



EFA Book on COPD in Europe.
Sharing and caring
Edited by Mariadelaide Franchi

A Snapshot of COPD in Europe,

Jean Ann Gilder
Scientific Communication srl, Naples, Italy



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

Edited by Mariadelaide Franchi



All you need to know
about COPD in Europe.

An unprecedented
collection of information
gathered by patients for
policy makers

Mariadelaide “Lally” Franchi

Editor of the EFA book on COPD in Europe



Founder and President of the
Italian Association of COPD
Patients

EFA Honorary Member

Honorary President of
FEDERASMA Italy

Co-Chairwoman of International
COPD Coalition

Background



- COPD is the 4th cause of death worldwide and is increasing
- COPD is preventable and treatable
- COPD is widely unknown and under recognised
- Information about COPD should build confidence and generate a positive outlook

Specific objectives & target audiences



- ✓ Raise awareness, highlight gaps but also what's best in Europe
 - ❑ The Media
- ✓ Inform, raise interest and awareness, and encourage action
 - ❑ Policy makers (EU and national)
- ✓ Inform and encourage collaboration with patient organisations
 - ❑ Healthcare professionals
- ✓ Share best practices and provide a tool for advocacy
 - ❑ EFA members and other COPD patient organisations
- ✓ Share best practices and provide a tool for internal and external work, i.e. patient organisations
 - ❑ Industry partner/s

Making the book

(see pages 101 and 102)



Phase 1: Building the questionnaire online

Phase 2: Identifying and contacting patients associations (total contacted: 36)

Phase 3: Analyzing the results and completing missing data (official national statistics...)

Phase 4: Writing the book

Phase 5: Revising the book with EFA and the Associations

Chapter Title



What is known

Summary of data

Key quotes

What the survey shows

Results of the survey

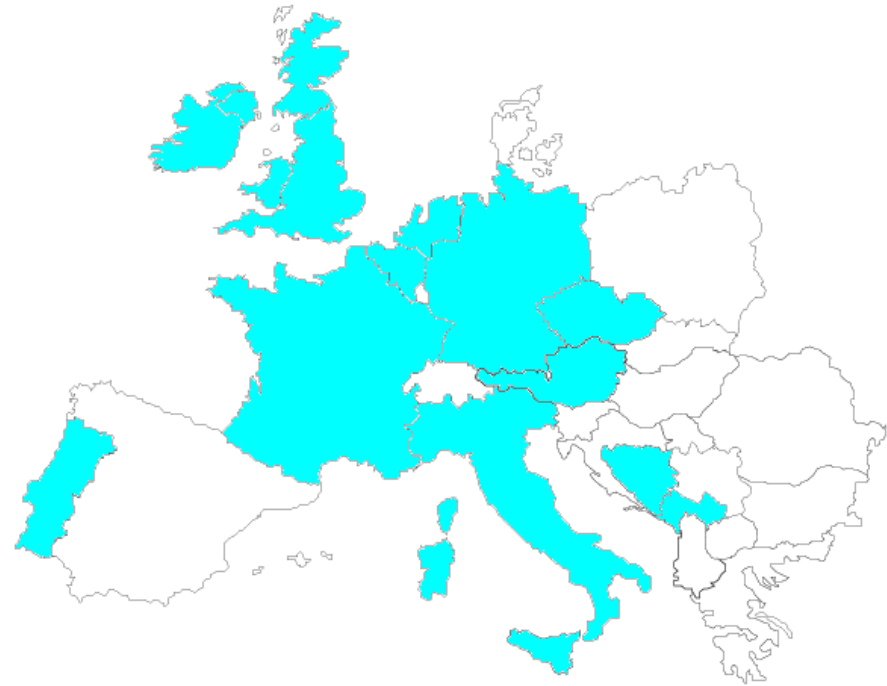
Patients
quotes

Take home messages

12 Participating Countries



- ✓ Austria
- ✓ Belgium
- ✓ Czech Republic
- ✓ Finland
- ✓ France
- ✓ Germany
- ✓ Ireland
- ✓ Italy
- ✓ Netherlands
- ✓ Portugal
- ✓ Serbia
- ✓ UK



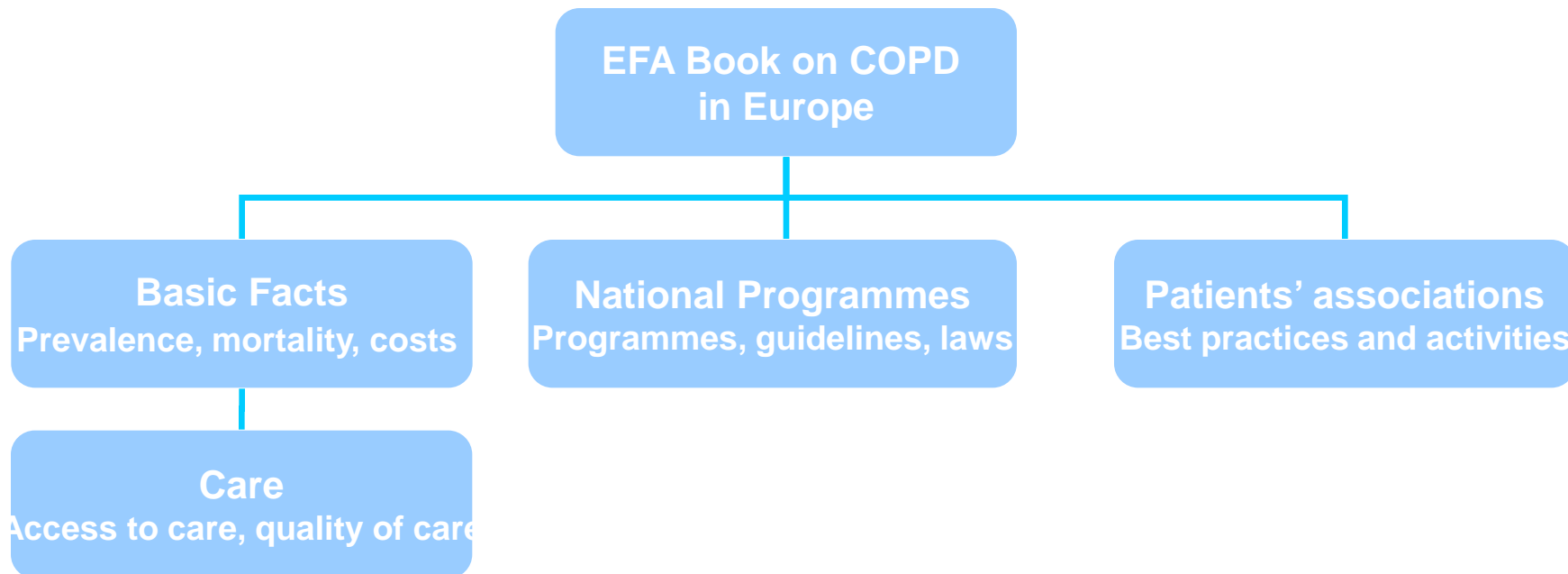
European Federation of
Allergy and Airways Diseases
Patients Associations

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Contents



COPD Prevalence

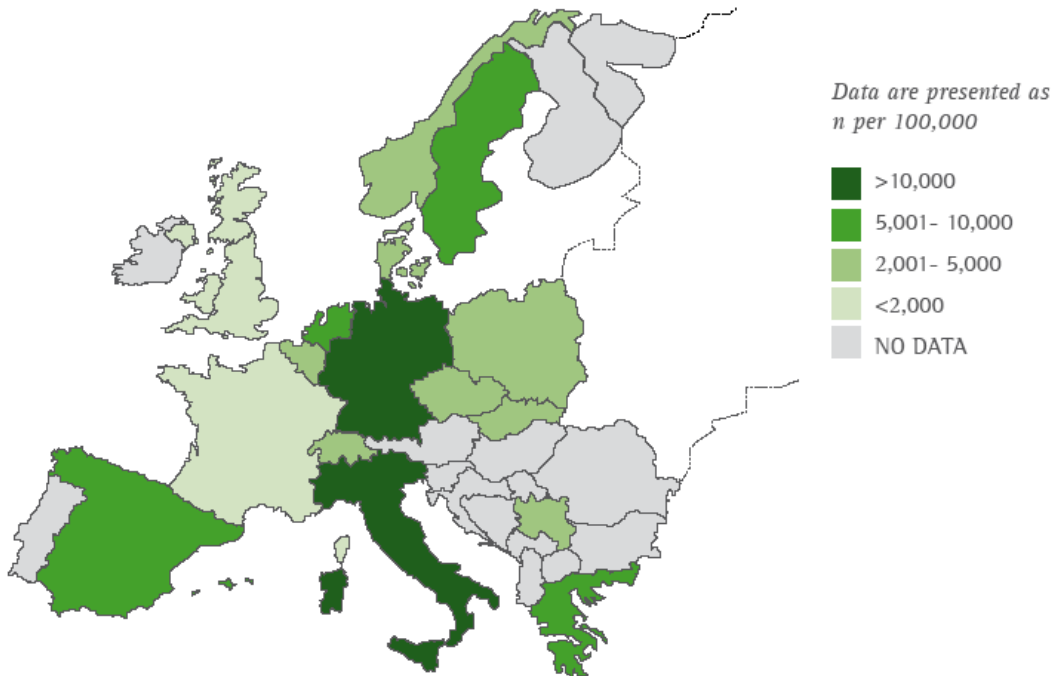


Organization for Economic Co-operation & Development

EFA Survey

The prevalence of COPD varies from 2% (NL) to over 10% (AUS & DE).

The prevalence among younger people (20-40 years old) is 3.6%.



Death Rate



From 0.209 per 1,000 (Finland) to 0.463 per 1,000 (Belgium).

A word of caution:

- *COPD is still unrecognized and death is often attributed to another disease.*
- *Different COPD definitions, and different methods of compiling statistics affect COPD mortality data.*

The Economic Burden



- The total annual financial burden of lung disease in **Europe** is nearly **€102 billion**.
- COPD accounts for almost half of these costs.
- Direct costs: €108,000,000 in Finland and £500,000,000 in UK.

Social Impact of COPD

In the patients' own words



‘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 patients are severely disabled.’ *Italy*

‘... In many cases, patients are diagnosed late, when they are already disabled.’ *France*

Access to care



- **Early diagnosis** → difficult/very difficult
 - *‘Only 50% of patients receive an early diagnosis.’ Italy*
- **Information and treatment options** → good information from associations, not so good from GPs
 - *‘There’s a lot of information but it is not coordinated.’ Germany*
- **Free treatment** → no country surveyed gives full free access to treatment COPD patients (except Wales in the UK)
 - *‘Patients in the UK still have to pay for oxygen concentrators.’*

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



Country	Access	Comment
Austria	Very easy	€4.9 is required for prescriptions up to a max of 2% of a patient's net wage.
Belgium	Difficult	Patients must pay part of the cost.
Czech Republic	Difficult	Insurance companies set cost limits to doctors for treatment. Patients must contribute to costs.
France	Easy	Some limitations due to reimbursement policies

Access to rehabilitation and support services



Background: Pulmonary rehabilitation reduces symptoms and improves the quality of life of COPD patients.

- Access to rehabilitation 'difficult' or 'very difficult' in 8/11 countries.
- 'Very easy' in Portugal.

Key messages

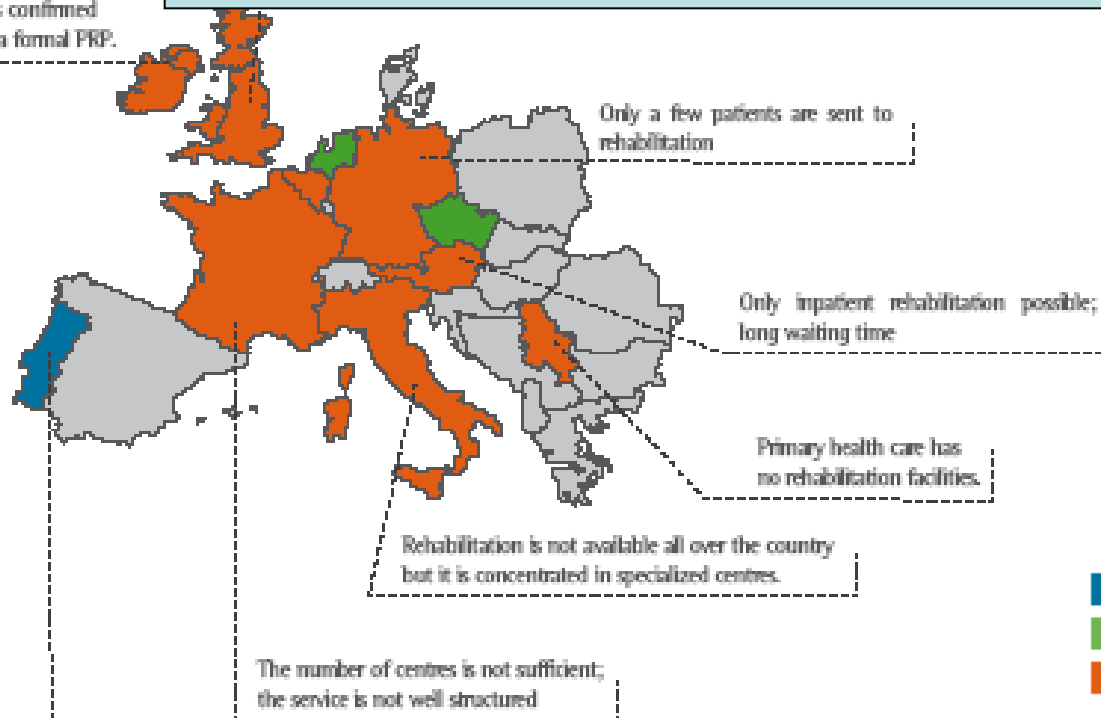
- National healthcare services are not fully aware that rehabilitation is important for the management of COPD.
- Access to these services varies in urban and non-urban areas.

Access to rehabilitation



The majority of people with COPD are diagnosed in primary care yet only 8% of GPs could access pulmonary rehabilitation services for their patients. Nearly 40% of acute hospitals confirmed that they had a formal PRP.

Chiesta immagine senza commenti



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

In partnership with patient associations, GOLD, the pharmaceutical industry and local municipalities, tests have been performed on World COPD Day and World no Tobacco Day.

The role of healthcare professionals in the countries surveyed



In all countries surveyed, **GPs** are responsible for early diagnosis, management of mild and moderate COPD and long-term follow-up.

Key messages

- Often **GPs** are not sufficiently aware of COPD or of the importance of early diagnosis
- **Spirometry** is not available for all patients at primary care level
- In most countries **pulmonary specialists** are highly qualified and their associations are active in national COPD programmes
- **COPD nurses, respiratory therapists and lung function technicians** are key in COPD management
 - Their role should be recognized and their number increased

National COPD Programmes

Take home messages



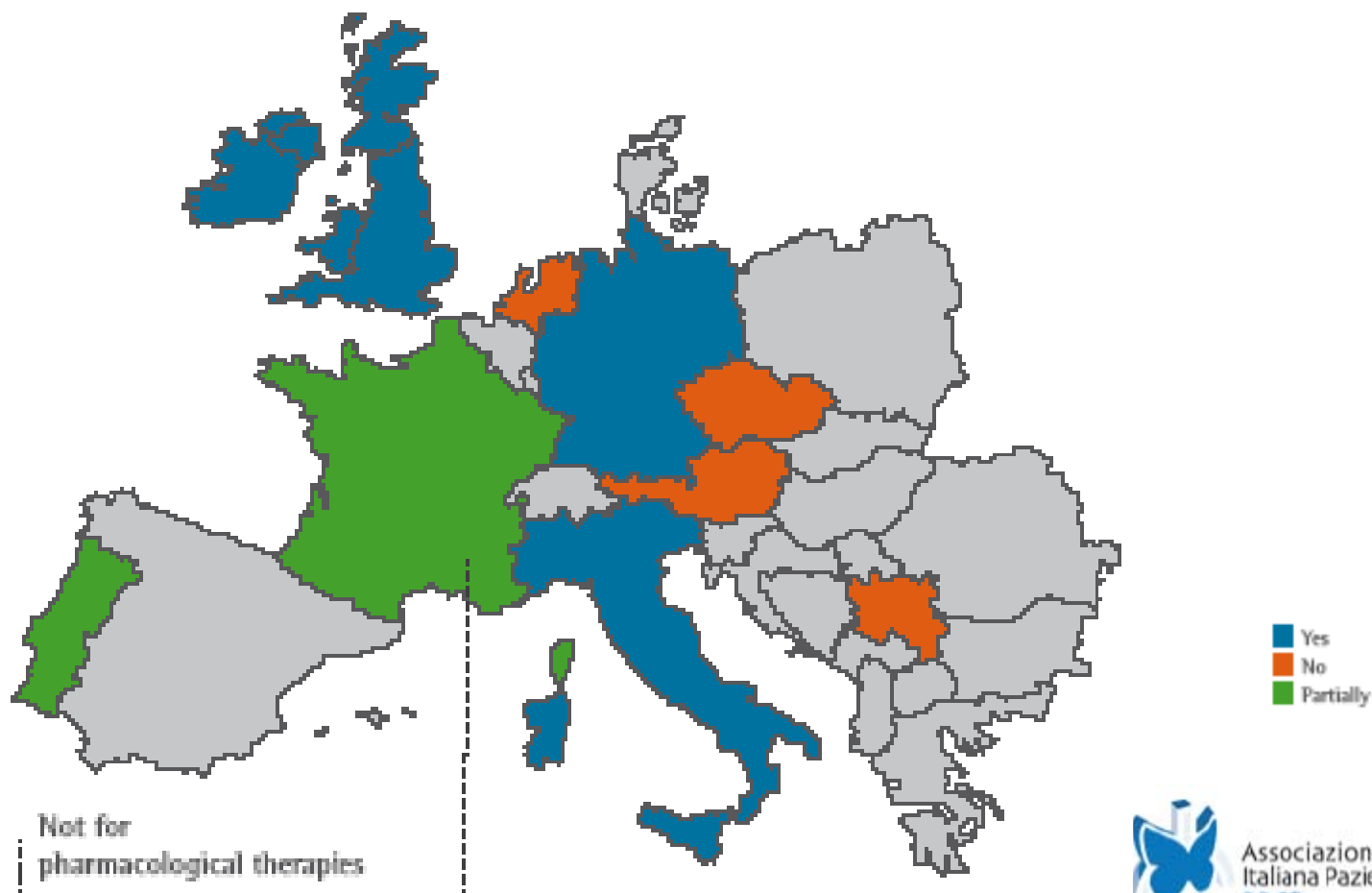
Action is urgently needed to avoid an adverse impact of COPD on national economic development. GARD 2007

- COPD places a severe economic burden on countries because of loss of working days, hospitalization and treatment.
- National COPD programmes are required to reduce the burden of COPD on families and on the health system.
- Such programmes should promote the prevention and control of COPD equally throughout their country.
- They should involve all stakeholders (Ministry of Health, GPs, specialists and other healthcare professionals, and patients associations).

Involvement of patients associations in producing COPD clinical guidelines



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



National Legislation for Healthy Air



Background

- Unhealthy air is particularly harmful for COPD patients
- Reducing the risk from indoor and outdoor air pollution is feasible
- Initiatives at national level require legislative actions

Legislation for air quality in the EFA survey – App. 4



Sharing: Best Practices for Smoking Cessation



Background

Over **709,000 adults**, including **19,000 non-smokers**, died in the EU-25 in 2002 from exposure to tobacco smoke at home and in their workplace. *European Commission*

EFA Survey:

- Help to quit smoking is 'easy/very easy' in most countries, and 'difficult' in Austria and Italy.
- In Austria pulmonologists, but not GPs, receive a contribution to help people quit smoking.
- An Irish survey showed that 94% of GPs found access to pharmacotherapy for smoking cessation is 'easy/very easy'

Sharing: Best Practices for Smoking Cessation



Examples of quit smoking initiatives (App. 6)

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.

Advocacy, Educational programmes & other initiatives



- Practically, all associations

Other practical stuff



In the EFA COPD Book you will also find a collection of practical information on COPD:

- ✓ Definition of COPD and comorbidities
- ✓ Self-assessment questionnaire
- ✓ Practical information to improve patients' conditions
- ✓ Travelling by air with oxygen therapy
- ✓ National guidelines (Appendices)
- ✓ National legislation on healthy air and smoking ban (Appendices)
- ✓ EC call for smoke free Europe by 2012

... and much more

Sharing and caring: Patients associations



- ✓ **MISSION:** 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.
- ✓ **FOCUS:** Prevention, early diagnosis, management and care of COPD

Sharing and caring: Patients associations



✓ ACTIONS

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

Often in collaboration with other stakeholders

Patients in action



✓ **Support groups**



✓ **Help lines**



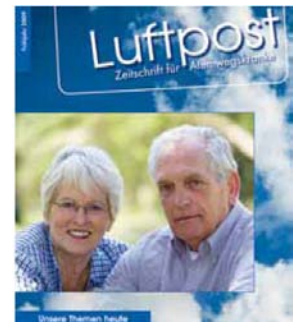
✓ **Books**

✓ **Posters**



✓ **Campaigns**

✓ **Newsletters**



Check the Book for more...

How Europe is doing: Successes



- ✓ The care of COPD patients has improved over the last decade
- ✓ COPD management guidelines have led to a better outcome for patients
- ✓ More attention is given to quality of life
- ✓ Prevention is improving also thanks to smoking bans in most European countries
- ✓ In many countries laws have reduced indoor and outdoor pollution
- ✓ Many countries have made advances in education, prevention and access to treatment

Outstanding problems ...

Future actions



- ✓ The epidemiological and social impact of COPD must be effectively recognized now.
- ✓ COPD still is largely unknown and underdiagnosed
- ✓ Early diagnosis must be improved
- ✓ Efforts should be made to standardize the level of care within individual countries and among countries
- ✓ Severely affected patients have great difficulty in accessing essential rehabilitation programmes.
- ✓ A coordinated and comprehensive strategy on COPD at European and national level is needed, taking into consideration local situations, and involving EU and national policy makers, and all stakeholders

This book is a tool!



“This book is part of a positive outlook for the future to tackle COPD.”

Lally Franchi



JUDAH





Thank you for your attention

Download the *EFA Book on COPD in Europe*

<http://www.efanet.org/documents/EFACOPDBook.pdf>