

Editors' introduction



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Respiratory medicine is one of the largest medical specialties, covering a diverse range of acute and chronic diseases, all of which impact on breathing. These diseases variously affect the lung substance, the lower and upper airway, and the blood vessels of the lungs. They include at least 10 major conditions and a much larger number of rarer and 'orphan' diseases. The commoner diseases comprise: acute and chronic infections (pneumonia, tuberculosis); malignancy (lung cancer); chronic airway diseases (asthma, chronic obstructive pulmonary disease, cystic fibrosis); interstitial and occupational diseases; pulmonary vascular disease (pulmonary thromboembolism, pulmonary hypertension); and obstructive sleep apnoea syndrome. The symptom common to all of these, and which usually causes patients to seek medical attention, is difficulty breathing (dyspnoea); often this is accompanied by other symptoms, particularly coughing, with or without the production of sputum or, less commonly, blood. Respiratory disease is a major cause of morbidity and mortality and is responsible for a very large proportion of the overall health and socioeconomic burden of illness.

Respiratory medicine developed largely from the care of patients with TB, the great scourge of the 19th century. Although TB declined dramatically in the developed world in the 20th century, it remains a major problem in many countries and still presents new challenges in the 21st century. Other diseases have, however, come to dominate the practice of respiratory physicians, most notably asthma, COPD (also known as chronic bronchitis and emphysema) and lung cancer. The major cause of both COPD and lung cancer is tobacco smoking and the 20th century – and ongoing – epidemics of these diseases are closely related to the epidemic of smoking. There has been an encouraging decline in tobacco consumption in many developed countries over the past 30 years but, in others, smoking rates remain depressingly high. Where smoking has declined, the prevalence of COPD in men has started to level off, but this is not yet the case in women and lung cancer continues to increase in both sexes. Although a reduction in both conditions is anticipated eventually, the considerable time lag of 20–30 years between tobacco exposure and the development of disease implies that both will remain major challenges for several decades yet. Furthermore, in some countries, tobacco consumption has shown little decline and in many less developed countries it is still increasing.

Asthma also increased in prevalence in many countries in the late 20th century; the precise reason(s) remain to be clarified but are in some way related to the 'western' lifestyle and increasing urbanisation. Although the peak of this asthma 'epidemic' seems to be passing in western Europe, evidence suggests that in many eastern

European countries the prevalence of asthma is 'catching up' as socioeconomic conditions improve and the lifestyle approaches that of western countries.

The prevalence of some other respiratory conditions is also increasing. The most noteworthy development is appreciation of OSAS as a major health and social problem. In retrospect, it is clear that the condition has been with us for centuries but it is only since the 1970s that it has been recognised as a major and common cause of morbidity. Although by no means restricted to the obese, it is closely related to weight and the increase is not just a matter of better recognition, but also represents a truly rising prevalence as obesity becomes more common. Another increasingly important influence on adult respiratory practice is disease in infancy and childhood. For example, the progressively improving survival of patients with CF means that it has become an important disease of adults; the recent increase in childhood asthma is likely to be followed by an increase in young (and subsequently older) adults with the disease; and the dramatically improved survival rate of very premature infants brings its own respiratory complications, which are now being seen in older children and young adults.

In contrast to specialties with a universally recognised name (e.g. cardiology, neurology), respiratory medicine has several synonyms. Respiratory physicians are known variously as pneumologists, pulmonologists, respirologists, lung doctors, chest physicians or thoracic physicians; in some countries where practice is still dominated by TB, specialists are known as phthisiologists. This variation tends to blur the identity of the specialty and causes confusion among the public.

In recent years, respiratory physicians have followed the general trend to greater specialisation and several subspecialties of respiratory medicine have developed to varying degrees in different countries. Larger respiratory departments now commonly have several physicians, each with particular expertise in, for example, asthma, CF, lung cancer or sleep disordered breathing. Increasingly, evidence shows the benefits for patients of such highly specialised expertise and this pattern is likely to accelerate in the future. Similarly, increasing specialisation is seen in other health professions, with specialist respiratory nurses and physiotherapists playing increasingly important roles in the investigation and care of patients.

The practice of respiratory physicians overlaps with other specialists in several situations, for example with intensivists for management of the acutely ill, with oncologists for lung cancer, with clinical allergists (allergologists) for management of asthma and allergic disease, and with neurologists for sleep disorders. In practice, patterns of provision of care vary from country to country and from centre to centre, with the expertise of the physician (and, increasingly, also of the specialist team of nurses and allied health professionals) being more important than the official designation of the post.

The first European Respiratory Society 'White Book' was published in 2003, with the aim of highlighting the health and socioeconomic burden of respiratory disease across Europe. It was well received by both health professionals and those responsible for organising healthcare, and the information it contained has been widely used by policymakers. After 10 years, the ERS considers it timely to update the information in order to illustrate how the specialty is changing and how recent trends are influencing practice. We hope that this new White Book will help to inform decision making about the future provision of healthcare for patients with respiratory disease and to highlight the conditions for which more facilities and resources are likely to be required, as well as areas where further research is most needed. As in the previous edition, we have interpreted 'Europe' liberally, by following the World Health Organization definition of the European region, *i.e.* including not only the conventional geographic boundaries, but also all the countries of the former Soviet Union. At the same time, we have also focused on the impact of respiratory disease on the 28 countries of the European Union. Inevitably, due to the diversity of respiratory diseases, the lack of universal definitions and suboptimal reporting systems, data for many diseases and many countries are incomplete. Another aim of this publication is to highlight these deficiencies and the urgent need for them to be addressed.

Foreword

World Health Organization Regional Director for Europe, Zsuzsanna Jakab



Zsuzsanna
Jakab

The lungs are essential for life. Yet respiratory diseases still remain a leading cause of death and disability in Europe and across the world.

The prevention and control of respiratory diseases is part of the WHO European Health Policy Health 2020, the noncommunicable disease (NCD) action plan for the WHO European region's implementation of the UN Declaration on NCDs; and our joint efforts to tackle tuberculosis through the Consolidated Action Plan to Prevent and Control M/XDR-TB 2011–2015. Our approach has been focused on the prevention of these diseases. We have made many efforts together with the ERS and others to prevent and reduce the risk factors for respiratory disease, through controlling infection, combating indoor and outdoor pollution, avoiding and preventing health inequalities and encouraging all parties of the WHO Framework Convention on Tobacco Control to fully implement the protocol and guidelines of this first international public health treaty. However, as the ERS Presidents note in their introduction to this book, a great deal more is needed to achieve better protection of lung health in Europe.

Part of the mandate of the WHO Regional Office for Europe is to monitor and report on the health of nearly 900 million people in the WHO European Region, and I very much welcome the important contribution this comprehensive *European Lung White Book* makes to our work and the tracking of the burden of respiratory disease in Europe in general. Indeed, it is 10 years since the 2003 version first provided health professionals with a comprehensive picture of not just the health burden of respiratory diseases, but just as importantly the health systems and socioeconomic impacts as well.

The *White Book* points to the progress that has been made in respiratory medicine and disease prevention in the Europe since the first edition a decade ago. Age-standardised rates of mortality from lung disease have gone down and hospital admissions have remained stable. Smoking rates may be falling from a regional perspective, but there remain high numbers of smokers in individual countries; and the effects of smoking carry a long-term burden. Despite improvements, therefore, great challenges remain. A major example is the lack of standard data collection, which hampers meaningful comparisons in many areas. This needs more recognition and deserves concerted action in partnership between governments, agencies such as the WHO and medical societies such as the ERS.

To this end, I believe that we need a real paradigm shift in the way we think about disease prevention and health promotion. We need an approach that is comprehensive and that takes health and health inequity issues into consideration in all policy areas. It is time for a new strategic vision that makes health – including essential lung health – a responsibility in all areas of government. Health 2020, together with partners such as the ERS, contributes to making this shift.

Foreword

European Commissioner Responsible for Health, Tonio Borg

Respiratory diseases are the third leading cause of death in the European Union. Over 20 million people in the EU suffer from asthma, and chronic obstructive pulmonary disease (COPD) affects 40 million Europeans. The total burden of lung diseases overall is even higher.

Action to address this challenge must be based on solid evidence. I therefore welcome the new edition of the *European Lung White Book*, which brings together broad, comprehensive, and accurate information on lung diseases in Europe, both for health professionals and for citizens.

This publication provides a good basis for policy makers to take decisions to prevent and address lung diseases. The EU is keen to continue contributing to the prevention of lung diseases, in particular through action on tobacco control and on environmental pollutants.

Indeed, in 2012 the Commission presented proposals to considerably strengthen EU tobacco products legislation and continuously monitors and supports member states' implementation of smoke-free environments. I am confident that such measures will help reduce the incidence in particular of COPD, for which smoking is the main cause.

It is also important that lung diseases are addressed in the wider context of chronic diseases and comorbidity, a particular concern in our ageing societies, as a follow up to the United Nations Declaration on Noncommunicable Diseases and through our EU reflection process on chronic diseases.

I am grateful to the authors, the European Respiratory Society and the European Lung Foundation for this important publication.



Tonio
Borg

Promoting respiratory health in Europe – a lot achieved, still more to do



Francesco
Blasi

The mission of the European Respiratory Society to alleviate suffering from respiratory diseases necessitates many activities including the promotion of scientific excellence, education and the exchange of best clinical practice. Key to all these activities is advocacy for lung health in Europe and beyond. The ERS has produced this new edition of the White Book because doctors, scientists, patients and policy-makers need a comprehensive basis on which to reach decisions and formulate policies about health, particularly in the complex and wide-ranging respiratory field.

A decade has now passed since the publication of the first White Book – the first ever comprehensive survey on respiratory health. In 2003, we had 15 members of the European Union; today, we have 28. The decade has seen not just the expansion of the EU but also the expansion of health and research initiatives benefiting Europe's citizens. Many of these developments have impacted positively on respiratory health.



Peter
Barnes

In research, health funding by the EU has increased steadily and the importance of basic and translational ("bench to bedside") medical research has been enhanced with the creation of a European Research Council and a dedicated, cross-cutting health theme in research framework programmes – including the latest, known as Horizon 2020 – the main EU funding instrument for research. Europe has been the driving force behind the first ever international public health treaty, the WHO Framework Convention on Tobacco Control. Its implementation across Europe has seen many positive developments, such as smoke-free areas, which have led to immediate improvements in respiratory health. The EU has also adopted ambitious air quality legislation, which has begun to reduce premature deaths from respiratory disorders. In the area of respiratory infections, we have seen better coordination in Europe with the setting up of the European Centre for Disease Prevention and Control (ECDC) and increased efforts by the WHO to tackle tuberculosis.



Klaus
Rabe

In all these areas, the ERS has been at the forefront in providing evidence-based proposals for greater action in science, research, control and prevention of lung disease. It commissioned the first comprehensive study on the impact of passive smoking in Europe, and will soon launch a dedicated web portal on the existing and emerging health effects of smoking. The ERS has presented the evidence on the serious health effects of indoor and outdoor air pollution and climate change, and led the call for improved air quality legislation in the EU. The ERS has been involved in many research framework projects, such as the innovative medicines initiative (IMI) and Marie Curie actions, and is a founding member and leader in the Alliance for Biomedical Research in Europe, which for the first time brings

together the leading European specialist clinical societies. The ERS has developed high European standards of postgraduate education through its School and the HERMES initiative.

While major progress has been made, we must not rest on our laurels. The ERS has reflected on what must be done to prevent the rise of respiratory diseases in the future and produced a forward-looking *European Respiratory Roadmap* (www.ersnet.org/roadmap) outlining the necessary action. This White Book provides the disease burden and socioeconomic case for actions laid out in the Roadmap, and we must act now if we are to protect future generations. There are five areas that need investment if we are to curb the rise in respiratory conditions in Europe: prevention, clinical care, research, education and data collection.

In the field of prevention, we need to step up efforts to minimise health inequalities. Health inequalities have significant economic implications for the EU and social inequality contributes to a higher proportion of deaths from respiratory disease than in any other specialty. We face many challenges, not least the impact of recent crisis-driven austerity measures. All those involved need to do more to promote and protect health, particularly for the most vulnerable segments of the population, and to ensure that a basic level of appropriate care and medical support is available to all those who are ill, regardless of income or demographics. In tobacco control, we must gradually phase out tobacco use completely, but in the interim, higher taxes, 100% smoke-free areas and plain standardised packaging with health warnings should all help to prevent young people from taking up the habit. Here, the strongest possible EU Tobacco Products Directive is crucial. In environment policy, we need to step up efforts to implement the WHO guidelines on air quality; Europe is falling far behind levels that are safe for our respiratory health.

As outlined in the concluding chapter of this book on recommendations and policy, we must see real implementation of the EU and United Nations commitments to take action on chronic diseases. This is particularly important with an ageing population, a declining labour force and the economic crisis in Europe. New approaches to clinical care are needed in order to ensure we can provide for future needs and eliminate health inequalities. We need to develop robust and simple methods to screen for sleep breathing disorders, lung cancer, chronic obstructive pulmonary disease and other chronic respiratory conditions as well as respiratory infections, as these will remain significant challenges at the clinical level. More effective screening would enable us to anticipate respiratory health burdens of the future.

Shifts from hospital-centred medicine to home care, from physician care to nurse care and from nurse care to self-management are inevitable. We must be prepared for this shift – training and education for professionals and patients will be fundamental. The use of managed clinical networks, multidisciplinary teams and collaborative efforts across the lines of healthcare can offer significant advantages in the treatment of complex conditions. In this way, patient treatment will focus on treating the patient, not just the disease.

Research and innovation are crucial to our understanding, optimal management and future treatment of respiratory disease. Presently, collaboration in Europe lacks a strong strategic framework for tackling chronic diseases, which is why the formation of the Alliance for Biomedical Research is important. Cross-fertilisation between clinical disciplines is vital. It can serve to accelerate the translation of basic science (which may be common to many disease processes) into clinical practice. We need a scientific platform in Europe to consolidate expertise and resources across borders, providing significant added value. This would address the currently fragmented research landscape in Europe and help accelerate the translation of discoveries into applications that will impact healthcare delivery in the future.

Most importantly, we hope that eventually there will be no need for a White Book! The most effective action that European governments supported by the European Commission could and should take is to standardise surveillance and data collection on all respiratory diseases; this would make a major contribution to efforts to save lives and to improve the care of patients.

We have achieved a lot – but Europe has much more to do to secure our future health and prosperity and give our lungs breathing space. The ERS is in an excellent position to continue playing a major role in improving the health of Europe.

The European Respiratory Society – the voice of respiratory health in Europe



The mission of the European Respiratory Society is to alleviate suffering from respiratory disease and promote lung health through research, sharing of knowledge, and medical and public education. The ERS, founded in 1990, is now a 10 000-member nonprofit professional society, devoted to respiratory medicine and science, comprising 11 scientific assemblies covering the full breadth of the field. Open to clinicians, scientists and other health professionals, the society draws its members from every continent and plays a leading role in improving standards of respiratory care in Europe and beyond. Its activities centre around four pillars: Congress, education, publications and advocacy.

The annual ERS Congress is the central event of the society's year. It attracts about 20 000 delegates, making it the largest annual scientific gathering in respiratory medicine worldwide and the primary forum in Europe for presenting research, exchanging knowledge and forging collaborations. While speakers include the world's leading experts in the field, the Congress also provides opportunities for young researchers to present their work to a wide audience, perhaps for the very first time. Outside the main Congress, the society organises an annual Lung Science Conference and a biennial Sleep and Breathing Conference (jointly with the European Sleep Research Society).

The ERS School runs educational events throughout the year, providing a range of hands-on and online courses and CME-accredited events and material. At the annual ERS Congress, the School provides a world-leading slate of postgraduate courses, seminars and 'meet the expert' sessions covering the whole spectrum of respiratory medicine. Resources from these events and many other ERS activities are collected on the ERS's Learning Resources website, a vast treasure chest of information. The School is also responsible for the HERMES initiatives, which aim to harmonise respiratory medical education in Europe. These ongoing projects cover seven major areas in respiratory medicine, and have led to the creation of core curricula and syllabi, several best-selling Handbooks and the highly regarded European examinations and diplomas in adult and paediatric respiratory medicine.

ERS publications are led by the flagship *European Respiratory Journal*, which publishes the best in original research and scientific reviews each month, reaching almost 1 million online readers each year. There are also two quarterly journals, both freely available online: the *European Respiratory Review* publishes state-of-the-art reviews and summaries of important recent findings, while *Breathe* is aimed at clinicians, allied health professionals and those in training, presenting practical, educational content and reaching over 16 000 print



subscribers. The *European Respiratory Monograph* publishes four books each year, each one taking an in-depth look at an area of respiratory medicine.

In addition to its head office in Lausanne (Switzerland) and publications office in Sheffield (UK), the ERS maintains an office in Brussels (Belgium), at the heart of the European Union (EU), focusing on advocacy for better respiratory health. Current activities include lobbying for stronger tobacco regulation and ensuring that respiratory medicine is well represented in new EU research funding programmes.

The above is just a brief overview of the activities of the ERS – more in-depth information can be found at www.ersnet.org. The society also produces clinical guidelines, funds fellowships for researchers and produces strategic reports such as the *European Respiratory Roadmap*. Working in concert with national respiratory societies through the Forum of European Respiratory Societies (FERS) and sister societies worldwide through the Forum of International Respiratory Societies (FIRS), the ERS is devoted to ensuring that 'every breath counts'.

The European Lung Foundation



The European Lung Foundation (ELF) was set up by the European Respiratory Society (ERS). It works alongside the ERS to bring together people living with respiratory conditions, the public and respiratory professionals to positively influence respiratory medicine. ELF's key role can be seen as being the public voice of the ERS and the public's voice in the ERS.

The heart of ELF's work is to bring the latest information and advances in respiratory medicine to people outside the respiratory profession, making it comprehensible to a nonspecialist audience and in a range of European languages. The majority of this information is disseminated widely through the ELF website – www.european-lung-foundation.org. The site contains a wealth of up-to-date content on respiratory health and disease, and provides downloadable factsheets and information, developed with patients and ERS experts, with a source of reliable and accurate patient information.

ELF is also responsible for communicating the ERS's scientific activities to the public and the press, preparing lay summaries and press releases to accompany major publications from the *European Respiratory Journal* and key abstracts from the ERS Congress.

For over 10 years, ELF has run public awareness campaigns and events centred around lung function testing. Initially, these were 'spirometry screening events', set up in major European cities to coincide with the annual ERS Congress. Working with international respiratory societies, ELF now coordinates a biennial global World Spirometry Day campaign, which in 2012 attracted participation from more than 65 countries.

ELF is working hard to ensure that people with lung diseases and the general public have the opportunity to influence respiratory research and guidelines at the European level. It has set up a network and advisory group of patient organisations across Europe, covering all respiratory conditions. ELF ensures patient involvement in the creation of clinical guidelines, through patient-oriented literature searches, online questionnaires, focus groups and patient versions of the final guideline. ELF invites patients to the ERS Congress, to meet clinicians and ERS leaders and make their concerns and opinions heard. Chapter 40 in this book covers this topic and ELF's role in detail.

ELF is excited about the production of the second *European Lung White Book* and the data therein. The ELF website will be relaunched to coincide with the publication of this book to ensure that the key messages from this important document are accessible to all.