

# EUROPEAN CONSENSUS REPORT 2022

THE

BURDEN

OF ATOPIC ECZEMA

This report reflects the outcomes of consensus meetings, held in June and October 2021, to explore the burden of atopic dermatitis/eczema (AD/E). It captures the views of a multidisciplinary panel of leading European healthcare professionals and expert patients. The report summarises the current situation, challenges, and solutions to improve the management of the disease and the lives of people living with AD/E.

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# FOREWORD

People affected by atopic dermatitis/eczema (AD/E) carry a heavy burden. The disease profoundly impacts the physical, psychological, social, and economic well-being of patients and their families. Despite new advances in how the disease is understood and managed, innovations and access to new therapy is still crucial. Many patients do not achieve disease control and this burden remains a daily challenge for millions of people in Europe.

Meaningful progress in addressing the quality-of-life issues faced by patients and parents/caregivers has been limited by misconceptions about the disease in society and at a political level. The seriousness of AD/E is poorly understood by many, while lack of education leads some to mistakenly believe that the disease is contagious – adding to the social stigma suffered by patients. We believe that this may explain the failure to develop a consensus among policymakers at European level on how to urgently address the needs of people affected by AD/E.

It is time to change this precarious situation. That is why we were pleased to come together with 15 key opinion leaders in the field to form a diverse and representative Consensus Committee. Our group, all co-authors of this report, includes dermatologists, psychologists, dieticians, nurses, paediatricians, GPs and, crucially, patients and carers. Together, we explored the burden of AD/E, reviewed the literature and best practice, discussed practical solutions and – above all – listened to one another's experiences.

This report is the fruit of our collective efforts. It builds on the findings of the 2018 EFA survey on severe AD/E and quality of life, the largest survey of its kind to date. That study highlighted the challenges that arise from late diagnosis, stigma, poor referral system, existing barriers to access timely specialist care, and the underestimation of the economic burden of AD/E. This report at hand elaborates on those challenges and points the way forward.

As co-chairs of the Committee, we are proud of this evidence-based report, which combines science with storytelling. It reflects the true burden of the disease and sets out a clear path for making sustainable changes in our healthcare systems. We hope it can be a tool for all stakeholders, including patients and healthcare professionals, to advocate for access to services and to enhance the quality of care available to the AD/E community in Europe.



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# INTRODUCTION

People with atopic dermatitis/eczema (AD/E) live with a chronic, inflammatory, systemic disease associated with skin-barrier disruption, immune dysregulation, multi-organ disorders, intense symptoms and side effects of therapies (1). AD/E has a global impact on patients' bodies, beyond the visible signs and symptoms affecting the skin (2). People with AD/E can have relapsing itch and pain, sleep disturbance and fatigue, and mental health symptoms (3, 4, 5, 6). The visible signs of AD/E include erythema (redness of the skin), lichenification (thickening, darker patches, and exaggerated skin lines from chronic rubbing), scaling, oozing or weeping, and prurigo growths (lumps on the skin) (7). These contribute toward profound functional disturbances that limit patients' ability to perform daily tasks. This can cause psychosocial distress and stigma (7, 8).

AD/E is considered the most common inflammatory skin disease, affecting up to 20% of children and adolescents worldwide (9). According to the estimates of the International Study of Asthma and Allergies in Childhood (ISAAC), AD/E affects 15% to 20% of children and 1% to 3% of adults worldwide (10). AD/E develops predominantly in early childhood and may persist in adulthood (11, 12). Children who already have persistent disease, later onset, and/or more severe disease may be more likely to have the condition in adult-

hood (13). Severe AD/E affects about 15% of the paediatric population worldwide (14). In Europe, the prevalence of AD/E has steadily increased over the last four decades (9).

The causes of AD/E are complex and multifactorial, with genetic predisposition, skin barrier dysfunction, altered immune responses, and environmental and lifestyle factors, being suspected as underlying and aggravating factors (15). AD/E is often considered the first step in the development of other atopic diseases, such as allergic rhino-conjunctivitis, asthma and food allergy (2, 11, 16). About 60% of children with AD/E are predisposed to develop one or more other atopic disease (9). Additionally, cardiovascular disease, certain cancers, and a range of autoimmune and neuropsychiatric conditions may be more common amongst patients with AD/E due to chronic inflammation (2, 15, 17, 18).

Patients with AD/E frequently suffer from depression, anxiety, and attention deficit hyperactivity disorder (19, 20) that can negatively affect their academic path, work, and social life. The chronic and relapsing nature of AD/E can impact enormously on patients' well-being and quality of life (QoL) (21, 22) and can be highly burdensome for families and relatives (16).

## Background

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The European Federation of Allergy and Airways Diseases Patients' Associations (EFA), as a patient-led organisation at European level, advocates to improve the lives of all people living with allergies and airways diseases and for disease prevention. EFA is committed to helping bring patient needs and views to European

policy decision-making, research priorities and development. EFA produces patient evidence and generates European social and political consciousness on AD/E, in collaboration with its national members and other groups in the health sector who can change the lives of patients with the disease.

In 2018, EFA released the *Itching for Life: Quality of Life* and costs for people with severe atopic eczema in Europe report. The report aimed to document and raise awareness of patient QoL and the costs of the disease, and to support patients living with the disease in Europe (21). Itching for Life featured a survey of 1,189 adults with severe AD/E across Europe, finding that these patients were suffering more than would be considered acceptable. Many had serious AD/E symptoms (45%) at the time of the interview, and despite receiving care, they reported having dry or rough skin (36%), itchy skin (28%), cracked skin (17%) and felt their skin was flaking off (20%) on an almost daily basis. The survey reflected a latent need for treatment improvements, as only 15% of people surveyed were highly satisfied with their current treatment), but called also for better support to access care: people with severe AD/E spent extra money on healthcare expenses (on average € 927,12 per patient annually), and had extra

spending on everyday necessities, such as personal hygiene, which costed 18% more on average per month compared to healthy individuals. Although a set of recommendations for policy initiatives were included in the report, many actions are still needed to effectively reduce the burden of AD/E in Europe (23).

In 2021, EFA invited a panel of leading European AD/E healthcare professionals and expert patients (see Consensus Committee Members page 49) to form a consensus committee. Two virtual consensus meetings were organised to discuss and agree on the current situation, challenges, and solutions to reduce the burden of AD/E in Europe. Consensus meeting participants represented several European countries and sectors (map 1). Through this collaborative initiative, EFA aims to inform healthcare policymakers and stakeholders on current unmet needs in the care of AD/E in Europe.

**Map 1. Consensus meeting participants' location in Europe**



This report summarises the agreements that emerged from both consensus meetings, comparing the statements made by participants with findings

from the literature. The approach taken to review the literature is shown in Methodology at page 50.

# THE PHYSICAL AND EMOTIONAL BURDEN

OF ATOPIC DERMATITIS/ECZEMA



# THE PHYSICAL AND EMOTIONAL BURDEN OF ATOPIC DERMATITIS/ECZEMA

The burden of atopic dermatitis/eczema can impact a person in various ways throughout their life. Learning to manage the physical and mental discomfort can lead to feelings of social exclusion by patients and their caregivers. This is shown through the different experiences of young, adolescent, and adult patients as they navigate different social environments and managing their treatment along with their healthcare providers.

## Living with AD/E as a child

Pruritus is the medical term for itchy skin. AD/E is per definition a pruritic diseases. As many as 60% of children with AD/E or 83% of children with flares are affected by severe pruritus (24). Children can become irritable and inattentive when experiencing severe pruritus, and parents often find it difficult to help prevent their child from scratching (25). Sleep deprivation caused by AD/E seriously compromises growth and cognitive performance in young children and reduces their QoL (6, 26). Pruritus is frequently associated with sleep disturbances (25). In a large study of 3,116,305 children aged 5 to 17 years with AD/E, almost 67% reported sleep disturbances which are more serious with the moderate and severe forms of the disease (27). The side effects of sleep disturbance include difficulty getting to sleep, decreased quality of sleep due to waking up

throughout the night, reduced total sleep time, difficulty waking up in the morning, daytime drowsiness and irritability (25). Self-reported sleep disturbances in children of school age are associated with depression, fatigue, and anxiety, in addition to inattention and impulsivity (27).

Behavioural problems as well as mental and emotional sequelae, including cognitive, functional and neuropsychiatric impairments often extend far beyond the existent physical manifestations of AD/E (25) (27). Maladjustment problems, sibling rivalry, abnormal psychological development, excessive dependency, clinginess, and fearfulness have all been reported in children with AD/E (25). The risk of attention-deficit hyperactivity disorder, conduct disorder, and autism, depression and anxiety is higher amongst AD/E children



of school age, and can continue or become exacerbated when the child's AD/E recurs (25) (28) (27).

AD/E interferes with activities such as bathing, playing outdoors or swimming, compromising the social interactions and functioning of the child. Poor socialization skills and low self-esteem are common during childhood with AD/E (25). A qualitative research study based on interviews and the analysis of drawings of 17 children aged between 8 and 12 years revealed that skin symptoms largely limited their lifestyles, particularly with respect to diet (having to avoid certain foods to prevent exacerbating symptoms), play and sports (to avoid sweating that causes itch, especially in the summer), and felt considerable pain when bathing or swimming (29). Feelings of frustration, anger and unhappiness because of the restrictions on their activities were commonly reported (29). In the words of caregivers taking part in the consensus meeting, the consequence of several dietary and activity restrictions is a physical and emotional burden that **'alters the dynamics of the entire family'**, affecting the patient, their parents and their siblings.

The stigmatisation of AD/E is defined by negative attitudes shown towards patients based on their visible symptoms and a lack of social acceptance because of their skin problems (30). AD/E Consensus Committee members highlighted the impact of stigma on children, adolescents, and adults with AD/E, as well as on their families and caregivers. Stigmatisation can arise from the misperception of AD/E as a contagious disease, due to the limited knowledge of the disease in society (31).

Patients and caregivers participating in the consensus meetings acknowledged the conflicts that this can trigger: There is **'bullying'**, but there is also **'self-exclusion from social activities' as 'families, youngsters, and children try to avoid certain social activities'**.

Teasing and bullying from peers due to negative misconceptions or misinformation regarding AD/E may start as early as in the kindergarten (32). Patients and caregivers taking part in the consensus meetings acknowledged that **'bullying can start from kindergarten'** onwards, making children feel rejected at an early age. A qualitative study showed that AD/E can be difficult to manage at school due to concerns about attracting unwanted attention from peers or a lack of convenient spaces to apply creams or emollients on time and with the required frequency (33). Furthermore, paediatric patients with AD/E may find that their teachers perpetuate this negative environment at school due to their limited knowledge of their skin disease, causing them to mistreat or completely ignore their students with AD/E (29, 32). Discrimination and stigmatisation may also happen in children's neighbourhoods making life with AD/E a traumatic experience for children (29).

Overall, difficult family dynamics, increased stigmatization among peers, and a negative self-image put paediatric patients with AD/E at risk of future psychosocial disruption and potentially suicidal behaviour (32). Furthermore, the long-term impact of bullying may have cost implications in terms of emotional distress, integrating into work and being economically independent in adulthood (34).

## Caring for a child with AD/E

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Caregivers of a child with AD/E can be involved in multiple aspects of patient care and symptom management such as managing time-consuming treatment

regimens, coordinating provider appointments, making decisions about household changes, dealing with financial, relational, and other care issues and providing

emotional and mental support to the patient and to other members of the family (35). Reconciling treatment expectations, symptoms burden, school performance and social functioning can be extremely challenging for parents and children with AD/E alike (29). A survey of 235 paediatric AD/E caregivers from all over the world revealed that 60% reported waking up two or more times per night to provide care; 67% reported decreased work performance; 70% reported reduced ability to socialize or take part in enjoyable activities; 82% reported to worry about symptoms returning when they were absent; 79% worried whether their child would outgrow AD/E; 76% worried about adverse events from treatments; 74% reflected feelings of guilt and helplessness; and 52% reported sadness or depression (36).

Research on how the SARS-COV-2 pandemic may have affected AD/E management showed that parents/caregivers reported improved AD/E control due to closures of educational settings, being at home and having more time available for managing their child's AD/E (37). On the other hand, the loss of physical contact with their support network, such as grandparents who assisted with child-care, made it more difficult to cope with some AD/E consequences, such as sleep disturbance (37).

Sleep deprivation is also a huge burden experienced by caregivers of patients with AD/E. Sleep loss can influence nearly all aspects of life including emotional state, mood, well-being, ability to concentrate and ability to take initiative (38). Impaired cognitive function is common, such as memory deficits and an increased sensitivity to stress and sound including hearing their children's voices. Tiredness, fatigue, anxiety and guilt are common amongst parents caring for young children with AD/E. Parents may change their routines, plans and behaviours to compensate for sleep loss (38). Research conducted throughout the first 11 years of childhood with AD/E has shown that mothers of children with AD/E are more likely to report

difficulty falling asleep, subjectively insufficient sleep, and daytime exhaustion, and that more severe child AD/E is associated with worse maternal sleep outcomes (39). However, child sleep disturbances may not fully explain maternal sleep troubles. Other factors such as the caregiver's psychological distress, anxiety or depression related to the child's condition may be potential determinants of sleep disruptions.

AD/E suffering causes high emotional distress for the patient, their parents and their siblings (28). Research on AD/E in children has shown that caring for paediatric patients can be an extremely time-consuming task for caregivers that impairs personal relationships within the family and decreases psychosocial functioning (40). The care needs of children with severe AD/E may impose major life-changing decisions such as parents or caregivers changing their jobs or careers, working more flexible hours or reducing working time, becoming self-employed or even remaining unemployed. Caregivers may miss work or experience decreased work productivity (38) (40). Caring for a child with AD/E may also influence parents' decisions about having more children (36). Patients and caregivers participating in the consensus meetings acknowledged that ***'sometimes parents feel they must dedicate more time to talk to and to care for the child with AD/E than for the other children, and they feel sorry and, of course, very, very concerned about not taking sufficient care of the other children simply because they don't have any more time available'***. AD/E also increases siblings' levels of distress, affects the parent-child relationship, and sibling bonds (41). Exhaustion, worry, and social isolation can be shattering for families of children with AD/E (36). Emotional fatigue is frequent and devastating amongst AD/E patients and caregivers (36, 41) entailing an increased risk of depression and anxiety which may go undiagnosed (42, 43).

Caregivers of children with AD/E frequently report fears of losing control of the disease that led to self-imposed social isola-

tion, rejecting social activities. Caregivers taking part in the consensus meeting noted that *'parents may increase social exclusion because they do not trust somebody else to care for the needs of their children and avoid, for instance, sleeping overnight at a friend's house or even going on family vacations because they are so afraid that they will lose control over the disease'*. Parents also eschew events or interactions where their child with AD/E might

be exposed to allergens or triggers (36). Fears and uncertainties have a longstanding impact on family dynamics. During the consensus meetings, caregivers further described that *'even when there is full control of AD/E, the family is still impacted, especially the parents because they are always concerned about whether there will be a flare, whether there will be an exacerbation of the disease because it is a chronic disease without a cure'*.

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*Parents may increase social exclusion because they do not trust somebody else to care for the needs of their children and avoid, for instance, sleeping overnight at a friend's house or even going on family vacations because they are so afraid that they will lose control over the disease.*

Additionally, parents prefer to avoid uncomfortable reactions from strangers to the appearance of their child's skin or to feel blamed or judged for their child's AD/E persisting despite treatment (36). Stigma and bullying affect both children and their caregivers. Patients and caregiv-

ers participating in the consensus meeting also mentioned that *'there are quite a few examples of parents being accused of neglecting their children, and that they are going to be reported to the social services. So, this is quite a big problem'*.

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*There are quite a few examples of parents being accused of neglecting their children, and that they are going to be reported to the social services. So, this is quite a big problem.*

Research on co-parenting of children with AD/E (understood as the process in which couples discuss the principles of child-rearing, share the burden of child-rearing, and cooperate with each other) shows that the parents' stress can affect the child with AD/E, increase the risk of conflict between spouses and decrease parental motivation (44). This is particularly troublesome for children with more severe AD/E who are at high risk of having challenging behavioural problems, and for their parents who struggle to manage the condition successfully. More profound child behavioural difficulties have been associated with more severe AD/E and greater parent stress, depression, parenting conflicts, and relationship dissatisfaction (45).

Caring for a child with AD/E may be more challenging for families with dysfunctional coping strategies or those who lack support. Healthcare professionals taking

part in the consensus meetings mentioned that in those cases in which ***'the parents have a conflict between each other, the success of the treatments goes down. So, it's very important that both parents or partners understand the disease and the treatments, and work in harmony'***. Likewise, healthcare professionals described that ***'when the treatment is given by a third party, interruptions that impact the well-being of the child may happen. So, it is very important to explain the importance of treatments to the other caregivers that are different from the parents'***. Research has shown that one-parent families may have higher levels of helplessness and aggression due to their child's scratching behaviour than do mothers living with a partner and a child with AD/E. Also, single mothers of children with AD/E experienced higher levels of in the family and the lowest rates of general life satisfaction (46).

## Living with AD/E as an adolescent

Adolescents are considered a particularly vulnerable population as they may struggle to seek social and professional support to deal with their AD/E. Cracking, burning, flaking, and bumps on the skin have been reported by more than 70% of adolescents with AD/E after itching and soreness or pain (47). During the SARS-COV-2 pandemic, young people reported higher stress that may have triggered AD/E flare-ups (37). Bronchial asthma, allergic rhinitis and persistent eczematous lesions may develop with an increase in the severity of AD/E during adolescence (48, 49).

Although AD/E can improve with age, for many it persists into adolescence or adulthood (50). As reported by patients and caregivers participating in the consensus meeting, ***'hope in a better future that implies an effective and sustainable control of AD/E decreases over time among patients with the disease due to not finding a cure or an effective solution for the disease'***. In this sense, interviews conducted with children 6 to 12 years old showed that many of them speak about eczema as a temporary or passing phase that should go away as they grow up (35).

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*Hope in a better future that implies an effective and sustainable control of AD/E decreases over time among patients with the disease due to not finding a cure or an effective solution for the disease.*

However, older participants expressed disappointment because they had not grown out of it yet even though others had (33). Persistence of AD/E during adolescence has been correlated with increased anxiety and difficulties in building relationships with peers (50).

Stigmatisation and discrimination decrease adolescents' self-confidence, self-reliance and reduce their QoL (47). Adolescents with AD/E commonly describe avoiding going out, hiding their skin, worrying about the appearance of the skin, and feeling low (47, 51). An online web survey conducted amongst 401 self-reported AD/E patients of 12 years and older in Italy revealed that AD/E students are frequently targeted with nicknames (31.3%) and jokes (30.1%) by classmates who are also excluding/isolating (22.1%) or being bossy (22.1%) with them. Embarrassment (41.9%), impotence (39.1%) and frustration (29.9%) have been the most quoted feelings associated with the disease (52). Self-isolation behaviours (65.6%), finding it too complex to interact with classmates of the opposite sex (51.5%), avoiding parties (44.2%), giving-up on other school activities (42.3%) and missing school days to avoid potential bullying situations (28.8%) have all being frequently described by the participants in the survey. Self-isolation was significantly more common when bullying was present. Notably, the memory of bullying can remain even in adulthood (55.2%, all ages) and faded over time (46.0% in 55+ year-group) (52).

AD/E has been associated with chronic school absenteeism, presentism and impaired study performance due to difficulties in keeping focus and concentration at school or doing homework (52, 53). Among different age groups from 12 years old onwards, absenteeism was more pronounced in the 12–15 year-group adolescents who also reported a significantly higher presence of itch and sleep difficulties (53). Parents of school-aged children with AD/E are more likely to miss work for caregiving compared with parents of those without AD/E which implies work absenteeism and loss of productivity for caregivers (54).

Adolescents can be torn between wanting their peers and families to understand and take their AD/E seriously while at the same time wanting to be perceived as 'normal' (51). From the perspective of the healthcare professionals taking part in the consensus meetings, making AD/E decisions can be particularly difficult as ***'adolescents do not have their own voice yet, but they do not want the parents to decide for them'***.

Although adolescents welcome the opportunity to take an active role in their AD/E management, new roles and responsibilities also come with initial apprehension and challenges, including communicating their treatment concerns and preferences with healthcare professionals, and feeling unprepared for transition to an adult clinic (48). Therefore, patients between 11 and 18 years of age with AD/E may be the most difficult population group to deal with (50, 48). Nonetheless, research shows that this patient group needs support to deal with their self-care, to identify triggers and flare-ups and to evaluate the success of treatment. They also need psychosocial support to find a balance between accepting the long-term nature of the disease while hoping it will go away (50). In adolescents and young adults, the disease may distort their life planning and affect their professional choices (55). AD/E in adolescence has been associated with suicidal ideation and psychosomatic disturbances (56, 57). Overall, the experience and burden of AD/E vary over patients' lifetimes and are different for everyone.

According to the participants in the consensus meetings, healthcare professionals ***'need to pay attention to the embarrassment that the adolescent and the young people with a chronic skin condition may feel when they are meeting healthcare professionals'***. Likewise, ***'it is also very important to consider the barriers that young people sometimes face when they are addressing the healthcare system and healthcare professionals. Drop-off from consultation happens because young people do not feel understood in terms of how they feel and see themselves. Also,***



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*Need to pay attention to the embarrassment that the adolescent and the young people with a chronic skin condition may feel when they are meeting healthcare professionals.*

*because they may get lost in the system at the point of transiting from the paediatric to the adult clinic. It becomes a serious problem as lack of professional supervision of the disease implies an increase in the burden of AD/E for a long time, poor treatment, and increased risk of other associated diseases’.*

One consequence of an insufficient transition process may be that young adults with preschool/school-age on-

set of AD/E may be unsure about how to treat and manage the disease (58). Healthcare professionals taking part in the consensus meetings emphasised that *‘adolescents need to build confidence in meeting healthcare professionals to keep them in the consultation and within the system. The various concerns that are common at their age should be addressed, including the financial problems that treatments for the disease may imply to them’.*

## Living with AD/E as an adult

Adults with AD/E experience distressing flares, itchiness, skin rash and pain which severely compromise their daily life. Twenty-nine impactful signs and symptoms have been highlighted by adults with AD/E and are shown in text box 1 (47). Redness, dryness, rough skin, and rash are all signs experienced by more than 70% of adults while itch and pain are the most common and burdensome symptoms. Fatigue, gastrointestinal discomfort, and joint pain are also present. Adults with severe AD/E have more severe itch and pain, more comorbidities, worse sleep and higher levels of anxiety and depression than adults with mild and moderate AD/E (59).

Patients and caregivers taking part in the consensus meetings reported that *‘it becomes impossible to move around, to cook, to clean, even to go to the store or to keep medical appointments because the disease is so painful, with the itch being so devastating that normal daily life is an unachievable goal’.* Regrettably, the AD/E consensus committee members acknowledged that patients often become accustomed to chronic pain and itch, which imposes undue suffering and discomfort.

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*It becomes impossible to move around, to cook, to clean, even to go to the store or to keep medical appointments because the disease is so painful, with the itch being so devastating that normal daily life is an unachievable goal.*

**Table 1. Most frequently reported signs and symptoms reported in adults and adolescents [adapted from Grant L et al. (47)]**

<b>Symptoms</b>		<b>Signs</b>	
		<ul style="list-style-type: none"> <li>• Itch (Pruritus) <sup>C</sup></li> <li>• Burning/tingling sensation <sup>C</sup></li> <li>• Heat <sup>C</sup></li> <li>• Skin sensitivity <sup>A</sup></li> <li>• Sensitivity to sun <sup>A</sup></li> <li>• Soreness/pain/tenderness <sup>C</sup></li> <li>• Skin irritation <sup>A</sup></li> <li>• Skin tightness <sup>A</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Redness(Erythema) <sup>C</sup></li> <li>• Skin darkening or lightening <sup>C</sup></li> <li>• Dryness (Xerosis) <sup>C</sup></li> <li>• Roughness <sup>C</sup></li> <li>• Bumps (Papules) <sup>C</sup></li> <li>• Blisters/welts (Vesicles) <sup>A</sup></li> <li>• Hardening (Induration) <sup>C</sup></li> <li>• Flaking <sup>C</sup></li> <li>• Cracking (Fissuring) <sup>C</sup></li> <li>• Scaling <sup>C</sup></li> <li>• Peeling <sup>C</sup></li> <li>• Fissures <sup>A</sup></li> <li>• Thickening (Lichenification) <sup>A</sup></li> <li>• Thinning skin <sup>A</sup></li> <li>• Excoriation <sup>A</sup></li> <li>• Crusting <sup>C</sup></li> <li>• Bleeding <sup>C</sup></li> <li>• Oozing/weeping (Exudation) <sup>A</sup></li> <li>• Edema/swelling <sup>C</sup></li> <li>• Unusual sweating (Trans-epidermal water loss) <sup>A</sup></li> <li>• Scabs <sup>C</sup></li> </ul>
A	Reported in adult research only (literatura review, clinical interviews (n=5) or patient interviews (n=28))		
B	Reported in adolescent research only (n=20)		
C	Reported in both adult and adolescent research		

Adults with AD/E can suffer severe sleep disorders. This can include difficulty falling asleep, frequent waking episodes, shorter sleep duration, and feelings of inadequate sleep which can affect day-time functioning and work productivity (60). Patients can find themselves in a vicious cycle: sleepiness leads to anxiety and emotional distress which in turn causes more sleep deprivation (61). In turn, anxiety and emotional distress exacerbate the symptoms of the disease (28). The result is that itching, scratching, pain, bleeding, and poor sleep profoundly and negatively impact patients' physical and emotional wellbeing.

Anxiety has also contributed to the exacerbation of the symptoms of AD/E during the SARS-COV-2 pandemic. About 60% of AD/E patients experienced disease exacerbation in the early waves of the COVID-19 outbreak (62). Periods of staying at home may have improved the routine and application of topical treatments for some patients, but imposed difficulties with handwashing for others (37). Psychological stress was frequently explained by concerns related to the possibility of infection, a changed working life and possible loss of income, general pandemic-related conditions, worry about physical survival, amongst others (63).



Participation in virtual support groups, increased daily activities including regular exercise, and the teaching of techniques to reduce stress – including relaxation, hypnosis, and cognitive-behavioural therapy – can ease the psychological burden (62).

People with AD/E are at higher risk of developing rheumatoid arthritis and inflammatory bowel disease in adulthood (64). AD/E, rheumatoid arthritis and inflammatory bowel disease are characterized by chronic inflammation that contribute to the chronic nature of these conditions. Thus, rheumatoid arthritis and inflammatory bowel disease may be initiated by a sustained skin inflammation (18).

Adults with AD/E are emotionally burdened by feelings such as trying to hide the eczema, feeling guilty about eczema and having problems with intimacy (8). Sadness and anger due to disease are common (65). Stigma, social isolation, and the AD/E itself weaken patients' self-confidence, self-acceptance, and self-esteem. As patient participants in the consensus meeting put it: ***'it is not only a problem about choosing clothing or shaving or wearing makeup, we as patients with atopic dermatitis are not able to look ourselves in the mirror, or to see our reflection in any kind of surface'***.

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*It is not only a problem about choosing clothing or shaving or wearing makeup, we as patients with atopic dermatitis are not able to look ourselves in the mirror, or to see our reflection in any kind of surface.*

Adults who grew up with severe AD/E in childhood have significant delayed social development compared to patients who grew up with mild or moderate AD/E or no disease in childhood (66). Those who had severe AD/E in childhood had fewer friends in adulthood, were less likely to spend leisure time with their friends and were less likely to belong to a group of friends. They also went less frequently to a bar or disco during secondary school, and less often reported having been a member of a sports club during their primary and secondary school years (66).

AD/E negatively affects adults' ability to face life due to the worries and the limitations derived from living with the disease (67). AD/E patients tend to avoid certain jobs that may particularly affect the skin including some in the healthcare sector, food preparation, cleaning, hairdressing, or automobile

industry which may imply a loss of opportunity (28). Professional stress may lead people with AD/E to avoid certain duties or business trips, presenting obstacles to career development (52). It has been suggested in the literature that dermatologists should advise their AD/E patients early on occupational aspects of their disease and suitable career choices, and provide careful guidance about prophylactic skin protection (11).

The psychological well-being of adults with AD/E is impacted in multiple ways: the itching, the visibility of the disease, the lack of information about AD/E, the impaired performance at work, the ongoing search for an effective treatment, and feelings of frustration and helplessness when solutions do not work (67). Patients' self-esteem and self-confidence are diminished (8, 65). From the perspective of patients participating in the



*For adults it is very hard to get jobs due to severe symptoms, or because of stigma and discrimination as patients may be considered 'contagious' anywhere they go.*

consensus meetings, **'existential crisis is something that adults with AD/E are facing because for adults it is very hard to get jobs due to severe symptoms, or because of stigma and discrimination as patients may be considered 'contagious' anywhere they go'.**

Absenteeism from work may be due to physician appointments as well as due to the worsening of symptoms and AD/E flares. Patients may miss an average of 12 working days per year due to their AD/E (65). Workers who experience discrimination due to AD/E report more pronounced absenteeism (52). Even at work, patients often experience decreased productivity (so-called presenteeism) due to loss of sleep and anxiety (60). AD/E strongly determines rates of sick leave as well as the risk of losing or having to change job.

Greater AD/E severity has been associated with lower work productivity in adults (68). A study conducted in Germany estimated that indirect costs of AD/E may reach €483 per patient-year due to incapacity to work and productivity loss (69) (See Table 1, financial section).

Furthermore, research shows that AD/E may influence the sexual lives of patients and their partners (70). Thus, sexuality-related problems can be highly burdensome and distressing, causing a decrease in sexual desire and QoL (70). Healthcare professionals' taking part in the consensus meetings reported that **'sexual problems are a big issue, especially for the partners, and it is something that usually people don't discuss and are not willing to speak about but has a very big impact on the people's lives'.**



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# THE DIAGNOSIS AND CARE BURDEN

OF ATOPIC DERMATITIS/ECZEMA

# THE DIAGNOSIS AND CARE BURDEN OF ATOPIC DERMATITIS/ECZEMA

People with AD/E can face a challenging patient journey. Patient journey refers to the sequence of care events (medical and non-medical consultations, referrals, hospital admissions, among others) which a patient follows from the point of entry into the healthcare system triggered by the disease until they are discharged from hospital (71). However, the literature on the AD/E patient journey has shown a remarkable lack of consensus on various aspects of the routine diagnosis and treatment of AD/E, suggesting a limited implementation of clinical practice guidelines as well as complex real-world scenarios probably due to the increasingly broad therapeutic landscape (72).

## Diagnosis of AD/E

AD/E is often diagnosed in childhood. Parents who suspect that their children may have the disease are often quick to seek medical advice. Awareness of the disease in childhood has grown and there is also evidence that parents with a history of AD/E have higher levels of knowledge of symptoms and treatment (73). From the perspective of the healthcare professionals taking part in the consensus meetings, *‘atopic dermatitis is more and more known by lay people in the public. If the children have atopic dermatitis, a mother will know that it can be something like this. Almost every parent we meet*

*in consultations knows what atopic dermatitis is’*. However, healthcare experts acknowledged that *‘parents have fears and questions, such as: does my child really have it? Is this a fate for the rest of life or for the future? Does the child have allergy or atopic dermatitis? Is atopic dermatitis an allergy? Does the child have both things?’*

Overdiagnosis of AD/E in children may happen. Healthcare professionals participating in the consensus meeting reported that *‘we have seen over-diagnosed children where people thought it would*

*have been atopic dermatitis but in fact, it wasn't. We have seen misdiagnosis of atopic dermatitis due to some rare immunodeficiencies'. Misdiagnosis of AD/E seems infrequent in medical practice compared to other skin diseases (74).*

In contrast, adults with AD/E are slower to seek medical attention. According to healthcare professionals taking part in the consensus meetings, **'adults with**

**AD/E may postpone seeking medical advice, giving little importance to a disease of the skin that may be considered less urgent compared to other medical conditions'**. Adults may first seek information via informal channels, such as social media rather than visiting a physician or a specialist (75). This approach would lead to a delay in diagnosis and proper treatment.

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*Adults with AD/E may postpone seeking medical advice, giving little importance to a disease of the skin that may be considered less urgent compared to other medical conditions.*

## Referral to a dermatologist or specialist in AD/E

Patients experience significant variation in referral practices across countries and regions (21). Time to see a dermatologist specialising in AD/E can be very lengthy in many European countries (21). For instance, according to patients and caregivers taking part in the consensus meetings **'in Portugal patients may have to wait three to four months until the first consultation with the specialist in dermatology or allergology in the public health system'**.

Participants from other countries reported that, **'it may take several years until a specialist sees a patient with severe AD/E who has been poorly controlled and lived in distress for a long time'**. Healthcare professionals further emphasised that **'in middle aged adults and elderly patients and in children, it takes time until they can be seen by a specialist and the proper diagnosis is made'**.

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*It may take several years until a specialist sees a patient with severe AD/E who has been poorly controlled and lived in distress for a long time.*

This can be explained, at least in part, by differences in how healthcare systems are structured. According to the view of

healthcare professionals participating in the consensus meetings, **'it is important to distinguish between countries that have a**

***gatekeeping system where patients must go through a general practitioner (GP), and countries where people can directly access the dermatologist, and what this difference might imply’.***

In countries where referral to a specialist happens after visiting the GP, time to referral may be highly dependent upon GP training, current clinical practice guidelines and healthcare system structure, functionality, and culture (76). Regarding training of GPs, a survey conducted in the United Kingdom (UK) found that GPs acknowledged a paucity of dermatology training, and a lack of confidence in recommending potent topical corticosteroids in young patients (76). GPs also pointed out that due to service constraints, routine review of medication or disease was uncommon in clinical practice (76). In 2000, the National Health Service in England proposed a new role for primary

care physicians with additional specialist training, known as GPs with Extended Roles (GPwER) (77). It was expected that the GPwER would work as part of locally integrated services providing intermediate care which would relieve the pressure on hospital consultants. Dermatology has been at the forefront of the development and implementation of such services (77).

From the perspective of healthcare professionals taking part in the consensus meetings, ***‘effective referrals depend heavily on trust and good interactions between the primary and the specialised care sectors, and on existing referral pathways within each healthcare region’.*** Furthermore, the clinical experts participating in the consensus committee emphasised that ***‘mild to moderate AD/E should be managed in primary care and moderate to severe and severe AD/E should be managed by specialists’.***

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*Effective referrals depend heavily on trust and good interactions between the primary and the specialised care sectors, and on existing referral pathways within each healthcare region.*

A care process should be reflected in clinical practice guidelines, an issue also suggested by other authors (78). However, from the perspective of healthcare professionals taking part in the consensus meetings, ***‘clinical practice guidelines fail to reflect the role of the primary care physician in the management of AD/E, a crucial step to facilitate the diagnosis, entry and flow of the patient within the***

***healthcare system’.*** The Dutch College of General Practitioners published an example of practice guideline that recommends the referral to a dermatologist of an AD/E patient if their response to treatment is insufficient. Referring to a paediatrician may be considered for children with other atopic conditions (79). The risk is the loss of trust in the healthcare system by patients that eventually might drop out of the system.

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*Clinical practice guidelines fail to reflect the role of the primary care physician in the management of AD/E, a crucial step to facilitate the diagnosis, entry and flow of the patient within the healthcare system.*



## Patient-doctor communication during the AD/E consultation

Short consultation time can be a major hurdle for adequate doctor-patient communication. It can also adversely affect patients' healthcare and physicians' workload and stress (80). Research has shown that in the 18 countries that represent about 50% of the global population, patients spend five minutes or less with their primary care physicians (81).

According to healthcare professionals taking part in the consensus meetings, *'consultations last between two and five minutes per patient which is insufficient for a good communication and to build trust between the patient and the clinician, especially if the patient is a child and the parents need to obtain sufficient*

*information and understanding to make decisions'*. This is reflected in qualitative studies in which parents and GPs agreed that limited consultation time is a contributory factor for patients' lack of involvement in treatment decisions and for health concerns not being properly addressed (82). Longer consultations and forming a good caregiver-patient relationship are the strongest predictors of adherence to skin-care treatment (83). Most European expert dermatologists dedicated to AD/E would agree that time pressure during consultation, dictated by the locally installed reimbursement system, is the key component driving the low adherence of AD/E patients.

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*Consultations last between two and five minutes per patient which is insufficient for a good communication and to build trust between the patient and the clinician, especially if the patient is a child and the parents need to obtain sufficient information and understanding to make decisions.*

Parents of children with AD/E and healthcare professionals may have different views about the causes and best approaches to managing the disease (82). Daily treatment of a child's AD/E requires considerable time and dedication. Clear communication between doctors and patients/parents is essential to ensure a strong understanding of the consequences of undertreatment and the expected impact of treatment. Additionally, patients/parents are more likely to adhere to regular treatment when they feel included in the decision-making process. For that, open communication and empathy are

the cornerstones of a good physician-patient relationship (84). This can best be achieved through the use of everyday vocabulary rather than medical terminology.

Patients' beliefs and emotions related to the disease and treatments should also be explored during consultations to address concerns arising from long-term use of therapies (85). Doctors' incorrect assumptions about patients' baseline level of knowledge can lead to misunderstandings (84). Moreover, for chronic diseases such as AD/E, it is important to set the right treatment



goals (84). Terms such as ‘incurable’ or ‘chronic’ can be disappointing and discouraging for patients/parents (86). According to healthcare professionals participating in the consensus meetings, *‘all long-term conditions are, of course, incurable. But to patients, the term incurable can be very depressing and deflating. Clinicians should consider how to rebrand AD/E, how to think of ways*

*of communicating it, and the meaning of it to patients, taking into account how medical terms may impact on people’s beliefs and emotions. We need better ways of telling the story of the condition and its treatment, so that it helps people develop more adaptive, common sense, understandings of the disease that would enable them to engage more effectively with the treatment’.*

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*We need better ways of telling the story of the condition and its treatment, so that it helps people develop more adaptive, common sense, understandings of the disease that would enable them to engage more effectively with the treatment.*

## Treatment of AD/E

Patients are most likely to benefit from symptom relief, fewer flares and reduced use of other topical treatments when the appropriate emollient is used (87). According to qualitative studies, finding an emollient that suits an individual patient can be a long and difficult task. Patients, caregivers and GPs commonly go through a trial and error process before discovering the most suitable and appropriate emollient to ease the skin symptoms of AD/E (48, 82, 87).

Concern about the use of topical corticosteroids in parents of young children is a common reason for treatment discontinuation or interruptions and poor therapeutic outcomes (11). These concerns have also been reported by primary care professionals including GPs, pharmacists and paediatricians (88). In some countries, community pharmacists may even recommend a weaker formulation than the one advised by the physician (89). In these settings, it is necessary to train community pharmacists in AD/E therapies. Training

modules for pharmacists on the detection and management of topical corticosteroids concerns may improve practices and adherence to treatment (89).

Patients may feel highly unsatisfied and perceive their treatment options to be very much based on (and limited to) topical corticosteroids which can trigger concerns about long-term usage (84). Treatment reconciliation is also paramount for many parents who may feel uneasy about their children using long-term steroids, and for adults with AD/E on corticosteroids.

Patients participating in the consensus meetings also reported that *‘patients are being labeled with corticosteroid phobias. But it is very hard when the medicines are not working. For instance, being on corticosteroids for more than 30 years, which were not working, and doctors said that they should be working; that more and more may be needed, but corticosteroids were not working. So at*

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*We need better ways of telling the story of the condition and its treatment, so that it helps people develop more adaptive, common sense, understandings of the disease that would enable them to engage more effectively with the treatment.*

*the end, patients cannot use something that it is bad for them and take medicines that do not work as they should’.* Patients, caregivers and healthcare professionals taking part in the consensus meeting called for a holistic approach to routine care. This could incorporate nutritional advice, mindfulness, and other complementary therapies orientated towards improving patients’ QoL, and including analysing the microbiome of the skin.

People with AD/E often find natural remedies and alternative medicines attractive (12). Healthcare professionals participating in the consensus meetings recalled that *‘alternative medicine is widely used. And most patients have used it before they come to the consultation. Almost anybody who has AD/E longer than one year has tried an alternative medication’.* Patients and caregivers participating in the consensus meetings acknowledged that *‘patients go to alternative approaches because they are quite unsatisfied with current treatment; and because most healthcare professionals’ approach is ‘disease orientated’ instead of ‘patient orientated’.* Patients further emphasised that *AD/E is a chronic and devastating disease; it is something [that makes] you*

*want to jump out the window. And patients would try every alternative treatment that they could, if they don’t get the proper effect from what they use. Of course, they may not get [the desired effect] with the alternative treatments either, but at least they have tried because there is no other way to cope with the disease’.*

Misunderstanding of treatments, complexity of treatment regimen, lack of knowledge about the disease and therapeutic options, difficulties to access to innovative and systemic treatment for severe patients and overall lack of a personalised approach to therapy, dissatisfaction with treatment strategies, infrequent follow up, and the use of complementary and alternative medicine are all determining factors of poor adherence to treatments (90). Patients/parents have concerns about accumulating side effects from long-term, simultaneous treatments with corticosteroids to treat co-morbidities (e.g., topical use for AD/E, inhalers for asthma, and nasal sprays for allergies). Research has found that written long-term care help patients to anticipate the next steps in case therapies do not work and to decide when to move forward (91).

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*Patients go to alternative approaches because they are quite unsatisfied with current treatment; and because most healthcare professionals’ approach is ‘disease orientated’.*

## Continued and multidisciplinary care of AD/E

Close and continued care is needed to secure adequate control of AD/E, adherence to treatments and ongoing participation in consultations. In the voice of patients and caregivers taking part in the consensus meetings, ***‘to have continued care after diagnosis is of greatest importance. As patients or caregivers, we are told that we (or our child) have a chronic disease without a cure and will need a lot of care from healthcare professionals and families since AD/E is a chronic disease’.***

Self-management is sometimes very challenging, especially in moderate to severe cases of AD/E. So, it becomes paramount to have access to care nearby, as well as close follow up outside the medical appointments and consultations. However, follow up visits usually happens after some time (e.g., after three or six months) and with different physicians who are often unaware of the diagnosis or the story of the disease. This lack of continuity of care makes it difficult for patients to

comprehensively address the entire impact of the disease on the individual. Furthermore, the clinical manifestations of the disease vary considerably over time. A patient describes an experience shared by various AD/E patients during the consensus meetings as follows: ***‘It is a big problem that each time you go to the dermatologist or any kind of specialist you get another doctor, and the next appointment is in six months with a different doctor again. So, after the six months the other medical doctor sees you and says ‘what are you doing, you are neglecting your skin or the skin of your children’ because this doctor thinks that you should be doing something different. So, it is important that one or two of the same medical doctors always visit the patient’.*** Patients and caregivers participating in the consensus meetings emphasised that ***‘there is a lot more than the disease of the skin to be cared for as the whole body can be affected by AD/E even during remissions’.***



***There is a lot more than the disease of the skin to be cared for as the whole body can be affected by AD/E even during remissions.***

Patients do not always suffer from flares or have symptoms when attending a medical consultation. This can mean that, although their AD/E is not controlled, they cannot demonstrate this to doctors, despite needing additional medical support. Continued and multidisciplinary care are of utmost importance for AD/E patients. Patients participating in the consensus meetings reported that when they go to the doctor, they sometimes

find it difficult to explain their symptoms particularly if the medical tests find no additional problems. ***‘They try to explain that there are other problems, that they are having pains, but the test comes back normal, and doctors would not do much. So, the patient is suffering in silence. It is a big problem because we, as patients, are losing trust in medical experts and find no reason to go back to the specialists’.***



*They try to explain that there are other problems, that they are having pains, but the test comes back normal, and doctors would not do much. So, the patient is suffering in silence.*

In this scenario, patient reported outcome tools may allow doctors to follow-up patients more effectively and supervise the long-term effect of treatment, without necessarily having frequent consultations. The use of software (widgets), available of internet, or dedicated apps, can help doctors, patients and caregivers to fill out the questionnaires and to share the real course of the disease with the doctors (92). Telemedicine and teleconsultation are important for both patients and healthcare professionals to ensure the continuation of care (31).

Gaps in patient care can be identified and addressed by monitoring and evaluating care quality. The Atopic Dermatitis Quality of Care Initiative has proposed three levels

which can be applied depending on the setting (93): simple and easy approaches focused on goals, outcomes and patient experience; medium-level interventions that include consistent benchmarking of patient experiences for evaluation and monitoring; and advanced centres which may develop electronic patient dashboards and embrace external audit.

Coordinated and structured multidisciplinary care teams provide holistic patient care. Patients and healthcare professionals taking part in the consensus meeting agreed that nurses and dieticians should be part of a multidisciplinary team caring for AD/E patients. This approach has been implemented at centres around the world.

**Table 2. Multidisciplinary management plan of atopic eczema/dermatitis patients in Sao Paulo, Brazil**

At the University of São Paulo Hospital in Brazil, patients with AD/E are managed by a multidisciplinary team who conduct daily rounds. Each team member considers different aspects of patient care to ensure patients are holistically managed (31): (72).

- Dermatologists provide treatment plans.
- Nutritionists develop meal plans and follow dietary triggers.
- Allergist/Immunologists evaluate and follow immune function.
- Social workers organize treatment plans and help with managing AD/E in everyday life.
- Nurses assist with guidance, bathing, and application of topical medications.

Nurses play a crucial role in guiding patients in adopting coping strategies which can improve treatment success. Healthcare professionals taking part in the consensus meetings reinforced the idea that

***‘nurses help patients and caregivers better understand that although the disease may not be entirely controlled, the quality of life can be significantly improved; they also help patients and caregivers to***

***consider controlling other aspects such as the diet and environmental exposures that may diminish the response to medications***<sup>7</sup>. Nurses are key to addressing the patient's needs more comprehensively, and are in the best position to embrace both the patient and their families (94, 95). Thus, dermatology nurse specialists play a key role in providing education and substantial patient support within a multidisciplinary team. Nurse-led education and eczema schools may reduce disease severity and improve QoL by enhancing self-management, adherence and patient engagement (95).

Patients may not be aware of the existence of expert dietitians in the team and how helpful they can be in adjusting patients' diets. Although many patients believe it is important that physicians discuss with them the role of diet in managing AD/E, only a few consult their dermatologist on the issue (96). Up to half of patients show signs of food-specific allergies (linked to the IgE antibodies) and one-third of severe cases of AD/E may have positive symptoms triggered by certain foods (97). One possible reason for this is the ability of allergens, pollutants, and microbes to get through the skin where they trigger an immune response. For patients, this can lead to a vicious cycle in which they are susceptible to an allergic reaction which, in turn, exacerbates their condition and further weakens the skin barrier (98). A high proportion of children with AD/E are sensitive to foods. However, skin testing to identify potential food triggers is not recommended unless the patient has a history suggestive of food allergy and/or moderate-to-severe AD/E which is unresponsive to optimal topical care. Indiscriminate

testing can lead to a high proportion of false positive tests and harmful dietary restrictions (97). For most food allergens (except peanuts), there are no approved treatments. The standard of care remains avoidance of allergenic foods and acute management of allergic reactions with antihistamines, corticosteroids or epinephrine (adrenaline). However, allergen avoidance is difficult as many allergens to which patients are sensitive are common ingredients in foods (98). Dietitians can address the problem of food allergy as early as possible after the diagnosis of AD/E to decrease allergies or to reduce flare-ups. Furthermore, children, adolescents and adults need to be educated on recognizing the signs and symptoms of food reactions. Therefore, the role of nutrition counselling in AD/E holds paramount importance (99).

People with AD/E and their caregivers face high levels of stigmatization, social withdrawal, anxiety and depression. The stress caused by AD/E can make the symptoms of the disease worse. Preliminary evidence from psychodermatology, an evolving area of science that focuses on the interaction between the mind, skin and body, suggests that an increase in endogenous glucocorticoids can disrupt the skin's barrier function, leaving it vulnerable to inflammatory disorders like AD/E. The goal of psychodermatological treatment is to improve the condition of the skin and to teach patients/caregivers how to cope with the disease. This requires a multifaceted approach, and time and patience, to ascertain the needs of individual patients. Therefore, the multidisciplinary AD/E team should also include a psychiatrist and psychologist to deliver high-quality, tailored care to patients (100).



## Patient and caregiver education as part of the multidisciplinary care of AD/E

Educating patients and their caregivers can form part of multidisciplinary care (101). Health education may improve the treatment of children with AD/E, reduce catastrophic thoughts about AD/E and promote disease control (102). For instance, in a treatment and educational program developed in Utrecht (the Netherlands), children and adolescents were seen almost on a weekly basis in the outpatient clinic. They had five consultations with the dermatologist/dermatology nurse, four consultations with the paediatrician-allergist, and three consultations with the psychologist. Children and adolescents participated in workshops on how to apply topical treatments and were educated by the dermatology nurse; played AD/E knowledge games and took part in a group medical appointment on coping with AD/E and treatment compliance (103).

In Germany, France, the United States and other countries worldwide, educating children, adolescents, and adults plus the parents of children with AD/E leads to better coping with the skin disease, as well as to a reduction in the severity of the skin symptoms and

signs (120, 121, 104). In these models, a team consisting of a dermatologist, psychologist, nutritionist, and nurse practitioner offered an 'eczema school' (or 'atopy school') to interested patients with AD/E and their families. This patient education program consisted of three weekly two-hour sessions, which address proper skin care, the itch-scratch cycle, healthy nutrition, and the role of stress in AD/E (104).

Parents and caregivers of children with AD/E feel satisfied and more secure in dealing with their children's disease following workshops organised by an Atopy School, thus improving prognosis and QoL, according to a German and a Spanish study (121, 105). The sessions in Spain addressed five main topics: general skin care, topical treatments, concern about topical corticosteroids, allergology assessment, and psychological orientation for parents and children. The sessions were taught by a multidisciplinary team composed of dermatologists, a primary care paediatrician, a psychologist, and a paediatric allergologist. After the sessions, the topics were discussed among the parents,

**Table 3. Four-step therapeutic patient education program**

A therapeutic patient education program can be viewed as a four-steps process:

1. The first step aims to understand what the patient already knows, believes, fears and hopes for, in order to determine the patient's difficulties and resources. During this first step, barriers to adherence (e.g., concerns related to the use of topical corticosteroids, forgetfulness, time restraints, complexity, or cost of treatment) should be identified.
2. In the second step, educational objectives can be determined with the patient, based on their age, to establish the skills the patient needs to better manage the disease, according to capacities and resources.
3. The third step is about the acquisition of skills by the patient or their parents. Health providers use several different educational resources (e.g., patient-centred communication techniques, practical demonstrations, and educational tools). The development of a personal written action plan can help them adapt their treatment and promote better adherence to the treatment.
4. The fourth step concerns the assessment of the patient education. It should include biomedical outcomes, appropriate psychological scores, QoL scores and economic impact.

caregivers, and healthcare professionals (105). The sessions in Germany covered medical, nutritional and psychological issues, and were carried out by a multi-disciplinary team of dermatologists, psychologists and dieticians (121).

Educational tools can include websites, portals, videos, or mobile phone applications that can help patients to self-monitor and provide feedback to physicians, improving patient-doctor communication (31).

**Table 4. Examples of educational tools implemented in some European countries.**

- The “AgNeS” and “ARNE” programs are running for a decade and two decades respectively in many German sites such as Berlin, Hannover and Munich (Live With Eczema), and the published manuals for both education programs which include physicians, nurses, nutrition specialists and psychologists have served as a model for patient education for many other countries and programs (120, 121).
- The “Leef! Met Eczeem” (Live With Eczema) website developed by the University Medical Center Utrecht (UMCU) in Utrecht (the Netherlands) is a patient resource designed to explain AD/E, share treatment types and application techniques, aid in healthcare provider communications, explain how to deal with itch, and how to live with AD/E (106).
- “Walk of Skin” is an example of web gaming developed by Centre Hospitalier Regional Universitaire (CHRU) in Brest (France) and is designed to be interactive. It focuses on shared patient experiences and group education under the supervision of a health care provider (123)
- “Zalf” is an innovative smartphone application developed by UMCU (the Netherlands) for all patients who need to apply ointments. It is a convenient education tool to supplement patients’ information from healthcare professionals and allows less face-to-face consultation time spent educating patients on topical treatment application.
- In the UK, a digital tool for primary care consultation has been recently implemented due to COVID-19 pandemic, in which GPs and patients can communicate via a video-conference, share questionnaires, surveys or photos of the progression of the disease. In addition, specialists can also join consultations (107).

Furthermore, educational tools such as online gaming can be a way to not only educate patients but to monitor patient progress. This is the case with “Walk of Skin”, mentioned above, that supervises the patients’ progress while they share experiences and receive education (31).

Patient testimonies are also useful educational and advocacy tools to address a wider audience, stressing that AD/E is not contagious but that it comes with a heavy burden for patients and caregivers. Patient

testimonies and advocacy work may also encourage AD/E patients to seek intervention. Engagement is needed on social media channels to highlight individual stories. This can be a cross-border effort, with best practices and role models potentially coming from other countries. This advocacy work must also address fake news on AD/E and its treatment. There are many AD/E advocacy groups. Some examples are the National Eczema Association in the US, the National Eczema Society in the UK and EFA in Europe.



# THE FINANCIAL AND ECONOMIC BURDEN OF ATOPIC DERMATITIS/ECZEMA

# THE FINANCIAL AND ECONOMIC BURDEN OF ATOPIC DERMATITIS/ECZEMA

The lack of reimbursement of medically necessary products, such as emollients, makes the adequate treatment of AD/E challenging, and imposes a financial burden on patients and caregivers.

## Emollients

Emollients are the best-known strategy to reduce itch and soreness and to diminish relapse of AD/E symptoms. However, they are usually not reimbursed, and in some countries primary care providers are prone to avoid issuing prescriptions for emollients to save costs to the healthcare system (108). Paying for emollients out-of-pocket has a detrimental impact on patients' and families' finances. Moreover, in some countries, emollients are taxed as a commodity rather than a necessary medical treatment, which considerably increases their costs for people with AD/E. As reported by patients participating in the consensus meetings, **'emollients are necessary even for a mild form of the disease and emollients are taxed with**

***the maximum possible legal tax. So, the costs of emollients have a huge impact on the individual's and the family's budget. Emollients are considered luxurious products. So, this is a major concern for us because they are part of the treatment'***. Several studies have shown that high out-of-pocket costs are often a driver of treatment inefficiency as patients use emollients less often or in lower quantity than recommended. Ultimately, an insufficient or inadequate usage of emollients leads to poor clinical outcomes that require more follow-up visits and additional medications in the long term, increasing the costs to the healthcare system of caring for AD/E patients (108, 109).

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*Emollients are considered luxurious products. So, this is a major concern for us because they are part of the treatment.*

To ensure that emollient therapy can be reimbursed, it is necessary to review the classification of dermatology and cosmetic products to include emollients in the group of reimbursed products. The consensus-based European guidelines for treatment of AD/E published in 2018 included definitions for emollients and emollients plus (110). Emollients are defined as topical formulations with vehicle-type substances lacking active ingredients, whereas emollients plus refer to topical

formulations with vehicle-type substances and additional active, non-medicated substances (110). These established terms can be used for classifying emollients as basic therapies for skin care within the group of reimbursed products, and the list of emollients plus is growing (110, 122). **Kansaneläkelaitos** (The Social Insurance Institution of Finland) is an example of a healthcare system that reimburse emollient creams used in the treatment of a long-term skin conditions (110, 111).

## Healthcare costs

Besides emollients, other non-reimbursed medications include those used to ameliorate itch or sleeplessness that help to control AD/E more effectively. Patients taking part in the consensus meetings acknowledged that ***‘itch and sleeplessness are very serious symptoms that require treatment and reimbursement, and advocacy is needed for a thorough understanding***

***of the relevance of these symptoms of AD/E’*** amongst policymakers. In the long run, patients with poorly controlled AD/E symptoms use significantly more healthcare resources, including visits to a dermatologist and hospitalizations, and are more costly to the healthcare system and to society compared to well controlled AD/E patients (112).

“

*Itch and sleeplessness are very serious symptoms that require treatment and reimbursement.*

From the perspective of the healthcare experts participating in the consensus meeting, ***‘not moving from topical to systemic treatments soon enough’*** (therapeutic inertia) may predispose the patient to exacerbations and hospitalizations that can be otherwise avoided and increase the costs of the disease. Nonetheless, admitting patients into hospital is necessary in many cases (although not usual in all countries). In the view of healthcare professionals taking part in the consensus meeting, ***‘we need to keep in mind that in some countries, admitting patients to hospital is still a very safe and good thing to do to adjust the treatment properly and get people***

***out of flare, but it is not something that is usual in all European countries’.***

Additionally, as mentioned earlier, caring for patients with severe AD/E may imply major life changing decisions such as parents or caregivers changing their jobs or careers or remaining unemployed. For those caregivers who keep their jobs, the caregiver role may cause them to miss work or experience decreased work productivity (38, 40). Working arrangements recognising severe AD/E as a serious disease and granting eligibility for a compensatory scheme are needed.

Overall, the costs of AD/E vary across Europe depending on how costs are calculated (28). AD/E requires ambulatory and hospital care with a wide range of annual hospitalisations, medical visits, emergency

department visits, comorbidity costs (e.g. mental health), loss of productivity due to work/job impairment and out-of-pocket expenses reported (Table 1).

**Table 5. Published studies on the costs of AD/E in Europe**

**Total cost of atopic eczema/dermatitis**

COUNTRY, YEAR (REFERENCE)	STUDY POPULATION	RESULTS
Denmark, 1997-2018 <sup>(113)</sup>	Adult patients	➔ Total costs for patients with moderate-to-severe AD/E were €10,835 per patient during the study period (three years before and five years after the index date). This included direct costs for primary-sector visits, inpatient hospitalisations, outpatient contacts, prescription medicine and indirect costs of lost productivity.
Europe: France, Germany, Italy, Spain, and the United Kingdom, 2017 <sup>(114)</sup>	Adult patients	<p>➔ Total annual direct costs ranged from €2,242 to €6,924 and total annual indirect costs ranged from €7,277 to €14,236, depending on the level of disease severity.</p> <p>➔ Psychosocial comorbidities (i.e., sleep difficulties, depression, and anxiety) were observed in more than half of moderate-to-severe AD/E patients, and significantly associated with work-related impairment.</p>
Germany, 2017-2019 <sup>(69)</sup>	Adult patients	<p>➔ Direct costs: median €874 per patient per year</p> <p>➔ Indirect costs: €483 per year due to incapacity to work</p> <p>➔ Assuming a prevalence of 3.7% in the German adult population, the costs per year for treating adults with AD/E amount to more than € 2.2 billion</p>
Spain, 2000-2017 <sup>(115)</sup>	Paediatric patients <5 years old	➔ Direct medical costs of specialised care: €2,469 per patient per year
Spain, 2013-2014 <sup>(116)</sup>	Adult pa- tients	<p>➔ Annual costs reached €9.3 million (health care costs, 75.5%; loss of productivity, 24.5%), with an average unit cost of €1,504 per year.</p> <p>➔ The corrected average unit cost was greater in severe AD/E compared with moderate and mild disease (€3,397 vs. €2,111 vs. €885; respectively).</p>
The Nether- lands, 2016-2017 <sup>(112)</sup>	Adult patients with severe AD/E on systemic treatment	➔ Total costs per patient per year: €15,231 (direct costs + loss of productivity costs)

## Out-of-pocket costs for atopic eczema/dermatitis patients in Europe

COUNTRY, YEAR (REFERENCE)	STUDY POPULATION	RESULTS
Europe: Czech Republic, Denmark, France, Germany, Italy, the Netherlands, Spain, Sweden, the United Kingdom, 2018 <sup>(117)</sup>	Adult patients	<ul style="list-style-type: none"> <li>➔ Mean €927 per patient per year on healthcare.</li> <li>➔ Mean extra expending per month is €77.26: <ul style="list-style-type: none"> <li>➔ emollients and moisturizers (€27.63)</li> <li>➔ medication (€17.74)</li> <li>➔ doctors and hospitals (€8.68)</li> <li>➔ phototherapy (€8.48)</li> <li>➔ bandages (€7.12)</li> <li>➔ travel expenses (€5.69)</li> <li>➔ in-patient treatment (€1.94)</li> </ul> </li> <li>➔ Additional 18% expense per month on personal hygiene products (washing products, bedding, extra clothing).</li> <li>➔ People also reported spending extra money on everyday products such as gloves, cleaning products and food.</li> </ul>
France, 2018 <sup>(118)</sup>	Adult patients	<ul style="list-style-type: none"> <li>➔ Mean €350.5 per patient per year (range €0.00 to €4000 depending on disease severity)</li> <li>➔ Derived from consumption of medical and non-medical products (emollients, hygiene products, clothes) not included in the list of reimbursed products and services.</li> </ul>
Ireland, 2019 <sup>(119)</sup>	Adult and paediatric patients	<ul style="list-style-type: none"> <li>➔ 25% of those surveyed spend up to €2,300 annually on over-the-counter treatments, prescription treatments, alternative treatments and doctors' fees because of their or their child's AD</li> </ul>
Germany, 2017-2019 <sup>(69)</sup>	Adult patients	<ul style="list-style-type: none"> <li>➔ €377 - €497 (median €211) per year</li> </ul>

AD/E: atopic dermatitis/eczema

# CONCLUSIONS

AD/E is a chronic, inflammatory, systemic disease with combined effects of skin-barrier disruption, immune dysregulation, multi-organ disorders and intense symptoms. Commonly recognised as a disease of the skin in childhood, it also affects young people and adults. Symptoms go far beyond the skin to develop anywhere in the entire body. Itching and pain can be devastating and the suffering of patients with AD/E can become unbearable. During 2021, EFA brought together leading patients and healthcare experts to agree on the current needs, challenges and possible solutions to improve AD/E care in Europe. AD/E patients and healthcare professionals agreed on the many elements that explain the physical and emotional burden of the disease.

Awareness of the serious and chronic nature of AD/E needs to be raised in society and amongst policymakers. Stigma, lack of self-confidence, worry, hopelessness, and exhaustion are central to patients' and caregivers' experiences. Patients, caregivers and healthcare professionals taking part in the consensus meeting highlighted the key challenges to be addressed, including self-imposed social isolation, low self-esteem, school absenteeism, limited professional development, delayed medical consultations and loss to follow up. The cost of non-reimbursed treatments imposes an additional burden to AD/E patients and caregivers. Discontinued care pathways, lack of awareness and training, and misunderstandings/misconceptions around the disease and its treatment explain many of the unsolved challenges in the management of AD/E patients. Patients of all ages and their caregivers need individualised coping strategies to support everybody affected by the disease.

European countries should implement patient-centred, multidisciplinary, integrated care models. Training and sound criteria for

referral to specialists, as well as examples of best clinical practice, can help to improve the quality of primary care for AD/E. To deliver fair access to therapies (including systemic and innovative ones) and more efficient care of the disease, according to the disease's severity, authorities should revise reimbursement policies. The AD/E community can play its part in improving awareness amongst European legislators and politicians of the specific reimbursement needs of people with AD/E. Key decision-makers must grasp the magnitude of the financial burden of treatments on AD/E patients. The aim is to ensure that **'all AD/E patients have access to appropriate disease control remedies' as well as 'access to the necessary workspace, conditions and treatments so they do not have to choose a job based on their disease induced limitations. Career choices should be based on what patients desire, what they studied and what they feel a vocation for'**, as patients taking part in the consensus meeting expressed it.

In the view of patients and healthcare professionals participating in the meetings, there are many evidence-based ways to overcome these challenges. Several initiatives, organisations and entities across the world can serve as examples and can provide models to implement if sufficient political determination exists to improve the care of AD/E patients in Europe. Changing the burden of AD/E requires the participation of all stakeholders, including European and national policymakers. The consensus meeting participants have developed a series of concrete solutions to drive future change (**see next section**). These proposals have been analysed and agreed by the consensus committee. EFA has translated these proposals into a Call to Action targeting policymakers.

**PROPOSED  
SOLUTIONS  
AND ACTIONS  
TO TACKLE  
THE CHALLENGES  
OF ATOPIC DERMATITIS/ECZEMA**



# PROPOSED SOLUTIONS AND ACTIONS TO TACKLE THE CHALLENGES OF AD/E IN EUROPE

These proposals reflect the outcomes of the multidisciplinary panel of expert patients and healthcare professionals convened by EFA in 2021.

## Multidisciplinary approaches and education

- Take a **personalized and multidisciplinary approach** when designing interventions, considering physical and mental health and emotional well-being.
- Introduce **training in dermatology for psychologists**.
- **Involve nutritionists** to ensure a balanced discussion on dietary factors.
- Improve interactions between healthcare professionals; enhance dermatology knowledge among **GPs and paediatricians**.
- **Pharmacists and nurses** should have an enhanced role, depending on the primary care situation.

## A supportive environment for patients and carers

- Maintain **flexible working schedules** following the COVID-19 pandemic to help patients and carers manage their treatment.
- Use digital tools and platforms to facilitate medical/patient communication and **improve patient access to education** on AD/E.
- Embrace telemedicine solutions to **improve disease monitoring** and follow up.

- Increase knowledge-sharing and QoL by ensuring patients/caregivers can **access support groups**.
- Introduce **AD/E education in schools** to improve QoL of patients and carers.
- Support patients beyond their medical care, including in career guidance and by **fostering a ‘no-blame’ approach to non-adherence** with medication.
- **Give more time during medical consultations** to allow for more patient feedback and further explanation of treatment from doctors. Combine this with further preparation outside appointments to improve efficiency.
- Promote soft skills in medical training, including **empathy and listening**.

## Treatments and medicines

- Guarantee sufficient **access to necessary treatments**.
- **Develop methodologies and tools** to grade the impact of AD/E and inform prescribing decisions.
- **Introduce a new classification** of alternative medicines, or items that fall between cosmetics and drugs, to ease the financial burden on patients.
- **Create Centres of Excellence in AD/E** with ring-fenced budgets.
- **Study the costs** to the healthcare systems of different treatments, e.g., advanced treatments.

## Better patient pathways

- **Introduce national guidelines** to improve the patient pathway, including criteria for GPs referring patients to a specialist.
- **Agree quality standard pathways**, alongside patient-report experience measures, to improve treatment adherence

# CALL TO ACTION TO REDUCE THE BURDEN OF ATOPIC DERMATITIS/ECZEMA

# CALL TO ACTION TO REDUCE THE BURDEN OF ATOPIC DERMATITIS/ ECZEMA IN EUROPE

The European Federation of Allergy and Airways Diseases Patients' Organisations (EFA) calls for policymakers to recognise that AD/E is a serious, complex chronic disease, and that patients require long-term treatment and multidisciplinary care to cope with it. Policymakers must ensure that the patient journey for those diagnosed with AD/E is respected at each stage, from diagnosis to treatment and care, with a supportive environment for patients and their families. These recommendations for policymakers have been devised by EFA, based on insights from the multidisciplinary panel which informed the 2022 European Consensus Report on the burden of atopic dermatitis/Eczema in Europe.

1.

EFA recommends that policymakers should take the following steps to **reduce the physical and emotional burden** AD/E has on patients:

- ➔ **Improve health literacy** around allergy and AD/E to address misconceptions, reduce stigma, tackle false information on 'informal treatments' and encourage AD/E patients to seek intervention.
  - ➔ EFA calls on policymakers to support health information that stresses that AD/E is not contagious but that it comes with a heavy burden for patients and caregivers.
- ➔ **Support the continuation of remote and flexible working schedules, and financial supports**, to enable AD/E patients and carers to manage and consult on their treatment alongside everyday life.

2.

EFA recommends that policymakers should take the following steps **to improve the patient journey for AD/E patients**:

➔ EFA recommends that policymakers introduce structural changes in their national health systems, which would eventually **improve diagnosis of the disease**, by:

- ➔ Enabling healthcare systems to adapt their focus away from merely diagnosing the disease, to **include continuity of care and support** for patients and families.
- ➔ Respecting the newest clinical guidelines, establishing an **agile system of referral for AD/E patients** that clearly defines responsibilities between GPs and dermatologists at the earliest opportunity, and improving interactions between healthcare professionals. This must also include **enhanced education for primary care professionals and pediatricians**, so no diagnosis is missed.

**EFA calls for a statutory right to referral for each patient diagnosed with AD/E in Europe.** As part of this, maintenance care for patients should be managed by a specialist as the severity of the disease can change over time, while primary care physicians should have basic training and be aware of their referral network.

- ➔ Incentivising healthcare systems to **seek the right patient pathway** based on response to treatments and quality of life.

**EFA calls for a new clinical approach, where AD/E diagnosis is not static** but adapts based on the developing condition of the patient and latest scientific evidence, to support a patient-centred care pathway.

➔ EFA recommends that policymakers introduce structural changes in their national health systems, which would eventually **improve diagnosis of the disease**, by:

- ➔ **Support the introduction** of personalised treatment plans from day one of diagnosis, allowing AD/E patients to receive continuity of care from the get-go. This should also include further preparation outside regular consultation appointments, to improve efficiency.
- ➔ Reinforce existing national reference centers to cover and enlarge the expertise on severe AD/E
- ➔ Set up Centres of Excellence on AD/E, with multidisciplinary teams and ring-fenced budgets.
- ➔ **Train doctors** in soft skills to allow for doctor-patient discussions on therapies concerns and allow doctors to provide the right information to patients.

- ➔ EFA recommends that, to properly support the process of **developing new treatments for AD/E**, policymakers must:
  - ➔ **Introduce regulatory changes at EU level that ensure patients are involved** in the design and implementation of clinical trials.
  - ➔ Support the introduction of quality-of-life endpoints in all relevant clinical trials.
  - ➔ **Call on regulators to recognise** the limitations in current methodologies used to grade the overwhelming impact of AD/E and measure itch (e.g., EQ-5D), alongside developing new methodologies and tools for this purpose.
  - ➔ **Earmark EU funding for research** to help experts better understand the causes and mechanisms of AD/E and develop improved treatments.

Building on the example of U-BIOPRED and 3TR EU-IMI projects on asthma as a best practice, ***EFA calls for the introduction of an ambitious research project under the Innovative Health Initiative (IHI) on AD/E*** which in turn could lead to improved treatment, quality of life and, ultimately, prevention.
  - ➔ **Put the right policy frameworks in place to capitalise** on the opportunities offered by Real World Data to better understand AD/E and aid the development of new treatments.

**EFA calls for the establishment of national registries for AD/E** which will allow the collection of high-quality data, with the ultimate objective of improving care and outcomes for patients.
- ➔ Introduce health policy changes to guarantee that AD/E patients, especially those with comorbidities, receive the **best treatment and multi-disciplinary care**.
  - ➔ **EFA calls for a reinforced role for specialised nurses**, as their function is essential to instruct patients on treatment and disease management.
  - ➔ **EFA calls for an increased role for psychologists in AD/E care**, including training in dermatology as part of their curricula, to address the psychological element of the disease and encourage discussion on mind/body interactions.
  - ➔ **EFA calls for an enhanced role for pharmacists**, to support patients when necessary, according to the primary care situation. This should include training modules for pharmacists on the detection and management of topical corticosteroids concerns, which may improve practices and adherence to treatment.
  - ➔ **EFA calls for an enhanced role for nutritionists**, to create a more holistic approach to AD/E care and in recognition of the fact that intervention here can add to a multidisciplinary care approach and improve patients' quality of life.



➔ EFA recommends that, ***to install a supportive environment for patients addressing treatment and care***, policymakers must:

- ➔ **Support the financing, set up and integration of ‘atopic schools’ in national healthcare systems** as part of each AD/E reference center.
  - ➔ **Ensure that health systems are equipped to capitalise on the opportunities** offered by developments in digital healthcare, to ensure that the care options offered to AD/E patients are comprehensive. This should include the creation of a framework that allows AD/E patients to fully utilise telemedicine, providing options for the self-management and support of their condition.
- ➔ **Improve treatment adherence** and the patient pathway by looking at quality standard pathways and Patient Reported Outcomes (PROs) and introduce a ‘no blame’ approach to non-adherence.
- ➔ **EFA calls for more emphasis on AD/E flare-up prevention and disease management** to dramatically reduce the recourse to hospitalization due to AD/E

3.

EFA recommends that, in order to **reduce the financial and economic burden** on AD/E patients, policymakers must:

- ➔ **Introduce a new classification for the reimbursement of AD/E treatments** that guarantee patients sufficient access to basic necessary care such as emollients, bedding, clothing or nutritional support.
- ➔ **Recognise the societal and human costs of access delays**, particularly economic considerations such as lost productivity through work absence.

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# ABBREVIATIONS

<b>AD/E</b>	Atopic dermatitis/eczema
<b>EFA</b>	European Federation of Allergy and Airways Diseases Patients’ Associations
<b>GP</b>	General practitioners
<b>GPwER</b>	GP with an extended role
<b>HCP</b>	Healthcare practitioner
<b>ISAAC</b>	International Study of Asthma and Allergies in Childhood
<b>PCP</b>	Primary care practitioner
<b>QoL</b>	Quality of life
<b>UK</b>	United Kingdom
<b>US</b>	United States



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# METHODOLOGY

This report has been primarily developed from the views of the consensus meeting participants and complemented with data from publications identified in a literature review performed in PubMed following the search strategy described below (Table 2):

**Table 3. Literature search strategy**

<b>Scope</b>	<b>Europe (WHO definition of Europe) – only studies conducted in European countries</b>	
<b>Search period</b>	1st January 2001 – 31st December 2021; for similar topic/findings, the most recent publication was selected for comparison	
<b>Search engine</b>	PubMed, Google Scholar	
<b>Language</b>	English	
<b>Key terms</b>	Defined according to topic searched (always including “atopic dermatitis” “eczema”)	
<b>Data to extract</b>	<b>Statements (findings and figures) defining:</b> <ol style="list-style-type: none"> <li>1. current situation (results section of publications)</li> <li>2. challenges (discussion section of publications)</li> <li>3. solutions and recommendations (discussion section of publications, if available)</li> </ol>	
<b>Topics</b>	<ol style="list-style-type: none"> <li>1. Stigma</li> <li>2. Bullying</li> <li>3. Emotional burden</li> <li>4. Physical burden</li> <li>5. Adolescents (vulnerable population)</li> <li>6. Parenting, childcare</li> <li>7. Patient journey: Under- and over-diagnosis, referral to specialist, treatment and management, follow up, searching internet/social media for consultation</li> <li>8. Doctor-patient (and caregiver) communication: understanding of disease and treatment, adverse events</li> </ol>	<ol style="list-style-type: none"> <li>9. Multidisciplinary team approach to care: role of nurses, psychologists, pharmacists, nutritionists and dietitians, others</li> <li>10. Medical training: knowledge of disease and therapies (primary care doctors, dermatologists)</li> <li>11. Adherence to treatment (drivers of poor adherence/persistence in treatment)</li> <li>12. Use of complementary/alternative therapies</li> <li>13. Economic impact of the disease (cost of disease + societal perspective (out of pocket costs to patients) + drivers of inefficiencies)</li> </ol>

Publications of European studies were considered first. Publications of studies from other parts of the world were considered second. Findings from the literature served to substantiate and compare the views of patients and healthcare professionals taking part in the consensus meetings on the burden of AD/E.

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