

Raising the Bar for Better Standards of Care for Chronic Obstructive Pulmonary Disease (COPD)

European Policy Recommendations

November 2024



FOREWORD

Imagine coughing day after day. For years, you convince yourself that it is normal—a consequence of getting older, or perhaps it is just the cigarettes or the pollution in the air. But beneath the surface, your lungs are silently deteriorating, and the air does not flow as easily as it used to. Then, one day, you receive a diagnosis you have never heard of: chronic obstructive pulmonary disease (COPD). And, **by the time you learn the name, it is often too late.**

COPD is a progressive, life-altering condition with no cure, and it is the third leading cause of death globally. Yet, it can be prevented if only caught in time.

Unlike other major chronic diseases (e.g., heart diseases and diabetes) and cancer, **COPD remains shockingly underrecognized by both the public and policymakers.** A disease that steals the breath of 36 million Europeans and accounts for 6% of total healthcare spending in the European Union falls off the decision-makers' radar.

Lung health is at a critical juncture, with COPD representing one of the most significant challenges in public health. Despite this fact, there has been no significant action over the past decade to promote COPD prevention or optimise COPD management and treatment pathways. This report confirms the current situation: the number of individuals living with COPD in Europe has increased, there has been minimal progress in early diagnosis, care, and prevention, and the availability of best practices remains limited and not widely accessible to patients.

The *EFA report on Raising the Bar for Better Standards of Care for Chronic Obstructive Pulmonary Disease* not only depicts the current situation for COPD patients, but it is also a call to action. To halt COPD, policies must focus on **prevention of disease and on prevention of exacerbations and deaths.** It is high time to raise the bar for COPD standards of care by prioritising early detection, removing the stigma associated with seeking help, and establishing equitable, high-quality care for everyone affected. Moreover, it is necessary to invest in research to identify biomarkers for very early diagnosis and a cure for COPD.

EFA and our community of members—the patients' organisations—are ready to stand with policymakers, healthcare providers, and all stakeholders **to break the cycle of neglect.** We refuse to let smoking-related stigma or lack of awareness hinder early diagnoses and improved care. Together, we can ensure that COPD is no longer a forgotten condition but a central indicator to measure health equity and ultimately improve the sustainability of healthcare systems across Europe.

This report is a powerful tool in the journey to halt COPD. It deep dives into the status of prevention, awareness, and access to care, as well as access to digital health solutions in Europe. It provides a comprehensive and synoptic view of the management of COPD in 19 different countries, thereby facilitating the identification of trends and gaps, as well as national best practices and solutions to improve the patients' quality of care.

This report would not have been possible without the knowledge and participation of the EFA COPD Working Group, the #EFACommunity of members, and the tireless volunteer patients and representatives who, despite daily COPD struggles, have made this project real. Our gratitude also goes to our partners and corporate sustainable funding partners, whose commitment has laid the foundation for this essential advocacy work. Let us move forward together to ensure that COPD patients in Europe receive the voice, attention, and care they deserve to #KeepBreathing.



EXECUTIVE SUMMARY

Chronic obstructive pulmonary disease (COPD) is a preventable chronic condition that causes persistent, progressive airflow obstruction [1]. If left untreated or poorly managed, COPD can severely limit daily activities and lead to hospitalisations and death.

COPD is the third leading cause of mortality and is responsible for 6% of all deaths globally [2, 3]. In Europe, there are more than 36 million patients living with COPD [4]. Despite its significant impact on healthcare, public policies often overlook COPD and its overwhelming burden [5, 6].

The aim of the *EFA report on Raising the Bar for Better Standards of Care for Chronic Obstructive Pulmonary Disease* is to provide a comprehensive picture of the access to optimal care for COPD patients in 19 European countries (Austria, Belgium, Bulgaria, Czech Republic, Finland, France, Germany, Iceland, Ireland, Italy, the Netherlands, Poland, Portugal, Serbia, Spain, Sweden, Switzerland, Turkey, and the United Kingdom). The topics covered by the report are: epidemiology, early diagnosis, primary and secondary prevention, access to care, societal and personal costs of COPD, and research. The findings prompted EFA to develop policy recommendations to implement minimum standards of care for COPD patients in Europe.

EFA community of member organisations encourage policymakers to place COPD at the forefront of health agendas to effectively address it as a critical healthcare and sustainability issue.

The burden of COPD on European countries

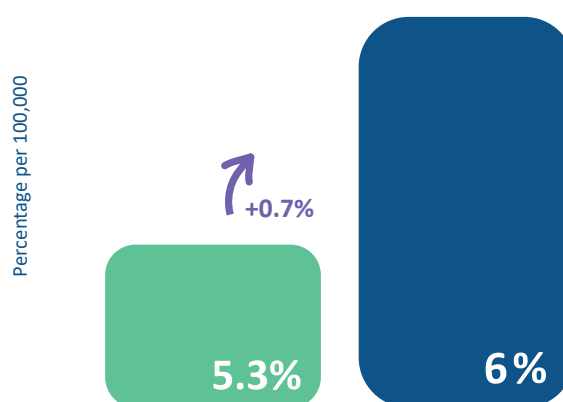
COPD places a considerable burden on healthcare systems, with annual direct costs of €38.6 billion, corresponding to 56% of the total cost of treating respiratory diseases and 6% of total healthcare spending in the European Union [7]. Lung health programmes, including public health initiatives for early COPD detection and prevention, as well as comprehensive COPD care management plans, effectively reduce the burden of COPD by increasing early diagnosis and reducing mortality [8].

The direct and indirect costs associated with COPD have steadily increased over time, mainly driven by poor pharmacological and non-pharmacological management of the condition. Hospitalisation costs range from €1,316 for mild COPD to €8,472 for severe COPD [9].

Indirect costs, largely due to decreased productivity and early retirement of patients, outweigh direct costs by over 60%. In addition, hidden costs related to informal caregiving and out-of-pocket expenses further impact patients and families, particularly those with lower incomes.

The EFA report found that only a few countries implement effective strategies for reducing COPD costs, and often they exist only in certain regions within a country.

Prevalence of COPD in Europe for 2011 and 2021



Data from the 2021 Global Burden of Disease study.

■ 2011 ■ 2021

Disease awareness and Prevention

Limiting exposure to risk factors, primarily cigarette smoking and environmental pollutants, can largely prevent COPD. Essential strategies include increasing access to smoking cessation programmes, incentivising primary care physicians to promote quitting, and implementing comprehensive smoke-free policies, also considering the rising threat of vaping among youth. Moreover, countries should adopt measures to improve outdoor and indoor air quality and mitigate the impact of climate change through legislation that promotes healthier indoor environments, pollution reduction measures and measures to protect at-risk individuals from the effects of climate change.

Early detection and diagnosis

Early diagnosis of COPD is essential for halting disease progression and improving long-term outcomes. Patients diagnosed with mild COPD may not experience a reduction in life expectancy compared to healthy people [10]. On the contrary, 75% of patients who were initially misdiagnosed went on to develop moderate to severe COPD, thereby increasing the risk of death [10, 11].



Unfortunately, COPD often remains undiagnosed due to a lack of awareness and limited access to simple diagnostic tests like spirometry.

National and regional policies should therefore establish proactive early detection policies that include public awareness campaigns and spirometry screening for people at risk.

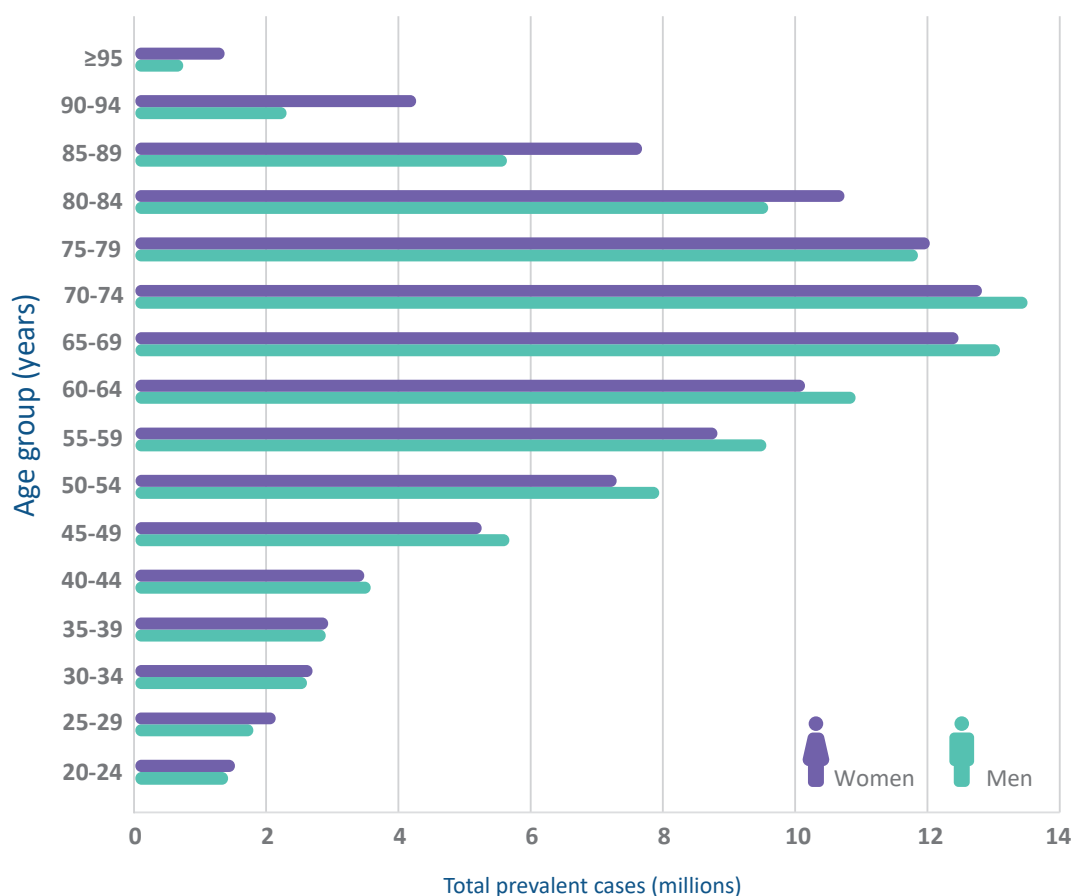
Furthermore, research into the pathophysiology and biomarkers of COPD could further facilitate early diagnosis, especially for nonsmokers [12]. EU funding should prioritise research on the development trajectories of chronic lung disease and for the identification of new biomarkers for very early diagnosis.

Access to COPD care: A fragmented picture

Along with early diagnosis, access to optimal care for COPD patients is the second pillar to prevent the progression of COPD. Regional and local differences hinder access to care, with patients living in rural and less populated areas facing the highest inequality in receiving adequate healthcare compared to those in more urban or populated areas.

EFA's report reveals profound health inequalities, as not all patients with COPD have guaranteed access to healthcare, including personalised management plans for all COPD patients and access to vaccination.

Worldwide prevalence of COPD, by age and sex in 2019



Modified from Safiri et al. 2022. Generated from Global Burden of Disease data. Creative Commons CC BY license.

Active living and improving quality of life

Maintaining an active lifestyle is crucial for improving quality of life, yet many patients struggle with physical activity as a consequence of decreased lung function, this leads to worse disease control and negative effects on mental and physical health [13]. Patients organisations propose community-based programmes to promote active living, but they require more structured funding to support these initiatives.

Digital health solutions for patients with COPD

Digital health solutions have the potential to enhance access to care, treatment adherence, and empower COPD patients to take an active role in their own care. Patients, particularly those of advanced age, are more comfortable using familiar technologies, such as smartphones [14]. Moreover, factors like digital literacy continue to impact access to telemedicine. Digital health initiatives should be designed to align with patients' preferences and should not replace in-person interactions with healthcare professionals [15].

The impact of Covid-19 on the care of COPD patients

COPD patients are more vulnerable to developing severe respiratory infections. Moreover, the restrictions due to the pandemics increased the feeling of isolation and hindered access to follow-up visits. The main impact of the pandemic on COPD care was the delay in diagnoses, after the pandemic years, the number of newly registered COPD patients decreased by 44%. Moreover, as a consequence of the increased demand for pulmonary rehabilitation for patients recovering from Covid-19 infection, COPD patients experienced restrictions in accessing such important therapy.

COPD IN NUMBERS

COPD is the third cause of death worldwide



of the **4%**
world's population



+ 36 million Europeans
have COPD



3.2 million
people die
of it each year

6%

of preventable
deaths



Direct costs
of
COPD



56%

of the total cost
of treating
respiratory diseases



6%

of the total
healthcare
spending

POLICY RECOMMENDATIONS

- 1 The Burden of COPD on Health**
Strengthening National and European Efforts to Address COPD
- 2 The Cost of COPD in Europe**
Strengthening National and European Approaches to COPD Care
- 3 Disease Awareness and Prevention**
Investing in Lung Health through Public Health Initiatives
- 4 Early Detection and Diagnosis**
Reducing COPD Progression through Early Detection and Awareness
- 5 Access to COPD Care**
Guaranteeing Health Equity for COPD Care
- 6 Active Living and Improving Quality of Life**
Creating a Supportive Environment for COPD Patients
- 7 Digital Health Solutions for Patients with COPD**
Developing Patient-Centred Digital Health Strategies for COPD
- 8 The Impact of Covid-19**
Ensuring Continuum of Care for COPD during Health Crises



1. The Burden of COPD on Health Strengthening National and European Efforts to Address COPD

General recommendation

Strengthening the capacity of national healthcare systems is crucial to effectively address the recurring gaps in COPD care. In order to do so, healthcare systems should enforce targeted prevention measures, improve coordination, and adopt a multidisciplinary approach to lung health.

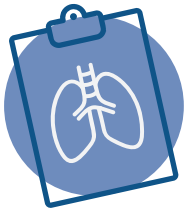
At national level

- **Establish national lung health plans:** Develop comprehensive national lung health plans integrated in public health policies that encompass both early and accurate COPD diagnosis and optimal care management. These plans should prioritise prevention of COPD and should aim to enhance the overall quality of care.
- **Integrate COPD education across medical curricula:** Promote training programmes on COPD for healthcare professionals, including for physicians, nurses, physiotherapists, and pharmacists. This training should emphasise early diagnosis, the administration of diagnostic procedures like spirometry testing, and effective management of COPD and its comorbidities.

At European level

- **Promote COPD data collection and monitoring:** Adopt systematic data collection and monitoring across Europe to better understand the impact of COPD on healthcare systems and its societal burden.





2. The Cost of COPD in Europe

Strengthening National and European Approaches to COPD Care

General recommendation

Establishing lung health plans is essential to anchor COPD management within primary care settings, thereby reducing costs for both healthcare systems and patients.

At national level

- **Break down silos for COPD multidisciplinary care:** Multidisciplinary COPD care in the primary care level improves the early detection of COPD, slows down the disease progression, enables better management of comorbidities, thereby reducing associated direct costs.
- **Design strategies to reduce COPD indirect costs:** Develop national strategies to tackle the indirect costs of COPD, such as sick leave, early retirement, and reduced productivity.
- **Pilot cost-effective prescription and reimbursement schemes:** Introduce pilot schemes for the prescription and reimbursement of early COPD interventions and scale up their cost-effectiveness.
- **Optimise the distribution of healthcare force to meet the needs of COPD patients:** Improve the organisation of healthcare workers to support COPD care by equipping primary care services with trained respiratory (community) nurses, and lung function testing devices to improve early detection.

At European level

- **Prioritise lung health and COPD in EU financial instruments:** Prioritise action on lung health and specifically on COPD through the EU4Health and Horizon programmes genuinely addressing chronic diseases.
- **Develop policies that support inclusion of COPD patients in the workforce:** Develop and promote supportive policies that keep and integrate COPD patients in the workforce to promote active living, thereby reducing preventable absenteeism and indirect costs associated with the disease.
- **Develop comprehensive lung health training programmes for healthcare professionals:** Earmark training programmes under the European Social Fund (ESF) aimed at incentivising healthcare professionals (including primary care providers, nurses, and physiotherapists) and medical specialists involved in chronic respiratory diseases to promote early diagnosis and optimal management of care for COPD.
- **Strengthen “Health at Work” Policies:** Integrate lung health into policies addressing occupational exposure to chemicals, in order to prevent respiratory diseases and to reduce healthcare costs associated to decreased lung function due to occupational exposure.
- **Enhance technical support for COPD care through WHO/Europe:** Guide WHO Europe Member States with roadmaps, technical support, and success indicators to strengthen healthcare systems’ capacity to monitor and deliver COPD care.



3. Disease Awareness and Prevention

Investing in Lung Health through Public Health Initiatives

General recommendation

Since COPD is a preventable disease, investing in lung health requires public health policies and actions aimed at preventing risk factors exposure and improving health literacy. Both angles, legislation and education, are fundamental to decrease the prevalence of COPD and improve healthcare outcomes.

At national level

- **Disseminate information on COPD risk prevention:** Support the dissemination of information on the prevention of risk factors for COPD, through public health measures aimed at increasing health literacy.
- **Adopt and enforce public health laws to protect lung health:** Implement and enforce public health legislation to protect lung health, including measures to reduce smoking and vaping, limit exposure to second-hand smoke for vulnerable groups and groups-at-risk, and offer free-of-charge support for smokers who wish to quit, including accessible smoking cessation programmes.
- **Reduce outdoor air pollution and provide public information:** Implement ambitious measures to tackle outdoor air pollution and improve access to public information on air quality, with advice specifically addressed at vulnerable groups such as chronic respiratory disease patients, especially in areas impacted by exceeding air pollution levels, such as big size cities, industrial and mining areas and regions dependent on the burning of fossil and solid fuels.
- **Improve indoor air quality:** Adopt a comprehensive framework to reduce indoor air pollution, including national and local schemes for health-based renovations (i.e., incentivising renovations in buildings where COPD patients live), ventilation improvements and building maintenance.
- **Prioritise measures to reduce the impact of climate change related risks on COPD patients:** Prioritise actions towards vulnerable populations, like people living with COPD and reduced lung function. Such actions should include early warning systems, healthcare systems and information plans to address risks such as wildfires and floods, expand green areas in urban environments to combat heatwaves, and reinforce civil protection mechanisms.

At European level

- **Strive for a “Tobacco-Free Generation” by 2040:** Escalate efforts to achieve a tobacco-free generation before 2040 through additional restrictions on the commercialisation and use of smoking and vaping products, and by expanding the enforcement of smoke-free environments to all indoor and public spaces, and private spaces where children are exposed.
- **Align EU air quality legislation with WHO standards:** Align European air quality legislation with WHO ambient air pollutant standards and ensure effective implementation at the national level.
- **Propose harmonised indoor air quality measures:** Harness scientific evidence to propose basic harmonised measures to address indoor air quality standards and performance.
- **Act on the WHO/Europe Budapest Declaration Commitments on Environment and Health:** Act on the commitment made in order to address the environmental and climate crisis that affects lung health.
- **Set minimum standards for civil protection services and promote research on the impact of climate hazards on lung health:** Propose minimum standards for civil protection services and for information during climate emergencies that affect air quality. Promote research on the impact of climate hazards on lung health, particularly on people with chronic respiratory diseases.



4. Early Detection and Diagnosis

Reducing COPD Progression through Early Detection and Awareness

General recommendation

Reducing the progression of COPD requires proactive measures, including early detection through lung health checks and targeted awareness actions.

At national level

- **Raise awareness of COPD symptoms and risk factors:** Conduct public awareness initiatives to promote COPD symptom recognition (i.e., dyspnoea, “shortness of breath”, chronic cough) while educating about risk-factors. These initiatives should be carried out in collaboration with civil society, particularly patients and healthcare professionals’ associations.
- **Strengthen primary care for COPD diagnosis:** Ensure that COPD diagnosis is widely accessible by strengthening capacity of primary care as the frontline in managing COPD. This involves training and incentivising general practitioners to routinely perform spirometry testing and enhancing the role of nurses in running lung health check-ups.
- **Provide lung health checks for at-risk groups:** Offer lung health checks for early detection of COPD in people who are symptomatic or at higher risk. Targeted groups include current and former smokers, patients with related comorbidities (i.e., asthma, Alpha-1, cardiovascular symptoms, osteoporosis) and those exposed to risk factors, such as chemicals, gas, fumes, and urban pollution.

At European level

- **Earmark EU funding for COPD research:** Allocate EU funds to support research on the lung function trajectories that may predict the development of chronic lung diseases, including the identification of new biomarkers for very early diagnosis, particularly among non-smoking patients.
- **Promote studies on the cost-effectiveness of early detection:** Support health economic studies on the cost-effectiveness of early COPD detection across European regions and pilot screening programmes anchored in primary care.
- **Expand digital networks for early COPD detection:** Invest in expanding and reinforcing digital networks to support early COPD detection. This includes harnessing the full potential of EU-wide registries, medical devices, machine learning technologies and the European Health Data Space.
- **Adopt a WHO Europe Lung Health Agenda:** Advocate for the adoption of a comprehensive and multistakeholder WHO Europe Lung Health Agenda to improve COPD prevention and care across the region.



5. Access to COPD Care

Guaranteeing Health Equity for COPD Care

General recommendation

To guarantee health equity for COPD, it is essential to scale up both the quality and availability of healthcare services, and to address the increasing shortages in the healthcare workforce.

At national level

- **Close gaps in access to COPD care:** Address disparities in COPD care whether they stem from rural-urban or disease-specific variations. Harmonise access to COPD care in countries where healthcare services are a regional competence.
- **Ensure access to timely COPD treatment:** Guarantee that COPD patients receive the right treatment at the right time. Ensure affordable access to the full portfolio of COPD care interventions, such as:
 - therapies for COPD,
 - widespread availability of oxygen,
 - smoking cessation programmes,
 - immunization against respiratory viruses,
 - out-patient and community-based palliative care.
- **Set up national COPD programmes to improve standards of care:**
 - Ensure adherence to clinical guidelines for COPD, including frequent monitoring, correct follow-up and patient centred approach based on health outcomes.
 - Establish a mandatory COPD management plan to be agreed between the patient and the physicians.
 - Centralise and ensure coherence in multidisciplinary COPD care, with specific focus on managing common comorbidities, such as other airways diseases, depression, obesity, cardiovascular disease, and osteoporosis.
 - Make pulmonary rehabilitation – both out-patient and virtual – integral to secondary prevention of COPD, ensuring that rehabilitation treatment programmes are systematically offered to all COPD patients following an exacerbation, regardless of their location.
 - Involve patient organisations in the development of national COPD programmes to ensure that patient needs and perspectives are represented effectively.

At European level

- **Reinforce primary care for chronic conditions:** Continue the investment in reinforcing primary care settings across EU Member States, with specific requirements for high-burden chronic conditions such as COPD and ensure effective integration of the primary care within the broader healthcare system.
- **Establish EU Centres of Excellence for chronic respiratory diseases:** Support the creation of a network of EU Centres of Excellence for Chronic Respiratory Diseases to better connect medical specialities to achieve optimal care, upgrade standards and patient pathways, and catalyse breakthrough interventions, including pulmonary rehabilitation and telemonitoring.
- **Promote health literacy for chronic respiratory patients:** Increase health literacy on the importance of accessing vaccination and immunisation against respiratory virus among people with chronic respiratory disease.
- **Set ambitious COPD care goals for the WHO Europe region:** Establish ambitious pharmacological and non-pharmacological target goals for COPD care in the WHO Europe Region.



6. Active Living and Improving Quality of Life

Creating a Supportive Environment for COPD Patients

General recommendation

A supportive environment is crucial to maximise the quality of life of people living with COPD and enhance their participation in decisions affecting their care.

At national level

- **Promote co-decision in personalised care and self-management plans:** Incentivise the co-decision of personalised and self-management plans that capture treatment, physical activity plans, and lifestyle options.
- **Adopt national social plans for employment and active living:** Adopt national social plans that promote employment opportunities and active living options for people diagnosed with COPD, thereby enabling them to maintain a better quality of life.
- **Facilitate collaboration with patient organisations:** Sustain a structured and permanent dialogue and collaboration with national and local patient organisations in order to assess limitations on COPD care and prevention and co-create solutions, such as community-based pulmonary rehabilitation activities.
- **Invest in patient organisations to diversify care options:** Provide unrestricted public funding and support to patient organisations at national and local level to diversify care options for patients. This could include coordinating with the healthcare system to provide patient education, counselling, and community-based services to COPD patients. Such measures will enable greater involvement of patients in their care.
- **Recognise informal caregivers for COPD patients:** Include COPD in the list of conditions that enable informal caregivers to be recognised for their support. Recognise financial dependency allowance and family entitlements (e.g., carers leave), proportionate to the burden and needs of caregiving.

At European level

- **Identify best-practices for active living with COPD:** Identify and share European best practices for policies that support active living for COPD patients, such as reasonable accommodations at work, adaptable disability schemes, and employer incentives.
- **Support digital health education projects:** Promote and support European-level digital health education projects aimed at lung health among the ageing population. Such projects should focus on basic pulmonary rehabilitation techniques, correct breathing, and lung function maintenance.



7. Digital Health Solutions for Patients with COPD

Developing Patient-Centred Digital Health Strategies for COPD

General recommendation

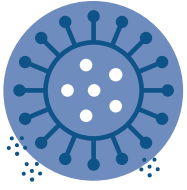
To effectively support people living with COPD it is essential to enable and develop digital health and care strategies that prioritise patients' needs and on usability.

At national level

- **Provide digital health services to optimise COPD care:** Offer access to digital health and care services that can optimise patients' in-person COPD care and self-management, such as telemonitoring, connected medicines, testing devices, and digital diaries.
- **Involve COPD patients in the design of digital technologies for health:** Offer access to digital technologies designed with and for the patients that are integrated in the healthcare system and provide training for healthcare professionals, patients, and caregivers on how to use the technology.
- **Enable virtual multidisciplinary teams and decisions for COPD:** Facilitate virtual multidisciplinary teams and decision-making processes for COPD, allowing patients to easily connect their primary, secondary, and tertiary care providers for optimal care decisions.

At European level

- **Support Real World Evidence studies on the onset of exacerbations:** Invest in and support real-world evidence studies to better understand the onset of COPD exacerbations (at individual and population level) to improve prevention, early intervention, and COPD management.
- **Adopt requirements for electronic product information to train on inhalation techniques:** Establish requirements for electronic product information of combination products that include video options on how to use the device in order to improve inhalation techniques for COPD.
- **Develop a multi-platform device for inhalation training:** Support the development of a multi-platform medical device to simplify training on optimal inhalation techniques for people with COPD, to ensure better use, concordance, and adherence of inhaled therapies.
- **Promote digital health literacy for COPD patients:** Foster digital health literacy to increase patient access to digital tools to support COPD management, thereby empowering patients to be active participants in their health status and care.
- **Integrate European Centre for Disease Prevention and Control (ECDC) monitoring of respiratory viruses for COPD prevention:** Incorporate the ECDC monitoring of respiratory viruses into COPD secondary prevention strategies to better protect patients.



8. The Impact of Covid-19

Ensuring Continuum of Care for COPD during Health Crises

General recommendation

To enable the continuity of care for people with COPD during health crises, it is essential to address specific vulnerabilities and establish robust preparedness measures to safeguard lung health and prioritise people with existing chronic respiratory conditions.

At national level

- **Assess and address vulnerability during health crises:** Identify and address the vulnerabilities and degree of dependency of COPD patients during public health emergencies, ensuring they receive uninterrupted care and support, particularly when healthcare resources are strained, including medicines and workforce shortages.

At European level

- **Strengthen EU preparedness for respiratory infections:** Enhance EU level preparedness to deal with respiratory infections and with the usual virus season, ensuring that healthcare systems are equipped to support COPD patients effectively.
- **Address medicine shortages to ensure availability:** Pay special attention to potential shortages of essential medicines for COPD ensuring timely measures to maintain their availability, especially during periods of increased healthcare demand.
- **Provide clear and science-based information on risks:** Deliver clear, transparent, and science-based information on the risks of people with chronic respiratory conditions against a given pathogen, thereby enabling patients to make informed decisions regarding their health.

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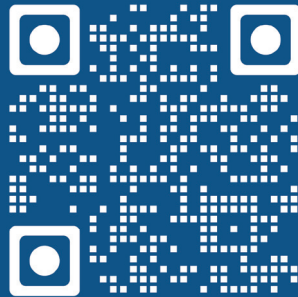
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