

# EFA Atopic Eczema Consensus Europe Project



#AtopicEczemaBurden

### Welcome

Whether you live with eczema or atopic dermatitis, care for someone with the condition, or are already actively involved with a patient association, your voice is important!

We need your support to ensure these recommendations successfully reach the policymakers at national level in Europe.

Check out the information, advice and assets provided, and start inspiring others to get involved.

Remember, together we are stronger! All is interconnected!

EFA Team

# How you can use this toolkit

The toolkit you have at hand has been designed to support you addressing a full range of issues affecting atopic eczema. The advocacy messages and materials it contains have been developed by the European Federation of Allergy and Airways Diseases Patient Associations (EFA). It is based on the advocacy work that EFA has been doing since 2018 to put atopic eczema under the radar and agenda of decision-makers at European level.

The recommendations have been developed together with the patient organisations members participating in EFA Atopic Eczema Working Group and with the European Atopic Eczema Consensus Committee.

The toolkit contains a series of materials that you may wish to use to drive change around atopic eczema in your own country and region. We hope it will be a source of inspiration, strategy, and ownership in your work.

- Inspiration: This material has been prepared as guidance for you or your association to drive change for atopic eczema at national level. It contains proposals on who are the decision makers and influential organisations that can help you at national level.
- > Strategy: The choice on who to address and how will be your own decision based on your knowledge of your national setup, politics and your own connections.
- ➤ Ownership: use this toolkit as yours. Feel free to adapt its materials, narrative, and recommendations to your own environment. Remember just one thing: when you are adapting it for local use, please include only the organization(s) of which you are a member.

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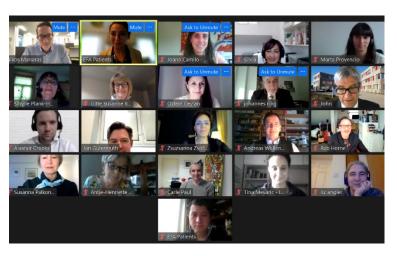
# Introduction to EFA Atopic Eczema Consensus Europe project

Despite growing awareness and advancements around skin conditions, the burden atopic eczema/dermatitis (AD/E) patients endure each day is not sufficiently recognised. The lack of a strong consensus on the burden of AD/E in Europe from the healthcare community leads to a persisting approach to give low priority to atopic eczema as a serious chronic disease. To fill the awareness and care gaps and develop a consensus position on the burden of AD/E on patients, in early 2021 EFA created the AD/E Consensus Europe project. The project led to:

- Development of a consensus report and policy recommendations on the disease burden of AD/E in Europe;
- Creation of a pan-European Consensus Committee, comprised of 15 key opinion leaders, amongst patients and healthcare professionals, to contribute to the creation of the consensus report by providing an understanding of the current situation from a medical and patient perspective.

The EFA's European Consensus Report 2022 – The Burden of Atopic Eczema (AECE Report) was launched in September 2022. To accompany the AECE Report and the policy recommendations of the Consensus Committee, an advocacy toolkit has been developed for the use at European and national level. The toolkit contains all the essential elements to support your advocacy on the basis of the AECE Report, from an outline of the target audience and the key messages to a template of an outreach letter to national authorities, as well as examples of social media messages for external outreach. The toolkit aims at providing patients with the support needed to develop their own advocacy campaign for reducing the burden of AD/E.





In the pictures, Atopic Eczema Consensus Europe Committee meetings members and facilitators.

# 1. The people that can help you drive change on atopic eczema

Patient advocates and the organisations representing them are very powerful stakeholders in health: they are at the centre of the healthcare system and therefore their health outcomes and feedback are the engine to keep care and prevention improving. However, patients alone cannot fix the system when things do not work.

Addressing the right people at the right time is crucial when seeking actual change. Such proactivity demands being strategic in your analysis of the field, carefully identifying your allies and developing trust and ultimately partnership towards the patients.

#### 1.1 How to identify the policy influencers?

Atopic eczema is a complex disease that requires multidisciplinary care. Such complexity means that patients and the organisations representing them act as truly connectors between departments of health and the government taking decisions affecting atopic eczema. Whether you prioritise advancing on a given topic or another, you might consider the options that could bring you higher impact at national level.

The AECE report provides recommendations in three different dimensions of atopic eczema (the physical and emotional burden, the patient journey, and the financial and economic burden). The policy influencers for these three dimensions might also vary.

In this section, we outline the **key stakeholder profiles to contact based on the AECE Report and policy recommendations of the Consensus Committee**. For each stakeholder, we have described their general role and identified their usual responsibilities. Moreover, the section maps out the rationale for why it would be useful to meet them, as well as concrete asks. This serves as a guide to ensure that you have all the policy influencer menu at hand to make the most of your time and resources.

#### 1.2 Institutional stakeholders

#### 1.2.1 Ministry of Health

Minister of Health (MoH)				
Why contacting them?	The MoH has overall responsibility for health policy at national level. This means that they are the most crucial stakeholder for engagement, given that they would be responsible for implementing the calls and recommendations developed by the Consensus Committee.			
What to ask them?	Implement the recommendations of the Consensus Committee, recognising the seriousness and complexity of AD/E, and ensure the patient journey is respected at each stage, from diagnosis to treatment and care, with a supporting environment for patients and families.			

Pharmaceutical Department				
Why contacting them?	These stakeholders will be particularly important for engagement on the recommendations of the Consensus Committee on the			
	development, timely approval, and availability of new AD/E			
	treatments at national level. Engage at a working level, in addition to high-level meetings with the Minister of Health.			
What to ask them?	Introduce regulatory changes to support the development of new treatments for AD/E and capitalise on the opportunities offered by			
	Real World Data to better understand AD/E and aid the			
	development of new treatments.			
Depa	artment with responsibility for mental health			
Why contacting them?	The psychological burden of AD/E was highlighted by the Consensus			
willy contacting them:	Committee. It is therefore important to engage with relevant			
	officials and advocate for the effects of AD/E to be included in			
	policies focusing on mental health, including an enhanced role for psychologists.			
What to ask them?	Support health information that stresses that AD/E is not			
	contagious and comes with a heavy burden for patients and			
	caregivers and support an enhanced role for psychologists in AD/E			
	care, including training in dermatology, to address the psychological element of the disease.			
Departmen	t with responsibility for pricing and reimbursement			
Why contacting them?	Support health information that stresses that AD/E is not			
	contagious and comes with a heavy burden for patients and			
	caregivers. In addition, support an enhanced role for psychologists			
	in AD/E care, including training in dermatology, to address the psychological element of the disease.			
What to ask them?	Introduce a new classification for the reimbursement of AD/E			
	treatments, to guarantee patients sufficient access to basic			
	necessary care and recognise the societal and human costs of access delays.			

## 1.2.2 Ministry of Research

Ministry of Research & Development/Innovation				
Why contacting them? Meet to stress the need for further research funding on AD/E,				
highlighting unmet medical need and the significant disease burde				
for patients.				
What to ask them?	Earmark funding at EU and national level for research to improve			
understanding of the causes and mechanisms of AD/E, along with				
	additional research funding to develop new AD/E treatments.			

### 1.2.3 Ministry of Education

Department with responsibility for the administration of education and oversight of educational institutions				
Why contacting them?	These stakeholders will be particularly important for engagement on the recommendations of the Consensus Committee on the development, timely approval, and availability of new AD/E treatments at national level. Engage at a working level, in addition to high-level meetings with the Minister of Health.			
What to ask them?	Introduce regulatory changes to support the development of new treatments for AD/E and capitalise on the opportunities offered by Real World Data to better understand AD/E and aid the development of new treatments.			
Department with re	sponsibility for liaising on scientific education in universities			
Why contacting them?  Engage to advocate for the inclusion of content related to thighlighted by the Consensus Committee, such as the includer dermatological problems in nutritional, psychological and redegrees.				
What to ask them?	Increase the role of psychologists, pharmacists and nutritionists in AD/E care by including training modules on dermatology as part of the curriculum.			

## 1.2.4 Regulatory stakeholders

Medicines Agency Head of the Agency/Department responsible for clinical trials coordination				
Why contacting them?	Given the crucial role of the medicines agency in the approval of new treatments for AD/E, engage to explain the importance of the timely approval of AD/E treatments, the introduction of quality-of-life endpoints and new methodologies to grade the impact of AD/E, using the recommendations of the Consensus Committee to demonstrate the agreed position of pan-European stakeholders.			
What to ask them?	Introduce regulatory changes to ensure patients are involved in the design and implementation of clinical trials. In addition, support the introduction of quality-of-life endpoints in relevant clinical trials and recognise the limitations of current methodologies used to grade the impact of AD/E and measure itch.			

# 1.3 Civil society stakeholders

### 1.3.1 Medical societies and healthcare professionals' association

Primary Care Medical Society					
Why contacting them?	Medical societies are trusted stakeholders, meaning that their support for the Consensus Committee recommendations would carry weight with the national government and result in a higher likelihood that the call for action is adopted into national policy.				
What to ask them?	Support the call for enriched education for primary care professionals, so no diagnosis is missed, and support the call for a statutory right to referral for each patient diagnosed with AD/E in Europe.				
	Nursing Medical Society				
Why contacting them?	Medical societies are trusted stakeholders, meaning that their support for the Consensus Committee recommendations would carry weight with the national government and result in a higher likelihood that the call for action is adopted into national policy.				
What to ask them?  Support the call for a reinforced role for specialist nurses, wh highlights their essential importance in treatment and disease management.					
	Nutritionist Association				
Why contacting them?	The involvement of nutritionists is essential for a holistic approach of AD/E. Securing the support of as many societies and associations as possible would add additional weight to the recommendations.				
What to ask them?	Support the call for an enhanced role for nutritionists, aimed at creating a more holistic approach to AD/E care.				
	Pharmacist Association				
Why contacting them?	Engaging with pharmacists would highlight the multidisciplinary nature of the project and provide an opportunity to explain what AD/E patients demand from them.				
What to ask them?	Support the call for an enhanced role for pharmacists, including the introduction of training for pharmacists on the detection and management of topical corticosteroids concerns.				
	Teaching/Education Association				
Why contacting them?	Bringing on board these associations would be particularly relevant for Consensus Committee recommendations related to the impact of AD/E on young people. Including non-medical stakeholders as supporters would give a broader scope to coalitions at national level.				
What to ask them?	Support the call for improved health literacy around allergy and AD/E to address misconceptions and tackle the emotional burden of AD/E.				

#### 1.3.2. Other Stakeholders

	Regional authorities (as needed)				
Why contacting them?	The calls and recommendations of the Consensus Committee should be presented to those with relevant competences, with health counsellors being involved as necessary based on the national context.				
What to ask them?	Implement the recommendations of the Consensus Committee, recognising the seriousness and complexity of AD/E. In addition, ensure the patient journey is respected at each stage, from diagnosis to treatment and care, with a supporting environment patients and families.				
Public Insurance Provider (as needed)					
Why contacting them?	Meeting to highlight the special and specific needs of AD/E patients and discuss the inclusion of other specialties under reimbursement schemes.				
What to ask them?	Introduce a new classification for the reimbursement of AD/E treatments, to guarantee patients sufficient access to basic necessary care and recognise the societal and human costs of access delays.				
European Federation	n of Allergy and Airways Diseases Patients' Association (EFA)				
Why contacting them?	EFA is the leading association of the AECE project, including the coordination of the Consensus Committee and the launch of the AECE report.				
What to ask them?	Notify EFA of the intention to contributing to the advocacy campaign on the basis of the AECE report and recommendations.				

# 2. Contacting the people that can help you advance on atopic eczema

Once you have identified who could help you in advancing prevention and care for atopic eczema, then you need to contact them.

In case you have already good insights, networks, and connections within the ministerial department you are addressing, you might make a phone call or request some action from their side in an informal way. However, we recommend you officialise your request with specific letters addressing the person or person in charge and documenting why you are asking for a meeting and for action.

#### 2.1 Who should receive your request?

Atopic eczema patient groups can seek support in many organisations and individuals.

Do not put boundaries and make your advocacy calls get known by a wide spectrum of policymakers. However, beware that each stakeholder might require some adaptation.

We encourage you to refer to your last meeting, last work addressing eczema that you are aware of in the country, or any personalised touch that can attract the attention of their services.

You can address your letter to the many stakeholders described in the "who can help you" section of the toolkit:

- Ministry of Health (Minister of Health, Pharmaceutical department, Department with responsibility for mental health, Department with responsibility for pricing and reimbursement)
- Ministry of Research and Innovation (Department with responsibility for innovation)
- Ministry of Education (Department with responsibility for the administration of education policy and oversight of schools, Department responsible for liaising on scientific education in universities)
- Regulatory Authority / National Medicines Agency (Head of the Agency)
- Regional Authorities (Health Counsellors)
- Public Insurance Provider (President, Representative responsible for government relations)
- Primary Care Medical Society (President, Representative responsible for government relations)
- National nursing association (President, Representative responsible for government relations)
- National nutritionist association (President, Representative responsible for government relations)
- National pharmacist association (President, Representative responsible for government relations)
- Teachers/Education associations (Representatives at local/national level, as necessary)

If you find it relevant and helpful, in your communications you can copy in EFA office and your national dermatology society.

### 2.2 Template model letter for national ministries of health

This toolkit includes a draft letter that can serve as a template for outreach at national level. The letter briefly refers to the messages and recommendations from the report, while allowing for adaptation to the local context and the organisation sending it out. These sections are highlighted in the letter. Please use it at your best convenience, adapting it where needed.

TITLE: Meeting request on atopic eczema care recommendation

#### Dear [INSERT NAME OF NATIONAL STAKEHOLDER],

On behalf of the European Federation of Allergy and Airways Diseases Patients' Associations (EFA), we are contacting you to share the results and recommendations of the EFA Atopic Dermatitis/Eczema (AD/E) Consensus Europe project.

The recommendations have been developed by a pan-European Consensus Committee, comprised of key opinion leaders amongst patients and healthcare professionals and facilitated by EFA, with the aim of informing the debate on access and quality of care for AD/E, based on the real burden of the disease across Europe.

[PLACEHOLDER]: Organisations are encouraged to add here their own reflections on the burden of AD/E in their country, to make the letter as relevant as possible for your national stakeholders. These

reflections can include considerations on:

- Access to treatment in your country
- The lack of multidisciplinary care for AD/E
- The challenges faced by HCPs working in this area
- The need for further awareness raising on the burden of AD/E

AD/E is an itchy, chronic relapsing skin condition that affects up to 25% of children and 2-8% of adults. Allergic inflammation results in a disturbed skin barrier and is associated with a major disease burden and impaired quality of life. AD/E affects a patient's social, educational, and work life and is highly burdensome for families and the wider population. Despite new advances in treatment possibilities in recent years, the burden that AD/E poses to patients is still not fully understood by policymakers. In addition, the need for multidisciplinary care to address the range of impacts from AD/E is not recognised nor addressed, a factor that is coupled with the persisting low priority for the disease among serious chronic diseases. To fill this gap, the attached Consensus Report and policy recommendations on the burden of AD/E in Europe have been devised based on the work of the Consensus Committee.

AD/E is a chronic, inflammatory, systemic disease with combined effects of skin-barrier disruption, immune dysregulation, multi-organ disorders and intense symptoms. 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. Therefore, it is vital for the current situation to be addressed, and for patients suffering from AD/E to be fully recognised and given long-term treatment and multidisciplinary care to cope with it.

Policymakers must recognise that AD/E is a serious, complex chronic disease. The patient journey for those diagnosed with AD/E must be respected at each stage, from diagnosis to treatment and care, with a supportive environment for patients and their families. Only be adhering to the recommendations of this report will the situation be addressed, and AD/E patients and their families be given the support they need.

The policy recommendations take into account the following factors:

- The physical and emotional burden of the disease;
- Diagnosis of AD/E and processes around the development of new treatments;
- The need to improve access to personalised treatment and care;
- The need to develop a supportive environment for patients addressing treatment and care;
- The **financial and economic burden** that AD/E has on patients.

We would be delighted to have the opportunity to meet with you [INCLUDE A TIMELINE IN WEEKS] and discuss this project as well as discussing the relevance of these recommendation on the healthcare environment in [INSERT COUNTRY NAME].

We thank you in advance for your consideration and look forward to discussing this further.

Kind regards,

[INSERT SIGNATURE AND TITLE]

**About EFA:** The European Federation of Allergies and Airways Diseases Patients' Associations (EFA) is the European voice for over 200 million people living with allergies and airways diseases. EFA brings together 42 national associations from 25 countries and channels their knowledge and demands to European institutions, while striving to achieve greater patient participation in decision making at local, national and European level.

Contact point: Valeria Ramiconi, Programme Manager: valeria.ramiconi@efanet.org

**About NAME:** [INSERT MODEL TEXT - e.g.: ORGANISATION represents XXX patients in COUNTRY NAME, coving A, B and C diseases. At national level, ORGANISATION regularly engages with policymakers and stakeholders to ensure the needs of the patients it represents are met. ORGANISATION is also active at European level, is an active member of EFA.]

Contact point: FIRST NAME LAST NAME, TITLE, EMAIL ADDRESS

**About the EFA Atopic Dermatitis/Eczema Consensus Europe project:** In 2018 EFA published the biggest Quality of Life survey report to date on Atopic Eczema/Dermatitis (AD/E) <a href="Itopics.">Itopics</a> Survey Report . The key points arising from the survey include:

- Patients often have a late diagnosis.
- Atopic eczema/dermatitis is often linked with stigma and grave emotional and physical
- burden, locked in flare ups
- Poor level of education for primary care and access to specialist
- Economic impact is underestimated

Despite growing awareness and advancement around skin conditions, the burden that AD/E patients endure each day is still not sufficiently recognised, nor is the need for multidisciplinary care to address the range of impacts AD/E presents. Awareness around these issues is currently only acknowledged among the AD/E community. To address this situation, the **EFA Atopic Dermatitis/Eczema Consensus Europe project** brought together 15 key opinion leaders from the AD/E community, including patients, patients' representatives, and multidisciplinary healthcare professionals) to discuss and build common ground of the burden caused by AD/E. The project culminated in the publication of the <u>European Consensus Report</u> on the Burden of Atopic Eczema, which represents the joint position of patients and healthcare professionals as well as including a series of policy recommendations to address the current, inadequate situations on AD/E across Europe.

# 3. Going public with your advocacy recommendations and campaign

Let's be frank. National authorities might choose to ignore your letters. However, that should not refrain you from educating, advocating, and seeking alliance to advance atopic eczema care, elsewhere.

The institutional stakeholders are the most important ones and sending them the letters and meeting requests are the priority number one on your list, but you have other many groups to convince, including your own patient peers and the healthcare professionals. Therefore, reaching out, disseminating the information, will be a great part of your work, and probably the most intense.

The following section proposes a one-year advocacy timeline that can be adapted based on your local context, the speed at which meetings with stakeholders are secured, and on the organisation's capacity and resources.

	Month 1				
	Actions	Timeline Re	esources		
1.	Publish European Consensus Report on the Burden of Atopic Eczema on organisation's website.	activities. • IT su	structure pport		
2.	Publication of EFA's Call to Action on the organisation's website.		esite estructure epport		
3.	Begin social media campaign – use of dedicated hashtag #AtopicEczemaBurden to tie into the work of other organisations at national level, use of infographics and materials provided by EFA in Consensus Report Advocacy Toolkit.	campaign to begin once Consensus Report and Call to Action are published on the organisation's website.  relev med (Link Insta			
4.	Hardcopies EN language of Consensus Report and hardcopies relevant national language.	of future outreach meetings. • Tran	ted materials slator for ort (if vant/if needed)		

	Months 2-3				
	Actions	Timeline	Resources		
5.	Begin outreach to stakeholders listed above, using the template outreach letter provided by EFA and translated to the national language, as relevant.	<ul> <li>To begin once materials are published and the social media campaign is underway.</li> </ul>	Translator for toolkit materials (if relevant/needed)		
6.	Circulate hard copies to key stakeholders in outreach meetings	Circulated in meetings, once arranged.	Report & toolkit materials translated (translator may be needed, as relevant)		
7.	Continue social media campaign – use of dedicated hashtag #AtopicEczemaBurden to tie into the work of other organisations at national level, use of infographics and materials provided by EFA in Consensus Report Advocacy Toolkit.	Ongoing throughout dissemination.	<ul> <li>Accounts on relevant social media channels (LinkedIn, Twitter, Instagram, Facebook)</li> <li>Regular monitoring of social media channels</li> </ul>		

8.	Use of Consensus Project presentation provided by EFA in the advocacy toolkit in outreach meetings with stakeholders and policymakers.	•	Ad-hoc use, dependent on outreach meeting.	•	Availability of staff and knowledge on the toolkit presentations.
9.	Present Call to Action during outreach meetings, requesting endorsement from stakeholders and policymakers	•	Ad-hoc use, dependent on outreach meeting.	•	Call to action materials prepared. Translator for call to action document (if relevant/needed).

Ongoing/Ad-hoc activities throughout dissemination			
Actions	Timeline	Resources	
10. Presentation of Consensus Report at key events	Constantly identify opportunities.	Consensus Report & toolkit materials (e.g. presentation) available (and translated if relevant)	
11. Identify other opportunities to promote the Consensus Report at key events and activities on social media	Constantly identify opportunities.	Social media monitoring	
12. Outreach to MEPs to further raise the profile of the consensus report	To consider once outreach meetings at national level are underway.	<ul> <li>Tracker of relevant MEP's (interest in the topic and/or relevant at national level)</li> </ul>	
13. Pitch the story to national media, following the endorsement of the Call to Action from stakeholders and policymakers	To consider once stakeholders and policymakers have endorsed the Call to Action.	Communication targeting the media/journalists	
14. Reach out to national-level influencers to promote the Call to Action	<ul> <li>Identify potential stakeholders</li> <li>Constantly identify opportunities.</li> </ul>	Call to action materials prepared	
15. Host an in-country event to officially 'launch' the report	To consider once stakeholders and policymakers have endorsed the Call to Action.	<ul> <li>Event location</li> <li>Identification of relevant stakeholders</li> <li>Sponsors</li> </ul>	

# 4. Starting your #AtopicEczemaBurden digital campaign

Informing the community about your asks and plans will make your campaign look more solid in the eyes of decision makers. In addition, it will provide you with opportunities to engage with your public, to get supporters and to learn about how much your plan is welcomed within your membership.

#### EFA is currently working on:

- social media posts to be used to promote the report and the recommendations on social media channels.
- calls to action depending on the topic
- one infographic per policy recommendation is also included to add a visual element to the posts.

The social media posts are aimed at a more general audience than the template letter and are intended for engaging external communication and creating awareness.

# **5. Gaining traction: presenting your Atopic Eczema** recommendations project

As you introduce your campaign and recommendations, you might realise that some would challenge your work and the methodology of what you propose. Against that threat, be always prepared to explain why EFA and you are taking this lead and the steps that were carefully taken to present this consensus. Insist on the representativity, the exhaustive desk review of scientific evidence that was conducted, and the daily burden that you and the patients that you represent are going through.

We have prepared a slide deck that provides with a step-by-step explanation of EFA's Atopic Dermatitis/Eczema Consensus Europe Project, its aims, and outputs. It takes in the composition and work of the Consensus Committee and the final policy recommendations. It also explains why this project has been conducted at European level.

The slide deck can be used during outreach meetings to present the project to the key stakeholders identified through the stakeholder profiles section of this toolkit. The slide deck also includes suggested speaking points in the notes section of key slides to be used during a presentation of the project.

### 6. Annexes

- 1. Atopic Eczema Consensus Europe (AECE) recommandations for social media and digital communications (**follow the QR code**)
- 2. EFA AECE project explanatory slide deck (follow the QR code)
- 3. Atopical Lives online photo series exhibition featuring atopic eczema patients and carers across Europe: https://www.efanet.org/campaigns/atopical

The European Federation of Allergy and Airways Diseases Patients' Associations (EFA) is a network of 46 allergy, asthma and COPD patients' organisations in 26 European countries and it works for European patients with allergy, asthma and chronic obstructive pulmonary disease (COPD) to live uncompromised lives, have the right and access to the best quality care and a safe environment.

Download the European Consensus Report on AD/E now



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#AtopicEczemaBurden

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