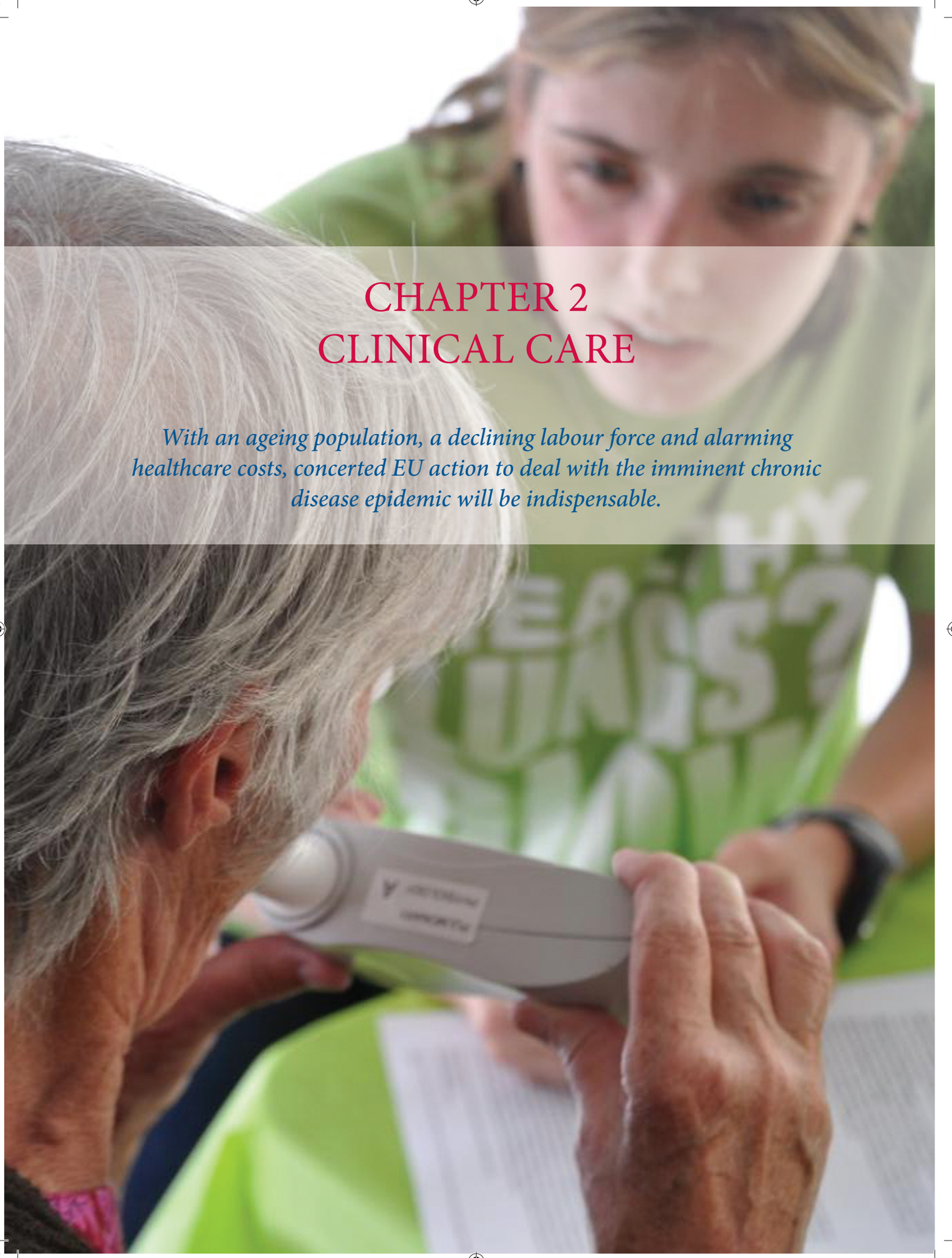

CHAPTER 2
CLINICAL CARE

With an ageing population, a declining labour force and alarming healthcare costs, concerted EU action to deal with the imminent chronic disease epidemic will be indispensable.

It is expected that by 2020 the estimated shortage of healthcare workers in Europe, which includes physicians, nurses, dentists, pharmacists and physiotherapists, will amount to 1,000,000. This will lead to an absence of coverage of 15% of the necessary care and it will be essential to attract more healthcare workers.[22] Moreover, the latest demography report of the European Commission shows that Europe's population is becoming both older and more diverse (fig. 7).

Another visible development in the population is the rapid rise of the "oldest old", *i.e.* the share of those aged 80 years and above. It is around 4% now, but will rise to 12% in 2060.[24] The growing share of the over 80 year olds will put a strain on the provision of services for the elderly, mainly in health and long-term care. A formidable challenge for curative medicine will be the shortage of doctors and nurses to deal with an ageing population and this growing epidemic of respiratory diseases, shown in table 2.

Table 2. Common non-malignant chronic respiratory diseases.

Asthma
Bronchiectasis
Chronic obstructive pulmonary disease
Hypersensitivity pneumonitis
Interstitial lung disease
Pneumoconiosis
Post-tuberculous lung disease
Pulmonary circulatory disease: pulmonary embolism, pulmonary hypertension and cor pulmonale
Pulmonary eosinophilia
Rhinitis
Sarcoidosis
Sleep apnoea syndrome

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FUTURE SHIFTS

Future developments will include shifts from hospital to home care, from physician care to nurse care, and from nurse care to self-management. Investing in measures aimed at improving quality of care is also effective, because catastrophic events resulting from poor care quality usually require a disproportionately

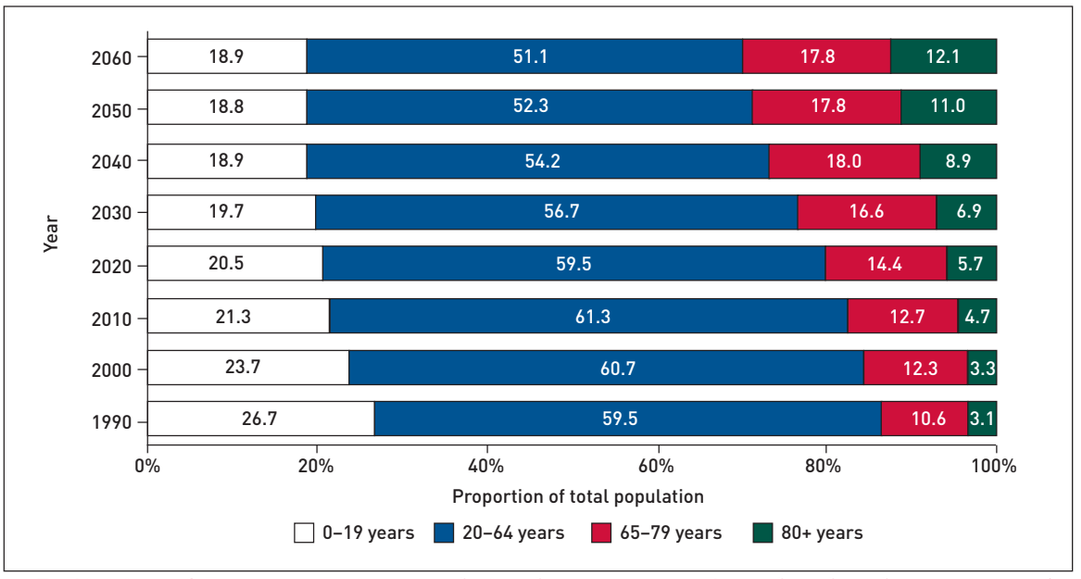

Figure 7. Division of European Union population by age group. Reproduced with permission from the publisher.[23]

[22] Neubauer K, Kidd E. Investing in Europe's Health Workforce of Tomorrow: Scope for Innovation and Collaboration. Summary Report of the Three Policy Dialogues. Leuven, European Observatory on Health Systems and Policies, 2010.

[23] European Commission. Demography Report, Report 2010. Brussels, European Commission, 2010.

[24] *Ibid.*

[25] Patel I. Integrated respiratory care: what forms may it take and what are the benefits to patients? *Breathe* 2010; 6: 253–259.

large use of resources, such as prolonged critical care stay. Sleep disorders and obesity, treatment of lung cancer, infections and tuberculosis will remain significant challenges for clinical care.

Chronic respiratory diseases are not only highly prevalent chronic diseases, but their prevalence is also increasing. While mortality due to cardiovascular disease and stroke has been decreasing, the mortality due to COPD has been increasing during the past three decades (fig. 8), indicating that COPD in particular, and chronic respiratory diseases in general, will become the diseases of the next decades.

AFFORDABILITY

Another major challenge will be the affordability of healthcare, as care for chronic diseases is costly. Costs are expected to rise further, mainly due to increasing costs associated with the ageing population in most European countries.[27] Higher healthcare costs may, however, prove to be cost-effective, and welfare and healthcare systems may remain affordable if combined with strong incentives to work longer, as in the Scandinavian countries.[28] Thus, a high degree of social protection is sustainable if it is intelligently designed. In addition, the willingness to pay for healthcare among the general public has been shown to be very high.

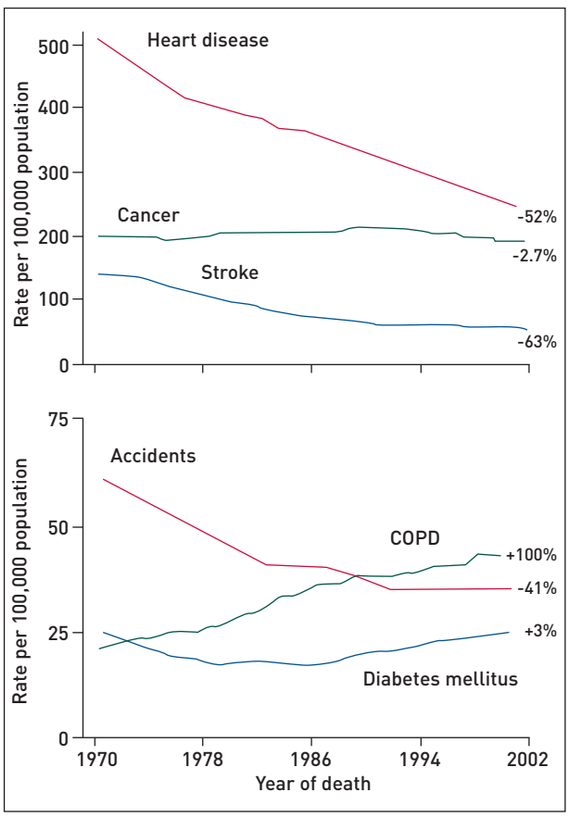

Figure 8. Evolution of mortality due to various diseases over the past 30 years. Reproduced with permission from the publisher.[26]

KEY POLICY RECOMMENDATIONS FOR FUTURE CLINICAL CARE

General

- There is a need for Member States to encourage the development of robust and simple methods for screening, *e.g.* for sleep disorders, lung cancer, COPD and other chronic respiratory conditions, including infectious diseases, as these will remain significant challenges at the clinical level.
- Common chronic diseases will require the development of clear protocols and evidence-based multidisciplinary guidelines, involving all relevant stakeholders, to ensure appropriate patient management and treatment. These guidelines should be Europe based.
- Registries are an invaluable resource in medical research. Patient registries represent valuable sources of medical and family history data and serve as a central information source where researchers can obtain data for analysis. Such registries should be set up at the European level.

Future shifts

- A shift from hospital-centred medicine to home care, from physician care to nurse care and from nurse care to self-management will be inevitable. Health systems in the EU need to prepare and adapt to this future shift.
- We support the efforts to improve care *via* the EU e-health agenda. The use of modern technology

[26] Jemal A, Ward E, Hao Y, *et al.* Trends in the leading causes of death in the United States, 1970–2002. *JAMA* 2005; 294: 1255–1259.

[27] Christensen K, Doblhammer G, Rau R, *et al.* Ageing populations: the challenges ahead. *Lancet* 2009; 374: 1196–1208.

[28] De Grauwe P, Polan M. Globalisation and social spending. *Pacific Economic Review* 2005; 10: 105–123.

(such as smart phones and applications) improves patient access, information and disease monitoring, and will lead to cost savings. The European Innovation Partnership on Healthy and Active Ageing should play a key role in extending the life span of people suffering from chronic respiratory diseases.

Affordability

- To face the growing pressure on healthcare systems in Europe, governments must be efficient when allocating budgets for healthcare and these should be set at slightly above the GDP growth level to ensure a competitive and efficient system.
- We urge Member States to incentivise procedures such as simple lung function tests and tobacco dependence treatment with obvious benefits such as early detection.

Accessibility

- Access to care will remain a key challenge in managing chronic respiratory disease. Tools and systems need to be activated across EU health systems to change the current dismal state of affairs.
- There is a need to optimise the availability, accessibility and quality of pulmonary rehabilitation, especially since it is acknowledged as cost-effective in patients with moderate or advanced COPD. Presently, less than 10% of eligible patients have access to rehabilitation.[29]

Table 3. Estimated prevalence (per 100,000) in Europe of some of the rare pulmonary diseases or diseases commonly affecting the lung.

Disease	Estimated prevalence
Acute respiratory distress syndrome	30
Idiopathic pulmonary fibrosis	27
α_1-Antitrypsin deficiency	25
Systemic sclerosis	16
Sarcoidosis	15
Dermatomyositis, polymyositis	14.8
Bronchopulmonary dysplasia	13
Cystic fibrosis	12
Small cell lung cancer	10
Tuberous sclerosis	8.8
Combined variable immune deficiency	7.5
Wegener granulomatosis	6.6
Primary ciliary dyskinesia	5
Congenital lobar emphysema	4.5
Acute interstitial pneumonia	3.8
Hereditary haemorrhagic telangiectasia	3.5
Mesothelioma	2.7
Langerhans cell histiocytosis	2
Idiopathic or heritable pulmonary arterial hypertension	1.5
Interstitial pneumonia with anti-synthetase antibodies	1.5
Hypereosinophilic syndromes, including pulmonary eosinophilia	1.5
Agenesia of the trachea	1
Churg–Strauss syndrome	1
Goodpasture disease	0.64
Birt–Hogg–Dubé syndrome	0.5
X-linked agammaglobulinaemia	0.5
Atrophic polychondritis	0.35
Congenital dyskeratosis	0.1
Lymphangioleiomyomatosis	0.1
Alveolar lipoproteinosis	0.1

Infectious diseases are excluded from this list. Data are from www.orpha.net

[29] Brooks D, Sottana R, Bell B, *et al*. Characterization of pulmonary rehabilitation programs in Canada in 2005. *Can Respir J* 2007; 14: 87–92.

- Improved access to end-of-life care, in particular for patients with non-malignant respiratory disease, is needed. Greater support from specialist nurses and specialist palliative care teams is required. Studies show that in the period leading up to death, only 2–3% of those dying from non-malignant disease access specialist palliative care.[30]

Applications of existing tools

- The EU action programme on rare diseases should be commended. Networks for the management of rare and orphan pulmonary diseases are starting to form. This is an encouraging development as, particularly for rare and orphan diseases, large-scale trials on a European scale are urgently needed for improved treatment of these diseases (table 3). A similar programme tackling chronic diseases, with an emphasis on respiratory diseases, is both feasible and necessary.
- There is a need to optimise the availability and quality of pulmonary rehabilitation in Europe, as rehabilitation is cost-effective. Pulmonary rehabilitation can reduce healthcare costs as a result of a reduction of hospital admissions and the length of stay, and healthcare systems should make a concerted effort to expand this existing and proven tool.

Future care models

- Integrated care models: the use of managed clinical networks, multidisciplinary teams and collaborative efforts across the lines of healthcare should be stimulated and funded in the Member States. These are crucial for the optimal management of complex conditions, and will need to be further developed across Europe (fig. 9).
- An analysis of the economic cost of COPD in the UK shows that 54% accrues from hospitalisation; a further 32% is equally divided between scheduled care and drug treatment.[32] An integrated care pathway with flexible shared-care arrangements between primary care and hospitals, facilitated by information technologies, has an enormous potential to decrease hospital admissions.
- The focus of chronic care models needs to be shifted toward addressing people in the early stages of chronic disorders. The ultimate aim should not be solely to manage disease, but to improve the prognosis of chronic disorders.

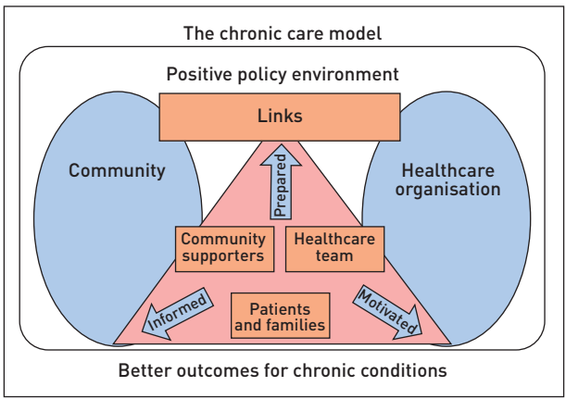

Figure 9. Diagram of the integrated care model proposed by the World Health Organization's Innovative Care for Chronic Conditions initiative. Interplay between the roles of patient/carer, healthcare/public health and community services is needed. Reproduced with permission from the publisher.[31]

New treatments, diagnostics and technologies

- For the next decade there is a need to promote and better coordinate organ donation within Europe, to promote the use of donation after cardiac death, extension of donor criteria, use of marginal donors, and most importantly, to further develop and extend the use of *ex vivo* lung repair. The need for donor organs by far exceeds the availability of donor lungs. The shortage of donor lungs is the main reason why only relatively few lung transplantations are performed every year, despite the high effectiveness of this life-saving method (fig. 10).[33]

[30] Davies L. Integrated care of the patient dying of nonmalignant respiratory disease. *Breathe* 2008; 5: 155–161.

[31] Roca J, Alonso A, Hernandez C. Integrated care for COPD patients: time for extensive deployment. *Breathe* 2008; 5: 27–35.

[32] Britton M. The burden of COPD in the UK: results from the Confronting COPD survey. *Respir Med* 2003; 97: Suppl. C, S71–S79.

[33] Oosterlee A, Rahmel A. Eurotransplant International Foundation: Annual Report 2009. Leiden, Eurotransplant International Foundation, 2009. Available from: www.eurotransplant.org/files/annual_report/ar_2009.pdf

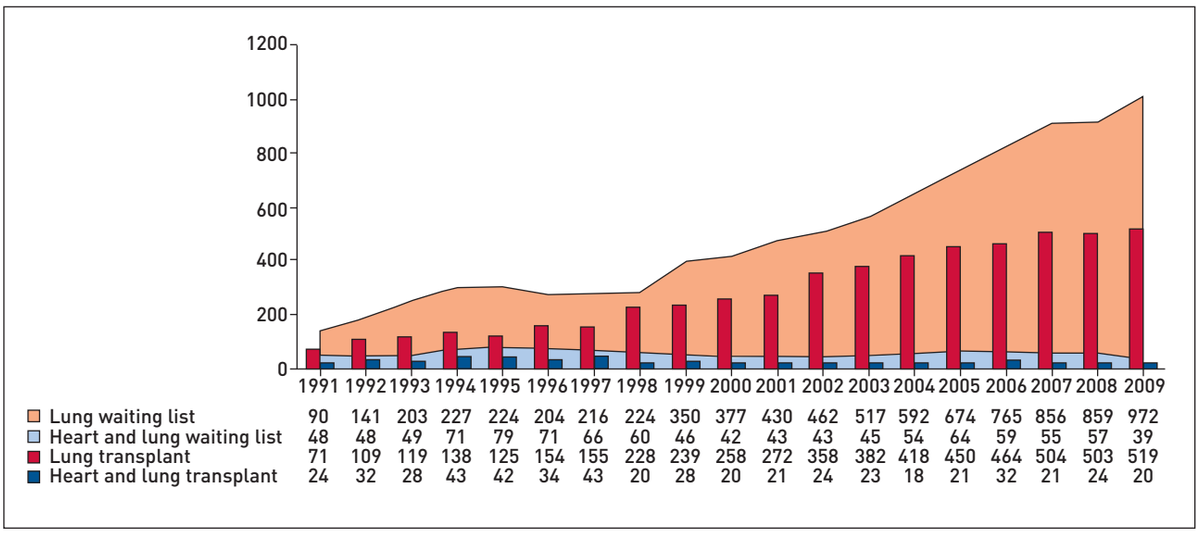

Figure 10. Dynamics of the Eurotransplant heart and lung transplant waiting list and transplants, and lung transplant waiting list and transplants, 1991–2009. Reproduced with permission from the publisher.[34]

- Strong political commitment is needed to foster the development of new formulations of antibiotics. Further development of vaccines against respiratory bacteria and viruses is a must. New insights into the antimicrobial response will help in the development of new strategies for fighting infection.
- Many technological innovations for diagnosis and treatment are expected to reach the clinic following validation, such as personalised medicine, video-assisted thoracic surgery, regenerative medicine, sensitive imaging techniques, laser surgery and use of tracer gases, *etc*. EU Member States must encourage investments in such invaluable innovations.

Home care, telemedicine and self-management

- In the next 5–10 years, there is a potential to increase and improve the use of home care and telemedicine, to form a valuable part of the disease management process. In that respect, it will be crucial for Member States to encourage adequate uptake of new technologies. However, in order to achieve this, appropriate training for healthcare workers will be necessary.

- In future it will be essential to adopt an integrated and holistic patient-centred approach to long-term chronic conditions, such as respiratory diseases, encompassing disease prevention and promotion of lung health, early diagnosis, monitoring and education, coordination of hospital and community-based care, and implementation of evidence-based guidelines.

- Specialist consultation clinics should be considered in order to improve both the self-management of chronic conditions and the communication between the medical professional and the empowered patient.

[34] *Ibid.*