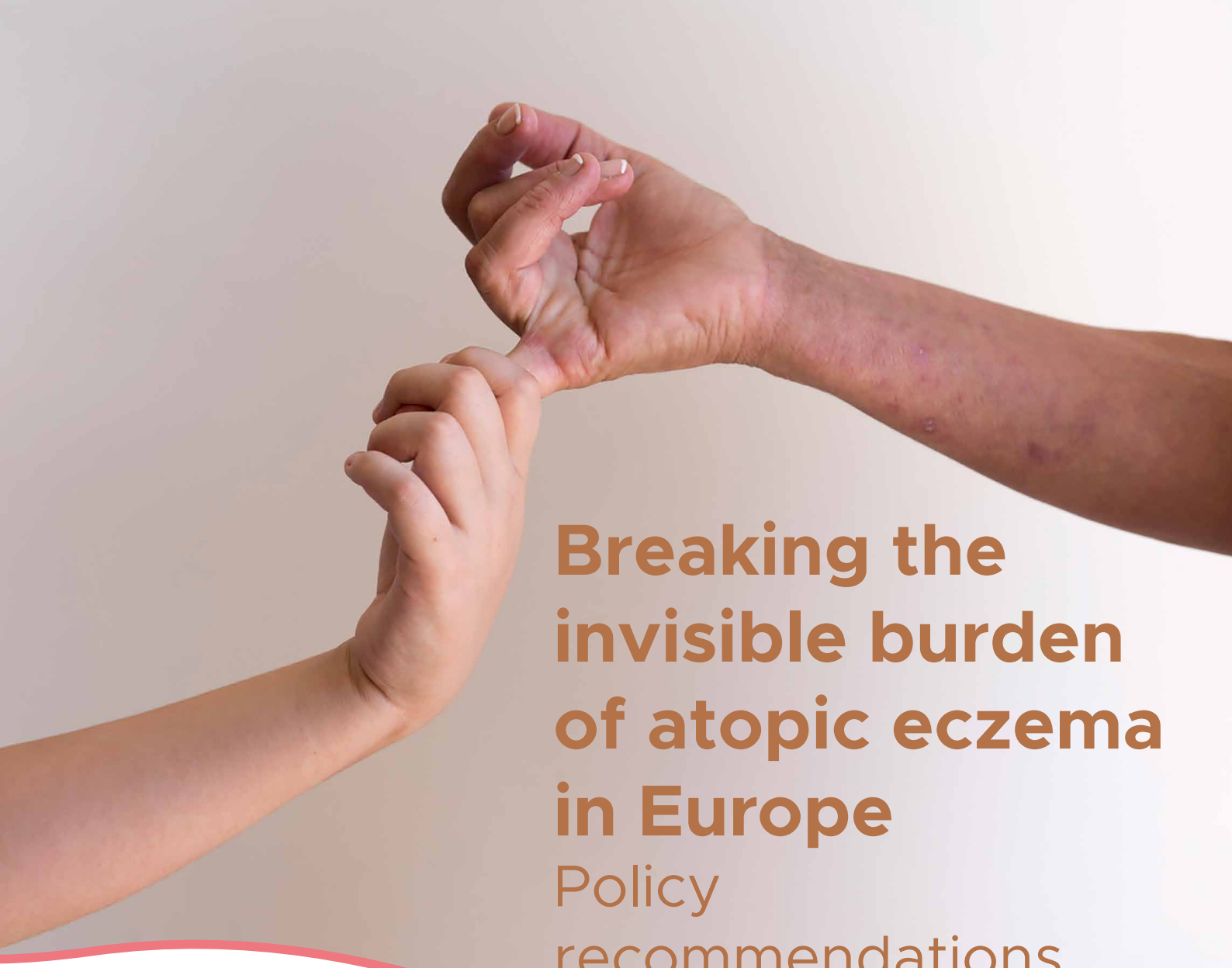


AtopicEczema **BREAK**

The Invisible Burden



Breaking the invisible burden of atopic eczema in Europe

Policy
recommendations

#BreakTheInvisibleBurden



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Diseases Patients' Associations

1. INTRODUCTION AND POLICY CONTEXT

Atopic eczema (AE) is the most common chronic inflammatory disease of the skin, affecting approximately 4.4% of adults and up to 18.6% of children/adolescents in Europe, with 20% of all cases accounting for moderate-to-severe forms. As a relapsing condition, it shifts between periods of remission and flare-ups.

The root causes of AE are traced back to a complex interaction of inherited, immunologic, and environmental factors. Genetic predisposition largely determines the vulnerability of the skin, making AE a disease that 'runs in the family'. However, it is mainly exposure to external factors, such as air pollution, allergens and other irritants, that triggers disease flare-ups.

At the same time, the different ways that the root causes interact are not fully charted or understood, which means that there might be other triggers, beyond external factors, that remain still unknown.

Aspects of AE physical and non-physical burden

Common symptoms include intense itching (pruritus – which when severe can cause great pain), red rashes, bleeding and oozing of the skin, as well as dry, cracked and crusty skin. Itching, in particular, is a key driver of disease burden, including a severely sleep deprived state, reported by the vast majority (90,1%) of those with moderate-to-severe AE.

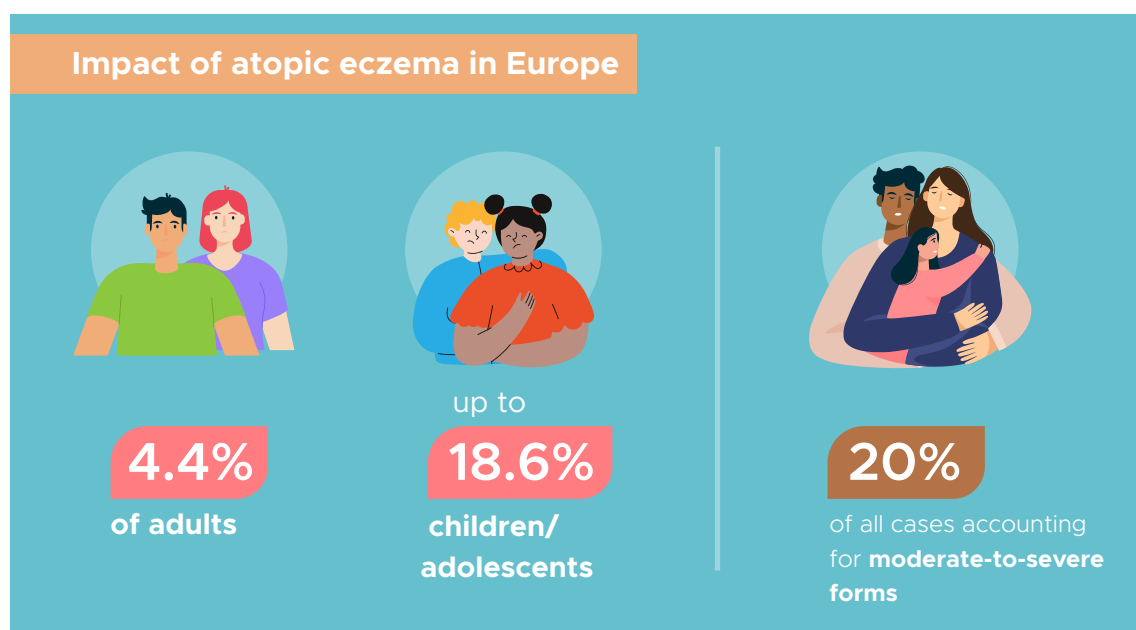
Part of AE's 'invisible' burden is linked to mental and social aspects. Prompted by the visibility of symptoms, people with AE often face bullying, feelings of shame, reduced self-esteem, social stigma and isolation and difficulties in building intimate relationships. Put together, one can easily understand why this burden can be devastating for those living with AE and their carers - impacting the whole family quality of life.

AE and health inequalities

AE presents numerous inequalities: according to the European Academy of Dermatology and Venerology (EADV), AE affects up to 20% of children and 2-10% of adults. The figures imply that AE is more prevalent in early years of life, and therefore children and adolescents are more vulnerable to its onset.

Children and adolescents living with AE may face additional challenges related to sleep disturbance, school performance, social participation, and psychological well-being, highlighting the need for age-appropriate support throughout the care pathway.

There is also a gender dimension, as AE prevalence is higher among adult women than in men, partially due to hormonal changes in women, especially during the premenstrual period and pregnancy.



In addition, AE is linked with higher frequency, severity and persistence in ‘non-white’ populations such as Asian, African and Latinos, as compared to people with lighter skin tones. Challenges around diagnosis, culture, and under-representation of these populations in dermatology trials, often lead to harsh realities where social misconceptions and stigma become far too common.

Finally, there is also a “postcode lottery” with large geographic inequalities affecting access to care and long waiting times, particularly in rural locations.

AE and comorbidities

AE is linked with various comorbidities, arising from the sensitisation of the impaired skin barrier. As such, AE has been portrayed as the first stage in the ‘Atopic March’, the disease sequence where one allergic or atopic condition leads to the others. In rough chronological order, these conditions include food allergy, allergic rhinitis, and asthma.

A less known and researched fact is that AE is associated with increased risk of non-atopic conditions, including cardio-metabolic diseases such as congestive heart failure and coronary artery disease; while other comorbidities include obesity and autoimmune diseases such as rheumatoid arthritis and inflammatory bowel disease, explained in part by shared genetic risks. Finally, the compromised skin barrier has been shown to increase the risks of bacterial and viral skin infections.

Policy context

Today, skin health stands at a turning point. In May 2025, the World Health Assembly adopted [resolution 78.15 on ‘Skin diseases as a global public health priority’](#), acknowledging the impact of skin diseases and identifying existing policy gaps. For long-neglected disease areas such as skin, the resolution represents a strong political commitment by Member States to act decisively at the national and regional level.

EFA has welcomed the WHA resolution on ‘Skin diseases as a global public health priority’ as a unique opportunity for the AE patient community in Europe. Indeed, the resolution spells out action areas echoing some of the most persistent gaps identified by the AE patient community, including:

Adequate budget for prevention and treatment

Support in data collection and mapping of skin diseases

Equitable access to affordable, high-quality care

Stronger integration of care services with mental health

Better education for healthcare professionals and patients

Promotion of research on skin diseases

Support patient organisations in their engagement and policy advocacy

The upcoming WHO Global Action Plan on Skin Diseases (GAP-SKIN), expected to be adopted in May 2027, promises to serve as ‘*a strategic framework for integrated, people-centred skin health services*’. Most importantly, it will mark the move towards implementation on the ground, identifying actions that can have a tangible impact on health outcomes for all skin patients, including those living with AE.

2. BREAKING THE HEALTH BURDEN OF ATOPIC ECZEMA: RAISING AWARENESS AND VISIBILITY

Busting the common myths around AE

'AE is just a rash', 'Come on, it can't be that bad', 'It only affects your skin, right?', 'Are you sure it's not contagious?', 'AE care is covered under dermatology', 'Just put on a skin lotion and you'll be fine'... These are just some of the most common myths surrounding AE, some of which patients living with AE and their carers face on a daily basis.

Looking at those myths carefully, one will identify concrete underlying drivers: a tendency to trivialise or simply an unwillingness to look beneath the surface. In fact, the existence of these myths around AE is nothing but a symptom of a poor level of understanding of AE and its burden, at both the societal and healthcare levels, as well as at the political level.

Crucially, mixed messaging on AE may also take place within the healthcare setting. Wrongful claims by healthcare professionals, especially regarding the impact of topical corticosteroids (TCS), may lead to unfounded 'corticophobia', erroneous treatment pathways, non-adherence to prescribed treatments, misuse of corticosteroids where these are available over the counter, and increased patient anxiety and permanent damage for the skin.

Reinforced by social media, which often spread misleading content on simplistic cures and solutions, misinformation is a major risk that indicates the need for better awareness and education on AE across all levels of society.

Patient organisations can play a valuable role in combating misinformation. Countering it also requires healthcare professionals, not only patients, receiving continuing education, the systematic provision of trusted patient information resources at diagnosis, improved digital health literacy, and consistent messaging across the care pathway (GPs, dermatologists, nurses, pharmacists).

The full reality about the AE health burden

The reality is that people affected by AE carry an enormous burden that goes far beyond the physical well-being, and touching mental, emotional, and social dimensions. This burden is largely invisible, in the sense that it is hidden from public, often happening behind closed doors as patients suffer in silence.

Physical symptoms tend to intensify psychological stress. The constant itching leads to sleep disruption (in 49,3% of the cases) and insomnia, anxiety and depression (in almost 1 in 5 patients), as well as daytime fatigue. In fact, the risk of anxiety and depression for AE patients is 60% to 68% higher compared to people without AE.

While up to half of AE patients report mental health challenges, only a few receive psychological support. Moreover, moderate-to-severe AE has been shown to double the odds of suicidal thoughts, a critical effect often overlooked during standard dermatological visits.

AE leaves a substantial footprint also on social aspects of life. The visibility of symptoms comes with a deep-rooted social stigma that exacerbates the mental health impact. People with AE often feel judged and defined by their disease, leading to low self-esteem and feelings of embarrassment in social settings.

At the same time, nearly half of adults with AE avoid social interactions or intimacy due to visible flare-ups and reduced confidence. Especially for children and adolescents, at this formative age, AE often leads to bullying and teasing at school, rejection by their peers. Cases of helplessness, as well as social withdrawal and isolation have also been widely reported.

In this light, it is no wonder that AE can also affect household relations, as almost 52% of caregivers report that managing AE has negatively impacted their family relationships.

3. BREAKING THE FINANCIAL BURDEN OF ATOPIC ECZEMA: UNWRAPPING THE ECONOMIC IMPACT

AE and the 'hidden costs' for patients, systems and the society

The burden of AE does not stop at the intense itching, the disrupted sleep and the mental health implications. It also incurs a significant direct economic burden for patients and their carers, but also indirectly for healthcare systems and society as a whole.

These 'hidden costs' and their impact have only marginally been explored. However, based on available data, EADV has estimated that the total annual expenditure associated with adult moderate-to-severe AE in Europe is estimated at €30 billion.

Patients living with AE heavily depend on long-term medicines and treatments to control their disease, especially during the flare-up spells. For them, the financial burden associated with AE, typically referring to over-the-counter treatments, doctor visits, skincare products, and complementary therapies, may extend substantially from what the healthcare system covers.

Healthcare systems and society also pay a heavy price

In particular, European data show that people with AE spend an average of €927 per year

on non-reimbursed healthcare products like emollients and moisturizers, with costs further increasing among those with moderate-to-severe AE. Of course, these estimates do not take into account additional costs shouldered by households that are key for people with AE if they want to prevent a flare-up, such as special clothing, bed sheets, and cleaning products; as well as other hygiene products.

AE bears a heavy cost also on healthcare systems, the average annual costs of the disease ranged from €1,572 to €6,993 per patient per year. Major cost drivers were medication use, dermatologist consultations, and hospitalisations due to treatment. Arguably, AE's implications for mental health play a key role here, driving up the costs for patients' care.

Finally, a significant indirect cost extending to the societal level is the productivity loss, as a result of the debilitating nature of the disease symptoms. AE is often associated with reduced productivity, often leading to absenteeism i.e. missed days from work and school; or presenteeism, where the performance at work and school is compromised due to sleep disturbance and intense itching. Evidence suggests that indirect costs linked to lost productivity often double or outweigh the direct costs for healthcare.

The cost of atopic eczema in Europe



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4. BUILDING THE ATOPIC ECZEMA CARE CONTINUUM: A PROBE INTO THE CURRENT GAPS IN AE CARE AND TREATMENT

Gaps in access to integrated AE care, including personalised therapies

AE is a complex disease, with a burden that goes far beyond the visible skin symptoms. Despite this multi-level impact, people living with the disease often do not receive the care that meets the challenge – and truly responds to their needs.

The nature of AE as a disease calls for an integrated approach. In practice this means connecting expertise across specialties, including primary care doctors, dermatologists, paediatricians, allergologists, nurses, pharmacists, psychologists, and nutritionists.

As such, multidisciplinary care would pave the way to a holistic care of AE, allowing more personalised care pathways, including appropriate referrals, better disease management and advice for daily care, as well as improved psychological support for patients in need. Without a doubt, better health outcomes and quality of life overall. This is why, according to GlobalSkin, 62% of patients and caregivers see a holistic treatment plan that includes consideration of both AE and other physical and mental health conditions as their number one care priority.

However, still today, AE care remains fragmented across Europe, as healthcare systems largely lack this level of coordination. This often leaves patients in a void, facing persistent unmet needs and navigating the system themselves without access to consistent care advice. According to a European study by EADV, 45% of participants under routine care continued to exhibit active, moderate-to-very-severe AE symptoms.

Meanwhile, access to care in Europe – whether it refers to specialist services, treatments, or education and support – remains highly unequal, with significant disparities both across and within countries.

Disparities among countries are even more pronounced in accessing advanced treatments. Personalised treatments, authorised by EMA for the treatment of moderate-to-severe AE, are often hard to reach for patients. This is due

to a combination of factors, including different national health priorities and healthcare budgets; variations in reimbursement policies and Health Technology Assessment; distorted, broken and secret European pricing systems, as well as prescription barriers for physicians in certain systems.

Addressing these disparities is essential because AE is not a one-size-fit all condition. Disease severity, itch burden, psychological impact, age, lifestyle factors, and associated comorbidities can vary considerably from one patient to another. Patients therefore benefit most from personalised care and treatment approaches that reflect their individual needs, preferences, and priorities, including appropriate education and support for self-management.

Education as a key factor

Another important factor in the broader discussion about AE care is patient education. Information and knowledge on the overall burden of AE including its effects on mental health, sleep, and daily functioning are vital. Information and knowledge on the latest available treatments are also vital in choosing an effective treatment pathway; while advice on daily care and paramedical support are key for patients to ensure proper self-management in the longer term.

A recent international survey, including European participants, found that patients continue to want better educational content. 42% wanted more information about triggers, 46% wanted questions to help them prepare for consultations, and 40% wanted better ways to communicate the impact of eczema to their healthcare professional.

Education of primary care doctors is equally important, especially in countries where they act as gatekeepers of the healthcare system. General practitioners and paediatricians need to be able to understand the burden of AE, know what good care for AE patients looks like and what the available treatments are.

5. POLICY RECOMMENDATIONS

What follows is a set of recommendations, addressed to policymakers at both the EU and national level, recognising the strong interlinks between the two levels of governance; as well as the numerous mechanisms available to policymakers, whether in Brussels or in the national capitals, to promote public health across Europe. They were developed in collaboration with the EFA Atopic Eczema patient community.

Our asks also reflect the key principles of the WHA resolution on ‘Skin diseases as a global public health priority’, looking towards the upcoming global, regional, and national action plans. Built in a targeted, action-oriented manner, the recommendations aim to offer crucial support in the implementation of the resolution.

Overarching policy recommendations for EU and national policymakers



Recognise and integrate AE into key EU frameworks on non-communicable diseases, including any successor of the EU NCD Initiative – Healthier Together (post-2027)



Establish an EU Joint Action focused on AE, formalising collaboration among EU institutions, Member States, and stakeholders; enabling research funding; and defining and achieving of joint disease-specific goals



Support the generation of data and evidence on the whole spectrum of AE health burden, including at national level, in support of policymaking; the existing awareness gaps and misinformation; and the reimbursement policies across the EU Member States

Theme-specific recommendations for EU and national policymakers

Increasing awareness and visibility of AE in EU policies, fostering better understanding of the emotional and social burden

1



Enable improved understanding of AE through dedicated communication campaigns, including supporting initiatives in the context of the World Atopic Eczema Day



Launch European-wide study to generate comparable data on the whole burden spectrum of AE



Fund further research on the underlying mechanisms of AE to improve understanding on its root cause and the interface of genetic and environmental risks

Reducing the financial burden of AE for patients, carers, healthcare systems, and societies

2



Launch a common European strategy to protect coverage of essential care for chronic diseases such as AE



Improve awareness on the economic aspects of AE, including evidence on the direct and indirect costs of AE

Moving from fragmented AE care and management towards addressing key gaps and strengthening patient care pathways across Europe

3



Promote integrated and genuinely multidisciplinary care for AE across health systems that involves all relevant specialties and disciplines, using AE as a case study for developing a European care model



Break persistent inequalities and geographical disparities, by improving expertise at the primary care level and healthcare delivery in areas where specialist services are limited



Enhance access to high-quality care and treatments, including personalised treatments and biologics currently beyond reach in many EU countries



Improve information and education of patients, including on daily care and self-management



Ensure better education for healthcare professionals, including paediatricians, for better recognition, assessment, and management of AE; as well as better knowledge on latest available treatments

We extend our heartfelt gratitude to the EFA Atopic Eczema Working Group Members for their valuable contributions and expertise in shaping and co-developing the policy recommendations presented in this document.

EFA extends our sincere thanks to our sustainable corporate partners Almirall, Incyte and Sanofi-Regeneron Alliance for their support through unrestricted grants for our Atopic Eczema Skin Needs project.



For more
information