well being of patients, their family and their carers. Indeed, many patients face the future with a sense of hopelessness, anxiety, and low self-esteem. Consequently, the management of patients should be tailored to address symptoms and improve the patient's quality of life and should include rehabilitation and educational programmes customized to the specific needs and environment of the individual patient [4]. Comorbidities and exacerbations negatively affect the patient's quality of life as well as their prognosis. Medications and education to help prevent future exacerbations should be considered a part of follow-up [4]. Studies on quality of life conducted in the countries participating in this survey are summarized in Appendix 2.

'Patients with COPD have more difficulties than the general population also in the domain of psychological functioning.' *Finland*

'Each treatment/intervention should be evaluated in the light of quality of life.' *France*

The overall approach to managing COPD should be individualized to address symptoms and improve quality of life. *GOLD Guidelines*

I learned how everyone has different experiences of the disease

'It's frustrating – you don't look sick, I can get up and put make-up on but I can't walk 10 yards without being out of breath. No matter how slow people walk it's never slow enough – I feel I have to walk faster to keep up but then I have to stop, gasping for breath. I'm not an old woman – no one expects you to be the way you are. I know there are stages to the disease and that I'm now at stage 4 – that worries me. My kids don't realise, I don't want to explain to them but I feel I should be preparing them. I'm conscious of the cutbacks affecting services. One hospital tells me as soon as I feel I can't cope I should go in. But in another they asked me questions like they think I'm institutionalised and that I'm coming in for the company – I don't know what to be doing. I don't go to hospital unless I have to – I keep hoping the nebuliser, oxygen and antibiotics will kick in. Hospital in the Home was great while it lasted – otherwise I'm taking up a bed when I don't need it when instead a health visitor could be coming to my home and giving the injection. With COPD you're not treated like an individual – everyone gets the same treatment and if you don't fit into the little box – tough. Yet at COPD class I learned how everyone has different experiences of the disease. For example, I thought home oxygen would be wonderful but soon realised when only 25% of your lung is working it won't make a lot of difference. But another woman can go shopping and do small jobs after her oxygen, I can't.

Quality of life of COPD patients – Take home messages

- The management of patients should be tailored to address symptoms and improve the patient's quality of life.
- Educational programmes customized to the specific needs of the individual patient can play an important role in improving the quality of life of patients, their families and carers.
- Rehabilitation is an important factor in quality of life because it aims at reducing symptoms and increasing the patient's physical and emotional participation in everyday activities.

5 National COPD Programmes

COPD should be a priority on the public health agenda of all countries, and national programmes should involve the Ministry of Health, GPs, specialists and other healthcare professionals, and patients associations.

Action is urgently needed to avoid an adverse impact of COPD on national economic development. GARD 2007

COPD places a severe economic burden on countries because of loss of working days, hospitalization and treatment. Indeed, among respiratory diseases, COPD is the leading cause of lost work days. This burden will increase if no action is taken. According to the WHO's Global Alliance against Chronic Respiratory Diseases (GARD), action is urgently needed to avoid an adverse impact on national economic development [60]. COPD should be a priority on the public health agenda of all countries, and national COPD programmes should involve the Ministry of Health, GPs, specialists and other healthcare professionals, and associations of patients.

Generally speaking, the main objective of national programmes is to promote prevention and control of COPD at a national level. Some specific aims of these programmes are:

- To improve the surveillance and awareness of COPD particularly as regards risk factors and prevention.
- To decrease the number of new cases of COPD in particular by reducing risk factors and by improving the home, work and school environment.
- To promote early diagnosis of COPD.
- To improve the health status and quality of life of patients with COPD.
- To promote access to the best available treatment based on the latest evidence.

- To promote patient education and self-care.
- To improve knowledge of COPD among healthcare professionals.
- To promote and support scientific research.

At the time of this survey, most participating countries had a national COPD programme supported by the national Ministries of Health or by doctors or patients associations (Table 8). Where there is a national programme, patients associations are actively involved as experts (France and Italy), as members of the working group responsible for the strategy of non-contagious chronic diseases (Serbia), or in collaboration with scientific societies (Ireland and the Netherlands). The UK expects to have a national programme within 2009.

National COPD programmes – Take home messages

- COPD places a severe economic burden on countries because of loss of working days, hospitalization and treatment.
- Action is needed to reduce the burden of COPD on families and on the health system.
- National programmes on COPD should aim at promoting prevention and control of COPD equally throughout each country.
- Programmes should involve all stakeholders (Ministry of Health, GPs, specialists and other healthcare professionals, and patients associations).

Table 8. Ongoing national COPD programmes in the countries surveyed

Country	Programme	Issuing Body	Website
Czech Republic	National Programme for the Improvement of COPD Quality Care and Efficiency	Czech Civic Association Against COPD	www.copn.cz
Finland	Chronic Bronchitis and Obstructive Pulmonary Disease	National Guidelines for Prevention and Treatment 1998-2007 Ministry of Social Affairs and Health	www.filha.fi and www.stm.fi
France	Programme d'actions en faveur de la broncho-pneumopathie chronique obstructive (BPCO) 2005-2010 [16]	Ministry Health	www.splf.org
Ireland	National Respiratory (COPD) Framework (as yet unpublished)	Health Service Executive, Irish Thoracic Society, Irish College of General Practitioners	www.irishthoracicsociety.com
Italy	GARD Italy (started in 2009)	Ministry of Labour, Health and Social Policies	www.ccm-network.it www.aiponet.it
Portugal	National Programme of Prevention and Control of Chronic Obstructive Pulmonary Disease	Ministry of Health and General Directorate of Health	www.dgs.pt
Serbia	The National COPD Programme (in progress)	Scientific Societies, Patients Associations and Ministry of Health	----
UK	A draft COPD Clinical Strategy is expected to come out for consultation later in 2009.	----	----

6 National COPD Guidelines

Clinical guidelines and recommendations should be based on the most recent scientific evidence.

COPD guidelines should be locally adapted. *GARD 2007*

Clinical practice guidelines have been established in many countries to improve the quality of patient care. According to GARD, COPD guidelines should be locally adapted by a working group of health professionals, the Ministry of Health and other stakeholders including patients [60].

The Global Initiative for Chronic Obstructive Lung Disease (GOLD), through a concerted worldwide effort of people involved in all facets of healthcare and healthcare policy, has established guidelines based on the scientific literature for the treatment and management of COPD. These guidelines, which are updated yearly, have been translated and locally adapted in many countries. In other countries, guidelines have been established by national scientific societies and/or health institutions. However, it is generally agreed that clinical guidelines and recommendations should be based on the most recent available evidence. For a list of guidelines available in the countries taking part in this survey see Appendix 3.

To ensure effective implementation of guidelines, patients should be involved in the process of producing the guidelines, either as consultants or as members of the guideline working group. Clinical practice guidelines are used in all the countries surveyed, however the patients associations were not always involved in developing these documents (Figure 5).

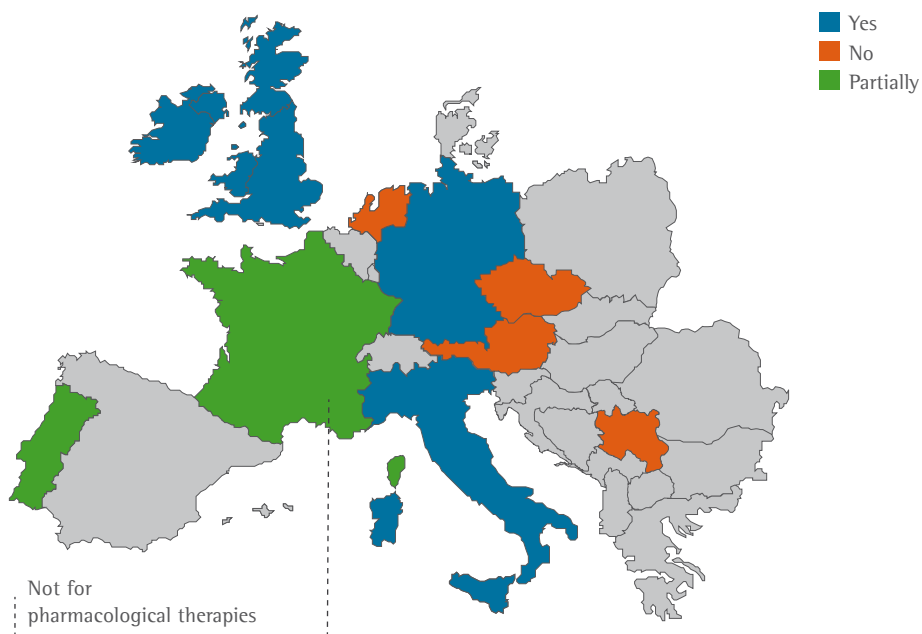


Figure 5. Patients associations involved in producing clinical guidelines.

COPD guidelines – Take home messages

- Clinical guidelines and recommendations should be based on the most recent scientific evidence.
- COPD guidelines should be adapted to local needs.
- Patients should be involved in the process of producing guidelines, either as consultants or as members of the guideline working group.

7 National Legislation for Healthy Air Quality

COPD patients have the right to a safe environment [40]. Unhealthy air is particularly harmful for COPD patients. Air pollutants like dust, fumes etc., can irritate the lungs and cause exacerbations. Patients have the right to live in a safe indoor and outdoor environment. Reducing the health risk caused by indoor and outdoor air pollution is feasible and requires a combination of public policy and protective steps taken by individual patients [4]. Initiatives at national level require legislative actions. The picture emerging from the EFA questionnaire shows that some steps have been made towards healthy air (see Appendix 4).

Healthy Air Quality – Take home messages

- COPD patients have the right to a safe environment.
- Reducing the risk from indoor and outdoor air pollution is feasible.
- Initiatives at national level require legislative actions.

Know Your Air for Health project

www.knowyourairforhealth.eu is a website targeted for people with allergy, asthma and COPD on air pollution in the EU. It gives information on EU air pollution legislation, national and local air pollution forecasts in the EU and things that people can do to protect themselves. According to EU legislation people who are particularly vulnerable to air pollution, such as people with respiratory diseases are entitled to targeted information in their country. This website showcases the role patient associations can play in implementing the EU legislation.

EFA and the Health and Environment Alliance (HEAL)

Sharing: Best Practices for Smoking Cessation

8

Over 79,000 adults, including 19,000 non-smokers, died in the EU-25 in 2002 due to exposure to tobacco smoke at home and in their workplace. *European Commission*

According to conservative estimates, over 79,000 adults, including 19,000 non-smokers, died in the EU-25 in 2002 due to exposure to tobacco smoke at home (72,000) and in their workplace (7,300). It is well recognized that smoking is the main cause of COPD. Not smoking is the most effective preventive measure and smoking cessation is the only intervention with a proven impact on the course of the disease [4]. Smoking prevention and cessation, together with diet and weight control, exercise and rehabilitation, has the potential to have a beneficial effect not only on COPD but also on its comorbidities [61]. In Europe, awareness about the hazards of tobacco smoke has led to calls to safeguard everyone's right to breathe smoke-free air, and to provide expert help for people who want to stop smoking.

Anti-tobacco policies are in force in many European countries thanks mainly to legislation promoted by the European Union. For updated information about smoking legislation in Europe visit www.smokefreepartnership.eu. Some form of antismoking legislation is in force in most of the countries participating in this survey (see Appendix 5).

Access to help stop smoking

In their 2008 consensus document, the International Primary Care Respiratory Group states that 'all primary care health professionals can increase smoking cessation rates among their patients, even when time and resources are limited. Medical and non-medical staff can support patients who choose to

Smoking is the main cause of COPD.

quit by providing information, referral to telephone counselling services, and behavioural counselling using motivational interviewing techniques where possible.' [62]. All interventions to help quit smoking should be tailored to each individual's circumstances and attitudes.

In most of the countries taking part in this survey, help to quit smoking is 'easy' or 'very easy' to access, whereas it is 'difficult' in Austria and in Italy. It is interesting to note that in Austria pulmonologists, but not GPs, receive a contribution to help people quit smoking. In a survey conducted among GPs in Ireland, 94% reported that access to pharmacotherapy for smoking cessation is 'easy/very easy'.

'National Health Service stop smoking programmes are available throughout the country, but few people are aware that smoking can cause COPD.' *UK*

Patient from Portugal

I couldn't let my smoking kill me

'I started smoking when I was a thirteen years old, and I was a heavy smoker for 39 years. Each day I smoked more and more. I was sinking in tobacco. In those days, smoking was a manifestation of manhood and I was completely ignorant about the consequences of smoking until the day I started to feel much more tired than my friends of the same age. Then I decided to visit a doctor and I underwent some medical examinations. I still remember the day: 2nd of June 1995, and I was diagnosed with COPD. It was at that very moment that I understood the disease and the implications for my daily life. I quit smoking on that day and only three days after I was already feeling the difference. I couldn't allow my smoking to kill me. Today I do medicines (I don't do oxygen therapy), I swim and I walk a lot and I cope very well with my COPD.'

The European Commission calls for a Smoke-Free Europe by 2012

On 30 June 2009, the European Commission adopted a proposal for a Council Recommendation on smoke-free environments. The Recommendation calls on Member States to act on three main fronts:

- Adopt and implement laws to fully protect their citizens from exposure to tobacco smoke in enclosed public places, workplaces and public transport as cited in Article 8 of the Framework Convention on Tobacco control, within three years of the adoption of the Recommendation.
- Enhance smoke-free laws with supporting measures such as protecting children, encouraging efforts to give up tobacco use and pictorial warnings on tobacco packages.
- Strengthen cooperation at EU level by setting up a network of national focal points for tobacco control.

Smoking cessation campaigns and initiatives

To be effective, anti-smoking campaigns should define their target (e.g., smokers or young people who haven't started smoking), give clear evidence-based information using a language and medium (newspaper advertising, television, national days etc.) appropriate for their target, be co-ordinated with other anti-smoking activities, and have a means to evaluate the short-term and long-term effects of the campaign.

The annual No Tobacco Day (N-TD) organized by the WHO is a focal point for a large number of tobacco control advocacy activities throughout the world. Each year is dedicated to a specific theme (e.g., Smoke-free environments, Tobacco-free sports, Health professionals against tobacco, etc.). The WHO

Smoking cessation is the most effective way to reduce the risk of having COPD and to slow its progression. *GOLD*

Effective actions are helplines, websites and public events.

provides material for use by patients associations, scientific societies, institutions etc., in events held in conjunction with N-TD. The theme of the 2009 campaign is 'Effectiveness of pictorial warnings'. Informational material from the 2009 campaign and the previous ones, including free download of the brochure and other material can be accessed at www.who.int/tobacco/en/.

At European level, the Help-EU campaign (www.help-eu.com), which targets mainly young people, gives advice about quitting smoking and discourages people from starting the habit. The website is translated in all EU languages, and radio and TV ads as well as events are organized throughout Europe. Another initiative that targets young smokers is the 'Quit & Win' competition that involves several European countries (including the Czech Republic, Finland, Germany and the UK) (www.quitandwin.net).

Other campaigns are implemented at national level (Appendix 6). Effective actions are helplines, websites and public events. Patients associations are frequently involved in these initiatives. In France, FFAAIR is involved in the World No Tobacco Day, together with the Ministry of Health and associations of health professionals. Dissemination includes the press as well as awareness events. The Irish Thoracic Society, together with the Irish Cancer Society, promotes the campaign 'Lose the smoker in you' targeted to smokers and to GPs. In Italy the Associazione Italiana Pazienti BPCO is actively involved in organizing the World No Tobacco Day and the National Breath Day [Giornata Nazionale del Respiro]. Both events take place throughout Italy and foresee posters, ads, media campaigns, etc. In Portugal, several events have been organized within the framework of the EU campaign 'For a life without tobacco'. The Serbian Ministry of Health promotes a 'Stop smoking' campaign.



*Anti-smoking cartoon by
Roberto Mangosi*

Identikit of the ‘quitter’

Married men living with non-smokers, who are mildly dependent on nicotine, who started to smoke late, and who have already quit for a relatively long period in the past.

Taking these elements into consideration, helps to understand who has more difficulty in quitting smoking and to intervene more incisively, when necessary.

L. Fabbri, VII Giornata Mondiale contro la BPCO, 2008

Smoking cessation – Take home messages

- Smoking is the main cause of COPD.
- Not smoking is the most effective COPD preventive measure.
- Smoking cessation campaigns should be tailored to the target they aim to reach.
- Helplines, websites and public events are effective smoking cessation tools.
- Smoking should be banned in all public places and workplaces.

'Speak up for the Patient': Advocacy, Educational Programmes and Other Activities

9

Associations of COPD patients share a number of common aims. All are very active in taking advocacy initiatives to improve the quality of healthcare for COPD patients and the quality of life of patients, their families and carers, and to obtain social-health services that meet the patient's real needs in an equal manner throughout the country. COPD patients associations also represent the interests of patients in relation to institutions, policy makers, legislators and other stakeholders. Advocacy campaigns are often conducted in partnership with the associations of pulmonary specialists and primary healthcare professionals at national, European and international level. Each association develops a series of operative models aimed at improving awareness about COPD, at mobilizing resources and filing complaints or protests at various institutional levels.

In addition to advocacy initiatives, COPD patients associations are often involved in national healthcare committees, and are called upon to give the patient's point of view in working groups established to develop guidelines and action programmes.

Taking action for policy making

Virtually all the associations who replied to the questionnaire are active in influencing policy makers, either as members of healthcare committees or by advocating with policy makers (Table 9).

In France, the FFAAIR is a member of the National Inter-Associative Committee on Health (CISS) that takes part in establishing national legislation. In Italy, where healthcare policies are established at both regional and national level, the association of COPD patients is a member of regional and national healthcare committees. The Portuguese patients

Patients associations advocate for social-health services that meet the patient's real needs in an equal manner throughout the country.

association Respira holds regular meetings with the members of the Healthcare Commission of the Portuguese parliament, whereas the Serbian association is active in the development of a National Strategy for COPD. Similarly, in the Netherlands, Astma Fonds is a member of the Lung Association and of the national study group for the development of General Care Standards for COPD. In the UK, the British Lung Foundation (BLF) has a dedicated communications team based at the head office in London that lobbies government and works with colleagues in Scotland and Wales to lobby the devolved governments. The BLF also works with the network of over 200 Breathe Easy support groups to help them campaign at a local level, and has representation on the Department of Health COPD Strategy Reference groups.



*World No Tobacco Day
2008 in Portugal*

Table 9. Advocacy campaigns carried out by the associations in recent years

Country	Advocacy Campaigns	Result
Austria	Petition to parliament for a stricter law to forbid smoking in all public places, especially restaurants, discos, etc.	Parts of this initiative began to be implemented in January 2009
	Initiative to include spirometry in the national preventive medical check-up programme.	Unsuccessful
	Initiative to convince the national sick fund to establish a pilot project for ambulatory pulmonary rehabilitation.	Negotiations ongoing
Ireland	Publication of the Inhale Report 2nd Edition [30].	Ongoing
	Correspondence and meetings with Health Service representatives about implementation of the National Respiratory (COPD) Framework.	Ongoing
Italy	Recognition of COPD as a 'chronic disease'.	Ongoing
	Prohibition of smoking in all public places, including offices, train stations, cars, etc.	Anti-smoking law
Netherlands	Smoke-free hospitality sector (hotels, restaurants, bars, pubs, casinos).	The hospitality sector is now smoke-free by law
Portugal	New oxygen therapy rules for medical gas suppliers.	Ongoing
	Report about access (reimbursement) to medicines.	Ongoing

Taking action in establishing guidelines and standards for treatment

COPD patients associations contribute to establishing standards of care and treatment, mainly by participating in the formulation of national guidelines or in national programmes together with policy makers and healthcare professionals (Figure 6).

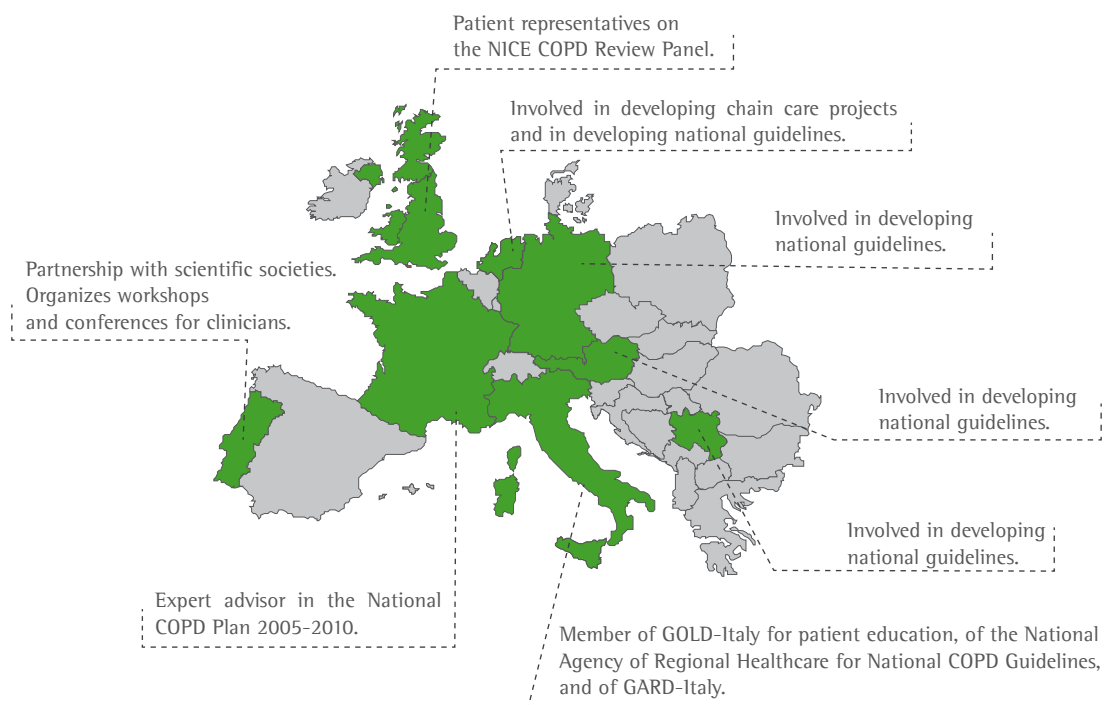


Figure 6. How patients associations are involved in decisions regarding healthcare policies

Taking action in educational programmes

As previously shown (see 'Access to educational programmes'), patients associations play a key role in education for patients, their families and carers, as well as fostering educational programmes for GPs and other healthcare professionals (Table 10).

In Austria, the Österreichische Lungenunion runs an education centre for patients and their carers. The FFAAIR in France organizes meetings for patients and carers and produces the FFAAIR magazine that contains educational information and tools. In Italy and Portugal, the associations promote educational activities in collaboration with the national respiratory societies. The Serbian Association occasionally organizes educational programmes in collaboration with university hospitals and with doctors and nurses. Most of the educational activities consist in public campaigns, meetings, and other promotional events. The Netherlands COPD Patients Association is a member of the Commission for the Education of GPs in the field of asthma and COPD. In the UK, the BLF provides education for patients through their network of Breathe Easy support groups, helpline and leaflets.

'Since April 2008, we've run 37 awareness raising events, tested 4171 people and referred 749 people with a low lung function to their GP.' *UK*

Table 10. Public initiatives to increase awareness of COPD organized by or involving the patients associations

Country	Initiatives
Austria	National awareness event in the city hall of Vienna attended by over 3500 people.
Czech Republic	Spirometry on World COPD Day.
France	Press conferences with the National Committee Against Respiratory Diseases. 'Tour de France by COPD patient': Jean-Marie, a COPD patient under oxygen therapy, cycled from Paris to Brest (500 km).
Germany	German Lung Day. Widespread public activities at the end of September to inform people about lung diseases.
Ireland	Local radio interviews with consultant respiratory physicians. Press release about implementation of the National Respiratory COPD Framework.
Italy	World COPD Days: National conferences with pulmonary specialists and patients. Mass media campaigns.
Netherlands	Mass media campaign and measurement of lung function in at-risk groups, organized at about 60 locations throughout the country.
Portugal	Press conference. Spirometry campaigns.
UK	COPD campaigns and lung testing events.

Doing volunteer work opened up a new world

'Eleven years ago I got a cold which did not go away, it turned out to be COPD. I quit smoking and was forced to quit my own company as well. I decided to become a volunteer for the Asthma Foundation. I have to make sure I don't cross my own boundaries; one meeting a day costs me all the energy I can muster. However, since I started doing volunteer work I have met so many new people, opening up a new world. Sometimes I joke that, in that respect, COPD is the best thing to ever happen to me.'

One of the things I do as a volunteer is advise carers and insurance companies about what matters to the COPD patient. As a patient expert, I promote healthcare better suited to the COPD patient reality. One thing I would like to achieve is prescribed exercise programmes covered for all COPD patients.

Another issue is the cooperation between the pulmonologist and the general practitioner. Often the pulmonologist will not pass a patient to the GP when his/her conditions improve, being wary of the GP's lack of knowledge. While a GP can hold on too long to a patient because he/she feels too responsible to let a patient be treated in the hospital. Together with insurance companies, I developed a system in which all COPD patients receive a treatment plan. It is a step in the right direction. But there is plenty more to do, such as creating a certification mark for GPs who do spirometry.'

10 Sharing the Care: Material and Campaigns Produced by the Patients Associations

The mission of COPD patients associations is to improve the health condition, quality of life and overall survival of patients and to advocate for the rights of patients, their families and carers.

To fulfil their mission, patients associations focus on two main topics:

- Prevention (by promoting initiatives to prevent the development of COPD, encouraging a correct and early diagnosis, and advocating for good quality indoor and outdoor air).
- The management and care of COPD (by improving the health condition and quality of life of patients, their families and carers; ensuring high-quality health services that correspond to the needs of patients; and ensuring that COPD patients have the same access to care as patients with other disorders).

The associations carry out their mission through various strategies, often in collaboration with healthcare specialists and other stakeholders:

- Support and information services for patients
- Advocacy to institutions
- Educational and awareness campaigns
- Promotion of scientific research

All the COPD patients associations that contributed to the EFA survey have produced a wide array of informative material and have organized events and services for patients, their families and carers, the general public, opinion leaders and politicians. Hoping in a cross-fertilization of ideas, examples of successful projects are provided in this section.

Education, information and support tools produced by the patients associations



AUSTRIA – Österreichische Lungenunion (ÖLU)

Website: www.lungenunion.at

Österreichische Lungenunion is a patient organization working for everyone affected by allergy or lung disease. We help people to understand and manage their condition. We do this by providing patient-centred information on paper, on the web, on the telephone and in our newly-built education centre.

Publications

Diagnosis and Treatment of COPD

Fitness and COPD

Breathing with COPD

Live with COPD

Oxygen Therapy

Target: Patients

Aim: To inform and to educate

Format: Leaflets, brief information

Funding: ÖLU and pharmaceutical industry

COPD Patient Manifesto

Target: Politicians

Aim: To inform and to support, and to influence key opinion leaders and politicians

Format: Booklet

Funding: Printing funded by pharmaceutical industry

Patient support groups

Aim: To exchange experiences, inform



and support

When: One evening a month

Helpline: 01 33 42 86

Target: Patients and caregivers

Aim: To support and inform

Content: Expert advice, quick help

Funding: ÖLU



Education Centre for COPD and Asthma Patients

When: 4 sessions of 2 hours

Target: Patients

Aim: To support and educate

Funding: ÖLU

World COPD Day: Public Awareness Days

Target: General public (about 5000 visitors)

Aim: To raise awareness and give information

Format: Press conferences, mass media

Funding: ÖLU



BELGIUM – Astma-en Allergiekoepel

Website: www.astma-en-allergiekoepel.be

Astma-en Allergiekoepel is a Dutch-speaking patients association that strives to inform the general public and individuals about asthma, allergy and COPD. The association supports patients and helps them to adapt their life and activities so they can cope with their disease. It represents the voice of the patients in dealing with the authorities. The association also raises awareness about indoor and outdoor air pollution and food allergies. It keeps in touch with French speaking colleagues and works on projects with them. The association generally organizes a conference every two years, and distributes informative material at exhibitions and fairs.

Leaflets

Target: Patients

Aim: To inform

Content: What is COPD and what you can do to live with it

Patient support groups

Helpline: 088/84321

Target: Patients and anyone looking for information and advice

Aim: Make information accessible

Content: Volunteers backed-up by professionals give advice

Funding: Astma-en Allergiekoepel

World COPD Day

Target: General public

Aim: To inform about the risks of smoking and what COPD means

Topics: COPD, tobacco smoke

Spirometry Day

On Spirometry Day, which takes place in November, the public can have a free spirometry test at their local hospital. The Pneumological Society organizes spirometry testing and newspapers give some background information.



CZECH REPUBLIC – Czech Civic Association against COPD (COPN)

[České občanské sdružení proti chronické obstrukční]

Website: www.copn.cz

Leaflets and booklets

COPD

Smoking cessation

Pulmonary rehabilitation

Poster

Pulmonary rehabilitation for patients



World COPD Day

When: Yearly (since 2003)

Target: Patients (usually 1300-1500 people every year)

Aim: To increase awareness about COPD

Contents: Informative leaflets, free spirometry

Videos

'COPD doesn't mean hopelessness'

'In Support of Life'

Shown on public television

Target: General public

Media campaigns

Press conferences and TV and radio COPD campaigns

International Questionnaire on COPD Awareness

Distributed in 2007 in the Czech Republic, Poland and Slovakia.

2,434 replies received.



FRANCE – FFAAIR Fédération Française des Associations et Amicales de malades, insuffisants ou handicapés respiratoires

Website: 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.

Publications

Mesure ton souffle [Measure your breathing]

Target: General public

Aim: To provide information about measuring respiration, and what is respiratory insufficiency

Format: Leaflet

Funding: Société MEDIFLUX

Et si c'était une BPCO?

[And if it was COPD?]

Target: General public

Aim: To give information on COPD

Content: What is COPD, epidemiology in France and in the world, and a questionnaire ‘Do you know COPD?’

Format: Booklet

Funding: Pfizer and Boehringer Ingelheim

Helpline: Réspir-Ecoute [Breathe - Listen]

FFAAIR is a federation of 40 associations from different regions; the helplines work at association level, for example, in Northern France the helpline number is 03 20 52 03 94 (Association ANFIR)

Target: Patients

Aim: To encourage and to inform about rights and possibilities

Funding: Local groups

Patient support groups

Target: Patients

Aim: To educate and support

Format: Communication and help

Funding: Local associations

Meetings of COPD patients organized by local associations

Aim: To encourage and to inform about rights and possibilities

Format: Meetings with patients and members of their families to discuss their problems

Funding: Industry and patients associations

World COPD Day

Target: The media, general public

Aim: To raise awareness among the general public

Format: Press conferences, meetings etc.

Funding: State, laboratories, auto-funding, hospitals

Charter of patients who receive home care

Published in January 2008

Aim: To encourage and to inform about rights and possibilities

Content: The rights and the responsibilities of patients who receive care at home and of healthcare personnel

Format: Booklet

Funding: Laboratories, industries and associations

FFAAIR Newsletter: La voix des AIR

Target: Patients and associations

Aim: To encourage and to inform about rights and possibilities

Format: Newsletter (available in print and on www.ffaair.org)

Funding: Industry, associations

FFAAIR Forum

Target: Patients

Aim: To encourage, and to inform about rights and possibilities

Format: Internet forum

Funding: FFAAIR





GERMANY - Patientenliga Atemwegserkrankungen e.V. (PLA)

Website: www.patientenliga-atemwegserkrankungen.de

The League of Patients with Respiratory Diseases (PLA) is a non-profit charitable organization. Its main aim is to provide information for adult patients suffering from chronic obstructive respiratory diseases, such as bronchial asthma, chronic obstructive pulmonary disease (COPD) and pulmonary emphysema. The bulk of our work is focused on COPD patients and their partners.

Leaflets

Asthma - What to do?

COPD - What to do?

Chronic cough - What to do?

The 10 most important recommendations for patients affected by COPD

What is smoke cessation good for?

The 10 most important reasons to become a non-smoker

Target: Patients and others who are interested in this subject

Format: Leaflets

Aim: To inform

Internet support

Target: Patients and others who are interested in this subject

Aim: To give recommendations, answer questions and give advice

Format: Three doctors specialized in lung diseases reply to questions

Patient support groups

Patientenliga Atemwegserkrankungen has 30 local groups in Germany and together with another COPD patients association, Selbsthilfegruppe Lungenemphysem – COPD

Deutschland, with which they cooperate, the association offers more than 70 local support groups.

Target: Patients and others who are interested

Aim: To inform and to exchange experiences concerning all aspects of the disease

Funding: Partly by health insurances and savings banks

Airway diseases - a help to help yourself

Target: Patients and others who are interested in this subject

Aim: Information

Format: Booklet

Annual Symposium on Lung Diseases

(organized by our co-operative partner COPD Deutschland e. V.)

Target: Patients and others who are interested in this subject

Aim: To inform and to exchange experiences

Format: Lectures by pulmonologists

Funding: Fees from exhibitors

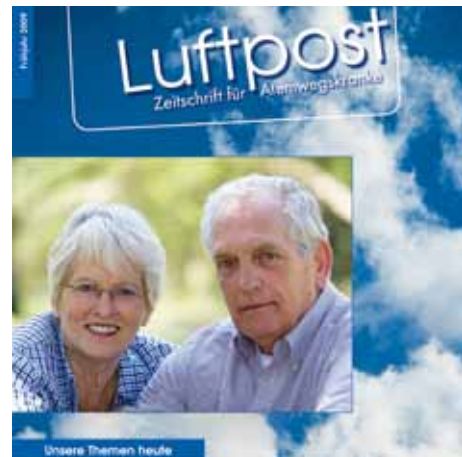
German Lung Day

More than 200 events in Germany, some local groups of Patientenliga participate.

Luftpost [Airmail]

Format: Newsletter

Contents: Articles mostly written by physicians specialized in airway diseases. Fifty-two pages, published twice a year. *Circulation:* 15,000. Estimated number of readers: 20,000–30,000.





Irish Thoracic Society

IRELAND – The Irish Thoracic Society

Website: www.irishthoracicsociety.com

The Irish Thoracic Society is the official society for healthcare professionals involved in the care of patients with chronic or acute respiratory disease on the island of Ireland. The Society promotes the highest standards of care for patients with respiratory disease through education, research, advocacy and public information activities.



Inhale Report

Target: Health professionals, policy makers, media.

Aim: To raise awareness of all respiratory diseases including COPD.

Content: Compilation of statistical data on respiratory diseases including COPD.

Funding: Pharmaceutical company sponsorship.

National Respiratory COPD Framework (not yet published)

Target: Government

Aim: To prevent and to treat appropriately.

Content: A framework for an integrated approach to diagnosis, prevention and treatment of COPD in the most appropriate setting.

Funding: Health Service Executive.



ITALY – Associazione Italiana Pazienti BPCO

Website: 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.

Publications

Esercizi respiratori raccomandati ai pazienti BPCO per continuare il percorso riabilitativo a domicilio [Respiratory exercises recommended for rehabilitation at home]

Target: Patients and carers

Aim: To give practical advice on rehabilitation.

Format: Booklet



Information about COPD and respiratory disease

Target: Patients and carers

Aim: To give advice on treatment and lifestyle

In collaboration with the Italian Association of Hospital Pneumologists (AIPO)

Un libro per respirare meglio [A book to improve breathing]

Target: Patients and carers

Aim: To give advice on treatment and lifestyle

Format: Brief information

Funding: Printing supported by pharmaceutical industry

Translation into Italian of the ICOPA report 2007 'A COPD patient perspective: The need to build confidence and a positive outlook'

Target: Patients associations and other stakeholders

Aim: To raise awareness about COPD, to inform about diagnosis and treatment and about the activities of associations worldwide

Format: Booklet

Funding: GlaxoSmithKline

Focus BPCO

Target: Patients and associations

Aim: To encourage, and to inform about rights and possibilities

Format: Newsletter (available in print and at www.pazientibpcO.it)



Diario del Paziente BPCO [COPD Patient's Diary]

Target: COPD patients

Aim: To keep a clinical diary. To inform and give advice on lifestyle and treatment

In collaboration with Associazione Libra and the pharmaceutical industry

Le poesie del respiro [Breathing Poems]

Target: General public

Aim: To raise awareness on COPD and patients' conditions



Dizionario del Respiro Online [Online Dictionary of Respiratory Terms]

This online instrument contains the most frequent and essential 'respiratory' terms in Italian translated into various languages.

Target: Patients affected by respiratory diseases, their families and carers

Aim: To facilitate travel

DVD

Riabilitazione respiratoria
[Respiratory Rehabilitation.
Programme of exercises that the patient can do at home]

Target: Patients affected by respiratory diseases, their families and carers

Aim: To enable patients who have received respiratory rehabilitation training to continue their exercises at home.



Campaigns

Ti aiutiamo a... [We help you to ...]

Target: Patients and carers

Aim: To inform about treatment and lifestyle measures, and to improve quality of life

E tu quanto fiato hai? [How much breath do you have?]

Target: General public

Aim: To increase awareness and to promote the use of spirometry for early diagnosis

Tante buone ragioni per vaccinarsi [Many good reasons for vaccination]

Target: Patients

Aim: To increase awareness on influenza and anti-pneumococcal vaccination

Funding: Industry

Senza fiato... ma non soli! [Short of breath but not alone]

Target: Patients, carers and general public

Aim: To promote support for COPD patients

When: Yearly on World COPD Day.

La forza del respiro [The strength of breath]

Target: General public

Aim: To increase awareness of the importance of an early diagnosis

and prevention of COPD

Funding: Public institutions



Non fare lo struzzo. Ascolta il tuo respiro [Don't bury your head in the sand. Listen to your breath]

Target: General public

Aim: To promote early diagnosis and symptom recognition

Funding: Industries

1st World Conference of COPD Patients

Rome, 14 June 2009

Toll free helpline: 800-961-922

Target: Patients and carers

Aim: To inform about COPD

Funding: Patient association

Surveys

The patients' main expectations (2006)

Prevention and lifestyles (2007)

Patients undergoing oxygen therapy at a healthcare centre in Rome (2007)

How patients perceive their disease (2008)

Patients undergoing oxygen therapy in the Province of Viterbo (2009)

Butterfly Project (on disease prevention) in Puglia and Sicily



NETHERLANDS – Astma Fonds

Website: www.astmafonds.nl

The mission of the Astma Fonds Association can be translated as: healthy lungs for everyone! Among our goals, stemming from the current policy plan, are:

- Actions that will motivate people with COPD to get sufficient exercise.
- Diminishing the occurrence of secondhand smoking and assistance with smoking cessation.
- Developing quality standards for healthcare from a patient's perspective.
- Giving people instruments for self-management.
- Creating understanding for people with COPD in the general public.



Leaflets

Target: General public

Aim: To inform about COPD

Content: Basic information

Funding: Patient association

Patient support groups

Target: Patients

Aim: To increase self-management

Topics: Education and information

Funding: Patient association

Helpline: 0900 2272596

Target: Patients

Aim: To inform about COPD

Content: Wide-ranging information about all matters concerning COPD. When information is not available, the helpline consults reliable, recent and relevant sources.

Funding: Patient association

COPD Days

Target: General public

Aim: To inform and to promote an early diagnosis

Topics: Awareness campaign and control of lung function

Funding: Astma Fonds



PORTUGAL – Respira – Associação Portuguesa de Pessoas com DPOC e outras Doenças Respiratórias
Website: www.respira.pt

Respira was founded on 9th February 2007. It is a national non profit organization for patients with diseases of the lower airways. Respira has three hundred members at present.

The main aims of Respira are to:

- Support tobacco prevention.
- Foster knowledge about COPD and other chronic respiratory diseases.
- Promote the state of the art of COPD treatments in association with health professionals.
- Support research and development of new treatments for COPD.
- Support people with COPD and their families, and establish self-help groups.
- Call for the specific rights of people with COPD and other respiratory diseases such as exemption of payment for treatment, and social subsidies according to income levels.

Leaflets

Target: General public and patients

Aim: To inform about COPD

Content: Information about Respira

Funding: Private companies

Booklets

Target: General public and health professionals

Aim: To inform, educate and support

Content: 'Learn to live with COPD'

Partnership: Respiratory Rehabilitation

Commission of the Portuguese

Scientific Society of Pneumology,

Funding: Pharmaceutical industry

Patient support groups

Target: Patients

Aim: To implement hospital visits and appointments with health professionals.

Funding: Respira

Helpline: (+351)96 492 67 08

Target: Patients

Aim: To inform and support

Funding: Respira

Days for COPD

Target: Patients and general public

Aim: To inform and to educate about COPD

Format: Conference (2007); Concert (2008)

Funding: Private enterprises

Other initiatives

Participation in World No Tobacco Days

Partnership with scientific societies in tracing patients who may have COPD

Interviews in the national media

Production of educational CDs for GPs based on interviews with patients

Funding: Partnership with pharmaceutical industry



SERBIA – JUDAH – Association for Asthma and COPD

Website: www.yudah.org.yu

Publication

Translated the GOLD Guidelines

COPD Days

JUDAH organizes events each year on World COPD Day.



British Lung Foundation

UK – British Lung Foundation

Website: www.lunguk.org

The British Lung Foundation is the only UK charity working for everyone affected by lung disease. We focus our resources on providing support for people affected by lung disease today; and work in a variety of ways, including funding world-class research, to bring about positive change, to improve treatment, care and support for people affected by lung disease now and in the future.

Health information leaflets

Air pollution and your lungs

COPD

Exercise and the lungs

Flu

Healthy eating and your lungs

Occupational lung disease

Pulmonary rehabilitation

Sex and breathlessness

Smoking and your lungs

Your home and your lungs

Target: Patients and their carers and

health professionals

Aim: To provide information and advice to patients, their families and healthcare professionals

Content: Patient advice about various lung diseases, treatments and healthy lifestyle advice

Funding: British Lung Foundation

Health information booklets

Asthma – how to get the correct diagnosis



Breathing tests

Children's lung conditions

COPD: Living with COPD

COPD - Diagnosis and treatment

Occupational lung disease

Stopping smoking

Coping with the final stages of chronic lung disease

Target: Patients and their carers and health professionals

Aim: To provide information and advice to patients, their families and health care professionals

Content: Patient advice about various lung diseases, treatments and healthy lifestyle advice

Funding: Free for the general public. Leaflets funded by the British Lung Foundation

Other publications

Invisible Lives report – COPD, finding the missing millions

Target: General public but particularly healthcare professionals in hotspot areas, politicians and journalists

Aim: To highlight where those at risk of COPD live in the UK so that the BLF can target these areas to try and identify those with undiagnosed COPD

Content: Health mapping research data provided by Experian to show top hotspots in the UK for COPD, case study stories and information about COPD

Funding: GlaxoSmithKline

Patient support groups

Target: Patients

Aim: To inform, educate and support Over 200 groups across the UK

Help Line: 08458 50 50 20

Target: Patients (adults and children) and parents.

Aim: To give advice, information and support



Self-support groups for anyone affected by lung disease
15,000 calls a year



Events

'Breath Easy' days – support network
Conferences twice a year
Lung function testing events in
COPD hotspot areas

COPD Days

National campaign on World COPD Day and smaller individual events throughout the year.

Research

The British Lung Foundation is working for positive change in lung health through its ground-breaking, world-class research. Funding new research into understanding, treating and preventing lung disease is a vital part of our work. Over the past 20 years, we have invested over £19 million on supporting research across all 43 different lung conditions.

11 COPD in Europe: Summing-up

COPD affects approximately 44 million people in Europe. It is the fourth cause of death worldwide and it is predicted to be the third cause of death by 2030. The total financial burden of COPD in Europe amounts to nearly €102 billion and it is expected to increase. Moreover, the social burden of COPD is also increasing; for instance, 21% of COPD patients are severely disabled.

Notwithstanding the severe impact of COPD on European society, COPD is a disease unknown to the general public, and neglected by the media.

Most Europeans – and probably most people worldwide – don't know what COPD is. COPD stands for Chronic Obstructive Pulmonary Disease. It is a common lung disease that obstructs the airways, making breathing difficult. It is not fully reversible and is usually progressive.

COPD affects mainly males and the elderly, but the prevalence among women and among the younger population is increasing. It is estimated that the prevalence among young people (20-40 years old) in Europe is 3.6%.

The main risk factor for COPD is active and passive tobacco smoking. Other risk factors are indoor and outdoor pollution, and occupational pollution (dusts and chemicals), and severe hereditary alpha-1 antitrypsin deficiency which is a rare condition.

Access to prevention, early diagnosis and treatment

COPD is preventable. The earlier it is detected, the better the results of treatment. Therefore, easy-to-access information about risk factors, prevention and the importance of an early diagnosis must be a priority in the fight against COPD.

Patients associations together with scientific societies have

made enormous efforts to increase awareness about COPD at governmental level as well among the general public. Despite these efforts, the condition is often diagnosed when the lung damage is far advanced. Unfortunately, an early diagnosis is a problem in all the countries that participated in the EFA survey.

The earlier COPD is detected, the better the results of treatment.

In a large number of cases, COPD can be diagnosed with a spirometry test. Spirometry is a simple non-invasive test that can be done in the GP's surgery. Often GPs throughout Europe are not sufficiently aware of COPD and often they cannot do spirometry. All hospitals and respiratory centres have spirometry equipment and can make an accurate diagnosis.

In a great number of cases, COPD can be diagnosed with a simple spirometry test.

There is a need to increase awareness of COPD, particularly among GPs. Primary care doctors should receive education about COPD, and training in the use and interpretation of spirometry.

Patients should have access to the best evidence-based treatment available.

Not only is COPD preventable, it is also treatable. A wide variety of pharmacological and non-pharmacological treatments can be used to improve the patient's symptoms and/or complications and quality of life. Patients should have access to the best evidence-based treatment available. Given the dismal predictions for COPD morbidity and mortality, the best management strategy is to provide optimum treatment tailored to each patient also considering comorbidities.

The best management strategy is to provide optimum treatment tailored to each patient also considering comorbidities.

In Europe, patients are entitled to reimbursement of part of the cost of treatment in most countries; no country in the EFA survey provides completely free access to care. The barriers in this area are related to limitations in reimbursement policies and excessive bureaucracy. More should be done at national and European level to remove obstacles to access to the best treatment for COPD patients.

Besides treatment, also lifestyle changes and rehabilitation

can play an important role in reducing symptoms, improving quality of life, and increasing the patient's physical and emotional participation in everyday activities.

'When I heard I had COPD in 2002, I had no clue what it was.'

In the countries surveyed, there are several barriers to education and rehabilitation. The main problem is difficulty in finding such programmes. Moreover, education and rehabilitation programmes are usually not uniformly available throughout the country, but tend to be concentrated in large towns. Consequently, COPD patients living in non-urban areas are at a serious disadvantage.

Access to home care and support services varies among European countries, and, again, particularly between urban and non-urban areas. However, from the EFA survey, it appears that access to home care and support services needs to be improved throughout Europe. These services are particularly important for patients with severe COPD who have great difficulty in carrying out day-to-day activities, and therefore feel they are a burden on their families. In these severe cases, home care and support services are essential also to ensure continuity of treatment, rehabilitation and education, and to improve the quality of life of patients and their carers.

'Being diagnosed with COPD was the peak of a lengthy and silent course whose symptoms I ignored as a smoker.'

Concerning the management of the patient with COPD, an integrated approach that includes coordination among the GP, the pulmonary specialist and other specialists, respiratory nurses, respiratory therapists and lung function technicians should be preferred. A chronic disease management programme for COPD patients that incorporates a variety of interventions, including pulmonary rehabilitation and implemented by primary care, may reduce admissions and hospital bed days.

Treatments and interventions should be tailored to improve the patient's quality of life.

To improve the quality of care of COPD patients, national guidelines and COPD programmes should be established and implemented. These should be evidence-based and adapted to

local conditions. Patients should be involved in the production of guidelines and programmes, either as consultants or as members of working groups.

COPD patients have the right to a safe environment

Unhealthy air is particularly harmful for COPD patients. Tobacco smoke is especially hazardous. According to conservative estimates, over 79,000 adults, including 19,000 non-smokers, died in the EU-25 in 2002 due to exposure to tobacco smoke at home (72,000) and in their workplace (7,300).

Reducing the health risk caused by indoor and outdoor air pollution is feasible and requires a combination of public policy and lifestyle changes taken by the patients themselves. In Europe, some legislative actions have been taken to ensure healthy indoor and outdoor environments and to ban smoking in public places, but more should be done, also to change people's habits.

Reducing the health risk of air pollution requires a combination of public policy and lifestyle changes by the patients themselves.

Sharing and Caring: The role of patients associations

The mission of COPD patients associations is to improve the health condition, quality of life and overall survival of patients and to advocate for the rights of patients, their families and carers.

To fulfil their mission, patients associations focus on:

- Prevention (by promoting initiatives to prevent the development of COPD, encouraging a correct and early diagnosis, and advocating for good quality indoor and outdoor air).
- The management and care of COPD (by improving the

health condition and quality of life of patients, their families and carers; ensuring high-quality health services that correspond to the needs of patients; and ensuring that COPD patients have the same access to care as patients with other disorders).

'It is a heavy burden for a patient to make sure that the advice given by one caregiver does not contradict the advice given by the others.'

The associations carry out their mission through various strategies, often in collaboration with healthcare specialists and other stakeholders:

- Support and information services for patients
- Advocacy to institutions
- Educational and awareness campaigns
- Promotion of scientific research

How Europe is doing

The care of COPD patients has improved over the last decade thanks mainly to initiatives like the Global Initiative for Chronic Obstructive Lung Disease, the Global Alliance against Chronic Respiratory Diseases, the European Respiratory Society, the European Lung Foundation, the European Network for Smoking Prevention, the International Primary Care Respiratory Group, the International COPD Coalition, the Health and Environment Alliance and the European Patients' Forum, as well as to medical societies and patients associations.

At a clinical level, COPD management guidelines have led to a better outcome for patients also because, in many instances, the patient is at the centre of an integrated management approach that emphasizes the importance of quality of life and rehabilitation for patients, and education for patients, their carers and doctors. At the level of prevention, enhanced sensitivity about the hazards of tobacco smoke has brought about smoking bans in most European countries. Similarly, enlightened laws have reduced indoor and outdoor pollution in many countries in Europe.

However, much still remains to be done at national and European level for COPD patients. For instance, severely affected patients have great difficulty in accessing essential rehabilitation programmes. While many countries have made advances in education, prevention and access to treatment, areas such as rehabilitation, support services and home care need to be improved. Similarly, more should be done in some countries to encourage an effective patient/doctor dialogue so as to improve the management of COPD. Lastly, efforts should be made to standardize the level of care within individual countries and among countries.

One conclusion arising from this project is that the epidemiological and social impact of COPD must be effectively recognized now. And, rather than dispersing initiatives, this is best done through a coordinated and comprehensive strategy on COPD at European and national level, taking into consideration local situations, and involving EU and national policy makers, healthcare professionals and all other stakeholders including patients associations. Indeed, the prevalence and mortality of COPD would not be so high had there been earlier interventions at institutional and political level.

References

1. WHO. The World Health Report 2002. Reducing risks, promoting healthy life. Geneva: The World Health Organization, 2002.
2. World Health Organization. Available at <http://www.who.int/respiratory/copd/en/> Accessed: 01/09/2009.
3. WHO. World Health Statistics 2008. Geneva: World Health Organization, 2008.
4. Global Initiative for Chronic Obstructive Pulmonary Disease (GOLD). Global Strategy for Diagnosis, Management, and Prevention of COPD, 2008.
5. European Respiratory Society (ERS) and European Lung Federation. European Lung White Book, 2003.
6. Huchon GJ, Vergnenegre A, Neukirch F, Brami G, Roche N, Preux PM. Chronic bronchitis among French adults: high prevalence and underdiagnosis. *Eur Respir J* 2002;20(4):806-12.
7. Lindberg A, Bjerg A, Ronmark E, Larsson LG, Lundback B. Prevalence and underdiagnosis of COPD by disease severity and the attributable fraction of smoking. Report from the Obstructive Lung Disease in Northern Sweden Studies. *Respir Med* 2006;100(2):264-72.
8. Takahashi T, Ichinose M, Inoue H, Shirato K, Hattori T, Takishima T. Underdiagnosis and undertreatment of COPD in primary care settings. *Respirology* 2003;8(4):504-8.
9. Shahab L, Jarvis MJ, Britton J, West R. Prevalence, diagnosis and relation to tobacco dependence of chronic obstructive pulmonary disease in a nationally representative population sample. *Thorax* 2006;61(12):1043-7.
10. Gross NJ. How much did biases in the study of chronic obstructive pulmonary disease medications and mortality affect the outcome? *Ann Intern Med* 2009;150(6):426; author reply 426-7.
11. Hardie JA, Buist AS, Vollmer WM, Ellingsen I, Bakke PS, Morkve O. Risk of over-diagnosis of COPD in asymptomatic elderly never-smokers. *Eur Respir J* 2002;20(5):1117-22.
12. Jensen HH, Godtfredsen NS, Lange P, Vestbo J. Potential misclassification of causes of death from COPD. *Eur Respir J* 2006;28(4):781-5.
13. Cerveri I, Corsico AG, Accordini S, Niniano R, Ansaldo E, Anto JM, et al. Underestimation of airflow obstruction among young adults using FEV1/FVC <70% as a fixed cut-off: a longitudinal evaluation of clinical and functional outcomes. *Thorax* 2008;63(12):1040-5.
14. Statistik Austria. Österreichische Gesundheitsbefragung 2006/2007. Wien, 2007.
15. Multiple authorship. Tuberkulóza a respirační nemoci, Zdravotní statistika, Vydává Ústav zdravotnických informací a statistiky ČR Praha 2, Palackého nám. 4, 2008.
16. Ministère de la Santé et des Solidarités. Programme d'actions en faveur de la broncho-pneumopathie chronique obstructive (BPCO) «Connaitre, prévenir et mieux prendre en charge la BPCO» 2005-2010, 2005.
17. Geldmacher H, Biller H, Herbst A, Urbanski K, Allison M, Buist AS, et al. [The prevalence of chronic obstructive pulmonary disease (COPD) in Germany. Results of the BOLD study]. *Dtsch Med Wochenschr* 2008;133(50):2609-14.
18. ISTAT. Condizioni di salute, fattori di rischio e ricorso ai servizi sanitari, 2007.
19. The National Institute of Public Health and Environment. Care for health. The 2006 Dutch Public Health Status and Forecasts Report. In: de Hollander AEM, Hoeymans N, Melse JM, van Oers JAM, Polder JJ, editors, 2006.
20. Stang P, Lydick E, Silberman C, Kempel A, Keating ET. The prevalence of COPD: using smoking rates to estimate disease frequency in the general population. *Chest* 2000;117(5 Suppl 2):354S-9S.
21. Firlel N, Lamprecht B, Schirnhofner L, Kaiser B, Studnicka M. [The prevalence of COPD in Austria. The expected change over the next decade]. *Wien Klin Wochenschr* 2007;119 (17-18):513-8.
22. Vondra V, Reisova M, Prazakova J, Mazakova H, Baly J, Roth Z, et al. [Prevalence of bronchial

- asthma, chronic bronchitis and bronchial hyperreactivity in the adult population in the Prague 8 district]. *Cas Lek Cesk* 1993;132(4):113-8.
23. Kotaniemi JT, Lundback B, Nieminen MM, Sovijarvi AR, Laitinen LA. Increase of asthma in adults in northern Finland? A report from the FinEsS study. *Allergy* 2001;56(2):169-74.
 24. De Marco R, Accordini S, Cerveri I, Corsico A, Sunyer J, Neukirch F, et al. An international survey of chronic obstructive pulmonary disease in young adults according to GOLD stages. *Thorax* 2004;59(2):120-5.
 25. Statistik Austria. *Jahrbuch der Gesundheitsstatistik 2007*. Wien, 2008.
 26. Scientific Institute of Public Health. Specific cause (icd9/icd10) mortality by year. Available at: http://www.iph.fgov.be/scripts/broker.exe?_service=default&_program=pspma.speccaus.sas
 27. Institute of Health Information and Statistics of the Czech Republic. Available at http://www.uzis.cz/news.php?mnu_id=1100 Accessed: 20/08/2009.
 28. Statistik Finland. Statistical databases. Available at http://pxweb2.stat.fi/Database/StatFin/databasetree_en.asp Accessed: 01/09/2009.
 29. Statistisches Bundesamt Deutschland. *Ergebnisse der Todesursachenstatistik für Deutschland - Ausführliche vierstellige ICD10-Klassifikation 2007, 2009*.
 30. Brennan N, McCormack S, O'Connor T. Ireland Needs Healthier Airways and Lungs - The Evidence. *The INHALE Report 2nd Edition*: Irish Thoracic Society, 2008.
 31. ISTAT. Cause di morte - Anno 2006. Available at http://www.istat.it/dati/dataset/20090302_00/ Accessed: 12/07/2009.
 32. The National Institute for Public Health and the Environment. *Chronische obstructieve longziekten (COPD)*. Available at http://www.rivm.nl/vt/object_class/kom_copd.html Accessed: 25/08/2009.
 33. Peto R, Lopez AD, Boreham J, Thun M. *Mortality from smoking in developed countries 1950-2000 (updated June 2006)*: Oxford, Oxford University Press, 2006.
 34. UK National Statistics. Available at <http://www.statistics.gov.uk/> Accessed: 01/09/2009.
 35. Irish National Respiratory (COPD) Framework: Irish Thoracic Society, Health Service Executive, Irish College of General Practitioners, 2008.
 36. Rennard S, Decramer M, Calverley PM, Pride NB, Soriano JB, Vermeire PA, et al. Impact of COPD in North America and Europe in 2000: subjects' perspective of Confronting COPD International Survey. *Eur Respir J* 2002;20(4):799-805.
 37. Federal Kenniscentrum voor de Gezondheidszorg Centre fédéral d'expertise de soins de santé Le Tiotropium dans le traitement des BronchoPneumopathies Chroniques Obstructives: Health Technology Assessment. *KCE Reports 108B*, 2009.
 38. Piperno D, Huchon G, Pribil C, Boucot I, Similowski T. The burden of COPD in France: results from the Confronting COPD Survey. *Respir Med* 2003;97 Suppl C:S33-42.
 39. Dal Negro RW. *Asma e BPCO: i costi sociali in Italia. La Salute del Respiro. Fattori di rischio, epidemiologia, costi e impatto sociale delle malattie respiratorie nella realtà sanitaria Italiana*. Milan: FrancoAngeli srl, 2009.
 40. COPD Patients' Bill of Rights. *First World Conference of COPD Patients. 2009; Rome*.
 41. Cazzola M, Bettoncelli G, Sessa E, Cricelli C. Primary care of the patient with chronic obstructive pulmonary disease in Italy. *Respir Med* 2009;103(4):582-8.
 42. British Lung Foundation. *Survey of GPs and respiratory specialists about their experiences of diagnosing patients with COPD and asthma, 2008*.
 43. International COPD Patients in Action (ICOPA) Taskforce. *A COPD Patient Perspective: The Need To Build Confidence and a Positive Outlook, 2007*.
 44. Celli BR. Chronic obstructive pulmonary disease: from unjustified nihilism to evidence-based optimism. *Proc Am Thorac Soc* 2006;3(1):58-65.
 45. Wongsurakiat P, Maranetra KN, Wasi C, Kositanont U, Dejsomritrutai W, Charoenratanakul S. Acute respiratory illness in patients with COPD and the effectiveness of influenza vaccination: a randomized controlled study. *Chest* 2004;125(6):2011-20.
 46. Lee TA, Weaver FM, Weiss KB. Impact of pneumococcal vaccination on pneumonia rates in

- patients with COPD and asthma. *J Gen Intern Med* 2007;22(1):62-7.
47. Technical Report: Survey of General Practitioners of Services for People with COPD 2007. Irish National COPD Framework: Irish Thoracic Society, Health Service Executive, Irish College of General Practitioners, 2008.
 48. Bousquet J, Dahl R, Khaltaev N. Global Alliance against Chronic Respiratory Diseases. *Eur Respir J* 2007;29(2):233-9.
 49. Nocturnal Oxygen Therapy Trial Group. Continuous or nocturnal oxygen therapy in hypoxemic chronic obstructive lung disease: a clinical trial. *Ann Intern Med* 1980;93(3):391-8.
 50. Report of the Medical Research Council Working Party. Long term domiciliary oxygen therapy in chronic hypoxic cor pulmonale complicating chronic bronchitis and emphysema. *The Lancet* 1981;1(8222):681-6.
 51. Rea H, McAuley, S, Stewart, A, Lamont, C, Roseman, P, Didsbury, P. A chronic disease management programme can reduce days in hospital for patients with chronic obstructive pulmonary disease. *Intern Med J* 2004;34:608-614.
 52. Mannino D, Homa D, Akinbami L, et al. Chronic Obstructive Pulmonary Disease Surveillance—United States, 1971–2000. *MMWR Surveill Summ* 2002;51(6):1-16.
 53. American Association for Respiratory Care. Confronting COPD in America: Executive Summary. Available at http://www.aarc.org/resources/confronting_copd/exesum.pdf Accessed: 01/09/2009.
 54. Jones PW, Harding G, Berry P, Wiklund I, Chen WH, Kline Leidy N. Development and first validation of the COPD Assessment Test. *Eur Respir J* 2009;34(3):648-54.
 55. Royal College of Family Physicians. Office of population censuses and surveys. Morbidity statistics from general practice 1981-82. Third national study. Series MB5 no. I London: Her Majesty's Stationary Office.
 56. Tirimanna PR, van Schayck CP, den Otter JJ, van Weel C, van Herwaarden CL, van den Boom G, et al. Prevalence of asthma and COPD in general practice in 1992: has it changed since 1977? *Br J Gen Pract* 1996;46(406):277-81.
 57. Haggerty JL, Reid RJ, Freeman GK, Starfield BH, Adair CE, McKendry R. Continuity of care: a multidisciplinary review. *BMJ* 2003;327(7425):1219-21.
 58. Associazione Italiana Pazienti BPCO. Il ruolo del medico di famiglia. II National COPD Conference 2007; Rome.
 59. Fabbri LM, Ferrari R. Chronic disease in the elderly: Back to the future of internal medicine. *Breathe* 2006;3:40-9.
 60. Bousquet J, Khaltaev N, editors. Global surveillance, prevention and control of chronic respiratory diseases: a comprehensive approach. World Health Organization, 2007.
 61. Fabbri LM. Impact of co-morbid conditions on care of COPD patients. First World Conference of COPD Patients. Rome, Italy, 2009.
 62. van Schayck OC, Pinnock H, Ostrem A, Litt J, Tomlins R, Williams S, et al. IPCRG Consensus statement: tackling the smoking epidemic - practical guidance for primary care. *Prim Care Respir J* 2008;17(3):185-93.

Appendix 1

Methodology

The main aims of this survey were to: (1) evaluate the state-of-the-art of COPD in European countries from an epidemiological, medical and social point of view as seen from the patient's perspective; and (2) illustrate the work done by patients associations to enable them to share best practices.

Research design

This survey involved EFA members and other relevant organizations from various European countries. The main topics (see Figure) covered by the questionnaire were:

- The socio-economic impact of COPD (indicators: COPD prevalence, mortality and death rate, socioeconomic factors etc.).
- Access to care: Information about access to care for COPD patients within national healthcare systems (indicators: access to early diagnosis, treatment and other services, presence and characteristics of national COPD programmes, availability and distribution of facilities etc.).
- Patients Associations, Best Practices and Policies: Information about best practices and policies regarding COPD that an association has implemented and/or promoted (indicators: presence and characteristics of the tools used by the associations for patient education, information and support, and advocacy initiatives etc.).

Data collection

The associations were invited to reply to an online questionnaire. A semi-standardized questionnaire was used, i.e., with a mix of closed and open-ended questions. Quantitative and qualitative data were collected. Open-ended questions guaranteed a greater respondent flexibility. Respondents were encouraged to use their own words, to state their point of view and to enrich their answers with opinions and experiences, thus revealing issues not originally considered by the compilers. This led to a better understanding of the social and psychological impact of COPD.

For epidemiological information, as well as information on national programmes, guidelines and legislation, the patients associations were invited

to consult their scientific boards, Ministry of Health, relevant scientific societies and other authoritative sources such as their National Institute of Statistics.

Sampling

Invitations to complete the questionnaires were sent via e-mail to EFA members and other relevant associations in Europe. Associations from Austria, Belgium, Czech Republic, Finland, France, Germany, Ireland, Italy, the Netherlands, Portugal, Serbia and the UK completed the questionnaire.

Data analysis

The replies were analyzed and missing information was collected by telephone and e-mail from the associations and/or from official sources or from the scientific literature. Data collected with open-ended questions were analyzed qualitatively, whereas information collected in numerical form are reported in tables. The data was evaluated also in the light of international guidelines, namely the Global Initiative for Chronic Obstructive Lung Disease (GOLD) and the European Respiratory Society/American Thoracic Society guidelines. The text was circulated among EFA Board Members, and the participating associations, and their comments were incorporated in the final version of the book.

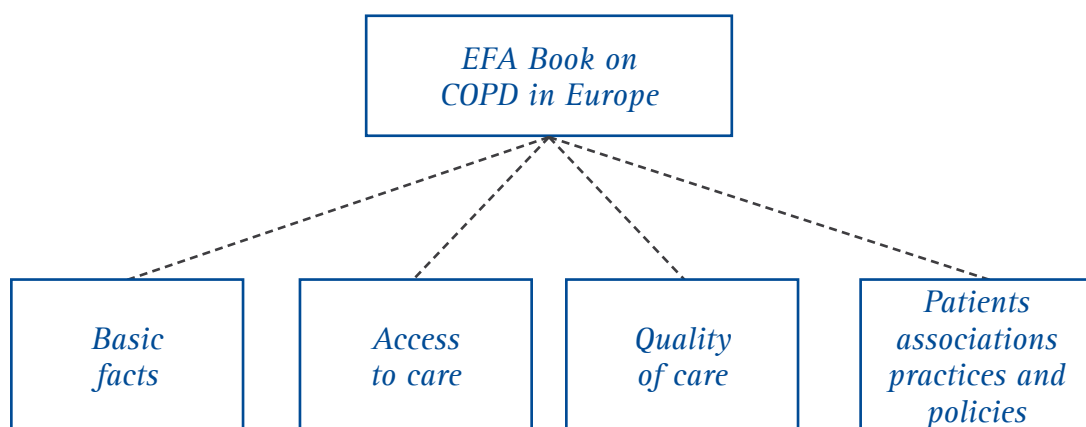


Figure. Concept map of main areas of investigation

Appendix 2

National studies on quality of life of COPD patients in the countries surveyed

Country	Reference	Brief Description
Czech Republic	Vondra V and Malý M. Health-related quality of life in COPD patients. <i>Interni medicina pro praxi</i> . 2003; 10:496-500.	SF-36 Questionnaire physical activity scores: 24 in 235 stage I-IV COPD patients; 10 in 166 COPD patients on long-term oxygen therapy; 42 in 232 patients with asthma; and 85 in 101 healthy individuals. The maximum possible score was 86.
Finland	----	Patients with COPD have more difficulties than the general population, also in the domain of psychological functioning. They often experience everyday life more negatively than the general population.
France	Roche N, Similowski T. <i>Qualité de vie et BPCO</i> . John Libbey Eurotext, 2007	It is important to evaluate each individual patient's quality of life, but this factor is sometimes underestimated. Each treatment/intervention should be evaluated in the light of quality of life.
Ireland	National Respiratory (COPD) Framework, 2008.	Psychological issues associated with the disease (depression, anxiety, loss of independence), and the importance of psychological supports for patients, and quality of life issues (challenges and frustrations of daily living - domestic duties, transport etc.).
Netherlands	Netherlands Institute for Health Services Research	COPD patients have a worse quality of life than the general population. They are physically and socially limited. Participation in work is low. They are socially deprived: about one-fifth cannot go on holiday, cannot buy new clothes, have no money to join clubs, and have to make debts.
Serbia	----	Studies have been performed in small groups of patients with a translation of the Saint George's Respiratory Questionnaire. All domains of the questionnaire were significantly decreased, but they were not correlated to FEV1.
UK	British Lung Foundation Survey	The British Lung Foundation conducts a yearly survey of patients with respiratory diseases and their carers, and has specific findings for patients with COPD and their carers.

Appendix 3

National COPD guidelines in the countries surveyed

Country	Guidelines	Issuing Organization	Topics Covered
Austria	Konsensus zum Management der COPD	Austrian Society of Pneumology	Early diagnosis Spirometry screening Pharmacological therapies Routine clinical assessment
	Verordnung von O2-Langzeittherapie und mechanischen Atemhilfen	Austrian Society of Pneumology	Oxygen therapy
	Richtlinien für die pneumologische Rehabilitation	Austrian Society of Pneumology	Rehabilitation
	National Guideline on Quality of Care	In progress (expected to be completed within 2009)	Quality of care
Belgium	Guidelines for the Treatment of COPD	Federal Ministry of Health	Treatment
Czech Republic	GOLD Guidelines	Czech Pneumological and Phthysiological Society	Early diagnosis Spirometry screening Pharmacological therapies Routine clinical assessment Oxygen therapy Rehabilitation Patient education
	GP Guidelines for COPD Management	Musil J., Vondra V., Konstacky S.	COPD management guidelines for GPs
France	Recommandations pour la prise en charge de la bronchopneumopathie chronique obstructive	Société de Pneumologie de Langue Française	Early diagnosis Spirometry screening Pharmacological therapies Oxygen therapy Rehabilitation
Germany	Recommendations for all doctors	Deutsche Gesellschaft für Pneumologie und Beatmungsmedizin e.V.	All aspects of diagnosis and therapy
	Recommendations for healthcare professionals involved in rehabilitation	Deutsche Gesellschaft für Pneumologie und Beatmungsmedizin e.V.	Rehabilitation
	COPD guidelines for patients	Ärztliche Zentrum für Qualität in der Medizin	Patient's education
Ireland	Spirometry Performance & Interpretation - GP Guidelines	Irish Thoracic Society	Spirometry screening

Italy	Essential levels of assistance	Ministry of Labour, Health and Social Policies	Quality and standards of care
	GOLD-Italy	GOLD-Italy and Scientific Societies	Early diagnosis Spirometry screening Pharmacological therapies Routine clinical assessment Oxygen therapy Rehabilitation Patient education
	National Guidelines on COPD	AGENAS Agenzia Nazionale Servizi Sanitari Regionali	In preparation
Netherlands	Guidelines for GPs and for lung specialists	National Organization of GPs and National Organization of Lung Specialists	Treatment
	Guidelines for GPs	National Organization of GPs	Diagnosis Treatment
	Guidelines for lung specialists	National Organization of Lung Specialists	Nutrition
	Guidelines for oxygen therapy	National Organization for Guidelines	Oxygen therapy
	A standard care for COPD	Foundation for Chain Care for COPD	Quality of chain care
Portugal	National Programme of COPD Prevention and Control	National Directorate of Health, GOLD-Portugal and the Portuguese Society of Pneumology	Early diagnosis
	Workshops	GOLD-Portugal, Local Councils and RESPIRA	Oxygen therapy
	Clinical Intervention Programmes	GOLD-Portugal, Local Councils, RESPIRA + INFAMED	Pharmacological therapies Rehabilitation Patient education
	Spirometry Programme	GOLD-Portugal and Portuguese Society of Pneumology	Routine clinical assessment
Serbia	GOLD Guidelines translated	GOLD-Serbia	Early diagnosis Spirometry screening Pharmacological therapies Routine clinical assessment Oxygen therapy Rehabilitation Patient's education
UK	National Institute for Health and Clinical Excellence (NICE) Clinical Guideline on COPD	NICE	Diagnosis Treatment

Appendix 4

Legislation for healthy air quality in the countries surveyed

Country	Indoor Air Quality	Outdoor Air Quality
Austria	----	Critical values for a number of air pollutants and possible actions to decrease them (e.g., temporary limitation of traffic in cities) Immissionschutzgesetz-Luft.
Belgium	There is a law but hardly any implementation except in social housing.	Outdoor air is monitored and action is taken during smog alerts.
Czech Republic	Law no 379/2005.	----
France	Law 30/12 1996 Environmental Code National programme to decrease outdoor air pollution 2001/81/CE of 23.10.2009.	Law 30/12 1996 Environmental Code National programme to decrease outdoor air pollution 2001/81/CE of 23.10.2009.
Germany	Gesetz zum Schutz vor schädlichen Umwelteinwirkungen durch Luftverunreinigungen, Geräusche, Erschütterungen und ähnliche Vorgänge (Bundesimmissionschutzgesetz – BImSchG) Veröffentlicht im Bundesgesetzblatt Teil I Nr. 71, ausgegeben zu (2002).	----
Ireland	Bans on smoking in public places and the workplace including bars and restaurants.	Ban on the marketing, distribution and sale of bituminous fuel. This was introduced in 1990 and now applies to 16 towns and cities throughout Ireland in an effort to reduce levels of winter smog.
Italy	Guidelines for the safeguard and promotion of a healthy indoor environment (GU 276, 27.11.2001, SO 252). Guidelines for the maintenance of air conditioning plants (GU n.256, 3.11.2006, SO n.207).	Italy implements the European Council Directive on ambient air quality and cleaner air for Europe (2008/50/EC) regarding outdoor air quality.
Netherlands	Government resolution on Indoor Air Quality of Schools.	National Collaboration Outdoor Air Quality.
Portugal	Energy performance and efficiency of buildings. Law 78/2006 April 4.	Establishment of action plans and objectives regarding air quality. Decree-law 276/99 July 23 and Decree-law 111/2002 April 16.
Serbia	----	Republican regulations.
UK	Ban of smoking in public places.	----

Appendix 5

Antismoking laws in the countries surveyed

Country	Smoking Cessation	Smoking in Public Places	Smoking in Workplaces
Austria	----	2004: Restriction of smoking in public buildings and in areas around them. 2008: Non-smoker protection law; restriction of smoking in the gastronomy area. Novelle zum Tabakgesetz -2004 BGBl. I Nr.167-2008 BGBl. I Nr.120.	Restriction of smoking in the workplace. Arbeitnehmerschutzgesetz §30 from 2004.
Belgium	Pregnant women are entitled to smoking cessation programmes free of charge.	Ban on smoking in all public places except in cafés.	Forbidden, but enforcement of the law is not verified, so some workers may continue to smoke.
Czech Republic	GPs must provide a short smoking cessation intervention. Law 379/2005.	Non-smoking areas in hospitals, schools, banks, government buildings, offices etc. (law awaiting Senate and Presidential approval). Law 379/2005.	Employees cannot smoke in the presence of another employee.
France	-----	Ban on smoking in all public places. Decree 2006-1386 of 15 November 2006.	Tobacco smoking is forbidden in all public places. Decree 2006-1386 of 15 November 2006.
Ireland	Tax on cigarettes: about 79% of the cost of cigarettes, which is amongst highest in Europe.	Ban on smoking in public buildings, hospitals, schools, restaurant kitchens, and on aircraft and trains.	Enacted 2004, smoking forbidden in all enclosed workplaces including bars and restaurants.
Italy		Smoking is forbidden in all indoor public places including all forms of transportation and bars. Smoking is allowed only in the open air. Legge a tutela dei non fumatori 10 January 2005.	Smoking is forbidden in workplaces. Legge a tutela dei non fumatori 10 January 2005.
Netherlands		Smoking is banned in the hospitality sector.	Smoking is banned in workplaces.
Portugal	Legislation related to smoking prevention, composition of tobacco products, ban on advertising, and ban on smoking.	Forbidden in all public places. Law 37/2007 August 14.	Smoking is forbidden in all workplaces. Law 37/2007 August 14.
UK		The entire UK is now smoke-free. Smoking is prohibited in enclosed or substantially enclosed public places and workplaces. Designated smoking rooms are not allowed. There are a few exemptions such as residential accommodation, designated hotel rooms, etc.	

Appendix 6

Smoking cessation campaigns and initiatives carried out in the last 3 years in the countries surveyed

Country	Campaign	Target/Aims	Organizer	Dissemination
Austria	KA-TSCHIK-IST-AN	Emphasis on non-smoking while driving.	Ministry of Health	www.katschikistan.at and ads in the press and on the radio.
	Rauchertelefon	Smoking cessation	Public Health Insurance Fund of Lower Austria	www.rauchertelefon.at and telephone hotline
Czech Republic	Quit and Win	Smokers	National Institute of Public Health	Leaflets distributed by regional public health institutes, www.quitandwin.net
France	Toxic Corp	To convey a negative image of smoking for young people.	INPES (Institut national de prévention et d'éducation pour la santé)	www.toxic-corp.fr
	World No Tobacco Day	To inform the general public about the negative effects of smoking and about ways of quitting.	Ministry of Health, associations of patients and health professionals, hospitals	All forms
Germany	Information for smoking cessation and COPD	Information for experts dealing with smoking cessation. Includes a section dedicated to information for patients.		www.uni-duesseldorf.de/AWMF/II/020-005p.htm
	Rauchfrei	All you need to know about becoming a non-smoker.		www.rauchfrei.de
Ireland	Lose the Smoker in You	Smokers	Irish Thoracic Society, Irish Cancer Society, Pfizer	Beer mats, outdoor ads, information for GPs
	National Smokers Quit Line	Smokers	Health Service Executive	CallSave 1850 201 203
	Health Service Executive (HSE) Tobacco Campaign	Smokers	Health Service Executive	Radio and TV ads, and www.hse.ie

Italy	World No Tobacco Day	General public	WHO, Lega Italiana Lotta ai Tumori	Posters, banners on websites, meetings
	Anno del Respiro 2009	General public	Scientific societies, Patients association	www.annodelrespiro.it posters, banners on websites, meetings
	Quit line	Smokers	Istituto Superiore di Sanità	Toll free number: 800 554 088
	Quit line	Smokers	Lega Italiana Lotta ai Tumori	www.lilt.it Toll free number: 800 998877
	Inspiro	GPs and smokers	Italian Society of Tobacology	www.tabacologia.org Courses, local help centres
Netherlands	In Every Smoker is a Quitter	Smokers	The Dutch Expertise Centre for Tobacco Prevention (STIVORO)	www.stivoro.nl , print, TV and radio spots, and TV programme.
Portugal	Quit Smoking Without Drama	General public	Pharmaceutical industry and Portuguese Society of Pneumology	Printed material, media
	Breathe Well	General public	General Directorate of Health	Printed material, media, internet
Serbia	Stop Smoking	----	Ministry of Health	----
UK	Smoke Free	Smokers	National Health Service	http://smokefree.nhs.uk , helpline 0800 022 4 332, support groups

EFA Sofia Declaration

Agreed at the 11th EFA Conference *Equality in Health for People with Allergy, Asthma and COPD in Europe*
- *Through prevention and self management to better quality of life*, Sofia, Bulgaria, 30 May – 2 June 2007

ALL patients with allergy, asthma & COPD

Comprehensive European and national programmes on

- Access to good, equal standards of care, no matter where you live in Europe
- High standards of and access to patient & professional education, information and new knowledge
- Healthy, unpolluted air to breathe indoors and out

ALLERGY – first priorities

European and national level

- Allergology recognised as a medical speciality across Europe
- Safe food: clear and understandable food labelling (packaged, unpackaged, catering, restaurants)

ASTHMA – first priorities

European level

- High standards of regulation for indoor and outdoor air pollution
- Funding for research

National level

- Reimbursement of medication

COPD – first priorities

European level

- Total ban of smoking in all public and workplaces
- Access to and awareness and understanding of early diagnosis

National level

- Access to and awareness and understanding of early diagnosis
- Access to rehabilitation

Conference Participants

Allergy and Asthma Federation, Finland
ANIKSI, Greece
Association of Allergic Children Clubs, Lithuania
Associazione Italiana Pazienti BPCO
Association of Bulgarians with Bronchial Asthma ABBA
Astmafonds, the Netherlands
Asthma UK
Astma-Allergiforbundet, Denmark
Association Asthme & Allergies, France
Austrian Lung Association
Czech Initiative for Asthma
Lithuanian Council of Asthma Clubs
Norwegian Asthma and Allergy Association
Norwegian Heart and Lung Associations
Pulmonary and Allergy Patients' Association of Slovenia
Swedish Asthma and Allergy Association
Swedish Heart and Lung Association
Vereniging Nederland-Davos, the Netherlands

European Federation of Allergy and Airways Diseases Patients' Associations (EFA) www.efanet.org

What is the European Federation of Allergy and Airways Diseases Patients Associations (EFA)?

The European Federation of Allergy and Airways Diseases Patients Associations (EFA) is a European network of allergy, asthma and COPD patient organizations that was founded in 1991 in Stockholm, Sweden.

EFA was created to combine the forces of national patients associations of asthma and allergy to obtain results at European level and to improve the health and quality of life of people in Europe affected by these diseases. Serving the interests of allergy and airways patients at national level is the primary responsibility of individual members, and EFA represents member organizations at European level and facilitates collaboration, sharing of knowledge and experiences. Chronic Obstructive Pulmonary Disease (COPD) was added to EFA's mandate in 2002.

EFA's founding countries were: Finland, Germany, Iceland, the Netherlands, Norway, Poland, Sweden and the United Kingdom. EFA membership now covers most of the European Union countries: Austria, Belgium, Bulgaria, Czech Republic, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Lithuania, Luxembourg, Netherlands, Norway, Portugal, Slovenia, Sweden, Switzerland and the UK. There are over 400,000 patients and carers in EFA member organizations.

EFA is an independent non-profit organization and its office is located in Brussels, Belgium.

Overall mission

EFA's mission is to draw together a European community of patient organizations that share responsibility for substantially reducing the frequency and severity of allergies, asthma and COPD, minimizing their societal implications, improving health-related quality of life and ensuring full citizenship of people with these conditions, as well as pursuing equal health opportunities in the field of allergy and airways in Europe.

Objectives

To accomplish its mission, EFA focuses on the following strategies:

1. To influence European Union policymaking in such a way that it will result in:
 - appropriate regulations for healthy (indoor and outdoor) air in Europe;
 - appropriate regulations on the quality (including accessibility) of healthcare for people with allergy, asthma and COPD;
 - appropriate regulations on societal participation of people with allergies, asthma and COPD;
 - adequate funding of demand-driven research on allergies, asthma and COPD.
2. To support the creation of a European network of strong and professional national organizations of people with allergies, asthma and COPD and a strong and professional EFA.
3. To empower member organizations to achieve equality in the way patients' interests are served, by exchanging experiences of:
 - influencing national policymaking on public health, societal participation and research in relation to allergies, asthma and COPD;
 - products and services for people with allergies, asthma and COPD;
 - increasing awareness.

Central values

In accomplishing EFA's mission, the central values are:

- The patient's perspective
- Involvement
- Sharing knowledge and experience
- Partnership and co-operation
- Visibility and presence
- Health equity in Europe

EFA Members

AUSTRIA

Österreichische Lungen-Union

Contact: Otto Spranger, Board Secretary
Obere Augartenstrasse 26-28
A-1020 Wien - Austria
Tel/Fax: +43 1 330 4286
email: office@lungenunion.at
web: www.lungenunion.at

BELGIUM

Astma-en Allergiekoepel vzw

Contact: Erika Colen
Park Heuvelhof 1
B-3010 Kessel-Lo, Belgium
Tel: +32 16 253111
Fax: +32 16 253116
email: info@astma-en-allergiekoepel.be
web: www.astma-en-allergiekoepel.be

Fondation contre les affections respiratoires et pour l'éducation à la sante (F.A.R.E.S.)

Contact: Martine Spitaels
Rue de la Concorde 56
B-1050 Brussels, Belgium
Tel: +32 2 5122936
Fax: +32 2 5123273
email: efa.belgium@skynet.be
web: www.fares.be

Prévention des Allergies absl

Contact: Martine Spitaels
Rue de la Concorde 56
B-1050 Brussels, Belgium
Tel/Fax: +32 2 5116761
email: efa.belgium@skynet.be
web: www.oasis-allergies.org

Branch in Luxembourg
Tel: +352 26431968

BULGARIA

Association of Bulgarians with Bronchial Asthma ABBA

Contact: Nikoleta Grigorova, President
5B Triditza str
3rd floor, office 304
BG-1000 Sofia, Bulgaria
Tel/Fax: +359 2 9804546
email: asthma@mail.bg
web: www.asthma-bg.com

CZECH REPUBLIC

Czech Initiative for Asthma

Contact: Ondrej Rybnicek
Sokolská 31
12000 Praha 2, Czech Republic
Tel/Fax: +42 0 224266229
email: cipa@volny.cz
web: www.cipa.cz

DENMARK

Astma-Allergi Forbundet

Contact: Thorkil Kjaer, Director
Universitetsparken 4
DK-4000 Roskilde, Denmark
Tel: + 45 4 3435911
Fax: +45 4 3435433
email: tk@astma-allergi.dk
web: www.astma-allergi.dk

FINLAND

Allergia-ja Astmaliitto (Allergy and Asthma Federation)

Paciuksenkatu 19
FIN-00270 Helsinki, Finland
Tel: +358 9 473351
Fax: +358 9 47335390
email: international@allergia.fi
web: www.allergia.fi

Hengityslitto Heli

Contact: Mervi Puolanne
Organization Director
Oltermannintie 8
FIN-00620 Helsinki, Finland
Tel: +358 20 7575134
Fax: +358 20 7575173
email: mervi.puolanne@hengityslitto.fi
web: www.hengityslitto.fi

FRANCE

Association Asthme & Allergies

Contact: Christine Rolland
3 rue de l'Amiral Hamelin
75116 Paris
Tel: +33 1 47 55 03 56
Fax: +33 1 44 05 91 06
email: ch.rolland@asthme-allergies.asso.fr
web: www.asmanet.com

Association Française pour la Prévention des Allergies (AFPRAL)

F-91240 St Michel sur Orge
Tel: +33 1 42535957
Fax: +33 1 48180614
email: afpral@prevention-allergies.asso.fr
web: www.prevention-allergies.asso.fr

Fédération Française des Associations et Amicales d'Insuffisants Respiratoires (FFAAIR)

Contact: Lilya Gentet, Volunteer
66 Boulevard Saint Michel
75006 Paris, France
email: liliabelenko@free.fr
web: www.ffaair.org

GREECE

ANIKSI

Contact: Marianella Salapatas
Board Secretary
Perikleous 7
N. Psychiko
154 51 Athens, Greece
Tel: +30 210 7726160

Fax: +30 210 7714626
email: sophia@hol.gr
web: www.allergyped.gr

GERMANY

Patientenliga Atemwegserkrankungen e.V.

Contact: Michael Köhler
Berliner Straße 84
55276 Dienheim, Germany
Tel: +49 6133 3543
Fax: +49 6133 924557
email: pla@patientenliga-
atemwegserkrankungen.de
web: www.patientenliga-
atemwegserkrankungen.de

IRELAND

Asthma Society of Ireland

Contact: Jean Holohan
Chief Executive Officer
26 Mountjoy Square
Dublin 1, Ireland
Tel: +353 1 8788511
Fax: +353 1 8128
email: reception@asthmasociety.ie
web: www.asthmasociety.ie

ITALY

FEDERASMA Onlus

Contact: Giorgio Salemi, Board Secretary
Via Ser Lapo Mazzei, 33
59100 PRATO (PO), Italy
Tel/Fax: +39 0574 607953
email: segreteria@federasma.it
web: www.federasma.org

Associazione Italiana Pazienti BPCO AIP-BPCO

Contact: Mariadelaide Franchi, President
Via Cassia 605, Italy
Tel: +39 06 332 53020
Fax: +39 06 332 59798
email: franchima@tin.it
web: www.pazientibpco.it

LITHUANIA

Lithuanian Council of Asthma Clubs

Contact: Lina Buzermaniene
Vilnius City University Hospital
Antakalnio Str. 57
LT 10207 Vilnius
Tel: +370 652 78 126
Fax: +370 52344203
email: lina.buzermaniene@pavb.lt
web: www.astmainfo.lt

Association of Allergic Children Clubs

Contact: Rasa Kvederiene
Eiveniy 2, Kaunas
LT-3007, Lithuania
Tel: +370 37 327092
Fax: +370 37 326431
email: salumara@gmail.com

Association of Asthma Patient Clubs

Contact: Egle Kvederaite, President
Vilniaus 25-8
LT-01119, Vilnius, Lithuania
Tel: +370 5 2121021
Fax: +370 674 29288
email: astma@takas.lt

NETHERLANDS

Astmafonds

Contact: Pim de Boer, AF Director of
Research and Erica Euving, AF Patient
Organisation Manager
Postbus 5, Speelkamp 28
NL-3830 AA Leusden, the Netherlands
Tel: +31 263255967
email: info@astmafonds.nl
web: www.astmafonds.nl

Vereniging Nederlands Davos (VND)

Contact: Jos Zoun
Postbus 512
NL-2800 AM Gouda, the Netherlands
Tel: +31 182 585390
Fax: +31 182 523067

email: jos.zoun@hotmail.com

web: www.nederland-davos.nl

Stichting Voedselallergie (Dutch Food Allergy Organization)

Contact: Erna Botjes
Postbus 207
NL-3860 AE Nijkerk, the Netherlands
Tel: +31 51 3682370
Fax: +31 33 4655098
email: ernabotjes@chello.nl
web: www.stichtingvoedselallergie.nl

Vereniging voor Mensen met Constitutioneel Eczeem (VMCE)

Contact: Bernd Arents
Postbus 26
NL-3860 AA Nijkerk, the Netherlands
Tel: +31 33 2471044
Fax: +31 33 4654964
email: efa@vmce.nl
web: www.vmce.nl

NORWAY

Norges Astma- og Allergiforbund (NAAF – Norwegian Asthma and Allergy Association)

Contact: Anne Elisabeth Eriksrud
Director of Policy
Postbox 2603
St. Hanshaugen
N-0131 Oslo, Norway
Tel: +47 23 353535
Fax: +47 23 353530
email: anne@naaf.no
web: www.naaf.no

POLAND

Polish Federation of Asthma, Allergy and COPD Patients' Organizations

Contact: Anna Doboszyńska, President
ul. Ptocka 26/24
01-138 Warszawa, Poland
Tel: +48 601 259402
email: anna.doboszynska@wp.pl

PORTUGAL

Portuguese Asthma Patients Association APA

Contact: Luís Miguel Vieira de Araujo
Rua Nova do Corim, 152
4425-151 Águas Santas
Maia, Portugal
Tel: +351 9 65416733
email: luisaraujo@apa.org.pt
web: www.apa.org.pt

SLOVENIA

Pulmonary and Allergy Patients' Association of Slovenia DPBS

Contact: Barbara Latkovic
Primoziceva 2
ZD Crnuce
1000 Ljubljana, Slovenia
Tel: +386 1 5616320
Fax +386 1 5616321
email: dbps@siol.net
web: www.astma-info.com

SWEDEN

Astma och Allergi Förbundet (Swedish Asthma and Allergy Association)

Contact: Carina Haag
Communications Manager
St. Eriksgatan 44, 5tr, Box 49303
S-100 29 Stockholm, Sweden
Tel: +46 8 50628200
Fax: +46 8 50628249
email: info@astmaoallergiforbundet.se
web: www.astmaoallergiforbundet.se

Swedish Heart and Lung Association

Contact: Ronny Weylandt, Director
Box 9090
SE 10272
Stockholm
Tel:+46 8 55 606 201
Fax:+46 8 668 23 85
email: ronny.weylantd@hjärt-lung.se
web: www.hjärt-lung.se

SWITZERLAND

aha! Schweizerisches Zentrum für Allergie, Haut und Asthma

Contact: Georg Schaeppi, Director
Gryphenhübeliweg 40
CH-3006 Bern, Switzerland
Tel: +41 31 359 90 10
email: gschaepi@ahaswiss.ch
web: www.ahaswiss.ch

Lungenliga Schweiz (Swiss Lung Association)

Contact: Corinne Zosso
Südbahnhofstrasse 14c, Postfach
CH-3000 Bern 17, Switzerland
Tel: +41 31 3782050
Fax: +41 31 3782051
email: c.zosso@lung.ch
web: www.lung.ch

UNITED KINGDOM

Asthma UK

Summit House
70 Wilson Street
London EC2A 2DB, United Kingdom
Tel: +44 20 77864900
Fax: +44 20 72566075
e-mail: info@asthma.org.uk
web: www.asthma.org.uk

The British Allergy Foundation

Contact: Peter Simmons
Communications Manager
3 White Oak Square
London Road
Swanley, Kent BR8 7AG, United Kingdom
Tel: +44 1322 619898
Fax: +44 1322 663480
e-mail: info@allergyuk.org
web: www.allergyuk.org

EFA is grateful to our sustainable corporate partners Boehringer Ingelheim and GlaxoSmithKline for supporting this project with an unrestricted educational grant.



Graphic Design: Konomedia
Printing: Grafica Metelliana

Italy, 2009



European Federation of
Allergy and Airways Diseases
Patients Associations

www.efanet.org