



A Roadmap: Inform, Prevent, Care

More than 200 million Europeans live with chronic allergies and airways' diseases, including asthma and COPD. To improve the lives of patients and to provide a way forward for multiple stakeholders, the European Federation of Allergy and Airways Diseases Patients' Associations (EFA) presents this roadmap on patient safety, access to healthcare and eradicating inequalities. In essence, a tool to facilitate information, prevention and care.

Allergy and asthma are among the most prevalent chronic diseases in Europe. Yet they are often under or misdiagnosed, leading patients to undergo incorrect, inadequate or no treatment at all. In addition, allergy, asthma and COPD tend not to receive the same level of attention as other chronic diseases. This leads to a lack of understanding about the causes and consequences of symptoms and disease progression; respiratory diseases are complex conditions and the triggering mechanisms are not yet fully understood. While significant improvements in health and care for patients have been registered in recent years, important challenges remain, including:

- (1) A lack of **patient information and empowerment**: asthma and COPD patients are far too often not actively involved in decision-making about their therapy: one-third of asthma and COPD patients do not feel involved in the decisions being made about their therapy;
- (2) An insufficient emphasis on **addressing and containing risk factors** for these diseases: only one-third of patients are satisfied with the efforts of their national governments to protect them against risk factors for developing and/or exacerbating asthma, COPD and other allergies and airways diseases;
- (3) **Unequal access to diagnosis and treatment**: 16% of asthma and COPD patients initially received a wrong diagnosis, taking on average between 4.5 and 5.2 years to receive a correct diagnosis.

In 2019, EFA launched the #ShowLeadership campaign to encourage relevant stakeholders – including patients and caregivers, healthcare professionals and policymakers – to take action and address the challenges faced by people living with allergies and airways diseases. With 26 policymakers and 50 supporting organisations, the #ShowLeadership campaign has already reached more than 260,000 people.

We cannot stop here. With a new European Parliament in place and a new European Commission set to take office, **we call on EU policymakers to act on reversing preventable allergies and respiratory diseases, and reduce the overall burden of these diseases. During the 2019-2024 legislative term, EFA therefore commits to working with the European Parliament and expanding engagement with the European Commission to:**

- **INFORM patients, policymakers and other relevant stakeholders to foster empowerment through patient education and literacy; the development, implementation and transformation of digital tools and evidence-based advocacy; and to promote policies that benefit patients;**
- **Develop policies that PREVENT the risks of becoming a patient or exacerbating existing conditions;**
- **Ensure equal access to the same high-quality CARE and tools for patients in all Member States.**

1. INFORM patients, policymakers and other relevant stakeholders to foster empowerment and promote policies that benefit patients

While patients know their risk-factors, informed and patient-centric policies in health and all other policy areas should rely both on the generation of robust evidence and on the expertise of patients living with allergies and respiratory disease.

European policymakers should ensure that adequate funding in research relevant to the needs of patients is prioritised and funded at the EU level. To this effect, it is critical to more systematically embed the patient voice and preferences in the policy-making process.

National and European research programmes, including Horizon Europe, should allocate the appropriate human and financial resources towards the development of **more efficient therapies as well as powerful diagnostic tools to prevent hospitalisations and disease exacerbations** for patients with asthma, COPD and other respiratory conditions. Particularly, the new Horizon Europe research and innovation missions on climate neutral and smart cities and adaptation to climate change must consider the impact on health to ensure their highest benefit for European citizens.

Patient empowerment and involvement in decision-making processes that affect health and well-being should be integrated and become a cornerstone of EU health policymaking. The structured and on-going consultation of patients in relevant working groups at the European Medicines Agency is part of the answer. Another critical step is the adoption and implementation of ***regional or national plans on chronic disease detection and disease-specific management programmes*** that are created in collaboration and primarily focused on patient-involvement. At the EU level, institutions should expand their ambitions for a plan focused on cancer as well as adopting a ***sound EU-Strategic Framework for the prevention of non-communicable diseases.***

2. Develop policies that PREVENT the risks of becoming a patient or exacerbating existing conditions.

Addressing the challenges faced by people living with allergies and airways diseases goes beyond the scope of health policy and includes **areas such as but not limited to environment, transport, research, employment and food**. We need coherent and robust EU and national policies that **address and reduce indoor and outdoor risk factors associated with allergies and airways diseases. Effective policies can support healthier and more productive lives**, by providing tobacco control, food information, reduced indoor and outdoor air pollution, better food labelling and reducing exposure to chemicals. This means that European policymakers need to ensure that the health of EU citizens is considered a central element within the ambitions of the European Green Deal, and reiterate the importance of a 'Health in All Policies' approach for all EU health-related policymaking processes.

AIR POLLUTION AND SMOKING

Limiting indoor and outdoor air pollution and traffic emissions as well as providing real-time information on air quality and pollution are priority measures to be taken by public authorities at the local, national and EU levels in the fight against respiratory and airways diseases. Currently, more than 50% of asthma and COPD patients feel that policy-makers are not doing enough to promote air quality information, while 38% think that public authorities do not protect them sufficiently from transport pollution. In view of the on-going fitness check of the EU Air Quality Directive, EU air quality legislation should be updated to meet the standards set out in the WHO Air Quality Guidelines. A compulsory, indoor air quality certificate for all new and renovated buildings should be developed. In addition, smarter building designs, energy efficiency measures and targeted actions against damp and moldy homes are needed.

Smoke-free environments in public spaces across Europe and the **promotion of more effective smoking cessation programmes** must complement the EU's efforts to improve air quality and eliminate risk factors for allergies and airways diseases. 92% of patients with asthma and COPD believe that smoking and second-hand smoke significantly impact their health. However, only one-third of patients feel that public authorities do enough to protect them from these risk factors.. The implementation of recommendations made by initiatives tackling first and second-hand smoke must be prioritised for the benefit of all European citizens.

FOOD LABELLING

One in five Europeans suffers from food reactions and seven million Europeans, mostly under 25 years old, are allergic to some kind of food. The generally-perceived best therapy is abstention from the allergen causing the reaction. These allergens must be recognisable to the consumer. The 2011 EU Food Information to Consumers Regulation recognises 14 allergens and requires mandatory allergen information for all packed and non-packed foods in Europe. However, many people living with food allergies experience misleading allergen labelling, resulting in negative effects on health and Quality of Life.

An all-encompassing EU-wide approach to precautionary allergen labelling in prepacked food as well as sufficient information on allergens in non-prepacked food is therefore needed. Industry best practices to avoid cross-contamination and harmonised and easily understandable wording for allergen labelling should become the gold standard across EU member states.

OTHER RISK FACTORS

Other potential risk factors, including **chemicals, unsafe work environments and consumer products that can directly or indirectly cause allergies**, particularly atopic eczema, must also be tackled. 83% of patients with COPD or asthma consider indoor air pollution from occupational activities to negatively affect their health, while 79% of patients believe that chemical products impact their condition. However, only one-third of patients feel that public authorities do enough to protect them from these risk factors.

Appropriate research funding around the causes that can worsen patients' conditions is needed. Chemical assessment and labelling in commercial products, as well as the identification of sensitisers to restrict their use and limit the exposure of high-risk groups, must be improved across Europe. Finally, more protective work environments, including preventive measures to limit exposure to pollutants, must be encouraged.

3. Ensure equal access to the same high-quality CARE for patients in all Member States

Patients with allergies and respiratory diseases increasingly require the provision of personalised care approaches and health systems that move towards patient-centric care models. The development and implementation of such models in the EU is indispensable for ensuring improved health outcomes and successful disease management. This is particularly true when we consider that 26% of asthma patients and 31% of COPD patients have ended up in the emergency room at least once in the previous year. This creates a significant burden for health systems and patients. In addition, the high psychological burden of diseases such as atopic eczema¹ further adds pressure on both patients and healthcare budgets.

Currently, only about one-third of asthma and COPD patients have access to specialised centres and less than one-fifth of patients can access patient-centred or multidisciplinary care. ***Patients with allergies and respiratory diseases need European guidelines that support the move towards personalised treatments, facilitate access to specialist and multi-disciplinary care, and encourage higher involvement of respiratory specialists, including nurses.***

Digital patient-driven data must be recognised and used in clinical, regulatory and policy decision-making processes and further developed through adequate European-level research programmes and projects. Cross-border healthcare and the digital exchange of patient data across Member States must be expanded - a true digitalisation of healthcare at European level as outlined in the Commission Communication on enabling the digital transformation of health and care in the Digital Single Market has long been overdue. This also includes initiatives and programmes to encourage the uptake of digital tools by all participants in the healthcare system and the promotion

¹ 30% of patients with severe atopic eczema symptoms suffer high psychological strain and depressive mood according to EFA "Itching for Life" report:
<http://www.efanet.org/resources/library/3373-european-report-itching-for-life-quality-of-life-and-costs-for-people-with-severe-atopic-eczema-in-europe>

of digital literacy amongst patients and healthcare professionals. Finally, **better access to non-pharmacological treatment and psychological support** for patients with allergies and airways diseases and their caregivers needs to be systematically ensured.

Each of us has a story, but we all share common challenges. Therefore, EFA actively invites all stakeholders to join together in this initiative as participants, creators, facilitators and drivers in improving the situation for people living with allergies, asthma and COPD in Europe. **Only together is change possible.** This roadmap on patient safety, access to healthcare and eradicating inequalities serves as a guidepost for patient organisations and policy makers to reach these attainable goals. EFA welcomes you in joining that mission.

Show your commitment to allergy and airways diseases patients: #ShowLeadership!

*All data cited in the Roadmap has been extracted from the EFA Active Patients Access Care Report (2019) and from the EFA Atopic Eczema – Itching for Life Report (2018). Both reports are available on the EFA website: www.efanet.org.