Medical respiratory specialists

Introduction

(i)

Key points

- Multidisciplinary teams (comprising many different healthcare professionals) are increasingly important for the care of patients with various respiratory diseases.
- Respiratory staffing and training are affected by wealth and productivity of a country, history of medical development, societal influence of medicine and political priorities.
- The number of respiratory physicians per 100 000 population varies 10-fold between different European countries.
- Paediatric respiratory medicine is a recognised specialty in only a minority of countries.

In a changing world, the modern respiratory physician has had to adapt to new pressures and responsibilities. Two decades ago, the average respiratory physician was almost entirely selfsufficient and carried out his practice relying solely on his own experience and competence. He treated patients with tuberculosis (TB), pneumonia, airway disease, bronchiectasis, pulmonary embolism, interstitial disease and cystic fibrosis (CF) without the need to refer patients to other physicians or specialist units. He would refer patients with lung cancer for radiotherapy or thoracic surgery, but he performed all his own bronchoscopy and pleural procedures, and administered chemotherapy sparingly on his own. He would confer with thoracic surgeons and radiotherapists when the need arose. Occasionally, he would telephone a bacteriologist or pathologist and he would refer to the intensive care unit only in exceptional circumstances.

Since then, a radical change has taken place. Today's respiratory physician is just as likely to be female as male. There are new clinical challenges, such as sleep breathing disorders, infections in the immunocompromised host, drug-resistant TB, adult CF, complex bronchoscopic techniques and noninvasive ventilation. It is widely accepted that no single respiratory physician can be expected to be competent in all these diverse areas. As a consequence, there has been a great increase in overall numbers of respiratory physicians; most physicians now have areas of special interest; and subspecialisation has increased technical staffing

CONCLUSIONS

The modern respiratory physician has had to adapt to new pressures and responsibilities

levels in respiratory departments, most of which now have well-equipped pulmonary function laboratories able to carry out spirometry, plethysmography, single-breath diffusing capacity and exercise testing.

The concept of the multidisciplinary team (MDT) has emerged. Initially, these were limited to the care of lung cancer patients and included respiratory physicians, oncologists, radiotherapists, radiologists, pathologists, palliative care physicians and thoracic surgeons. The MDT meets weekly and usually discusses all lung cancer patients, not just those who are being considered for active management. This development is now seen as essential for patient care, but is also recognised as being an invaluable teaching and learning experience. There are now other MDTs dedicated to the treatment of TB, asthma, chronic obstructive pulmonary disease (COPD), interstitial lung disease and sleep breathing disorders.

Although physicians still predominate in MDTs, many other healthcare professionals are now involved. Previously, respiratory nurses' activities were restricted to contact tracing in TB, but now they play a major role in asthma, COPD, lung cancer and CF. In some countries, much of the clinical care of patients with airway disease has devolved to nurses, both in hospitals and in the community. In defined areas, nurses now prescribe, usually on the basis of an agreed protocol. Patients with lung cancer are regularly supported and counselled by specialist nurses who may also have a role in expediting management. In sleep disorders and neuromuscular disease, pulmonary function technicians and physiologists are wholly integrated into the MDT and are often responsible for supervising domiciliary (home) ventilation.

Throughout Europe, respiratory physicians have led the way in implementing these profound changes in the profession. However, the pace of change has varied greatly across Europe. Manpower levels and academic and training infrastructure in any medical specialty result from many interacting variables. These include the wealth and productivity of the nation, its history and traditions of medical development, the societal influence of the medical profession and the priority of medicine in the political spectrum.

In addition, the increasing complexity of medical care brings unexpected pressures on manpower within individual medical specialties. This is clearly evident in respiratory medicine. TB referrals may be made to infectious diseases departments; pneumonia in the elderly to geriatric departments; lung cancer to oncologists; asthma to allergologists; and patients with sleep breathing disorders to otolaryngologists or neurologists. Respiratory physicians believe justifiably that they best serve the interests of these patients and need to defend the role of their specialty in these areas.

It is therefore important to monitor trends in respiratory staffing levels. The data incorporated in this chapter were obtained from the responses to a questionnaire that was sent to members of the Forum of European Respiratory Societies (FERS) and European Respiratory Society (ERS) national delegates. The response rate was 68%, with the majority of nonresponders from eastern Europe.

Figure 1 shows the numbers of adult respiratory physicians in European countries per 100 000 people (mean 4.4 per 100 000). The range is large, with Macedonia having 1.16 respiratory physicians and Greece 10.56 per 100 000. A contributory reason for this may be that Greece has few general practitioners and patients consult specialists for complaints that would be dealt with by primary care doctors in other countries. The same pattern is evident in cardiology: in a 2007 survey carried out by the Union of European Medical Specialists (UEMS), there were 22.6 cardiologists per 100 000 people in Greece compared to the European mean of 6.9. A further reason for the large difference in numbers of respiratory physicians is the previously mentioned increase in some European countries of other groups of health professionals who now perform duties that were previously



Figure 1 – Adult respiratory physicians per 100 000 people.

the exclusive preserve of doctors. In addition, as also discussed above, other specialists may treat patients with respiratory diseases.

The data in the first edition of the White Book are not directly comparable with these new data because the definitions of some of the categories were slightly different; for example, in some countries, retired respiratory physicians were previously included. Therefore, the apparent reductions in numbers of physicians in Italy, Slovakia and Finland are misleading and do not indicate a real decrease. However, in Hungary, the number of respiratory physicians has fallen. This is attributed to poor recruitment and emigration of doctors to western Europe.

Respiratory physicians comprise 1.48% of all doctors (figure 2), but the mean for Albania, Macedonia, Poland and Bosnia is 2.75%, which may reflect the challenge of TB and multidrug-resistant (MDR)-TB in eastern Europe.

The numbers of trainees and adult respiratory physicians per 100 000 people are shown in figure 3. Greece has the highest number of trainees: 2.2, compared to the average of 0.69 per 100 000. There is no obvious correlation between the number of adult respiratory physicians and trainees but calculation of the ratio of adult physicians to trainees shows marked differences (figure 4). The mean ratio is 8.3 but the range is large, from 34.3 for Georgia to 1.4 for Ireland. Many of the countries with the higher ratios, often from eastern Europe, have large numbers of TB doctors who are classified as respiratory physicians but are not thought to require replacement by fully trained physicians. Italy appears to have a high physician/trainee ratio, but the trainee number is an estimate and may not be accurate.

Figure 5 shows the number of paediatric respiratory physicians. Many countries do not recognise paediatric respiratory medicine as a separate specialty and children are cared for by adult physicians, paediatricians or allergologists. The data for trainees in relation to paediatric respiratory physicians are also shown. It would seem that Albania is planning to advance the specialty since it has only two trained paediatric respiratory physicians but has 19 in training.



Figure 2 – Adult respiratory physicians as a percentage of all doctors.



Country

Figure 3 - Adult respiratory physicians and trainees per 100 000 people.



Figure 4 - Ratio of adult respiratory physicians to trainees. #: adult and paediatric combined.

Data on medical schools, university departments and respiratory professors are shown in figure 6. Only five countries, all in western Europe (Spain, UK, France, Italy and Germany), have more than 30 medical schools. The number of medical schools usually corresponds with the number of university departments, although Germany is a notable exception with fewer than half of medical schools associated with an academic department of respiratory medicine. In that country, respiratory medical training is often carried out independently of a medical faculty, as noted in the first edition of the White Book. Indeed







Figure 6 – Numbers of medical schools, university respiratory departments and adult respiratory medicine professors.

in many European countries, including those with university departments of respiratory medicine, a large part of respiratory specialist training is carried out in non-university units. Europe is clearly following the US pattern of appointing personal or titular professors who are not heads of departments. France has almost three times as many professors as university departments of respiratory medicine.

In summary, although these data do not allow direct comparison with those in the first edition, they do illustrate interesting differences among the countries of Europe in relation to the organisation of respiratory medicine. In particular, it may be helpful to the health authorities and universities of the less well-developed countries to appreciate how their situation compares with more developed countries.

MAJOR RESPIRATORY

MAJOR RISK FACTORS

DVERVIEW

34

Allied respiratory professionals

Introduction

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Key points

- Allied health professionals (physiotherapists, technologists/ scientists, nurses, psychologists, occupational therapists, nutritionists) are involved in the prevention, diagnosis, evaluation, treatment and management of acute and chronic respiratory diseases.
- Respiratory technologists are involved with the development, clinical application and monitoring of new diagnostic and therapeutic procedures.
- Respiratory physiotherapists have expanded their traditional roles such as sputum clearance techniques to areas including pulmonary rehabilitation and supervision of noninvasive ventilation.
- Respiratory nurses are engaged in the holistic care of patients with lung diseases and are often involved in preventive programmes.
- There is considerable overlap between the responsibilities of allied respiratory professionals and, depending on local circumstances, similar roles may be played by respiratory technologists, physiotherapists or specialist nurses.

In recent decades, the management of patients with acute and chronic conditions has become multidisciplinary. Essential elements of respiratory patient management are now carried out by healthcare professionals such as physiotherapists, technologists/scientists, nurses, psychologists, occupational therapists, nutritionists, *etc.* Allied respiratory professionals (ARPs) are involved in the prevention, diagnosis, evaluation, treatment and management of acute and chronic respiratory diseases.

Physiological diagnostics have become a cornerstone of the classification of many diseases (chronic obstructive pulmonary disease (COPD), asthma, interstitial lung diseases, obstructive sleep apnoea syndrome, *etc.*), and spirometry (lung function testing) is now increasingly used by ARPs in many areas as a basic screening test to establish the appropriate therapeutic pathway. The measurement of lung function, arterial blood gases and oximetry, as well as the assessment of physical fitness or adherence to the agreed treatment, have also become important in determining the appropriate patient pathway. These tests, and many others, are now widely used to support the physician and the respiratory team.

ARPs are particularly involved in the rehabilitation of patients with chronic respiratory conditions, and are often the patient's first point of contact. In recent years, there has been increasing evidence for ARP-led interventions, serving to strengthen their Comprehensive care plans for older people with chronic respiratory diseases need to include training for respiratory nurse specialists in hospitals and the community

professional and academic role in disease management programmes. Consequently, the education and transfer of knowledge between different professional groups has become increasingly important in order to ensure that evidence-based research is translated into clinical practice.

This chapter will discuss the different professional positions within the ARP field, outlining the roles and responsibilities of each, and the areas requiring future development.

Respiratory technologists and clinical scientists

Respiratory technologists and clinical scientists perform lung function tests and study respiratory physiology and pathophysiology. They are concerned with the development, clinical application and monitoring of new diagnostic and therapeutic procedures in respiratory medicine. Respiratory technologists perform investigations in patients at rest as well as during exercise, by measuring lung volumes, airflow, gas transport across the alveolar membrane and blood oxygenation. They are also responsible for the calibration, maintenance and quality control of equipment.

Respiratory technologists perform sleep studies and sometimes run therapy services for patients with asthma, COPD and fibrotic lung disorders. The sleep medicine field has seen significant growth in recent years due to the high prevalence of sleep breathing disorders and growing public awareness of these conditions. Sleep medicine is a multidisciplinary specialty, in which ARPs such as technologists, scientists and nurse specialists play a key role. Many technologists are directly involved in performing and scoring sleep studies (figure 1) according to established guidelines. Their role involves providing patient education and developing treatment plans based on patients' needs. Good patient education and training is vital; the success of continuous positive airway pressure (CPAP) treatment, for example, is directly related to patient education.

Respiratory technologists and clinical scientists participate in activities that help raise awareness about the causes and prevention of pulmonary diseases. They support the development and promotion of smoking cessation programmes, pulmonary function screening, air pollution monitoring, allergy warnings, and other public education programmes. Allied respiratory professionals are involved in the prevention, diagnosis, evaluation, treatment and management of respiratory diseases

66



Figure 1 – Scoring a sleep study.

Training

It is difficult to accurately determine the training and education level of respiratory technologists and clinical scientists in Europe, due to a lack of data. The content and duration of their education differs greatly between countries, and consequently the harmonisation and standardisation of education and training is an ongoing challenge.

As part of its HERMES (Harmonised Education in Respiratory Medicine for European Specialists; hermes.ersnet.org) project, the European Respiratory Society (ERS) has set up a task force to establish a European spirometry certification programme, the European Spirometry Driving Licence. The task force aims to provide a platform that consolidates basic spirometry knowledge with more in-depth postgraduate education in respiratory physiology (figure 2). In time, this should lead to the development of a pan-European spirometry qualification, which standardises measurement quality and reliability throughout the continent. This goal is outlined in the European Respiratory Roadmap.

The professional field of respiratory technology and clinical science should aim to:

- improve the supply of scientific and technology personnel so that an adequate number of professional staff is available to deliver a high-quality scientific service
- strengthen and modernise education and training through use of the HERMES project framework
- develop an infrastructure with an attractive career pathway, so that high-quality staff are recruited and retained



CONCLUSIONS

thinking As with other health professionals, the right balance between the development of practical skills and academic knowledge needs to be achieved. Vocational training must be undertaken predominantly within the hospital environment due to the need for access both to patients and sophisticated equipment.



Figure 2 - The European Spirometry Training Programme.

ensure the contribution of respiratory technologists and clinical scientists is fully recognised within the ERS

A thorough modernisation of education and training in this area is also required, in order to provide:

- more interprofessional education and training
- joint training in communication skills .
- common learning programmes that are based on core skills, to enable students to switch careers and training paths more easily
- continuing professional development and lifelong learning
- a learning environment that supports evidence-based practice •
- augmentation of existing professional education and training programmes, and regulatory standards

The creation of a curriculum for respiratory technologists and clinical scientists requires:

- modular courses designed to enhance interprofessional learning
- flexible delivery accessible to students from diverse backgrounds
- a focus on competence, with skills training mapped to international standards .
- education that promotes problem identification, problem solving and critical •

Respiratory physiotherapists

Physiotherapy (or physical therapy) is primarily concerned with developing, maintaining and restoring an individual's maximum movement and functional ability. It includes examination/assessment, evaluation, diagnosis, prognosis/ planning of treatment, intervention/treatment, and reexamination. The conceptual framework most frequently used by physiotherapists is the international classification of function; the main goal of this classification is to enhance the patient's participation in everyday life. In patients with respiratory conditions, physiotherapy includes, but is not limited to, chest physiotherapy or clearance of secretions, and breathing exercises. In recent years, the evidence base for the use of physiotherapy in the form of exercise training has grown in many areas, ranging from intensive care to chronic respiratory conditions (see chapter 29).

Physiotherapy services can be used at all ages and at all stages of disease, from early diagnosis, through chronic illness, to acute episodes and care at the terminal stage. As such, physiotherapists have a clear and specific role in most clinical care pathways. The physiotherapist's role in patient care includes assessment, advice, education and hands-on intervention. Traditionally, respiratory physiotherapists aid the mobilisation and removal of secretions. However, this is only one of the many problems physiotherapists can address. They aim to:

- maintain or improve exercise tolerance
- improve functional abilities (*i.e.* carrying out daily tasks)
- maintain and improve physical activity, coaching patients toward improving healthy behaviour
- reduce breathlessness and the work of breathing
- improve the efficiency of ventilation
- support weaning from mechanical ventilation and set up noninvasive mechanical ventilation
- mobilise and aid the expectoration of secretions (coughing up of mucus)
- improve knowledge and understanding
- reduce (thoracic) pain

Physiotherapists who specialise in treating patients with respiratory disease have a background in respiratory physiology, exercise and muscle physiology, exercise training, and the principles of behaviour change. Further subspecialisation may include particular expertise in mechanical ventilation, aerosol delivery and pulmonary rehabilitation.

A physiotherapist should achieve the above aims with the goal of evidence-based practice in mind, *i.e.* they should know

OVERVIEW

MAJOR RESPIRATORY DISEASES

the most effective intervention, based on the evidence, and integrate this knowledge and its application with clinical judgment and patient preference. Recently, evidencebased treatment guidelines have summarised and endorsed the role of physiotherapy in the treatment of patients with respiratory conditions. A patient's contact with their physiotherapist is often frequent and of a relatively long duration. This means the physiotherapist is ideally placed to help relieve anxiety, boost confidence and deliver appropriate information or advice.

Physiotherapy typically commences with a comprehensive assessment of the patient's respiratory function, breathing pattern, respiratory muscle function and exercise capacity. Assessment of skeletal muscle function is particularly important, as this forms a major barrier to normal functioning in many respiratory patients. Based on this information, an evidence-based therapy plan is developed.

Physiotherapists often use mechanical devices, such as intermittent positive-pressure and CPAP equipment; tools that have been used in the profession since the mid-20th century. With the resurgence of interest in, and greater sophistication of, noninvasive ventilation techniques, physiotherapists have a greater armoury to turn to. Many individuals with life-threatening respiratory failure can be successfully managed in this way, avoiding intubation. Similarly, carefully selected devices can assist in mucus clearance. Exercise equipment has long been used in pulmonary rehabilitation programmes; however, physiotherapists may also use supplementary oxygen, noninvasive mechanical ventilation, complex training modalities or neuromuscular electrical stimulation to enhance the effectiveness of exercise training in respiratory patients. One specialised technique in particular is specific inspiratory muscle training using resistive breathing, which is used to alleviate breathlessness in patients with inspiratory muscle weakness.

Physiotherapists are important clinical team members in intensive care units, respiratory wards, outpatient clinics and palliative care services. The role of physiotherapists is widening as health services place a greater emphasis on chronic disease management and the maintenance of patient independence and function: where appropriate, patients are increasingly managed in the primary care setting, with the advent of domiciliary and hospital-at-home services.

Like their colleagues in other professions, physiotherapists should have greater involvement in tackling unhealthy behaviour (smoking, inactivity) in all aspects of healthcare. Ensuring that these skills are acquired is an important educational aim in the years to come.

Training

Like nurses, respiratory physiotherapists are often nonspecialised. However, in many European countries, increasing numbers specialise in respiratory physiotherapy and rehabilitation. The ERS has encouraged such specialisation by launching the HERMES respiratory physiotherapy programme, which aims to provide a standardised postgraduate programme of education and training. In a survey conducted to support this initiative, 64% of 107 respondents from over 30 countries reported that physiotherapy training is organised as an academic training programme in their country; 43% of these respondents reported that undergraduate training takes 3 years to complete and 32% reported that training modules are spread over 4 years.

Respiratory nurses



Although much of the care that respiratory patients receive at a primary, secondary and tertiary level is provided by nonspecialised nurses, patients in many European countries are seen and managed by respiratory nurse specialists. Respiratory nurses are engaged in the holistic care of patients with lung diseases, with the aim of maintaining the highest nursing standards, while working in collaboration with other members of a healthcare team. Specialist nurses work in various settings (inpatient and outpatient hospital departments and patients' homes) and, in addition to providing patient care, they are often involved in preventive programmes (*e.g.* smoking cessation and patient education).

Role

Respiratory nurses are sometimes involved in the development, clinical application and monitoring of new diagnostic and therapeutic procedures. They participate in research that aims to improve health and prevent disease. and collaborate in investigations involving patients with lung disease. Respiratory nurses are involved in almost all care programmes for patients with respiratory diseases including pulmonary hypertension, asthma, COPD, tuberculosis, transplantation, respiratory oncology, sleep disorders, and cystic fibrosis; they play a crucial and specific role in the care, education and self-management of patients within such programmes. In each care programme, they also have specific tasks: they monitor and treat patients, and ensure that patients adhere to the agreed therapy. As care moves away from the classical 'clinic' setting, respiratory nurses are also becoming active in the primary care of patients with COPD and asthma. This shift should be accompanied by proper education in the management of respiratory patients.

Respiratory nurses have an important role in patient education, the enhancement of patient self-management and the management of care. For more than 20 years, the British Thoracic Society (BTS) has recommended that respiratory nurse specialists should be attached to all respiratory medicine departments to act as a link between the hospital and the community. Several studies have examined the role of respiratory nurse specialists. It has been shown that they are effective in guiding self-management in asthma patients, and in coordinating an integrated care pathway focusing on identification, early intervention and management in COPD, including supervision of early hospital discharge and long-term care. An Australian study has shown the beneficial effects of domiciliary respiratory nurse intervention in the care of COPD

Physiotherapists should have greater involvement in tackling unhealthy behaviour – smoking and inactivity

SPECIAL FIELDS OF RESPIRATORY CARE

patients: although mortality was unchanged, involvement of an outreach respiratory nurse as part of a shared-care approach resulted in improved health-related quality of life.

A programme in Kilkenny, Ireland has identified that comprehensive care plans for older people with chronic respiratory diseases need to include training for respiratory nurse specialists in hospitals and the community to address the following areas of patient care:

- use of long-term oxygen
- accurate diagnosis
- appropriate use of medication
- monitoring of treatment efficacy
- community/hospital rehabilitation programmes, where appropriate
- smoking cessation
- multidisciplinary assessment and intervention
- recognition of early warning signs of an exacerbation with rapid access to appropriate services

Similar programmes exist in Spain and are predominantly led by respiratory nurses. A recent meta-analysis has highlighted the effectiveness of nurse-led programmes and has particularly shown the effects on health-related quality of life.

In patients with complex therapeutic schemes (*e.g.* patients suffering from pulmonary hypertension, those on long-term oxygen therapy and those receiving noninvasive mechanical ventilation), specifically trained nurses are key to ensuring quality care. More and more tele-health applications are used and overseen by respiratory nurses, allowing for remote monitoring and the adjustment of therapy.

An increasingly important element of the specialist respiratory nurse's role is to act as a clinical study nurse and coordinator. As respiratory nurses excel in providing patients with information at patients' level of understanding, and are trained in patient interview skills and the techniques relevant to respiratory research, they often run clinical trial units and help engage patients in clinical trials.

Respiratory nursing websites (see box) describe the respiratory nurse's role as promoting pulmonary health in individuals, families and communities, and caring for those with pulmonary dysfunction throughout their lifespan. Respiratory nursing care is preventive, acute or critical, and rehabilitative. A respiratory nurse may be employed as a staff nurse, clinical nurse specialist, nurse practitioner, nurse manager, supervisor, coordinator, director, executive, nurse educator, or research nurse; they are employed by hospitals, extended care centres, private companies, health departments, office practices and clinics. The Standards of Nursing Care for Adult Patients with Pulmonary Dysfunction developed by the Nursing Assembly of the American Thoracic Society (ATS) in 1989 offers a detailed guide to respiratory nursing clinical care.

Respiratory nursing websites

Nurse.com - www.nurse.com Respiratory Nursing Society - www.respiratorynursingsociety.org Association of Respiratory Nurse Specialists - www.arns.co.uk European Respiratory Society Nurses Group - http://www.ersnet.org/assemblies/ allied-respiratory-professionals/item/146-nurses.html American Thoracic Society Nursing Assembly - www.thoracic.org/assemblies/nur/ index.php PRACTISING RESPIRATORY MEDICINE IN EUROPE

Training

Professional societies at a regional level have a key role to play in training and education. Much of the nursing care that respiratory patients receive is provided by professionally trained nurses. In many disease areas, however, there is a need for specifically trained nurses with a Masterslevel degree or similar. Postgraduate education may allow respiratory nurses the opportunity to train to become leaders of care programmes. Within the ERS, the Nurses Group (part of the Allied Respiratory Professionals Assembly) ensures such training at a European level. Similarly, the ATS has a dedicated Nursing Assembly. Its mission statement summarises the aim of respiratory nurses as follows: 1) to prevent disease and disability in respiratory, critical care and sleep-related conditions; 2) to improve the management of symptoms resulting from these conditions; and 3) to enhance end-of-life and palliative care. The Assembly has also composed a formal list of research priorities for respiratory nurses

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Primary care practitioners

Introduction

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Key points

- Primary care practitioners are the cornerstone of any health system. They have a role in prevention, diagnosis, patient engagement and supported self-management, treatment and palliation.
- There is currently an unacceptable level of variation in access to primary care between European countries.
 Priorities should include an adequate supply of, and ready access to, primary care practitioners who diagnose and treat disease early and refer effectively to appropriate specialists.
- Primary care practitioners can play important roles in smoking-cessation strategies, reducing exposure to tobacco and indoor smoke during maternity and in newborns, improving children's health, reducing adult asthma exacerbations and providing holistic care for patients with COPD.
- Primary care offers a cost-effective and appropriate way to address the global burden of chronic respiratory disease. Its potential is constrained, however, by national health policies that do not recognise its strengths.

The World Health Organization (WHO) states that the only way to cope with today's global disease burden is through better access to, and application of, the principles and approaches of primary healthcare.

This chapter summarises the potential positive impact of primary care practitioners on the burden of respiratory disease in Europe, and describes how they could improve access to care and health outcomes. In particular, we should support the calls of the WHO and the Non-Communicable Disease (NCD) Alliance to take action now to combat chronic lung disease. Primary care needs to be made stronger, with less variation of investment between countries and faster progress towards the goals of the 62nd World Health Assembly (WHA62) resolution.

In a survey of nine countries, the WHO Global Alliance against Chronic Respiratory Diseases (GARD) found that, over a 5-year period, the proportion of patients with respiratory symptoms consulting primary care providers for any reason ranged from 8.4–37%. This reflects the high prevalence and variation of respiratory disease, underlines the need for primary care to be equipped to deal with it, and highlights the fact that some primary care services have the potential to do even more, given the right support. The only way to cope with the global disease burden is through better access to, and application of, the principles and approaches of primary healthcare

Primary care practitioners

Primary care practitioners are the cornerstone of any health system. They have a role in prevention, diagnosis, patient engagement and supported self-management, treatment and palliation. They can work with populations and with individuals. The principles, values and health economics of primary care have been fully described by the WHO (see Further reading).

The current variation in access to primary care, and the increasing divide between the growth in numbers of general practitioners and specialists is unacceptable. According to a report produced by the Office for Economic Cooperation and Development (OECD), there are more specialists than generalists in most European countries, with the exception of Romania and Portugal. Yet the existence of easily accessible, person-centred primary care is associated with a more equal distribution of health in populations that do not necessarily benefit from an overabundance of specialists. In cash-limited health systems, the priority should be an adequate supply of primary care practitioners who diagnose and treat disease early and refer effectively to appropriate specialists. Literature reviews have shown that inappropriate referrals to specialists lead to more tests, an increase in false-positive results and poorer outcomes than appropriate referrals. While in many European countries the primary care model is general practitioner-led, this is not the case in many other countries, where nurses, physiotherapists or other healthcare workers take the lead. The model chosen is less important than the quality of the intervention and the belief system that drives it. The value of the consultation must be to enable patients and their families to be active partners in their care and to recognise the likely existence of multiple comorbidities, particularly in older patients. In some countries, a primary care team provides the necessary skills; in others, individual practitioners have to display a wider range of diagnostic and enabling competences.

Primary care and chronic lung disease

It is internationally recognised that in order to better manage the economic impact of the growing burden of chronic lung disease, preventive, educational and management strategies need to be refined. Primary care is pivotal, but in order to perform its role

Useful websites

- World Health Organization What we do: data and evidence, health topics, events www.euro.who.int/en/what-we-do/health-topics/Health-systems/primary-health-care/policy This website draws together WHO policy on primary care and evaluation reports on the state of primary care in many European countries using the WHO Primary Care Evalution Tool.
- The Lancet Health policy and papers for chronic diseases and development, launched in November 2010 www.thelancet.com/series/chronic-diseases-and-development
 The Lancet's series of papers was an important contribution to the United Nations high-level meeting on chronic non-communicable diseases. The papers cover a range of diseases, including chronic obstructive respiratory diseases, and present strategies for substantial health gains, monitoring and scaling-up of interventions.
- International Primary Care Research Group tobacco dependence resources www.theipcrg.org/display/RESTOB/Home These free resources offer practical tools and evidence to improve healthcare professionals' success in helping their patients to stop smoking.



competently, it needs standards, guidelines and education that are developed specifically for primary care, that acknowledge the limited resources available in many countries, and that answer the questions relevant to primary care using evidence derived from long-term real-life pragmatic studies on populations that reflect primary care practice.

A role for primary care practitioners

Smoking

The International Primary Care Respiratory Group (IPCRG) regards smoking as tobacco dependency, and support to stop smoking as an effective treatment as well as a preventative intervention. This policy should encourage clinicians to take the problem more seriously and to see it as their core work. As primary care clinicians see very large numbers of patients, even the relatively small guit rate achieved from a brief intervention could make a huge impact in absolute numbers. Therefore, the IPCRG advises primary care clinicians to develop a 1-minute smoking cessation strategy that could be used with all patients who smoke. Smoking includes hookah (or waterpipe) smoking, which, although sometimes considered harmless, is in fact a form of tobacco dependency with associated adverse effects. Cannabis smoking also has adverse respiratory effects similar to those of smoking tobacco. A recent UK report found that a 1% increase in smoking rates in patients with asthma or chronic obstructive pulmonary disease (COPD) was associated with an increase in admission rates of a similar magnitude; stop-smoking support is an important treatment.

Maternity and newborn care

Tobacco smoking impairs lung growth and development, predisposing infants to respiratory disorders in early life.

MAJOR RESPIRATORY DISEASES

RESPIRATORY MANAGEMENT

SPECIAL FIELDS OF **RESPIRATORY CARE**

CONCLUSIONS

Poorly controlled asthma is associated with poor maternal and fetal outcomes in pregnancy, and there is evidence of the under-treatment of asthma in pregnancy even in high-income countries. Experience in low-income countries suggests there is extremely low or no awareness among local communities of chronic diseases such as asthma and COPD. Primary care teams with a respiratory interest can be powerful advocates for stopping smoking and can be champions for evidence-based and locally appropriate strategies to reduce tobacco dependency and indoor smoke, especially that caused by burning biomass fuel.

Children's health

Asthma and rhinitis (which often coexist) represent the most common NCDs among children. According to the ARIA (Allergic Rhinitis and its Impact on Asthma) study, early treatment of (allergic) rhinitis may positively influence asthma development. Despite advances in many countries in recent decades, children are still not optimally managed, and this compromises their schooling and examination performance. However, effective interventions are available that can be delivered safely in primary care.

Asthma mortality is high in countries where access to 'controller' drugs is low. The NCD Alliance has called for universal access to good-guality, affordable asthma inhalers, and eligible countries should be urged to take advantage of the Asthma Drug Facility of the International Union Against Tuberculosis and Lung Diseases (the Union). The current WHO cost-effectiveness evidence table could usefully be revised to indicate which drugs are 'best buys', rather than just 'good buys'.

Deaths in children and young adults peak in the months when allergen levels are high; healthcare systems should make pollen calendars and other seasonal information available to predict and mitigate some of this risk.

Adults: asthma and cost-effective care

In countries with more advanced primary care, proactive primary care management of asthma (including available anti-inflammatory and bronchodilator treatments) can prevent most exacerbations. If exacerbations occur, most can be handled in primary care without the need for hospitalisation. The OECD therefore suggests that high hospital admission rates may be an indication of poor quality of care or a lack of access to properly funded and supported primary care. There is considerable variation in care between countries and there are substantial opportunities for improvement. Better continuity of care with a family doctor may be associated with a lower risk of admission in all age-groups for 'ambulatory care-sensitive conditions' – conditions without complications that can often be managed in the community rather than in hospital, such as asthma and COPD. Where hospital care is required, integrating and improving coordination with primary care can be effective in reducing (re)admissions.

An example of the benefits of improving primary care is seen in Finland where, despite increasing incidence of asthma, a systematic 10-year programme based on primary care resulted in a decrease in hospital days and disability payments, as well as associated costs.

Chronic obstructive pulmonary disease

Strong primary care is fundamental to the prevention of COPD as it provides support for a reduction in exposure to tobacco smoke, recognises and establishes an

early diagnosis, engages patients in active exacerbation management, and provides ongoing care for patients with established disease through to the end of their life. Spirometry testing should be developed in primary care, along with access to exercise programmes, multidisciplinary collaboration, and effective communication between primary and secondary care for those who need admission to hospital. Importantly, primary care professionals are ideally placed to address the holistic needs (physical, psychological, social and spiritual) of COPD patients as the disease progresses towards end of life.

Improving access to care is more likely to reduce hospitalisation rates for COPD than attempting to change patients' propensity to seek healthcare or eliminating variation in physician practices. Better public funding of primary care is likely to improve access.

Influenza vaccination plays its part in reducing exacerbations of both COPD and asthma. However, there is substantial national variation in its uptake; for example, in 2008, uptake in the Czech Republic was 21.2% in those aged more than 65 years, compared with 77% in the Netherlands, and an average coverage of only 54.2% in 18 European Union countries.

Where infrastructure allows, a registry or database of asthma and COPD patients should be maintained in order to enable long-term review. In addition, given the uncertainty about the best-value interventions for COPD, a dynamic database of international primary care COPD registries would help to answer relevant real-life research questions.

Conclusion

The global burden of chronic respiratory disease will have an increasing impact on the economy and health, affecting the practice of respiratory medicine in Europe. Primary care offers a cost-effective and appropriate way of addressing this burden. However, some of its potential is constrained by national health policies that do not recognise its strengths and therefore do not invest in reimbursement, education, recruitment or procurement strategies which strengthen and sustain its role and contribution.

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SPECIAL FIELDS OF RESPIRATORY CARE

CONCLUSIONS

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Specialist clinical training (HERMES)

Specialist training in respiratory medicine



Key points

- There is wide variation in the duration and content of respiratory medical training in Europe.
- The free movement of labour within the European Union has created a need for internationally recognised standards of competence in medical specialties.
- The HERMES methodology has been set up to enable the creation and implementation of a full set of educational standards, from syllabus to individual assessment and accreditation of training centres.
- HERMES projects are now under way in seven areas of respiratory medicine.

An important mission of the European Respiratory Society (ERS) is the promotion of lung health through medical education, a central part of which is the training of future respiratory specialists (postgraduate training) through the ERS School.

There has been a clear need to harmonise and improve education and training in Europe. In part this has been driven by the advent of free movement of labour within the European Union and the consequent need for national registration authorities to agree criteria on the competence of medical specialists from other countries. Recognising this need, the ERS launched the HERMES (Harmonised Education in Respiratory Medicine for European Specialists) project in close cooperation with the European Union for Medical Specialists (UEMS),



Figure 1 – The four phases of a HERMES project.

The HERMES activities will have a real and significant impact on the care of patients with respiratory disease throughout Europe

the Forum of European Respiratory Societies (FERS) and the European Board for Accreditation in Pneumology (EBAP). An educational task force established by the ERS School and consisting of experts representing the above organisations, along with a member of the Permanent Working Group of European Junior Doctors, plus representatives from several European regions, developed a strategy to define optimal educational standards in order to achieve better harmonised training of specialists in respiratory medicine. The strategy comprises four project phases (figure 1).

Development strategy for educational standards

The European task force, supported by the ERS School, applied a specific methodology consisting of facilitated group discussions, a modified Delphi consensus-building process and plenary meetings, to develop and produce a series of core documents setting out the agreed European consensus recommendations for each HERMES phase.

Syllabus phase: 'what'

This phase aims to develop generally accepted European syllabi representing the content of the required knowledge (what respiratory specialists should know for their initial training in general respiratory medicine, and subsequently the additional knowledge required for those who choose to undertake more advanced training in a specific subspecialty area).

Curriculum phase: 'how'

This phase aims to develop generally accepted recommendations for a full European curriculum, providing an overview of the entire content of the educational programme, not only what respiratory specialists should know, but also how competencies in respiratory medicine should be taught, learned and assessed. In addition, this phase also includes development of detailed recommended curriculum training modules, expressing objectives in terms of the knowledge, skills, and behaviour and attitudes required to complete each module.

In addition to the syllabus, other parts of the curriculum such as assessment and accreditation are also developed in greater detail in separate phases of the project as set out below.



Assessments phase

In the assessments phase, European assessment methods are developed. The first of these was the introduction of a voluntary knowledge-based examination in adult respiratory medicine with multiple-choice guestions (MCQs), developed and run in close cooperation with the Institute of Medical Education in Bern, Switzerland, to assure high-quality professional educational standards. The examination is based on the examination blueprint – which comprises weighted examination topics from the 2006 syllabus – and is composed of 90 MCQs which must be answered in 3 hours. Only successful candidates who are already gualified as national respiratory specialists are eligible to receive the ERS Diploma in Adult Respiratory Medicine, as a recognised European qualification to mark their high quality and commitment to high-level knowledge. The examination is also used for regular revalidation, and is open to trainee specialists to test their knowledge. Following the success of the adult examination, a paediatric version has also been introduced.

More recently, the ERS School and HERMES task forces have seen the need to move beyond MCQ examinations based solely on the assessment of knowledge. Task forces are now investigating direct observation of procedural skills (DOPS) and other assessment methods for subspecialty areas of respiratory medicine.

Accreditation of training centres phase

The accreditation phase will enable European training centres in respiratory specialties to apply for ERS/EBAP accreditation. The purpose of accreditation within the HERMES initiative is to ensure that training centre networks whose educational programmes in respiratory specialties reach the required level of excellence are certified as such.

Development of this project phase requires two key steps:

- 1) Documented minimum criteria for a training centre.
- 2) Detailed processes and supporting documentation to
- determine whether the prerequisites are met.

The second step refers to the accreditation process itself and is based on the well-established accreditation practice of site visitation.

Network of supporting initiatives

The successful implementation of the HERMES educational standards in respiratory medicine is dependent not only on the core activities but also on a network of supporting initiatives, including preparation courses for the examination, educational resources, and e-learning activities for example (figure 2).





 Postgraduate courses • Hands-on workshops

The HERMES projects

The important milestones reached by the first HERMES project to establish European standards for training in adult respiratory medicine provided clear evidence that similar methodology could be employed in the standardisation of education in other specialty areas of respiratory medicine (figure 3).

Adult respiratory medicine

A survey conducted in 2005 jointly by the ERS and the pneumology section of the UEMS showed large variation in respiratory training between countries, particularly concerning the length of the training period (ranging from 3 to 7 years for prespecialist training and 2.5 to 8 years for specialist training). Although UEMS issued a recommendation on training requirements in Europe in 1994, which was updated in 2002, a benchmark analysis in 2005 revealed that wide discrepancies still existed in the length and quality of training in respiratory medicine (figure 4).

A further survey conducted by the ERS showed that not all countries have a unified syllabus and training programme, that some do not even have an 'exit' examination and that a few countries have no official list of accredited training centres. This confirmed the need to develop standardised educational documentation and activities in adult respiratory medicine and to move through each of the phases for development of European standards. This model was used in a similar way for all of the other HERMES projects, but is described in detail here only for adult respiratory medicine.

Syllabus development

Experts from 29 countries came together to develop the syllabus, and input was sought from all clinical specialist members of the ERS and national respiratory societies. The final consensus-based syllabus was published in 2006. It contained 229 competencies, split into 51 modules and nine sections:

- 1) Structure and function of the respiratory system
- 2) Knowledge of respiratory diseases

MAJOR RISK FACTORS

DVERVIEW



Figure 3 – The HERMES projects.

- 3) Symptoms and signs
- 4) Diagnostic procedures including monitoring techniques
- 5) Treatment modalities and prevention measures
- 6) Core generic abilities
- 7) Competence in fields shared with other specialities
- 8) Knowledge of associated fields relevant to adult respiratory medicine
- 9) Further areas relevant to adult respiratory medicine

The syllabus also included recommendations about the levels of knowledge required for each item listed. No recommendation was made relating to numbers of procedures to be performed in order to become qualified, but clear recommendations were made regarding overall training duration and structure.

General recommendations were divided into sections pertaining to:

- Clinical field of respiratory medicine
- Principles underpinning the development of a curriculum for respiratory medicine
- The education of respiratory medicine trainees
- Assessment
- Characteristics and responsibilities of key training personnel
- Accountability and regulation
- Quality assurance, validation, accreditation and evaluation of the programme.



Figure 4 – Training practice periods in adult respiratory medicine, 2005. Intensive care has been indicated for those countries where a specific number of months are included in mandatory training. However, it must be noted that intensive care is also included as mandatory modules covered within respiratory medicine or internal medicine training of other countries. France: the 24 months indicated under internal medicine is elective training time for the trainee. It is possible that trainees may decide to spend this training in another specialty, for example cardiology, internal medicine or a further 2 years in respiratory. Germany: 6 months' intensive care medicine is covered within the assigned mandatory training for respiratory medicine and internal medicine. Slovenia: no common trunk training exists before entering either internal medicine or respiratory medicine. Spain: 5 months' intensive care medicine is covered within respiratory training. UK: dual training in internal medicine and respiratory medicine is a total of 60 months.

Curriculum development

The final curriculum contains 34 disease-based modules structured in a form which can be implemented and taught in practice, setting out the main core competencies that trainees are required to have knowledge of and demonstrate competence in. It also lists existing clinical guidelines pertaining to the modules.

Assessment development

The first European examination in adult respiratory medicine took place in 2008 at the ERS Annual Congress, and examinations have been held at each subsequent Congress. Candidates who pass the examination are eligible to be awarded the European Diploma in Adult Respiratory Medicine only if they have already acquired their national diploma as a specialist in adult respiratory medicine. Since 2010, trainees studying for their national specialist qualification have also been allowed to sit the European Examination as an exercise in in-training self-assessment of their progress, but such trainees are not eligible for the diploma until successful completion of their training. Local examination as an in-training or self-assessment examination annually. In 2012, the examination took place for the first time in Moscow for in-training and self-assessment candidates.

The aim is for the European examination to be officially recognised in all European countries. Since 2008, Switzerland has used the HERMES European Examination in Adult Respiratory Medicine as the official part of its national exit examination for

SPECIAL FIELDS OF RESPIRATORY CARE A survey conducted in 2005 ... showed large variation in respiratory training between countries adult respiratory medicine specialists. Austria also formally recognises the HERMES European examination as equivalent to its official national exit examination, and avenues for collaboration with authorities in Greece, Ireland, Malta, Portugal, Romania, Saudi Arabia, Spain, Sweden and the UK are being explored. The number of voluntary participants, including candidates from outside Europe, is increasing, and it is hoped that the examination will gain international recognition as a state-of-the-art knowledge assessment.

Accreditation of training centres

The criteria for accreditation have been developed and agreed, and were published in December 2010. Following bestpractice guidelines in accreditation of postgraduate education established by the World Federation of Medical Education, the ERS has partnered with the accreditation body EBAP.

Training centres or networks that gain accreditation will benefit from receiving a label of quality, gaining visibility and attractiveness for trainees and potentially being in a better position to secure research funding. Accredited centres (and those aspiring to accreditation) will be incentivised to develop or maintain high-quality training programmes and facilities.

The next challenge will be to implement an accreditation process. A pilot programme of three or four training centres is planned, in collaboration with EBAP.

Paediatric respiratory medicine

The paediatric assembly of the ERS published a syllabus specific for paediatric respiratory medicine in 2002, together with recommendations on training centres on a tertiary care level. In order to update this syllabus, a Paediatric HERMES task force was launched in 2007. Following the structure of the adult HERMES project, the new syllabus was published in 2009 and on the basis of this syllabus curriculum recommendations were developed, together with a special assessment toolbox. These were published in 2010. The first European examination in paediatric respiratory medicine took place in 2011.

Future tasks are the development of training networks and the accreditation of European training centres, with the aim of harmonising and standardising training in paediatric respiratory medicine across Europe. As with the adult HERMES project, the primary goal is to achieve quality control for all aspects of training, to facilitate free movement of trainees across centres and nations and to deliver the best care to children with respiratory diseases.

Spirometry

An ERS survey of national spirometry training programmes and research in the literature, conducted in 2008, confirmed

CONCLUSIONS

the lack of training opportunities, under-utilisation of spirometers and diagnosis based on inaccurate results. A task force was created to set educational standards for the training and certification of spirometry.

A complete training programme was published in 2011, defining the length of training, the target audience and educational methods required for training.

It is intended that the spirometry training programme will be delivered at a national level by trained and experienced spirometry teachers. Therefore a 'train the trainer' course programme to train future spirometry teachers was designed. This was launched during the ERS Congress in 2012, and will be repeated each year. The training programme is designed to equip course directors with the knowledge, skills and tools to deliver a complete spirometry training programme and to acquire a 'European Spirometry Driving Licence', thus enabling a new generation of health professionals, nonmedical as well as medical, to perform high-quality spirometry tests. In addition, a set of training guidelines for certification, standardised educational documents for participants and trainers, a spirometry website and assessment guidelines on spirometry testing, will be produced.

Respiratory critical care

A respiratory critical care educational task force was launched in 2009. The project's overall aim is to harmonise training in respiratory critical care medicine throughout Europe. Respiratory critical care can be defined as part of intensive-care medicine, dealing with specific respiratory problems; or as part of respiratory medicine, specifically respiratory failure that does not need direct access to general, medical or surgical intensive care units.

A syballus with 19 comprehensive modules was finalised in 2011, and plans are in motion to develop a European curriculum and, as a further step, to provide the groundwork for a diploma in respiratory critical care medicine. The curriculum will define the level of competence for adult respiratory physicians not directly involved in multidisciplinary critical care but who need knowledge of respiratory critical care. This is a first step towards a European diploma in respiratory critical care open to all physicians specialised in adult respiratory medicine who deal with intermediate respiratory intensive care units or specialised units dedicated solely to pulmonary critical care.

Sleep

To address the increasing importance of respiratory sleep medicine as a subspecialty of respiratory medicine, the respiratory sleep HERMES task force and project was launched in 2009. The rationale for the project emerged from a needs analysis across 35 European countries, which confirmed the diversity and varying duration of respiratory sleep training and certification.

The project aims to establish common standards for both physicians and nonmedical practitioners. The consensus-based core syllabus, comprising nine modules, was published in 2011. On the basis of the syllabus the task force is preparing a curriculum to describe how the knowledge and skills should be taught and learned, with a view to developing an assessment in respiratory sleep medicine. As the curriculum is mainly intended for trainers, the task force is producing further educational materials (including a handbook, published in 2012) on respiratory sleep medicine to aid future trainees.

Thoracic oncology

The ERS considers comprehensive and multidisciplinary educational standards for thoracic oncology to be an important component of its mission to alleviate the suffering of patients with respiratory disease, including malignancies. The HERMES project methodology will be adopted to develop consensus-based educational standards and also to strengthen this subspecialty. The initiative is being carried out in collaboration with representatives from societies involved in thoracic oncology: the European Society of Thoracic Surgeons (ESTS), the European Society of Medical Oncology (ESMO) and the European Society for Radiotherapy and Oncology (ESTRO). One of the main objectives is to provide a comprehensive review of the current status of thoracic oncology training and certification in Europe. Another goal is to examine how to raise skill levels in thoracic oncology. This can be achieved through developing consensus-based standards with a European syllabus and curriculum and recommendations for a certification programme.

Respiratory physiotherapy

The respiratory physiotherapy HERMES project began in 2012. The project aims to develop a postgraduate respiratory physiotherapy training programme with a specific training period defined by task force members. The project will closely follow the development strategy for educational standards defined through HERMES.

Conclusion

The HERMES methodology has now been applied across many of the subspecialty areas of respiratory medicine and is providing a range of consensus documents and activities for the education and training of respiratory specialists. These activities will have a real and significant impact on the care of patients with respiratory disease throughout Europe.

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ERS School and postgraduate education

Introduction



Key points

- The ERS School's aim is to develop educational programmes and training opportunities in respiratory medicine for physicians and allied health professionals.
- The HERMES (Harmonised Education in Respiratory Medicine for European Specialists) project was set up to establish a European syllabus and curriculum for the practice of respiratory medicine. HERMES now holds yearly examinations in adult and paediatric respiratory medicine.
- Every year, the School organises more than 40 educational sessions during the ERS Annual Congress and six to eight 3-day external courses, intended to provide a deeper understanding of a selected topic.
- A number of ERS educational publications are available: Breathe, the European Respiratory Monograph, the ERS Handbook of Respiratory Medicine, Self-Assessment in Respiratory Medicine, and the ERS Handbook of Respiratory Sleep Medicine.

The European School of Respiratory Medicine, later named the European Respiratory Society (ERS) School of Medicine after integration into the ERS, was established in 1993 by Professor Jean-Claude Yernault. The School's mission from the beginning has been to develop educational programmes and training opportunities in respiratory medicine for respiratory physicians and allied health professionals. To achieve these aims, the School is run by a democratically elected committee that represents all branches of respiratory medicine. The chair of the School committee is also part of the ERS's core leadership group.

During the early years, the educational activities of the School focused on the organisation of postgraduate (PG) courses held during the annual ERS Congress. Gradually, however, the scope broadened: 'external courses' are now held outside the parameters of the congress; the very successful educational journal *Breathe* (www. breathejournal.org) was launched in 2004; and the School's online e-learning platform contains a huge range of learning resources (www.erseducation.org).

These resources are valuable sources of continuing medical education (CME) and continuing professional development (CPD) for respiratory practitioners worldwide. The mission from the beginning has been to develop educational programmes for respiratory physicians and allied health professionals

The HERMES projects

In 2005, the ERS School made a considerable leap forward with the launch of HERMES (Harmonised Education in Respiratory Medicine for European Specialists, hermes. ersnet.org). The HERMES project partners the Forum of European Respiratory Societies (FERS) with the Union Européenne des Médicins Spécialistes (UEMS) for the development of a European syllabus, a European curriculum, criteria for training centre accreditation in Europe, and an examination for qualification as a European specialist in adult respiratory medicine. The first adult respiratory medicine examination was held in 2008. Since then, almost 500 respiratory specialists and 350 trainees have taken the examination. The examination has also been adopted by some European countries as the knowledge-based element of their own respiratory specialist training: Switzerland has used it as the written part of its national certification examination since 2008; in the Netherlands, it has been used as an obligatory in-training assessment since 2010; and Austria recognises it as an equivalent to its national certification.

Further developments came with the expansion of the HERMES project to cover paediatrics. The first European examination in paediatric respiratory medicine was held in 2011.

The School's educational activities for specialist trainees are now developed and carried out using the HERMES methodology, and a 'family' of seven active HERMES projects is now in place (table 1; see also chapter 36). Recently, the HERMES Respiratory Sleep

Adult respiratory medicine Paediatric respiratory medicine European Spirometry Driving Licence Respiratory sleep medicine Respiratory critical care medicine Thoracic oncology Respiratory physiotherapy

 Table 1 – HERMES (Harmonised Education in Respiratory Medicine for European Specialists) projects.

DVERVIEW

MAJOR RISK FACTORS

Medicine and the HERMES Respiratory Critical Care Medicine syllabi have been published, with the aim of defining the competences required of European respiratory physicians in these fields (further information can be found in chapter 36).

The ERS School web platform

The ERS School website was launched in 2000, and has been continuously developed and expanded (figure 1). It boasts peer-reviewed presentations, journal articles and guidelines as well as a growing range of videos, interactive clinical cases and online courses. The material is organised by topic into 'educational tracks' and users can personalise the site according to their field of interest. Many of the materials on the site are accredited as CME activities by the European Board for Accreditation in Pneumology, and users can earn CME credits (recognised in most European countries) by viewing or taking part in them.

ERS School Courses

The key event in the ERS School year remains the society's annual congress. Every year, the School organises about 20 PG courses, 16 Meet-the-Expert seminars and six Morning Seminars, all of which are held during the annual ERS Congress. These courses are intended to provide basic



Figure 1 - The ERS School website, a personalised view.

The ERS School will also seek to provide team-based programmes, adjusted to meet local needs knowledge and practical skills in various fields of respiratory medicine. Some include practical facilities and interactive sessions, and popular topics include noninvasive ventilation (NIV), respiratory sleep disorders, rehabilitation, exercise testing, asthma, chronic obstructive pulmonary disease (COPD), interstitial lung disease, lung cancer, lung imaging and pulmonary hypertension. More than 2000 participants attend these events each year.

The School also organises between six and eight 3-day external courses each year. The most popular course topics include interventional procedures, respiratory sleep medicine and NIV. These courses are intended to provide a deeper understanding of the selected topic, with more than half of the time devoted to practical and interactive sessions.

In 2012, the first HERMES Summer School was held to help candidates prepare for the HERMES European examination in adult respiratory medicine. The course programme covered all of the important topics in the HERMES syllabus and included revision of the supporting literature and multiple-choice questions. Similar courses will be organised in the future by national respiratory societies under the supervision and approval of the ERS School.

School publications

The School is very active in the field of educational publication: in addition to *Breathe*, the quarterly educational journal, the *European Respiratory Monograph* (*ERM*) book series (erm.ersjournals.com), is also published four times a year. Each *ERM* covers a specific area of respiratory medicine, providing clinicians at all levels with a series of comprehensive up-to-date reviews.

In 2010, the first edition of the *ERS Handbook of Respiratory Medicine* was published, and a second edition is being published in 2013. The content of the Handbook follows the HERMES syllabus and curriculum and provides a compact guide to each of the key areas of respiratory medicine. It has been extremely popular, drawing a worldwide readership. Buoyed by this success, the School published two new handbooks in 2012: *Self-Assessment in Respiratory Medicine*, a companion to the adult handbook, comprising clinical scenarios with multiple-choice questions and explanations; and the *ERS Handbook of Respiratory Sleep Medicine*, which closely follows the HERMES respiratory sleep medicine syllabus and covers the causes, diagnosis and management of adult and paediatric respiratory sleep disorders.

Educational research seminars

Recently, the School reasoned that there was a need for critical self-reflection on the current state of educational policies within the ERS, and that the future directions in respiratory medical education needed to be determined. To this end, the first ERS educational research seminar was organised in Dublin in June 2011. Experts in respiratory medicine and medical education, including colleagues from the American College of Chest Physicians (ACCP) and the American Thoracic Society (ATS), met to discuss future trends and challenges in respiratory medical education. The 2-day seminar covered topics such as the evolution of medical education, challenges in educating

respiratory healthcare professionals, the harmonisation of medical education in Europe, knowledge transfer, instructional methods (including simulation and skills training), electronic learning (e-learning) and CME, and personal electronic learning records (e-portfolios). The School is planning to organise further regular educational research seminars to improve the methodology and the quality of its educational resources.

Skills-based, hands-on learning

The School is placing ever-greater emphasis on hands-on, simulator and virtual teaching techniques. This is driven by a number of factors, including a decrease in training time (resulting in reduced exposure to patients), recognition that the acquisition of practical skills matters as much as acquiring knowledge, and the simple fact that patients do not like to be practised on. The most popular School activities currently include 'hands-on' bronchoscopy, cardiopulmonary exercise testing, NIV and ultrasonography courses. A bedside course on COPD management also ran for the first time in 2012, combining theoretical and skills-based training.

Strategic developments in the School

Professional reassessment (revalidation)

In addition to providing educational programmes for respiratory trainees, the School recognises that it has a responsibility to provide continuing medical education for all respiratory physicians, both senior and junior, as professional reassessment and revalidation is becoming increasingly important. Continuing medical education is likely to be a blend of knowledge-based education with face-to-face activities, e-learning, skills-based training and refresher courses. Importantly, physicians need to be able to demonstrate that their learning has influenced and improved their practice and patient care. A particular effort is being made to create these resources, and simplify their management in personalised e-portfolios.

Allied health professionals

The School provides educational programmes for allied health professionals. A major practical initiative of the School has been the establishment of the HERMES European Spirometry Driving Licence, which aims to standardise the accurate performance of spirometry tests and the interpretation of the data they provide. The first 'train-the-trainer' full-day PG Course took place in 2012, with the aim of disseminating good practice as widely as possible. The HERMES respiratory physiotherapy programme is also now under way and plans to publish its syllabus soon.

The School has a key role to play in this area, as there is an unmet need to provide extensive training opportunities for allied health professionals, both at an international level and in many European Union countries. The School will also seek to provide team-based programmes, adjusted to meet local needs: many, if not most, healthcare professionals now work as part of a multidisciplinary team.

Evaluation of School activities

Rigorous evaluation and the incorporation of feedback are essential to the improvement of the courses offered and their structure and design. The use of a simple questionnaire at the end of a session is no longer sufficient. Consequently, the School has sought the continued input and advice of a medical educationalist and CME experts.

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DVERVIEW

CONCLUSIONS

Respiratory research

Introduction

III (Ì)

Key points

- Imaging makes a major contribution to diagnosis and monitoring in respiratory medicine, so the constant improvement of imaging techniques has a significant impact on the specialty. Techniques such as real-time MRI, three-dimensional ultrasonographic computing and 'visiology' are deepening our understanding of a range of conditions.
- Genomics, proteomics and metabolomics are among the biological monitoring tools that are increasing our knowledge of diseases from cystic fibrosis to cancer. Biomarkers such as exhaled volatile organic compounds offer potential improvements in disease monitoring, while pathogen genomes are providing new insight into infectious threats.
- 'Biological' drugs are increasingly important in respiratory medicine, using antibodies and antagonists to block or modify disease mechanisms, oncogenes and metabolic pathways in asthma, COPD, idiopathic pulmonary fibrosis, cancers and pulmonary hypertension.

Respiratory diseases, whether acute or chronic, communicable or noncommunicable, impose a major global burden and affect millions of people. Despite the high prevalence of respiratory disease, only 4.3% of the health budget in the European Union's (EU) seventh Framework Programme for Research and Technological Development (FP7) was dedicated to respiratory research. Nevertheless, several large-scale local and international population studies have been and are being performed in order to gauge the prevalence and incidence of respiratory diseases and their associated risk factors. Some of these studies have been in progress for more than 20 years, among them the European Community Respiratory Health Survey (ECRHS) and its follow-up surveys. A more detailed discussion of these long-term studies is available in the online supplement.

Recently, several research areas strongly linked to the pathogenesis of respiratory disease have been identified as priorities by the EU. These areas include

- 1. Early origins of lung diseases
- 2. Lifestyle and lung health
- 3. Lungs and the environment
- 4. Lung defences and infections
- 5. Lung diseases in an ageing population

Table 1 - Five over-arching themes in lung research.

MAJOR RESPIRATORY DISEASES

CONCLUSIONS

Web and smartphone applications enable patients and physicians to monitor diseases such as asthma in daily life

tobacco, the environment, nutrition and physical activity. Lung research encompasses a wide range of diseases and can be classified according to major themes that cover both the origins and consequences of diseases in an evolving scientific environment. Five major themes have been identified by the European Respiratory Society scientific committee, relating to childhood, lifestyle consequences, environment, lung infections and ageing (table 1).

Respiratory diseases are often diagnosed at an advanced stage but hopefully, thanks to progress in investigational technologies (such as imaging and biomarkers), more patients will benefit from diagnosis and management earlier in the course of their disease. However, there is still a long way to go. Over the past 40 years, only nine new major respiratory drugs have been developed and we urgently need new medications and treatments for several respiratory diseases, as discussed later.

Fields of research

Early origins of lung diseases

The number of very premature babies who survive into childhood will continue to increase over the coming years and as a consequence, the number of children with chronic lung disease is also likely to increase. Pre-natal factors are known to influence lung health later in life and both nutritional deficiencies and maternal smoking have epigenetic influences on the developing lung. These epigenetic factors even seem to have transgenerational effects, which continue from grandmother to mother to daughter. Life expectancy for several congenital defects has also increased markedly with improved care, as infants with cystic fibrosis or neuromuscular disease benefit from early intervention with new targeted biological approaches.

Prevention of severe early infection is important, in order to reduce the incidence of lifethreatening pneumonia or bronchiolitis, which can have consequences in adulthood in addition to their acute severe morbidity.

As well as impacting lung development, genetic and epigenetic factors related to the environment lead to alterations of defence mechanisms, with an undue inflammatory response to common allergens resulting in allergies in the form of rhinitis or asthma of varying severity, which often persist into adulthood. A more comprehensive understanding of these mechanisms is still needed in order to improve the treatments available.



Thanks to progress in investigational techniques, patients will benefit from earlier diagnosis

Lifestyle and lung health

It has become increasingly apparent that lifestyle can impact lung health markedly. Nutritional deficiencies impair lung growth, favour infections and can decrease the ability to control inflammatory processes due, for instance, to a lack of antioxidative factors.

Lack of physical activity, often combined with obesity, impacts on disorders such as asthma or chronic obstructive pulmonary disease (COPD). Obesity also leads to obstructive sleep apnoea syndrome (OSAS), a condition whose prevalence has increased steadily over the past decade across all EU countries due to both better recognition of the disease and the increasing obesity of the population in general. The cardiovascular and metabolic consequences of OSAS are now recognised to be significant and will add to the overall burden of disease in Europe in the next decade.

Active and passive smoking are major factors in the aetiology of COPD and, of course, lung cancer. Asthma and COPD are the most prevalent respiratory diseases in the EU and the prevalence of both is increasing, placing a major burden on healthcare systems. There is a need to identify all contributory factors in these diseases, both intrinsic and extrinsic.

Sexual promiscuity and poverty have a major impact on the epidemiology of tuberculosis (TB), with an increase of its incidence particularly seen in the HIV-infected population. Respiratory infections in general are also frequent in such situations.

Drugs used to treat a variety of diseases can cause serious lung injury, resulting in pulmonary fibrosis or pulmonary hypertension, with possible fatal outcomes. Further research into these effects should help the relevant agencies develop prevention and management recommendations.

Lungs and the environment

The lungs are essentially wide open to the environment and have a very large surface area (approximately equal to that of a tennis court). Inspired air is separated from the blood in the pulmonary capillaries by a barrier of only about 1 μ m. Inhaled particles of 2–10 μ m in diameter are deposited in the airways and exposure to allergens and other particles contributes to asthma in 6–10% of the population, as well as to COPD, which is induced by exposure not only to smoking but also to indoor and outdoor pollution. The relevant indoor factors have still not all been identified. New volatile organic compounds used in construction and other industries have

been added to better-known agents, such as sulfites, chlorates, isocyanates, and many other substances already known to be potentially toxic.

Asthma is an inflammatory disease of the airways secondary to known allergens and irritants, and several occupational agents have been shown to be responsible for its development. Some professions are well known to be at risk, such as bakers and carpenters; in other occupations, such as painting, building and hairdressing, asthma is induced by mechanisms that need to be further explored so that more effective preventive measures may be taken. Common cold viruses are also a very important trigger of asthma and, to reduce the ensuing morbidity, the mechanisms involved need to be better understood.

Carcinogens are abundant in tobacco smoke but other substances known to contribute to lung cancer originate in the environment. These include the radioactive element radon, which may be released naturally from the granite below houses, or asbestos extracted from mines and used for building insulation. Such compounds need to be identified and environmental exposure to them minimised. The mechanisms involved also need to be better understood in order to improve prevention and treatment.

As the climate changes during the coming century, environmental exposures are likely to alter, as atmospheric conditions and the distribution of flora and fauna change. This climate variation can to some extent be predicted and its impact on lung health needs to be further investigated.

Lung defences and infection

Acute lower respiratory tract infections (such as bacterial and viral pneumonia, influenza and respiratory syncytial virus infections) are the third most-frequent cause of death worldwide, accounting for 4.25 million deaths each year. The state of the lungs' defences and the occurrence of infections are closely linked. A better understanding of how infections are prevented by the upper and lower airways is required; once we know how the defences function, we will have a clearer understanding of the way in which environmental factors and nutritional deficiencies may alter these defences to allow airway infections or pneumonia.

TB remains a leading cause of death worldwide, and any weakening of lung defences favours the occurrence of active disease and its propagation.

Where feasible, improvements in lung defences should be promoted – by the use of efficient vaccines, for example. The effects of immune-modulating agents, such as those used in treating malignancy and autoimmune diseases, need to be better understood in order to mitigate the effects of the resulting impairment of defences and the consequent severe secondary infections.

Early diagnosis of emerging new pathogens is crucial to allow appropriate use of new and existing therapies. New respiratory viruses appear quite frequently and rapid, reliable methods for diagnosis and typing of the viral strains need to be developed in the community. New vaccines and antiviral agents are also needed. Multidrug-resistant infectious agents and emerging fungal infections in immunocompromised patients are among other new challenges and new drugs against them need to be developed and tested. Investigational technologies and imaging Biological monitoring and biomarkers New interventions and biological treatments

 Table 2 - Fields where further biomedical research is needed.

Lung diseases in an ageing population

As European populations age, maintenance of good lung health will become a real challenge for current and future physicians. With age, both the upper and lower airways develop atrophic changes in the mucosa and thus the natural defences are altered. Elderly people tend to have more aspiration during swallowing and neuromuscular insufficiency may worsen their ability to cough. Humoral and cellular immunity also tend to alter with ageing. All these factors participate to varying degrees in the marked increase in lung infections that is seen with ageing, and the associated high morbidity and mortality. Physical activity, a comprehensive vaccination policy and good nutrition may help to prevent debilitating infections.

Ageing causes a reduction in the gas-exchange surface of the lungs, which may lead to a reduced capacity to oxygenate the blood. The airways become more collapsible, which contributes to obstructive lung disease. Prevention of undue inflammation related to environmental factors might decrease the effects of this natural decline in airway function.

Lung injury related to inhaled particles or to infections can produce scarring, sometimes leading to lung fibrosis and respiratory insufficiency. Some of these fibrotic processes may also be related to defects in natural repair and/or to a higher incidence of autoimmune diseases among older people. These immune processes lead not only to scarring of distal airways, but also in some patients to vascular narrowing and a higher incidence of pulmonary arterial hypertension with age.

The tissues of the body are continuously renewed by the division of progenitor cells. With ageing, dysregulation of these regeneration processes can occur, leading to various thoracic malignancies and tumours. Better knowledge of the effects of carcinogens should lead to improvement in effective prevention measures. Malignancy is also related to genetic factors and the identification of these may result in more individualised diagnostic screening and more personalised treatment.

Advances in respiratory biomedicine

Investigational technologies and imaging

Imaging methods are improving constantly. In respiratory medicine, imaging makes a major contribution to the precise diagnosis and the monitoring of therapy. Several new investigational and imaging techniques are beginning to become available, but in many cases there is still room for improvement in their application. Examples include the following.

- Real-time magnetic resonance imaging (MRI) for pathophysiological assessment, for example in pulmonary hypertension.
- Metabolic imaging with improved positron emission tomography scanning, in particular in the fields of oncology and inflammatory diseases.
- Improved analysis of three-dimensional computed tomography, applied, for example, in emphysema, fibrosis and assessment of tumour volume.
- Three-dimensional ultrasonographic computing for better assessment of pulmonary hypertension, vascular anomalies and pleural disease.
- Functional imaging using *in vivo* confocal microscopy. Such imaging allows analysis of: vasoactivity phenomena during hypoxia; ischaemia reperfusion events; or migrating ('homing') cells in pathological processes such as tumours or inflammatory diseases.
- Advances in interventional pulmonology. These techniques can be applied in the airways, the pleural space or the mediastinum. Among the more important are the superDimension endoscope, the confocal laser micro-endoscope, optical coherence bronchoscopy and auto-fluorescence bronchoscopy.
- Nanotechnology to target the *in vivo* inflammatory processes of tumoral cells for diagnostic or therapeutic purposes.
- Development of 'visiology': techniques that combine imaging with physiological measurements.
- Web and smartphone applications so that patients and physicians can monitor diseases such as asthma in daily life and facilitate the use of rescue medication or understand the role of environmental exposure for asthma control.

Biological monitoring and biomarkers

Many novel tools are now being used or are under development for improved diagnosis and better measurement of the evolution of diseases.

Several of these novel tools come under the heading of 'omics': genomics, proteomics, metabolomics and so on. Genomic analysis is already important, and will become even more so for the diagnosis of congenital conditions such as cystic fibrosis, neuromuscular diseases and some of the more severe rare diseases. Genetically determined oncological predispositions will also be more easily detectable in future. Proteomics and metabolomics in breath condensate enable monitoring of inflammatory disease before and after treatment.

Other potential biomarkers of disease include: blood microRNAs for the diagnosis of cancer, infections and rare diseases; and exhaled volatile organic compounds as a measure of lung inflammation and to detect some cancers.

Deep sequencing of the genomes of pathogens, meanwhile, will allow precise identification of new pathogens and monitoring of the appearance of resistance to available therapies.

In terms of environmental exposures, individual exposure assessments for indoor and eventually outdoor pollution, including irritants or oncogenic compounds such as radon, may improve our understanding of the health effects of these substances. Monitoring of the environment can also increase our understanding of some types of asthma and causes of COPD other than smoking. This should be coupled with epigenetic studies to unravel the influence of the environment on the expression of such diseases.

Finally, improved clinical monitoring using a telemedicine approach has the potential to greatly improve personalisation of treatment, and thus disease outcome.

New interventions and biological treatments

So-called 'biological' approaches are increasingly prominent in respiratory medicine, and new devices for ventilatory support or endoscopic procedures are constantly becoming available. New approaches to personalised medicine are also needed, in order to encourage patients to 'own' their treatment. Emerging and likely future developments include:

- New biological treatments using antibodies or antagonists against receptors in order to interfere with the inflammatory mechanisms in diseases such as asthma, COPD, idiopathic pulmonary fibrosis, pulmonary hypertension and tumour growth. Examples include CXCR2 antagonists, phosphodiesterase 4 inhibitors, endothelin-receptor antagonists and kinase inhibitors. Blocking interleukin (IL)-5 or IL-13 in severe eosinophilic asthma is already becoming a reality, a prime example of personalised medicine.
- The development of antagonists of metabolic pathways, in order to inhibit oncogenes or signalling molecules in oncological processes and inflammatory processes such as those involved in pulmonary hypertension or idiopathic pulmonary fibrosis.
- The development of novel anti-ageing drugs for treating COPD and its associated conditions.
- Targeted and customised therapies for lung malignancies.
- The advent of improved delivery systems for inhaled drugs.
- Better use of borderline donor organs and improved understanding of the causes and potential treatment of ischaemic reperfusion phenomena in lung transplantation.

New approaches to personalised medicine are needed, to encourage patients to 'own' their treatment

SPECIAL FIELDS OF RESPIRATORY CARE

CONCLUSIONS

Prevention of chronic graft dysfunction remains a priority.

- In tissue engineering and biotechnology, the development of lung regeneration technologies as an alternative to transplantation. The recent success of tracheal transplantation onto a scaffold has been a first step.
- Basic research on the cellular and molecular properties of stem cells, providing new insight into their homing, engraftment, differentiation and biological effects; these are positive steps on the way to future therapeutic use.
- Further development of artificial lungs for treating both acute respiratory insufficiency and end-stage lung diseases, either to allow recovery of lung function or as a bridge to lung transplantation. New extracorporeal gas-exchange devices are becoming available, with arteriovenous or venovenous devices allowing more long-term support for failing lungs.
- Development of novel endoscopic treatment strategies, such as endoscopic volume reduction and thermoplasty.
- The use of technology to increase patients' 'ownership' and management of, as well as responsibility for their disease.
- International collaboration between governments, nongovernmental organisations, academic science and the pharmaceutical industry in the development of antibiotic and antiviral drugs as well as of new vaccines.
- Increased capacity and use of rehabilitation programmes and further development of self-management approaches.

Conclusion

Respiratory medical research is vital for the future health of Europe. National and European research programmes must reflect this to a greater extent in the next decade. More translational research is needed to bring scientific advances and knowledge into clinical practice, and to this end, there is a great need to find effective ways for collaboration between research disciplines. The Alliance for Biomedical Research in Europe (www.biomedeurope.org), grouping 20 major medical and research societies, has been established in order to promote and advocate for biomedical research at the European level.

Research in the field of respiratory disease will allow us to unravel the molecular mechanisms that are the origin of major diseases. The important roles of lifestyle and the environment are becoming much clearer, and minimising their adverse effects will require political as well as research action.

We are entering an era in which many new technologies will become available for improved imaging, for more specific biomarkers and for more precise targeting of metabolic pathways. These should allow earlier and more specific diagnosis, as well as better targeted and personalised treatments. Initially, these developments might appear costly, but more personalised medicine may be cost-saving, by decreasing the number of side-effects of current therapies, improving disease outcomes and promoting more healthy ageing.

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Respiratory journals and publications

Introduction



Key points

- The range of respiratory journals has expanded as the specialty has developed.
- Strong peer review is an essential component of scientific and medical publishing, providing a layer of rigorous quality control and feedback.
- As publishing becomes more complex and the volume of research grows, ethical guidelines have become necessary and organisations such as COPE have been set up to provide assistance to authors and editors.
- The internet has revolutionised scientific publishing, speeding up processes and creating new publishing models.
- Research funders, governments and others have begun to push hard for open access publishing of original research.

Scientific journals are the forum where new research is published and debated, and provide a vital record of scientific and clinical progress. Although publishing is changing rapidly, journals and books remain vital and dynamic elements of the scientific ecosystem.

Respiratory medicine has grown as a specialty over the past few decades and the increasing number of subspecialty research topics has resulted in a large portfolio of respiratory journals to cater for these different areas, in addition to general medical journals. The prime function of most respiratory journals is to publish original research work but they will usually also contain reviews relevant to clinical practice. However, other publications have a predominantly educational emphasis. Some of the major respiratory journals are listed in table 1.

Many respiratory publications are affiliated with national or international societies and may be either owned wholly by the society, such as in the case of the publications of the European Respiratory Society and the American Thoracic Society, or co-owned, such as Thorax which is co-owned by the British Thoracic Society and BMJ Publishing Group Ltd. Various business and strategic decisions underlie the reason for being a self-publishing society or whether to outsource to a commercial publisher. Some journals are not affiliated to any society and are owned by a commercial publisher. Regardless of who owns

Correspondence on published articles is key to the interaction and engagement of the journal with its readers

Rank	Publication title	Impact factor
1	American Journal of Respiratory and Critical Care Medicine	11.041
2	Thorax	8.376
3	European Respiratory Journal	6.355
4	CHEST	5.854
5	Journal of Heart and Lung Transplantation	5.112
6	Journal of Thoracic Oncology	4.473
7	American Journal of Respiratory Cell and Molecular Biology	4.148
8	Respiratory Research	3.642
9	Journal of Thoracic and Cardiovascular Surgery	3.526
10	American Journal of Physiology – Lung Cellular and Molecular Physiology	3.523
11	Annals of Thoracic Surgery	3.454
12	Lung Cancer	3.392
13	Current Opinion in Pulmonary Medicine	3.119
14	Tuberculosis	3.033
15	Journal of Aerosol Medicine and Pulmonary Drug Delivery	2.894

Table 1 – List of the top 15 publications in the Respiratory Systems category and their 2012 Journal Citation Report impact factors.

a specific publication and whatever its focus, editorial freedom must always be preserved.

Over the years, many of the respiratory journals in existence today have developed from smaller-readership publications as their affiliated societies grew, some have resulted from a merger of two or more journals, some have broadened their scope and some have changed their names to reflect the development of respiratory medicine as a specialty. The advent of the web has increased the accessibility and visibility of journals and has also enabled faster publication of research papers. The introduction of online submission systems has greatly facilitated submission of manuscripts to journals and enabled faster and more coordinated peer review, and most journal editors now deal with an increasing number of submissions year on year (figure 1).



Most journal editors now deal with an increasing number of submissions year on year



General medical journals

Respiratory articles and reviews are also published in general journals, but the competition to publish in general journals such as the *New England Journal of Medicine* and the *Lancet* is generally much greater. These articles mainly tend to be large clinical trials or papers that are of interest to wide groups of healthcare professionals and will often span primary and secondary care. Many of the general journals triage papers and will provide rapid decisions about the suitability of a paper before the peer-review process.

Types of journal article

Most of the high-impact respiratory journals publish the majority (around 60–80%) of their articles as original reports of research findings. It is usual practice for there to be a collection of editorials in each issue that either comment on an original paper or highlight some other important issue in respiratory practice.

Respiratory journals also publish reviews of topics, either singly or as part of a series. Review articles tend to be commissioned although unsolicited submissions are possible. Most editors will request that any potential topics for review articles are first discussed with the editorial team to avoid overlap and duplication. One of the most highly regarded types of article is the systematic review. The authors of a systematic review seek to address a research question by conducting a thorough literature search for all published studies addressing that question. Systematic reviews often contain a meta-analysis, which uses statistical techniques to combine and analyse the results of the studies found.

Correspondence on published articles is key to the interaction and engagement of the journal with its readers and should be encouraged. Some journals also accept research letters, which are short reports of pilot research data and observations. Publication of research output as a research letter does however preclude publication of the data in an original paper.

Peer review in respiratory journals

All editors strive to have the highest-quality papers in their journals. It is not possible for journal editors and their editorial teams (which may comprise deputy editors and associate editors) to have the knowledge to deal with all respiratory topics and thus utilising peer reviewers is important. Peer review has been in used in journals for over 300 years and is an important part of the editorial process, as constructive criticism during peer review leads to improvements in the final published paper and ensures that only the best papers are published.

Peer review plays a role in determining whether the research work is original, the stated objectives are achieved and the results plausible. However, the final decision as to whether a paper is suitable for publication and whether it will be of interest to its readers always rests with the editorial team. Authors may challenge peer-review comments or an editorial decision of rejection but review and reversal of any decision should only take place if a genuine mistake has been made in the peer-review process.

As with authors, peer reviewers should also declare any potential competing interests. Increasing work commitments may mean that some reviewers have to decline invitations to review or may never return their review.

The increasing complexity of submissions has led to a need for expert statistical review in some cases and drawing on the experience of a peer reviewer with such experience is incredibly useful.

Assessing quality and status of respiratory journals

Around the world, research assessment exercises are carried out to evaluate the research conducted by higher education institutions and the main measure of the quality is the status of the journal in which researchers publish their work.

Success and status of a journal are therefore important, although they are difficult to quantify. The commonest approach though has been to use the 'impact factor'.

Constructive criticism during peer review leads to improvements in the final published paper and ensures only the best are published While useful, it is not without its disadvantages and one of its limitations is that it only reflects the past 2 years of citations. The impact factor is calculated from numbers of citations and articles published. Using the example of the 2012 impact factors (released in 2013), these reflect the total number of citations in 2012 to all articles (including reviews, editorials and letters) divided by the number of original papers and reviews published in a given journal in 2010 and 2011. The top-ranked respiratory publications by impact factor are shown in table 1. A 5-year impact factor can also be calculated and may be more representative of the importance and application of a research paper as it may take some time to translate research findings into clinical practice.

Impact factor is also often used by librarians as one of the criteria for determining how their materials budgets (*i.e.* money available for subscriptions) for each faculty should be spent, which has implications for a journal's visibility and finances.

In order for a journal to have a high impact factor, citations need to be high. This has led to editors changing the content of their journal, often publishing fewer articles and not publishing certain categories of paper, such as case reports, that have lower citations. However, it is the editor's responsibility to ensure that their journal has an appropriate balance of respiratory papers and that the journal's target audience is appropriately served.

Publication ethics

In recent years, medical publishing has become more complex (not least because of the increasing pressure on researchers to publish) and this has led to journal editors dealing with many other issues, apart from simply reviewing scientific content, which take considerable time and effort. The field of publication ethics and best practice has developed and various bodies like the Committee on Publications Ethics (COPE) and the International Committee of Medical Journal Editors (ICMJE) have developed policies and guidance on competing interests, criteria for authorship, data falsification and fabrication, and duplicate or redundant publications.

There has been much progress achieved in clinical trial registration, and journals subscribing to the principles set

SPECIAL FIELDS OF RESPIRATORY CARE

CONCLUSIONS

out by ICMJE require authors to register their trials prior to their commencement in a publicly available registry that is open and searchable.

Advances in publishing

Considerable advances have been made in medical publishing with the proliferation of the internet. Manuscript submission and peer-review systems are now entirely electronic and faster, more efficient and transparent. Research papers now have an increasing amount of associated data and/or methodology and this can be published online alongside the paper, ensuring the data are available to the research community without occupying excessive space in print formats. Articles can be also posted online immediately on acceptance ahead of being allocated to an issue, allowing faster dissemination of research findings. Video clips and other materials can also be posted online, especially when there is a need to describe a specific interventional procedure. Podcasts with descriptions and discussions about current issues and their contents can be helpful to draw the reader's attention to key articles.

Publishers are also adopting new publishing models such as continuous publication, which allows full citation details to be available immediately upon online publication, bypassing the need for a publish ahead of print stage.

As smart phones and tablet devices are becoming more widespread, this technology has also been channelled into medical publications. Recently, the ERS launched an ERS publications app for the iPhone and iPad, providing easy access to the full text and images of both the *European Respiratory Journal (ERJ)* and the *European Respiratory Review (ERR)*.

Paper is not dead however: many of the current respiratory journals still publish in print and, to date, only a few have made the move to being online only. A number of factors will affect this decision for publishers and societies, including (to name just a few) advertising income, library preference, costs of printing and postage, reader feedback and society membership benefits.

Open access

Open access is an umbrella term for publication models that allow anyone to read articles online, regardless of whether they have a subscription to the journal. Momentum and support for open access is growing among authors, readers, funders and governments. As a result of this, publishers and their journals will clearly have to adapt.

In the UK, for example, the Research Councils UK (RCUK) launched a new policy in July 2012 stating that all peer-reviewed published research funded by RCUK from 1 April, 2013 must be open access, either *via* a 'green' (*i.e.* self-archiving) or 'gold' (author-pays) approach, which has been supported by the government.

In July 2012, the European Commission outlined measures to improve access to scientific information produced in Europe. The Commission will make open access to scientific publications a general principle of Horizon 2020, the European Union's Research & Innovation funding programme for 2014–2020.

For several years now, funding bodies such as the US National Institutes of Health, the Wellcome Trust and the Europe PMC Funders Group have mandated that authors to whom they have provided funding will provide a copy of their final peer-reviewed author-supplied manuscripts for public archiving in compliance with requirements (ranging 6–12 months from official publication in the journal in which the author is publishing his article.

Publications of the ERS

The ERJ is the flagship journal of the ERS and publishes original research articles, editorials, commissioned and unsolicited reviews, and letters on all aspects of respiratory medicine. In addition to the ERJ, the ERS also publishes a number of other publications. This rich publishing portfolio is central to the aims of the ERS, and one of the society's 'pillars', providing a forum for sharing and disseminating knowledge and appealing to the whole respiratory community including younger readers. The *ERR* is a guarterly publication that is free to access and consists of state-of-the-art reviews, editorials and correspondence, in addition to summaries of the most important recent research findings. The European Respiratory Monograph is the book series of the ERS, and each monograph is focused on a specific topic in respiratory medicine with up-to-date reviews by clinicians on topics relevant to clinical practice. Breathe is a magazinestyle educational journal publishing clinical review articles. editorials, case studies and specific educational tools. The ERS also publishes a successful range of Handbooks and ad hoc publications, such as the European Lung White Book.

Conclusions

The success of any respiratory journal will ultimately depend on the influence that it has on its readership. It is the responsibility of editors and their editorial teams to ensure that they are fulfilling the needs of their target audience, so that respiratory journals as a whole will continue to equally serve both the global research community and practising respiratory clinicians.

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Patient organisations and the European Lung Foundation

Introduction

Key points

- Patients' organisations have traditionally provided support services and a platform for members to share their experiences. Increasingly, however, they are becoming activist, taking a role in public awareness campaigns and advocacy for more research or better healthcare, and forging international partnerships with like-minded groups.
- By training 'expert patients', organisations are making sure patients have an input into new guidelines and treatment recommendations, and healthcare planning.
- Key challenges for the future include maintaining funding levels – particularly for organisations devoted to rare diseases – addressing health inequalities and improving the health literacy of the public.
- Across Europe, a total of 164 respiratory patient support groups have been identified, representing more than a dozen different disease areas.

In the past decade there have been many influences on the way we deliver healthcare. One of the most important transformations has been the way patients and carers are engaged in decisions about healthcare. The acceptance that patients, particularly those with long-term conditions, are experts in their own disease has been at the heart of these changes. Increasingly this experience and insight is being harnessed in healthcare, policy and research in order to ensure goals that are responsive to the needs of patients, leading to better outcomes and improvements in health and wellbeing. People are being encouraged to get involved in a structured and effective way in order to have an input in the future of their condition.

So what is the role of a patient organisation in this climate? A patient organisation is defined by the European Medicines Agency as 'a not-for-profit organisation which is patient focused, and whereby patients and/or carers represent a majority of members in governing bodies'.

This chapter looks at patient organisations – their roles and how they have evolved, and the impact that they have on healthcare. Examples of these activities will be provided from a network of pan-European and national respiratory patient organisations.

The European Lung Foundation (ELF) was founded by the European Respiratory Society (ERS) in 2000. Its aim is to bring together patients, the public and respiratory professionals to positively influence respiratory health. ELF works to communicate and



SPECIAL FIELDS OF RESPIRATORY CARE

The political impact of patient organisations has also grown as they strive for action and change

translate the work of the ERS to those outside the respiratory profession. However, more importantly in the context of this chapter, ELF works to ensure that patients and patient organisations have the opportunity to influence respiratory research, guidelines and ultimately care.

In June 2011, ELF carried out a Europe-wide survey to identify respiratory-oriented patient organisations. The initial search was carried out in English, as was the online survey. A total of 164 organisations were identified and 88 (54%) responded to the survey. The results obtained will be considered here in relation to the prevalence of lung disease across Europe.

Finally, this chapter will look to the future to see what challenges patient organisations face and how collaborating with professional organisations and speaking with one voice is vital to the future of lung health. The views and opinions of European respiratory patient organisations have been invited and incorporated.

The role of patient organisations

Patient organisations have traditionally provided a supporting role for patients, but their activities are constantly developing and evolving. Here, the evolution of patient organisations and their activities in three fields is discussed, and specific examples of activities are given from respiratory patient organisations in Europe.

1. Supporting and advising

Historically, the sharing of patients' experiences of their own disease was the key reason for the establishment of patient organisations. One of the first organisations to provide support was Alcoholics Anonymous, which was set up in 1937 in the USA. Such organisations offered secure and supportive environments to share experiences and advice. Decades later, this remains a crucial function of the majority of patient organisations. However, the means by which this support and advice is shared has changed.

Many patient organisations still provide face-to-face opportunities to meet and discuss. An example of this is the British Lung Foundation (BLF) Breathe Easy groups, which have been set up in various regions of the UK (www.lunguk.org/supporting-you/breathe-easy/ breatheeasygroupsacrosstheuk). However, much interaction now takes place online,

EU-funded initiatives

PatientPartner (www.patientpartner-europe.eu)

The aim of this project was to identify patients' needs for partnership in the context of clinical trials. Moreover, the project led to a well-organised and sustainable communication platform and guidelines, to enable mutually beneficial interactions between patients and clinical trial professionals.

VALUE+ (www.eu-patient.eu/Initatives-Policy/Projects/ValuePlus)

The objective of the VALUE+ project was to exchange information, experiences and good practice regarding the meaningful involvement of patients and patient organisations in European Union-supported health projects at European and national level.

Patient groups have become involved in scientific and therapeutic activism

66

through blogs, internet forums and websites. An example is the Pulmonary Hypertension Association (PHA) Europe web tool 'Time Matters' (www.phtimematters.org), which aims to give patients a voice. Here, patients and carers can post their hopes for the short-, medium- and long-term future and share their fears with others. A number of patient organisations also provide phone services, nursing support and even experts in indoor air quality for their members and the public.

Patient organisations help people to understand their condition(s). Many still provide comprehensive and clear information on paper, but this is being supplemented with websites, videos and social media. The Asthma Society of Ireland provides an asthma checklist describing what people with asthma should expect from a visit to their general practitioner, and has published inhaler technique videos (www. asthmasociety.ie/inhaler). The Lovexair Foundation Spain has produced a documentary about COPD and a₁-antitrypsin deficiency (www.lovexair.com/en/page5/page5.html) to educate people about the conditions.

2. Making change happen

Many organisations have developed an advocacy role, and represent the collective identity of their members in the public and political domain. Patient advocacy groups fight for public recognition of their disease through awareness campaigns, the speed and efficiency of which have been revolutionised by using websites, e-mail and social media. The political impact of patient organisations has also grown as they strive for action and change, and increasingly patient organisation representatives are included in official bodies advising on health policy and care decisions.

For World Asthma Day 2011, Asthma UK launched 'Get it off your Chest', an awareness campaign using an online map. Over 1800 people with asthma shared their stories. Asthma UK presented the stories to UK Members of Parliament during a reception, which enabled them to highlight the seriousness of

CONCLUSIONS

asthma. Nationally, many patient organisations work with their governments and health services. In 2008, the French Federation of Associations of Patients with Respiratory Insufficiency or Handicap (FFAAIR) developed a charter for patients who receive care at home. Created by patients and for patients, it outlines the rights and responsibilities of home-care personnel and patients in order to guarantee effective and high-quality care. The French Minister of Health and 24 societies representing care providers have now signed this charter.

3. Providing the patient perspective

More recently, patient groups have become involved in scientific and therapeutic activism. The concept of the 'expert patient' or the 'expert of experience' has developed. The aim of the expert patient is to input into research and healthcare using his or her unique expertise – as someone who has first-hand experience of a disease. Although this concept is well accepted in many areas, the evidence to show the impact it can have is still evolving. Many patient organisations have developed processes and methodologies to ensure that their members are fully prepared to get involved in areas such as research and clinical trials, and ensure that patients are available to participate wherever needed. Several European Union-funded initiatives have also brought together patient organisations from across Europe to help others engage as experts in their own disease (see EU-funded initiatives).

Patient organisations are also playing an increasingly key role in research funding. facilitating more research and directing where money is spent. The Netherlands Lung Foundation (Long Fonds; www.longfonds.nl) started to involve patients in research and in research and health policy in 1997. In 2007, the Long Fonds established a dedicated advisory board, consisting of patients with respiratory diseases. This board helps to develop standards of care, care guidelines and translations of these guidelines into lay language, as well as establishing research priorities, developing criteria to evaluate research from the patient's perspective, implementing research policies, evaluating research proposals in annual grant rounds, and monitoring ongoing research projects.

Public and patient involvement in European projects has become a key requirement when securing funding. A good example in the respiratory arena is a project called 'Unbiased BIOmarkers in PREDiction of respiratory disease outcomes (UBIOPRED)'. a project in which ELF is a partner providing the means for public dissemination of information about the project (www.UBIOPRED.european-lung-foundation.org). Patients working with the Long Fonds and Asthma UK have played a key role in key stages of the UBIOPRED project: in the development and wording of the proposal itself, in the ethics committee and the safety monitoring board and on the content and tone of the website. The patients involved were also able to give their advice to the project as a whole when there were difficulties with the recruitment rate of subjects for the project.

Distribution of activities

What is clear from the ELF respiratory patient organisation survey is that most patient organisations today carry out a variety of roles. Indeed, the examples given only represent one activity of each of the organisations. Figure 1 shows the response of the surveyed patient organisations to the question of what activities they perform for and on behalf of patients. The data suggest that the majority carry out the traditional core activities of a patient organisation, including support and providing information, but that additional roles are growing and developing.

Pan-European patient organisations

As there is no central registry for patient organisations across Europe or the globe, it is difficult to ascertain how many of them there are. It is clear though that the size and infrastructure of these bodies varies enormously and that the number of voluntary organisations is growing, with more of them representing specific diseases as well as more umbrella organisations across Europe and the world. The increase in the number of pan-European bodies reflects the desire of patient organisations to be part of larger-scale collectives and to be represented at the European level while still maintaining their own identity.

The ELF survey revealed that 87% of national and pan-European respiratory patient organisations are keen to work collaboratively at the European level to raise awareness of lung health, 80% are interested in joining the ELF network of patient organisations, 73% want to be able to participate in the ERS Congress and 52% want to work together to produce patient information. Table 1 lists the pan-European patients organisations that work with ELF.

Respiratory diseases





ELF brings together a network of patient organisations from across Europe

> Figure 1 – Activities of respiratory patient organisations. The graph shows the proportion of organisations surveyed that carry out a given activity. Source: European Lung Foundation respiratory patient organisation survey.

SPECIAL FIELDS OF	RESPIRATORY CARE

Organisation	Description	
The European Federation of Asthma and Allergy Patients organisations (EFA)	A network of European allergy, asthma and COPD patients' associations uniting national patient associations at the European level. EFA aims to make Europe a place where people with allergy, asthma and COPD have the right to the best quality of care and a safe living environment and to live uncompromised lives, and are actively involved in decisions influencing their health	
CF Europe (CFE)	CFE is the federation of national CF associations in Europe and represents people with CF and their families from 39 European countries. CFE works in close collaboration with other international organisations and is an active partner in several European projects	
Pulmonary Hypertension Association (PHA) Europe	The primary objective of PHA Europe is to establish close cooperation between the members of the organisation, European institutions, international organisations and public institutions worldwide	
Alfa Europe	Alfa Europe's aim is to provide a European information and resources network for patient support groups and linked associations, health professionals, institutions and industry who wish to improve and extend their knowledge of a ₁ -antitrypsin deficiency	
European LAM Federation	The European Lymphangioleiomyomatosis (LAM) Federation focuses on supporting LAM research and coordinates communication with existing LAM patient groups	

Table 1 – Pan-European patient organisations working with the European Lung Foundation. Descriptions are adapted from the organisations' own statements.

sarcoidosis, lymphangioleiomyomatosis, mesothelioma, primary ciliary dyskinesia, obliterative bronchiolitis, aspergillosis and rare and orphan lung diseases.

ELF brings together a network of patient organisations from across Europe committed to working together to improve patient care in Europe. This group actively input into the work of the ERS, by being involved in task force and guideline groups, by providing patient speakers at the ERS annual conference and by taking part in EU advocacy work and in public awareness and media campaigns. Pan-European and national patient



Figure 2 – Disease areas covered by respiratory patient organisations identified by the European Lung Foundation respiratory patient organisation survey. COPD: chronic obstructive pulmonary diease; ILD: interstitial lung disease; PAH: pulmonary arterial hypertension; AATD: a₁-antitrypsin deficiency.

groups also actively involve ELF, the ERS and other European and global healthcare professional organisations as partners in their projects and advocacy.

In order to facilitate this interaction, ELF is developing a training programme for patients and their carers, to give them the knowledge and confidence to interact with professionals, policymakers and the media (www.EPAPonline.eu). This programme aims to provide information to help patients discover how they can play a role in the development of guidelines, research and policy and also to signpost them to other European resources, such as the European Patients' Academy on Therapeutic Innovation (EUPATI) project, which aims to provide information to patients on medicines research and development (www. patientsacademy.eu).

Challenges

Despite their expansion, pan-European and national respiratory organisations face many challenges, which were identified in the 2011 survey as:

- Funding, especially in the current economic climate. Patient organisations are striving to improve their efficiency and to keep costs to a minimum. Many are using strategic planning to focus and prioritise their activities.
- Ensuring that patients' voices are heard in policy and implementation processes both at a national and European level.
- Finding meaningful ways to interact with healthcare professionals.
- Competition between and within patient organisations and professional societies, preventing useful collaboration and hindering progress.
- Rare-disease patient organisations struggling to establish themselves and find the support they need to function effectively.

The future



As this chapter has highlighted, collaboration is key for successful and productive activities. Equal partnerships between patient organisations and also with professionals and policy-makers must be built and sustained in order to ensure that messages are clear and consistent, and to allow for coordination and better resource use.

Other key priorities for the future of European respiratory patient organisations include:

Improving the image and standing of patient organisations

Partnerships between patient organisations, professionals and policymakers must be built and sustained

SPECIAL FIELDS OF RESPIRATORY CARE

CONCLUSIONS

in general and ensuring patient groups representing rare or orphan diseases have adequate support.

- Developing innovative methods to ensure an increase in funding, including donations, fundraising, corporate giving and sales. This will also lead to increased support for research.
- Ensuring that patient information and care is based on guidelines and providing it where it is needed most, often at the point of diagnosis or on discharge from hospital.
- Addressing health inequalities and health literacy to ensure that people across Europe are able to obtain the same information and access resources that enable them to better manage their condition.
- Ensuring that patients have more input into research and healthcare at local, national and European level.
- Ensuring that care for chronic respiratory diseases looks to new technologies (*e.g.* tele-health) and where appropriate alternative treatments.
- All the patient organisations consulted for this chapter have ambitious and impressive plans for the coming 5–10 years. We all look forward to a future where all patients are supported and empowered, and able to contribute to a brighter and better future for themselves and for lung health.

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