



European Allergy and Asthma Youth Parliament

Growing up with Allergy and Asthma – How EU policymakers can support young allergy and asthma patients to live better lives

Inform | Prevent | Care - A policy guide for change

A POLICY GUIDE FOR CHANGE

Millions of children and young people live with **allergies and asthma** in Europe today. Allergy is the most common disease among children in Europe, which means that many will live with it for most of their lives. Asthma can begin at any age, but most often it starts in childhood. After allergies, it is one of the most common chronic diseases in children.

Despite these startling facts, as we grow up and become socially active, we often feel that the needs and demands of young people are not sufficiently reflected in policy discussions and frameworks on prevention, care and disease-management. This is despite that, as young patients, we face **different problems and difficulties** than older patients.

Meanwhile, we are also equipped with a **different set of tools, skills, and capabilities** to handle our allergies and asthma. Our unique knowledge can help guide policymaking to create long-lasting frameworks for people with allergies and asthma.

Independence and personal flexibility is key for young people. Simple things such as socialising,

working, **travelling and moving abroad should not be a privilege** of only those who do not live with a chronic disease. EU policy should also consider the needs of young people who do not take part in EU mobility schemes such as Erasmus, but enter work after finishing school and may be subject to environments at work that impact their health. A clear step towards **digital disease-management** will be crucial to overcome these inequalities.

The **voice of young patients** needs to be listened to. Being the next, but also the digital generation, we need to be involved in decisions being taken now that affect how we will live with our diseases over the next decades. Whenever digital solutions for health are discussed or developed, we need to be part of those debates.

Providing guidance on information, prevention and care, these recommendations serve as a **guide for change**, and present the young patients' perspective on a **future oriented and fit-for-youth** European health policy framework.

As young patients with allergies and asthma, we:

- ... face different problems than adult patients,
- ... have distinct needs, priorities and capabilities for our diseases,
- ... need your support to make our collective voice heard,
- ... would like to see a 'youth-in-all-policies' approach in EU decisions

Support us in making the young patients voice heard!

INTRODUCTION - MAKING YOUNG PATIENTS LIVE BETTER LIVES

Allergies and asthma are among the most prevalent chronic diseases in Europe, especially for children. While these diseases affect millions of adults in the EU 27, that also a huge number of young people lives with allergies and asthma is a widely neglected fact.

Young allergy and asthma patients: A population bigger than Belgium

In Europe alone, around 10 million people below the age of 45 live with asthma. This number rises to **13.5 million** when including those who live with allergies or atopic eczema below the age of 25. It is foreseen that by 2025, one in two Europeans are going to suffer from an allergy.

To put into perspective, this means that a young population bigger than that of Austria, Belgium or Czech Republic is affected by allergies and asthma.

First-hand stories and experiences

Young patients who have grown up with a chronic disease understand the **physical and emotional burden** that comes with handling allergies and asthma throughout childhood and during adolescence, and in the transition to adulthood.

EA² Youth Parliament - Making the young patients' voice heard

It is for this reason that the European Federation of Allergy and Airways Diseases Patients' Associations (EFA) formed the **European Allergy and Asthma Youth Parliament** in early 2020. Young patients, medical professionals and students from across Europe - whether living in an EU-27 country or not - came together to share their ideas, experiences and concerns, and provide their personal and country-level perspectives. This direct partnership between patients and medical professionals/students is key for better health outcomes and Quality of Life.

From the start, the group brainstormed on young patients' needs, priorities and capabilities. It has developed from a couple of individuals into a European community eager to **improve the lives of young patients**. A community that speaks with a strong and united voice, representing the needs and demands of millions of young allergy and asthma patients in Europe. A community that will expand, with more young patients and doctors joining the conversation!

With this paper, we are presenting our **guide for change**. Our proposed recommendations show how YOU, as EU policymakers, can support young allergy and asthma patients to live better lives.

FACTS: European Allergy and Asthma Youth Parliament

10 virtual coordination meetings

10 months of collaboration

Severe Asthma

9 EU and non-EU countries represented

Food allergy

1.280 minutes of discussions

Atopic Eczema

21 years; average age of participants

Allergy

11 participants' languages

10 patient representatives

3 scientific advisors

Asthma

RECOMMENDATIONS - A POLICY GUIDE FOR CHANGE

INFORM: Involve young allergy and asthma patients in policy decisions affecting their health.

" Often I feel like people don't take me serious when I say that I have issues with allergies. I mean, why do they question my suffering?"

People go through major transitions during their youth. Becoming a teenager brings significant changes, physically, mentally, and socially. Meanwhile, early adulthood is a period characterised by continuous evolution – including moving from school into the labour market or further education. This leads to new social environments and relationships, and exploring new places and ways of living.

Going through a period of life with many changes, living with a chronic condition such as allergy or asthma comes with uncertainties and a self-awareness that forces young patients to prioritise their disease during this decisive life-time. This can limit the choices of young people living with allergy or asthma at a time they should have the chance to explore many possibilities.

For millions of young people living with allergies and asthma, adaptation is an everyday experience. Yet, as young patients we are aware that our opportunities to cope with our diseases are rather different compared to adult patients. Our limited income or savings and restrictive health insurance schemes do not reflect the mobility and occupational needs of young patients in Europe.

Input, impact and information

An important action point needed is to **increase awareness of allergies and asthma**, and reduce stigmatisation from the broader public.

The burden of these complex diseases is still largely misunderstood, which leads to underestimated perceptions of its impacts, and sometimes even incidents of **social discrimination** because of allergy or asthma.

As young patients we see schools and universities as opportunities for **public information campaigns**. Educational settings can create a multiplier effect towards a better collective understanding of allergies and asthma: whether it is in the canteen for food allergens or the indoor air quality in classrooms. Patients, parents, and educational staff can be excellent ambassadors to disseminate basic information about allergy and asthma, as well as the related national and EU policies to overcome them.

We also recognise the need for **research on the current trends of allergy and asthma**, as well as their economic, social and Quality of Life burden. Aside from generating facts on the prevalence of the disease both at national and EU level, this would help develop a **register for severe allergic disease** to improve surveillance and monitoring, and increase opportunities for disease management.

Monitoring and disease management can also be benefitted via public investment to setup disease-specific European networks of excellence.

Open channels for open discussions

Digital tools and social media allow policymakers to **connect directly with young patients, to understand their realities and help them cope**. Putting young patients at the centre of discussions affecting our health is key for establishing effective and future-oriented health policy frameworks.

INFORM: Our recommendations to EU policymakers

- **Appreciate young patients' distinct needs, qualities and priorities, and take them on board in decisions about allergy and asthma health**
- **Engage with us in 'spreading the word' to reduce ignorance about the negative impacts allergies and asthma have on patients' lives and stop discrimination based on disease**
- **Support awareness-raising initiatives and campaigns at local level e.g. via school/student ambassadors, and help disseminate their outcomes**
- **Invest in research on allergy and asthma prevalence, prevention, and care, with a focus on patients' Quality of Life. The development of a severe allergic disease register to improve surveillance of allergy trends in the EU could help in this respect**
- **Make use of digital and social media tools to allow fresh, real feedback from young patients on their realities, involving them in the decision-making process**

PREVENT: Ensuring healthy environments that do not compromise our lives.

“ I always have to do a risk assessment before an activity to determine whether it is safe for me or not. I also need to have a plan in case I get an asthma attack.

Young allergy and asthma patients are like the ‘canary in the coal mine’, in the sense that we are radars of (and highly sensitive to) unhealthy environments and environmental changes.

According to the European Environment Agency, around 400,000 annual premature deaths in the EU are linked to polluted air. This means that air pollution is the single deadliest environmental **health risk**. There is no doubt why the Eurobarometer places climate change, air pollution and waste as the three most important environmental issues for young Europeans.

Indoor and outdoor air pollution makes our diseases worse

Emissions from the transport, industrial, and building sectors are a major health concern in most EU cities and countries. Moreover, climate change is also increasing **airborne pollen**. This impacts young allergy and asthma patients’ Quality of Life as **symptoms and diseases worsen**.

But young patients might also not be safe indoors as unfit **indoor environments can trigger or worsen allergies and asthma**. Mouldy, damp, or badly ventilated buildings, closed spaces filled with tobacco smoke, furniture on public transport or schools that is made out of fabric which attracts dust mites, pollen and pet hair – all of these can have a large impact on young allergy and asthma patients’ health. This limits

our access to public spaces. It affects not only our ability to engage in educational and work environments, but also socially.

Moreover, real-time information is important. Digital tools can generate knowledge on crucial risk factors, such as the different pollen seasons or outdoor air pollution. If packed into **digital-friendly, accessible information 24/7**, these tools can be valuable help in preventing worsening of our disease symptoms.

Allergens and irritants in food and consumer products

Another leading concern for young patients is the food we eat, given the prevalence of food allergy among young people. While the EU has made recent advances in making food information more accessible and available, issues such as **precautionary allergen labelling (PAL)** are still **not based on standardised rules**. The risk of inaccurate allergen information has considerable consequences for young patients, causing us to either take risks that can be fatal, or to not eat food.

Moreover, given that **no EU country requires mandatory training in allergen management** for food business staff, there is often a lack of even basic knowledge of food allergies. This creates a constant feeling of risk, avoidance of public occasions, and also social isolation of young patients which impacts our mental health. This could be prevented by **targeted EU action on allergen management**.

Young people with allergies are also limited by what we can buy. Perfumes, detergents, and certain types of clothing contain **chemical substances** that can trigger allergic reactions when used. Young people with atopic eczema are especially affected. This is often an overlooked factor and makes even basic things such as buying and washing clothes difficult. Here again, access to information on the substances included, including via electronic means, is key.

PREVENT: Our recommendations to EU policymakers

- **Take action to tackle outdoor air pollution and reduce harmful emissions from all sources in line with EU’s zero pollution ambition**
- **Address indoor air pollution by ensuring healthy, well-ventilated buildings, and encouraging and tackling exposure to second-hand smoke in closed spaces**
- **Think allergy and asthma health when shaping actions to tackle climate change**
- **Support research on better digital tools to generate information about certain environmental risk factors e.g. pollen and air pollution**
- **Harmonise the application of Precautionary Allergen Labelling on prepacked food across the European Union**
- **Regulate better product labelling and encourage the development of patient-friendly tools to identify allergens and other harmful substances in food and consumer products**

CARE: Digitalising disease management for flexible and affordable treatment and care

“ Unfortunately, I have lost contact with my doctors because I had to move a lot for my studies.

Mobile phones, watches, smart homes, self-driving cars, drone-delivery, industry, business, transport, and research: we are in a **digital revolution**. For us young patients, digitalisation has framed the world we know, becoming our way of life.

Yet how can it be, that the ways we manage our chronic diseases are not digitalised? How is it that **video consultations with our doctors** are not yet an option for all when it is suitable? How can we not have **digital health records and EU-wide electronic prescriptions**? And finally, how can we not allow young patients to follow our treatments adapted to individual needs and personal action plans through **digital apps and tools** all around Europe?

Digital apps and tools for improved and more flexible treatment and care

As young allergy and asthma patients, it is key to explore the full potential of technology for informative, diagnostic, and disease-management tools. Digital health can help us administer and adhere to our treatment, monitor our symptoms, avoid triggers and prevent flare-ups. It is with these solutions that we can increase our personal **flexibility to deal with our diseases**.

To become fully usable, these tools need first to be **standardised and evaluated for their trustworthiness**. Only then will we be able to live, work, and travel across borders without fearing for our health in case of a sudden disease flare up.

Moreover, digital tools can help us and our doctors make the **transition from paediatric to adult care** easily, without losing knowledge or quality of care. As a result, our employment and education

opportunities should not be limited by our health.

Let's not exclude chronic disease patients from these opportunities. Let's develop schemes for treatment and care that reflect the **need for more flexibility** and that fully applies digital health, whether eHealth or mHealth disease-management applications.

Financial hardship due to healthcare costs and access to treatment

Our financial security as young patients is also affected by allergy and asthma. Essential long-term treatments, over-the-counter medicines, and medical equipment for allergy and asthma become **far too often unaffordable or inaccessible**, especially for young patients with low or no income.

Reimbursement policies differ tremendously across countries, which **increases inequalities** in Europe. But **we see allergy and asthma neglected across the whole EU-27**. The majority of European countries only offer full refunds for symptomatic treatment and offer partial reimbursement for base medicine to diagnose or treat allergy.

We envisage a future where people living with a chronic disease can **cover their needs without out-of-pocket costs**. In addition, we would like the EU to champion coordination to ensure access to treatment for all, and avoid shortages. In the long-term, we believe that an **EU with a stronger mandate on health policy** can lead to better health outcomes and healthier lives.

Support scientific research on allergy and asthma treatment and care

As young patients, we have full confidence in **scientific research to create new treatment and care pathways**. Scientific breakthroughs can bring great benefits in our quality of life and relieve the burden of the disease.

In turn, the EU can greatly benefit from the input of young patients and medical professionals when developing the basic priorities of its research policy, thus allowing for a **research agenda** tailored to the needs of young population.

CARE: Our recommendations to EU policymakers

- **Facilitate the establishment of a broad EU-level regulatory framework for online consultations and digital monitoring applications to facilitate disease management for young patients**
- **Regulate for the standardisation and user-friendliness of innovative technological tools to enable effective management of the disease, while providing options to assess their reliability**
- **Better integration of the youth perspective to enable a personalised approach to diagnosis, treatment, and care via digital means**
- **Enable equal access to medicines and eliminate out-of-pocket costs for the treatment of allergy and asthma**
- **Support scientific research in allergy and asthma treatment and care integrating the input of young patients and medical professionals**

THE EUROPEAN PARLIAMENT INTEREST GROUP ON ALLERGY AND ASTHMA

was launched on 25 March 2015 as a result of a long-standing collaboration between the European Academy of Allergy and Clinical Immunology (EAACI), the European Federation of Allergy and Airways Diseases Patients' Associations (EFA), and a group of forward-thinking Members of the European Parliament (MEPs), who are committed to tackle allergy and asthma in Europe.

CONTACT US

For more information on the Interest Group on Allergy and Asthma please contact the Secretariat.

office@allergyasthmaparliament.eu

#EPAllergyAsthma

#EA2Youth

