



# A misunderstood skin disease:

Mapping the policy response  
to atopic dermatitis

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## ABOUT THIS REPORT

*A misunderstood skin disease: Mapping the policy response to atopic dermatitis* is a report written by The Economist Intelligence Unit, and sponsored by Pfizer and the International Alliance of Dermatology Patient Organizations (GlobalSkin). It considers the healthcare system approaches and policy responses to the management of atopic dermatitis (AD), often referred to as atopic eczema.

The research reviews AD care across eight countries, representing a cross-section of the World Health Organisation regions, World Bank income bands and health system types. These countries are: Australia, Brazil, Israel, Italy, South Africa, Taiwan, the UK and the US. It explores a number of factors that play a part in the development of high-quality services for patients with AD.

This report is based on several strands of research, as follows:

A comprehensive literature review carried out by EIU Healthcare, a specialist research division of The Economist Group, to identify key themes that impact on people's experience of living with AD and how this could be improved. The themes identified formed the basis of an Atopic Dermatitis Scorecard (the scorecard) measuring the progress being made against key indicators in eight countries.

An expert panel convened in London on May 9th 2018 to provide insights on the scorecard and health systems' response to AD and patients' experiences of living with the disease. The panel participants (listed alphabetically by surname) were:

- Henrique Akira Ishii, patient representative, Associação de Apoio à Dermatite Atópica, São Paulo, Brazil
- Shulamit Burstein, founder, Israeli Association for Atopic Dermatitis, Israel
- Francesca Cipriani, paediatrician, University of Bologna, Gozzadini Children's Hospital, Italy
- Zandile Mazibuko, clinical head of dermatology, the University of the Free State, South Africa
- Magali Redding, CEO, Eczema Outreach Support, Scotland
- Tim Smith, vice-president, advocacy and access, National Eczema Association, US
- Cheryl Talent, president, Eczema Association of Australasia, Australia
- Amena Warner, head of clinical services, Allergy UK, UK

Desk research and in-depth interviews with five experts drawn from clinicians, patient groups and charities. Those interviewed were:

- Paul Charlson, general practitioner (GP) with a special interest in dermatology/GP with an extended role, Hessle, East Yorkshire and Leeds, West Yorkshire, UK
- Susanna Palkonen, director, European Federation of Allergy and Airways Diseases Patients' Associations, Brussels, Belgium
- Roberto Takaoka, founder, Associação de Apoio à Dermatite Atópica, São Paulo, Brazil; dermatologist and co-director, Atopic Dermatitis Clinic, University of São Paulo Medical School Hospital, São Paulo, Brazil; and president, Brazilian Atopic Dermatitis Association, Brazil

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- Tsen-Fang Tsai, dermatologist, Department of Dermatology, National Taiwan University Hospital and National Taiwan University College of Medicine, Taipei, Taiwan
- Amena Warner, head of clinical services, Allergy UK, UK

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## EXECUTIVE SUMMARY

Atopic dermatitis (AD), also known as eczema or atopic eczema (AE), is a common chronic inflammatory non-communicable skin disease that often manifests itself in flares of dry, red and itchy skin. It is not a well-understood disease. Lifetime prevalence can vary widely across the globe, ranging from 9% to 32%.<sup>1</sup>

For those without direct experience, it can be challenging to understand the lengths to which cracked, itchy skin can overwhelm a person's quality of life, as well as affect the lives of their family and caregivers.

This report will first examine the impact of AD on patients and its considerable social, financial and economic impacts. Then, we explore health strategies to address AD and the challenges patients often have in navigating their health systems. It will then look at the adoption of best practices, including integrated care, and the role of patient groups in supporting patients. Finally, it will provide an outlook on the key issues for policymakers and actions they may take to improve AD care.

The appendix includes details on the scorecard methodology and development.

Key findings of the research include:

- **AD is a chronic, relapsing skin disease that is often misunderstood and stigmatised, with extensive social and psychological impacts.** AD typically begins in early childhood, and patients generally experience intense itching, loss of sleep and bleeding from scratching, which can cause immense emotional distress. These negative effects can affect the academic, work and social life of both patients and their caregivers, at great psychological and financial cost. As there is no cure for AD, its sometimes lifelong management can be taxing for patients and caregivers. AD is also associated with co-morbidities such as depression, anxiety and asthma.
- **Incomplete data capture threatens progress.** There is a lack of consensus on scoring systems for the severity of AD, the terminology around the disease, and poor capturing of epidemiological and impact data. Many studies and clinical trials use different methodologies and measures and cannot be easily compared. While researchers have looked at the impact of the disease on patients' physical, psychological and social wellbeing as well as the effect of AD on parents' or carers' quality of life, there are still some gaps. The lack of co-ordinated impact data makes it difficult for policymakers, who fund and commission services, to make evidence-based decisions that ensure sufficient resources are allocated to managing AD.
- **Further primary healthcare professional training on AD could improve patient outcomes and reduce pressures on secondary care.** Health systems are challenged to provide better care for AD patients. Most patients are managed in primary care by a family physician or a general practitioner (GP). However, due to a limited amount of dermatology training at this level, primary care management is often suboptimal. And due to the limited amount of time doctors can spend with patients, many AD sufferers do not feel "heard" and can become dismayed with the system.

<sup>1</sup> See Appendix.

It is suggested that medical education curriculums evolve to include more dermatology training to better understand the quality-of-life aspects of the disease, and better inform care and treatment.

- **Specialists are in short supply.** Many referrals to specialists could have been triaged at the primary care level, but for moderate and severe cases, consultations with specialists—mainly dermatologists—are a necessary part of disease management. Workforce numbers are critical, but this research finds some countries have too few dermatologists and other AD specialists and that wait times can exceed two months. Government funding could incentivise specialists in this area, and better management by primary care could lessen the referral demand.
- **Multidisciplinary care can benefit patients, as they have multifactorial needs.** The ultimate goal of multidisciplinary care is to deliver comprehensive and integrated healthcare services that provide patients with the knowledge, skills and confidence to better manage and treat their AD and quality-of-life issues. Studies show these clinics have a positive impact on patient's overall treatment and out-of-pocket costs. However, there is limited funding available to support integrated centres of care and often they rely on funding and support from government, agencies or non-profit organisations.
- **Patient groups help fill the gaps left open by their healthcare systems.** Patient advocacy groups and charities say they are inundated by requests from AD patients for basic information about managing their disease. These groups assist AD patients in understanding their disease, navigating the healthcare system and even developing programmes to address psychosocial needs. The services they offer may help to support shared decision-making with health professionals. All AD stakeholders, including policymakers, healthcare professionals, patient advocacy and support groups, caregivers, and the private sector, should work together towards a united strategy and messaging around AD.

# CHAPTER 1: THE IMPACT OF ATOPIC DERMATITIS

<sup>2</sup> Larsen FS, Hanifin JM. Epidemiology of atopic dermatitis. *Immunology and Allergy Clinics of North America*. 2002;22(1):1-24.

<sup>3</sup> Hanifin JM, Reed ML. A population-based survey of eczema prevalence in the United States. *Dermatitis*. 2007;18: 82–91.

<sup>4</sup> Henriksen L, et al. Incidence rates of atopic dermatitis, asthma, and allergic rhinoconjunctivitis in Danish and Swedish children. *Journal of Allergy and Clinical Immunology*. 2015;136: 360–366.e2.

<sup>5</sup> Kay J, et al. The prevalence of childhood atopic eczema in a general population. *Journal of the American Academy of Dermatology*. 1994; 30:35–39.

<sup>6</sup> Edwards T, et al. Insights into future therapeutics for atopic dermatitis. *Expert Opinion on Pharmacotherapy* 2018; 19(3): 265-278.

<sup>7</sup> Ridd MJ, et al. Systematic review of self-management interventions for people with eczema. *British Journal of Dermatology*. 2017; 177(3):719-734.

<sup>8</sup> Tsakok T, et al. Atopic dermatitis: the skin barrier and beyond. *The British Journal of Dermatology*. 2018; Jul 03.

<sup>9</sup> Available at: <https://www.eczemaexposed.com/understanding-eczema>.

<sup>10</sup> Kantor R, et al. Atopic dermatitis, atopic eczema, or eczema? A systematic review, meta-analysis, and recommendation for uniform use of 'atopic dermatitis'. *Allergy: European Journal of Allergy and Clinical Immunology*. 2016;71(10):1480-5.

<sup>11</sup> Langan SM, et al. What Is Meant by a "Flare" in Atopic Dermatitis? A Systematic Review and Proposal. *Archives of Dermatology*. 2006;142(9):1190–1196.

<sup>12</sup> Le Roux E, et al. GPs' experience of diagnosing and managing childhood eczema: a qualitative study in primary care. *British Journal of General Practice*. 2018;68 (667): e73-e80.

## ***What is atopic dermatitis?***

AD, also known as eczema or atopic eczema (AE), is a common chronic inflammatory skin disease that affects 10-20% of children and 2-10% of adults worldwide.<sup>2,3,4,5</sup> It can be a highly visible disease that can present as patches of cracked, even crusty and oozing skin, sometimes covering significant parts of a person's body.

AD primarily impacts the skin and is not considered life-threatening, but the effects go well beyond appearance. With incessant scratching, AD can affect sleep, leading to anxiety and depression. Some feel the disease limits their career prospects, social opportunities and education. Today, AD is recognised as a global public health concern because of its prevalence, cost and impact on the quality of life of patients and their caregivers.

The science behind AD is still developing, with a range of novel therapeutics in drug development.<sup>6</sup> The disease often begins in childhood, but can also present in adulthood.<sup>7</sup> The pathophysiology of AD is complex, involving genetic and environmental risk factors, with dysregulation of the immune system playing a key role.<sup>8</sup>

It is understood that the disease is caused by an overactive immune system causing inflammation in the skin. Scratching the inflamed skin area, while providing temporary relief, often makes matters worse as it breaks down the outer skin layer. This makes it easier for foreign substances to enter the skin, and when this occurs in AD patients, their immune system reacts, worsening the rash and the desire to scratch. The cycle continues, increasing the risk of infection.<sup>9</sup>

The disease can be typically described as "mild", "moderate" or "severe", but flare-ups are different for every person. However, due to the lack of standardised measures of the disease's prevalence and severity, patients experiencing similar symptoms may be classified differently across regions and by specialists.<sup>10</sup>

AD is a relapsing, remitting disease that is often treated pharmacologically when it flares up, but it is not always recognised in the medical field as a chronic disease.<sup>11</sup> A UK qualitative study exploring GPs' experiences of AD found there was an overall feeling that, due to competing demands of chronic disease management and multimorbidity in an ageing population, dermatology was seen as a low priority in general practice.<sup>12</sup>

## ***The question of prevalence***

The disease typically starts in young children but it can continue on and off for a person's lifetime. Until recently, it had been assumed that most children would "grow out" of their AD. However, a systematic

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review of longitudinal studies, in which more than 13,000 children with AD were followed into adulthood, found that the difference in childhood prevalence and prevalence after age 12 decreased by around only 1%, suggesting that this assumption may not be as reliable as once thought.<sup>13,14</sup>

Historically, studies have suggested that 3-5% of adults may first present with AD after 18 years of age,<sup>15,16</sup> but adult onset is also reportedly increasing.<sup>17</sup>

On a global scale, an estimated 300m people had dermatitis in 2010 (including atopic, contact and seborrheic dermatitis), up from 225m in 1990.<sup>18</sup> However, these figures are difficult to estimate due to gaps in data and the lack of standardised identification and classification.

The Economist Intelligence Unit Atopic Dermatitis Scorecard finds a lifetime prevalence—the percentage of people within a population who will have AD at some point in their life—ranging from 9% of the population in Israel to 32% in Australia (see Figure 1 and the Appendix). Half of the countries reviewed in the scorecard published this prevalence data within the past 5-10 years, and none have reported in less than 5 years.

Yet the prevalence of AD may still be underestimated because, according to our expert panellists, there are patients who never present, and patients who self-treat or use complementary therapies. These patients tend to not be included in epidemiological studies.

Simple, standardised data capture and validated diagnostic criteria are necessary to improve treatments, steer research and inform policy.

### US: UNKNOWN?

Notably, the US population's lifetime prevalence data are marked as "unknown" in the scorecard (see Figure 1). However, US prevalence data are available, but the methodology is not consistent with the other seven countries in the scorecard. For example, in 2003 US prevalence was reported over the course of 12 months (period prevalence) as 8.7% to 18.1% for children, depending on the state.<sup>19</sup> And according to another study, one-

year US prevalence ranged from 7.2-10.2% in adults.<sup>20</sup>

The scorecard considers only lifetime prevalence measures; specifically, the percentage of people within the national population who will have atopic dermatitis at some point in their lives. This is another example of how difficult it is to compare data across countries.

<sup>13</sup> Abuabara K, et al. The prevalence of atopic dermatitis beyond childhood: A systematic review and meta-analysis of longitudinal studies. *Allergy: European Journal of Allergy and Clinical Immunology*. 2018;73(3):696-704.

<sup>14</sup> Yu AM, et al. The prevalence of eczema beyond childhood: A systematic review and meta-analysis of longitudinal studies. *Journal of Investigative Dermatology*. 2017;137(5):S39.

<sup>15</sup> Ingordo V, et al. Adult-onset atopic dermatitis in a patch test population. *Dermatology*. 2003;206:197-203.

<sup>16</sup> Ozkaya E. Adult-onset atopic dermatitis. *Journal of the American Academy of Dermatology*. 2005;52:579-582.

<sup>17</sup> Global Burden of Disease Collaborative Network. *Global Burden of Disease Study 2016 (GBD 2016) Results*. Seattle, United States: Institute for Health Metrics and Evaluation (IHME), 2017. Available from <http://ghdx.healthdata.org/gbd-results-tool>.

<sup>18</sup> Deckers IAG, et al. Investigating International Time Trends in the Incidence and Prevalence of Atopic Eczema 1990–2010: A Systematic Review of Epidemiological Studies. *PLOS ONE*. 2012;7(7):e39803.

<sup>19</sup> Shaw TE, et al. Eczema prevalence in the United States: data from the 2003 National Survey of Children's Health. *Journal of Investigative Dermatology*. 2011; 31(1):67-73

<sup>20</sup> Silverberg J. Public health burden and epidemiology of atopic dermatitis. *Dermatologic Clinics*. 2017; 35(3):283-289

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<sup>21</sup> Gochnauer H, et al. The Psychosocial Impact of Atopic Dermatitis. *Advances In Experimental Medicine And Biology*. 2017;1027:57-69.

<sup>22</sup> Shin J, et al. Psychiatry outpatient visits by atopic dermatitis patients varying in the complexity of their prescriptions: A nationwide cohort study conducted from 2005 to 2013. *Medicine (Baltimore)*. 2016;95(49):e5411.

<sup>23</sup> Rønnstad ATM, et al. Association of atopic dermatitis with depression, anxiety, and suicidal ideation in children and adults: A systematic review and meta-analysis. *Journal of The American Academy Of Dermatology*. 2018; 79(3):448-456.e30.

<sup>24</sup> Allergy UK and Sanofi Genzyme. Seeing Red: Getting under the skin of adult severe eczema. 2017. Available at: [https://www.allergyuk.org/assets/000/001/411/Seeing\\_Red\\_Report\\_FINAL\\_25.04.17\\_original.pdf?1508228476](https://www.allergyuk.org/assets/000/001/411/Seeing_Red_Report_FINAL_25.04.17_original.pdf?1508228476).

<sup>25</sup> Drucker AM, et al. The Burden of Atopic Dermatitis: Summary of a Report for the National Eczema Association. *Journal of Investigative Dermatology*. 2017; 137(1):26-30.

<sup>26</sup> Drucker AM, et al. Audit: burden of eczema: the burden of disease of atopic dermatitis. San Rafael, CA: National Eczema Association, 2015. Available from: [https://national-eczema.org/wp-content/uploads/2016/06/NEA-report-final12\\_30\\_2015.pdf](https://national-eczema.org/wp-content/uploads/2016/06/NEA-report-final12_30_2015.pdf).

<sup>27</sup> Zuberbier T, et al. Patient perspectives on the management of atopic dermatitis. *Journal of Allergy and Clinical Immunology*. 2006; 118(1):226-32.

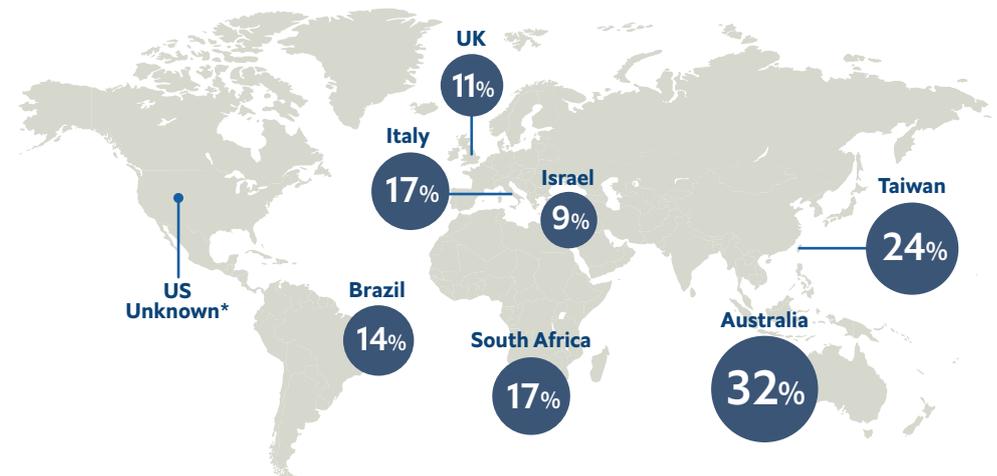
<sup>28</sup> Eczema Society of Canada. Atopic Dermatitis Quality of Life Report: moderate to severe disease 2016/2017 survey results. Available at: [https://eczemahelp.ca/wp-content/uploads/2017/08/ESC\\_QUALITY\\_OF\\_LIFE\\_REPORT\\_2017.pdf](https://eczemahelp.ca/wp-content/uploads/2017/08/ESC_QUALITY_OF_LIFE_REPORT_2017.pdf).

<sup>29</sup> Chalmers JR, et al. Report from the fifth international consensus meeting to harmonize core outcome measures for atopic eczema/dermatitis clinical trials (HOME initiative). *British Journal of Dermatology*. 2018; 78(5):e332-e341.

<sup>30</sup> See Appendix.

**Figure 1: AD is a global public health issue with an increased lifetime prevalence worldwide trend. Lifetime prevalence: percentage of people within the population who will have AD at some point in their life**

(countries chosen on basis of inclusion in The Economist Intelligence Unit scorecard on AD)



\*The Economist Intelligence Unit found many studies looking at US one-year prevalence or prevalence with a sample, but these did not meet our criteria of lifetime prevalence.

Source: see Appendix

## Understanding and quantifying the burden

### Psychosocial

The skin is the largest organ, and it is on display for other people to see and make judgments. When a person has AD, there is a deep psychological impact from managing public perception and social stigma,<sup>21</sup> which is in addition to living with the symptoms and handling often onerous and messy treatments to control the disease.<sup>22</sup>

Patients describe it as emotionally, physically and often financially draining. Although AD isn't fatal, it is associated with psychological problems such as depression and suicidal ideation.<sup>23</sup> For example, one report finds that more than 70% of patients with severe AD reported feeling depressed as a result of their condition.<sup>24</sup> And many patients report anxiety, frustration, sleep disorders, isolation and embarrassment, and trouble forming relationships.<sup>25,26,27,28</sup>

Yet quality-of-life impacts are not completely measured. And although clinicians are now largely encouraged to assess the disease's impact on the quality of life during patient visits, the methods to log and value these data are not standardised.<sup>29,30</sup>

According to Dr Roberto Takaoka, a dermatologist who practices in Brazil, "AD is much deeper than the skin. It affects the emotional side of the patient, impacts [their] social life and has a psychological and financial impact. The family as a whole can be affected because AD is definitely much more than just an itchy rash."

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Patients often seek swift and miraculous cures. Some are unable to make progress in their career, education or undertake social or recreational opportunities due to their AD, and instead try all kinds of costly and time-consuming therapies and routines, which lack the cure factor they are looking for, explains Dr Takaoka. “They may not want to go out to work, may not be able to hold down certain jobs or go out to school,” he says.

According to a study of more than 2,000 AD patients in eight countries, flare-ups—when the disease temporarily becomes more severe—disturbed the sleep of patients for an average of 7.3 nights per episode and about 67 nights per year. And patients with severe AD reported 14.6 nights’ sleep lost per flare, equivalent to 162 nights per year.<sup>31</sup> Furthermore, 86% of patients reported that they change their approach to at least one type of everyday activity while in flare, such as bathing, diets and choice of clothing.<sup>32</sup> And a third said AD flares negatively affected their school, home and social life.<sup>33</sup>

Susanna Palkonen, director of the European Federation of Allergy and Airways Diseases Patients’ Associations in Brussels, who has AD, thinks that the more severe the symptoms of AD are, the higher the risk of depression. “When you have a flare-up it affects the way you feel. You do not feel beautiful, that’s for sure.” She also explains that the intense itch of AD can be triggered by stress and emotional factors.<sup>34</sup>

Dr Tsen-Fang Tsai, a dermatologist in Taiwan, explains that patients have to deal with feelings of rejection and low self-esteem, which can lead to social distancing. “In Taiwan there are cosmetic concerns about how the skin looks and people think those who have AD are unclean if skin lesions are on exposed areas of their body.”

In search of a solution some patients will seek skin-bleaching treatments or resort to laser treatments because of the pigmentation problems, points out Dr Tsai.

### GERMANY ACTING TO REDUCE STIGMA

Countries can take steps to fight social stigma and educate the public about visible skin diseases, thereby helping patients feel more accepted by their peers. In 2018 Germany’s Federal Ministry of Health started to fund ECHT EVAL 2018-20—a research project aimed at gathering data and developing strategies

to better educate the German public about visible skin diseases, with the goal of generating more respect for patients and removing fear that patients’ skin conditions are infectious, ultimately increasing patients’ quality of life.<sup>35,36,37</sup>

### Families and caregivers

The families and caregivers of people with AD also have to deal with the impacts on a day-to-day basis. Parents report spending around 60 minutes a day managing their child’s AD,<sup>38</sup> and may take time off work to manage a child’s illness at home or go into school to apply treatments.

<sup>31</sup> Zuberbier T, et al. Patient perspectives on the management of atopic dermatitis. *Journal of Allergy and Clinical Immunology*. 2006; 118(1):226-32.

<sup>32</sup> *ibid*

<sup>33</sup> Nørreslet LB, et al. The impact of atopic dermatitis on work life - a systematic review. *Journal of the European Academy of Dermatology and Venereology*. 2018;32(1):23-38.

<sup>34</sup> Pawankar R, et al. *White Book on Allergy*. World Allergy Organization. 21 Apr 2010. Available at: <http://www.worldallergy.org/UserFiles/file/WhiteBook2-2013-v8.pdf>.

<sup>35</sup> Reduce Prejudice. SRH University of Health. 24 Apr 2018. Available at: <https://www.gesundheitshochschule.de/de/news-detail/news/vorurteile-abbauen/>.

<sup>36</sup> ECHT-EVAL 2018 – the German project implementing the WHO ‘Global Report on Psoriasis’. 12 Sep 2018. European Academy of Dermatology and Venereology (EADV) via PR NewsWire. Available at: <https://www.prnewswire.com/news-releases/echt-eval-2018-the-german-project-implementing-the-who-global-report-on-psoriasis-811859199.html>.

<sup>37</sup> Translating the WHO psoriasis resolution into the public: the German federal program against stigmatization 2018-2020. *ResearchGate*. 5 Apr 2018. Available at: <https://www.researchgate.net/project/Translating-the-WHO-psoriasis-resolution-into-the-public-the-German-federal-program-against-stigmatization-2018-2020>.

<sup>38</sup> Drucker AM, et al. The Burden of Atopic Dermatitis: Summary of a Report for the National Eczema Association. *Journal of Investigative Dermatology*. 2017; 137(1):26-30.

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Emotionally, the care can be arresting. Parents of AD patients report feeling emotional distress, guilt and anxiety.<sup>39,40</sup> It has also been shown that the families of children with a high severity of AD have a 6.6 times higher probability of experiencing a low family quality of life than their less-severe counterparts.<sup>41</sup> And according to a 2006 AD patient and caregiver study, carers may feel more anxiety about the next flare-ups than patients.<sup>42</sup>

With the impacts on families and caregivers in mind, The Economist Intelligence Unit's scorecard reviewed the eight countries' relevant guideline for AD for acknowledgment of the issue, and for recommendations of specific interventions to support families and caregivers and include a referral process.

The research finds that only South Africa and the UK fully address the wider impact of AD on families and caregivers in guidelines (see Figure 2). The other countries only partly or have no mention of family impact in their guidelines.

**Figure 2: Assessment of the wider impact of AD on families/carers**

Australia	Brazil	Israel	Italy	South Africa	Taiwan	UK	US
0	0	1	0	2	0	2	1

0=no; 1=mentioned briefly in guidelines and acknowledges that AD impacts on families/carers; 2=guidelines recommend one or more specific interventions and a referral process.

Source: see Appendix.

In South Africa, the guideline states: "quality of life impairment usually involves the entire family" and recommends a routine (non-urgent) referral if the AD "is giving rise to serious social or psychological problems for the child, parent or carer".<sup>43</sup> Guidelines used in the US (and relied upon by Israel) only briefly acknowledge this: "Along with the affected individual, other family members may also suffer as a result of being awakened."<sup>44</sup>

### SCHOOL SUPPORT PROGRAMMES

Schools and nurseries can be difficult environments for children with atopic dermatitis (AD). They often contain many common triggers for flares, such as uncomfortable uniforms, and hand washing with harsh soap and rough paper towels. Under these conditions, students may sometimes go for long stretches without being able to apply treatments. The flares can disrupt children's learning, and parents are often at a loss to address the issues.

Eczema Outreach Support, a UK non-profit, has created discussion guides for parents approaching schools or nursery about their child's AD needs. These include education materials for school administrations, and suggestions for teachers that can have a big impact, such as agreed signals by a student that lets staff know if they are uncomfortable.<sup>45,46</sup>

<sup>39</sup> Marciniak J, Reich A, Szepietowski JC. Quality of Life of Parents of Children with Atopic Dermatitis. *Acta Dermato-Venereologica*. 2017; 97: 711–714.

<sup>40</sup> Smith SD, et al. Corticosteroid phobia and other confounders in the treatment of childhood atopic dermatitis explored using parent focus groups. *Australasian Journal of Dermatology*. 2010; 51(3):168-74.

<sup>41</sup> Jang HJ, et al. Family quality of life among families of children with atopic dermatitis. *Asia Pacific Allergy*. 2016;6(4):213-219.

<sup>42</sup> Zuberbier T, et al. Patient perspectives on the management of atopic dermatitis. *Journal of Allergy and Clinical Immunology*. 2006; 118(1):226-32.

<sup>43</sup> Sinclair W, et al. Guidelines on the Management of Atopic Dermatitis in Adolescents and Adults in South Africa. *South African Medical Journal*, 2008; 98(4 Pt 2):303-19.

<sup>44</sup> Eichenfield LF, Tom WL, Chamlin SL. Guidelines of care for the management of atopic dermatitis: Section 1. Diagnosis and assessment of atopic dermatitis. *American Academy of Dermatology*. 2014; 70(2):338-51.

<sup>45</sup> Eczema Outreach Support. Guidance for speaking to school/nursery about your child's eczema needs. Available at: <http://www.eos.org.uk/wp-content/uploads/2018/09/EOS-Guidance-for-speaking-to-school.pdf>

<sup>46</sup> Eczema Outreach Support. Available at: <http://www.eos.org.uk/wp-content/uploads/2018/09/EOS-Tips-for-your-Childs-Teacher.pdf>

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### Financial

The full opportunity costs associated with AD are difficult to capture.<sup>47</sup> For example, patients tend to miss more days of work per year due to the disease, and notably more in severe cases.<sup>48</sup> Absences from work due to illness or presenteeism (where employees are present at work, but illness may impair their productivity) can also limit people's career prospects, reduce their confidence in applying for promotions or lead to resignations.<sup>49</sup>

More directly, a patient's medical costs—particularly in healthcare systems where doctor visits and therapies are not covered—can be significant. According to the expert panel, in lower-income families, this can lead to gaps in care, or, in families with multiple AD patients, having to choose which or whether children can receive treatment at all.

According to one systematic review of patient impact and the economic burden of AD, patients' and caregivers' total costs increased as disease severity increased. And even mild AD imposed substantial costs.<sup>50</sup>

Some countries have policies in place to ease the burden. For example, according to our panel experts, AD qualifies as a disability under the UK's 2010 Equality Act,<sup>51</sup> enabling patients to access financial support. A disability allowance can be used to provide bedding and clothing spoiled by blood from scratching and topical treatments.

### Economic

Healthcare systems costs for AD vary by country and can be difficult to calculate both at the primary and secondary care level. And not all value models take the same approach: epidemiological impacts are not always captured, and some aspects, like mental health system costs, may not be touched on at all. It is also difficult to find up-to-date information. This highlights how multi-faceted the economic impact of AD can be and why its measurement is so challenging.<sup>52</sup>

However incomplete, the existing estimates show that the burden of AD is significant. In the US alone, the economic burden of care—medical visits, medication and indirect productivity, and caregiver costs—was estimated to be US\$5.3bn in 2015. This includes direct medical costs of over US\$1bn and lost productivity of US\$619m.<sup>53</sup> However, this estimate does not include the cost of over-the-counter products, presenteeism or absenteeism for causes other than medical visits.

In the UK, the total annual expenditure for AD is estimated to be £465m (US\$616m), including patient costs of £297m (US\$394m) and costs incurred by the National Health Service (NHS) of £125m (US\$166m). These economic costs include absenteeism at work, which is common among AD patients. However, these figures are dated from 1996, and are likely to be higher at present.<sup>54,55</sup>

### Additional health risks

Co-morbidities associated with AD are still being researched, although some linkages have been identified.<sup>56</sup> For example, an estimated 70% of patients who have severe AD will develop asthma compared with 20-30% of those who have mild AD and 8% of the general population.<sup>57</sup> The severity of the patient's AD is also linked to the development of allergic rhinitis and to elevated levels of

<sup>47</sup> Drucker AM, et al. The Burden of Atopic Dermatitis: Summary of a Report for the National Eczema Association. *Journal of Investigative Dermatology*. 2017; 137(1):26-30.

<sup>48</sup> Nørreslet LB, et al. The impact of atopic dermatitis on work life – a systematic review. *Journal of the European Academy of Dermatology and Venereology*. 2018;32(1):23-38.

<sup>49</sup> Drucker AM, et al. The Burden of Atopic Dermatitis: Summary of a Report for the National Eczema Association. *Journal of Investigative Dermatology*. 2017; 137(1):26-30.

<sup>50</sup> Hebert AA, et al. Patient impact and economic burden of mild-to-moderate atopic dermatitis. *Current Medical Research and Opinion*. 2018; 27:1-10.

<sup>51</sup> Legislation.gov.uk. (2010). Equality Act 2010. Available at: <http://www.legislation.gov.uk/ukpga/2010/15/contents>.

<sup>52</sup> Drucker AM, et al. The Burden of Atopic Dermatitis: Summary of a Report for the National Eczema Association. *Journal of Investigative Dermatology*. 2017; 137(1):26-30.

<sup>53</sup> Bickers DR, et al. The burden of skin diseases: 2004 a joint project of the American Academy of Dermatology Association and the Society for Investigative Dermatology. *Journal of the American Academy of Dermatology*. 2006; 55(3):490-500.

<sup>54</sup> Sach TH, et al. Economic evidence for the prevention and treatment of atopic eczema: a protocol for a systematic review. *Systematic Reviews*. 2016;5:90.

<sup>55</sup> Herd RM, et al. The cost of atopic eczema. *British Journal of Dermatology*. 1996; 135(1):20-3.

<sup>56</sup> Thyssen JP, et al. The association with cardiovascular disease and type 2 diabetes in adults with atopic dermatitis: a systematic review and meta-analysis. *British Journal of Dermatology*, 2018;178(6):1272-1279.

<sup>57</sup> Bantz SK, et al. The Atopic March: Progression from Atopic Dermatitis to Allergic Rhinitis and Asthma. *Journal of Clinical and Cellular Immunology*. 2014; 5(2): 202.

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Immunoglobulin E (IgE) antibodies<sup>58</sup>—which are produced by a person’s immune system when it overreacts to an allergen, and often causes symptoms in the nose, lungs and throat or on the skin.<sup>59</sup>

Not all AD has a genetic link, but Dr Takaoka notes that: “Within a family you may find a father who has asthma and a child who has AD because there is a hereditary aspect to this disease.”

Dr Tsai adds the itching will produce lesions and the itch will worsen the function of the skin barrier. “Scratching can produce secondary bacterial or viral super-infections and inflammation can result in eczema herpeticum, a severe complication caused by herpes simplex virus requiring systemic anti-viral therapy,” he notes.

Some studies have suggested that patients with AD are more likely to take up additional behavioural risks. For example, one study finds that adults with AD are more likely to smoke cigarettes and drink moderate to heavy amounts of alcohol than those without AD, and that they are more likely to start those habits at a younger age.<sup>60</sup>

### ***The patient experience: treatment and care***

#### ***Without a cure***

AD—like many other chronic diseases—relies heavily on patients to self-manage their condition. The disease is primarily managed using moisturisers and emollients, which can soothe itching, reduce infection risk and help maintain the skin’s barrier function.<sup>61</sup> Flare-ups are managed using treatments such as topical corticosteroids (TCSs) and topical calcineurin inhibitors (TCIs), which dampen the inflammatory response. Other treatments may include phototherapy, antibiotics, oral steroids, oral or injectable immunotherapy, biologics, bandaging and other therapies.

Unfortunately, no cure exists for AD. Justifiably, treating a chronic disease is a major frustration for all involved.

Throughout a patient’s lifetime, a previously effective treatment may become ineffective, putting the patient into the cycle of doctor appointments, waiting times, referrals, and trial-and-error with other treatments, according to the panel. For example, a survey in Canada found that 43% of adults and 34% of children with moderate to severe AD have used ten or more different treatments to manage their disease.<sup>62</sup>

<sup>58</sup> Gustafsson D, et al. Development of allergies and asthma in infants and young children with atopic dermatitis—a prospective follow-up to 7 years of age. *Allergy*. 2000; 55:240-45.

<sup>59</sup> Immunoglobulin E (IgE) definition. Available at: [https://www.aaaai.org/conditions-and-treatments/conditions-dictionary/immunoglobulin-e-\(ige\)](https://www.aaaai.org/conditions-and-treatments/conditions-dictionary/immunoglobulin-e-(ige)).

<sup>60</sup> Silverberg JI, Greenland P. Eczema and cardiovascular risk factors in 2 US adult population studies. *Journal of Allergy and Clinical Immunology*. 2015; 135(3):721-8.e6.

<sup>61</sup> Hon KL, et al. Emollient treatment of atopic dermatitis: latest evidence and clinical considerations. *Drugs in Context*. 2018;7:212530.

<sup>62</sup> Eczema Society of Canada. Atopic Dermatitis Quality of Life Report: moderate to severe disease 2016/2017 survey results. Available at: [https://eczemahelp.ca/wp-content/uploads/2017/08/ESC\\_QUALITY\\_OF\\_LIFE\\_REPORT\\_2017.pdf](https://eczemahelp.ca/wp-content/uploads/2017/08/ESC_QUALITY_OF_LIFE_REPORT_2017.pdf).

### **NOT ALL TREATMENTS ARE MADE EQUAL**

According to the panel expert from South Africa, the cost of treatment, such as topical treatments, is an issue for the affected population. “We have high unemployment, yet people are being asked to spend half of what they earn on small tubes of cream.”

### **Adherence to treatments**

AD treatments are only effective if applied as instructed—at the appropriate time, in the right quantity, for the right purpose (such as on flares) and for the right duration. But due to the time, cost and discomfort associated with topical treatments, it's understandable that many patients, families and caregivers find adherence to treatment a struggle. And due to the often-lengthy procedures of applying topical treatments, many stop applying once a flare-up has passed.<sup>63</sup> Some patients are also making a decision not to use a medication based on their understanding of the risks around AD or because topicals can be messy and time-consuming to apply.

Not surprisingly, doctors are quick to point out that treatment failures are often due to patient noncompliance.<sup>64</sup> “Patients vary. Some will do whatever the doctor tells them to do and other patients are poor adherents to the treatment,” says Dr Takaoka. “They will change their medication or don't use the appropriate dose.”

Yet it is apparent from studies and interviews that many patients and caregivers are using treatments improperly as a result of inadequate education and support.

“What I do is I get the cream and show the patient how to do it,” says Dr Paul Charlson, a GP with a special interest in dermatology in the UK. “I get them to put it on and they say ‘oh, I didn't know you had to put it on the skin. I thought you had to rub it in’. They use a little pea-sized amount for a whole arm instead of a great thick layer.” He adds that when patients return and complain that a treatment is not working, “you need to review the treatment and make sure they are genuinely compliant because quite frequently they are not.”

### **Steroid phobia**

Studies also show a concern or irrational fear of TCSs, or “corticosteroid phobia”, is on the rise among patients, caregivers and even some healthcare professionals. Concerns about TCS safety can be common and, according to one systematic review, can reach 21-84% of patients or parents of children with AD across cultures, which is associated with a higher rate of non-adherence to treatment.<sup>65</sup>

In one study, 24% of patients admitted non-compliance to treatment because of these worries.<sup>66</sup> And some studies indicate doubt among health professionals, which could influence patients' adherence to treatment plans. For example, a 2016 study of caregivers of children with AD in France found pharmacists have only “moderate confidence” in topical steroids, which “may have a high impact on maintaining fear of corticosteroids in parents and patients.”<sup>67</sup>

These concerns with TCSs and TCIs may explain why some patients underuse anti-inflammatory drugs as well as fail to follow AD management guidance, says Dr Tsai.

Dr Tsai further points out that in Taiwan, a country known for “steroid phobia”,<sup>68</sup> which also has abundant advertisement of traditional Chinese medicine, patients are not willing to receive what is considered standard Western medicine. “Advertisement is forbidden for standard Western medicine

<sup>63</sup> Ridd MJ, et al. Systematic review of self-management interventions for people with eczema. *British Journal of Dermatology*. 2017;177(3):719-34.

<sup>64</sup> Ibid

<sup>65</sup> Li AW, et al. Topical corticosteroid phobia in atopic dermatitis: A systematic review. *JAMA Dermatology*. 2017;153(10):1036-42.

<sup>66</sup> Charman CR, et al. Topical corticosteroid phobia in patients with atopic eczema. *British Journal of Dermatology*. 2000;142:931-6.

<sup>67</sup> Raffin D, et al. Corticosteroid phobia among pharmacists regarding atopic dermatitis in children: a national French survey. *Acta Dermato-Venereologica*. 2015; 2016; 96(2):177-80.

<sup>68</sup> Stalder JF, et al. Topical corticosteroid phobia in atopic dermatitis: international feasibility study of the TOPICOP score. *Experimental Allergy and Immunology*. 2017; 72(11):1713-1719.

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but there is little regulation for traditional Chinese medicine”, he says. “They prefer Chinese medicine and will only use Western medicine for an acute flare.”

And although there is little evidence that traditional Chinese medicine (TCM) helps treat AD,<sup>69,70</sup> one survey of children in Taiwan with AD found the use of TCM to be popular. Thirty percent of caregivers of the children admitted to using TCM in the past year, commonly in the form of herbal tea and soup, and 60% believe that TCM helped improved their child’s AD, although less so for children with severe cases.<sup>71</sup>

<sup>69</sup> Gu S, et al. Chinese herbal medicine for atopic eczema. Cochrane Database of Systematic Reviews. 2013;9:CD008642.

<sup>70</sup> Traditional Chinese Medicine: In Depth. National Center for Complementary and Integrative Health (NCCIH). Updated July 2016. Available at: <https://nccih.nih.gov/health/whatiscom/chinesemed.htm>.

<sup>71</sup> Hon LE, et al. A survey of traditional Chinese medicine use in children with atopic dermatitis attending a paediatric dermatology clinic. *Journal of Dermatological Treatment*. 2015;16:3, 154-157.

## CHAPTER 2: ATOPIC DERMATITIS HEALTH STRATEGIES UNDER THE SPOTLIGHT

What's in a name? Eczema or AD? Or is it AE? Is a patient's flare-up classified as "severe" or "moderate"? Unfortunately, there is inconsistent terminology around this disease and this is often a point of contention for experts.<sup>72,73</sup> There is also unnecessary confusion for patients and healthcare providers: a systematic review of publications found AD is the most commonly used term and appears to be increasing in popularity.<sup>74</sup>

Without consensus, progress on recognition, research and data collection makes it challenging for researchers to identify relevant articles when researching the topic. For example, a 2017 systematic review identified that 64% of articles in the Medline database used the term AD and 47% used eczema.<sup>75</sup> Many articles used at least one term relating to the disease, but around 70-80% used only one.

It can also create problems for patients, physicians and researchers when describing the condition.<sup>76,77,78</sup> The strong belief among experts interviewed is that consistency of language is needed.

"Problems with AD begin with its title," says Amena Warner, head of clinical services at Allergy UK. "Clinicians always talk about AD, but the general public doesn't know what that means because they're personally talking about eczema. And patients don't realise that a lot of the time there are allergic triggers, so there is a lot of misconception around the whole disease area."

### **Substantial gaps in measuring and monitoring**

The Economist Intelligence Unit literature review and the expert panel found that there are a variety of disease-specific and generic severity measures and quality-of-life measures currently in use for patients with AD.

An examination of systematic reviews published in 2017-18 that compared treatments for AD found that nearly half reported issues with:<sup>79,80,81,82,83,84,85,86,87,88,89,90,91</sup>

- Heterogeneity across studies.
- Incomplete reporting of factors such as severity, interventions used (eg, delivery and dose).
- Use of varying outcome measures.
- Poor quality trial execution and reporting.
- Lack of randomised controlled trials.
- Lack of long-term follow-up.
- Lack of economic and cost data.

<sup>72</sup> Silverberg JJ, et al. What's in a name? Atopic dermatitis or atopic eczema, but not eczema alone. *Allergy*. 2017;72:2026–2030.

<sup>73</sup> Johansson SG, et al. Revised nomenclature for allergy for global use: report of the Nomenclature Review Committee of the World Allergy Organization, October 2003. *Journal of Allergy and Clinical Immunology*. 2004;113:832-6.

<sup>74</sup> Kantor R, et al. Atopic dermatitis, atopic eczema, or eczema? A systematic review, meta-analysis, and recommendation for uniform use of 'atopic dermatitis'. *Allergy* 2016; 71: 1480–1485.

<sup>75</sup> *ibid*

<sup>76</sup> *ibid*

<sup>77</sup> MD Magazine. What's in a Name: Atopic Dermatitis vs. Eczema. October 10, 2016. Available at: <https://www.mdmag.com/medical-news/whats-in-a-name-atopic-dermatitis-vs-eczema>

<sup>78</sup> Kantor R, et al. Atopic dermatitis, atopic eczema, or eczema? A systematic review, meta-analysis, and recommendation for uniform use of 'atopic dermatitis'. *Allergy* 2016; 71: 1480–1485.

<sup>79</sup> Yu SH, et al. A systematic review of the safety and efficacy of systemic corticosteroids in atopic dermatitis. *Journal of the American Academy of Dermatology*. 2018;78(4):733-40.e11.

<sup>80</sup> Ridolo E, et al. Allergen immunotherapy in atopic dermatitis. *Expert Review of Clinical Immunology*. 2018;14(1):61-8.

<sup>81</sup> Huang R, et al. Probiotics for the treatment of atopic dermatitis in children: A systematic review and meta-analysis of randomized controlled trials. *Frontiers in Cellular and Infection Microbiology*. 2017;7(Sep).

<sup>82</sup> Ridd MJ, et al. Systematic review of self-management interventions for people with eczema. *British Journal of Dermatology*. 2017;177(3):719-34.

<sup>83</sup> Snast I, et al. Are Biologics Efficacious in Atopic Dermatitis? A Systematic Review and Meta-Analysis. *American Journal of Clinical Dermatology*. 2018;19(2):145-65.

<sup>84</sup> Mattered U, et al. Oral H1 antihistamines as 'add-on' therapy to topical treatment for eczema: A Cochrane systematic review. *Allergy: European Journal of Allergy and Clinical Immunology*. 2017;72:782.

<sup>85</sup> Nankervis H, et al. What is the evidence base for atopic eczema treatments? A summary of published randomized controlled trials. *British Journal of Dermatology*. 2017;176(4):910-27.

<sup>86</sup> González-López G, et al. Efficacy and safety of wet wrap therapy for patients with atopic dermatitis: a systematic review and meta-analysis. *British Journal of Dermatology*. 2017;177(3):688-95.

<sup>87</sup> Chopra R, et al. Efficacy of bleach baths in reducing severity of atopic dermatitis: A systematic review and meta-analysis. *Annals of allergy, asthma & immunology: official publication of the American College of Allergy, Asthma, & Immunology*. 2017;119(5):435-40.

<sup>88</sup> Shi ZF, et al. The Traditional Chinese Medicine and Relevant Treatment for the Efficacy and Safety of Atopic Dermatitis: A Systematic Review and Meta-Analysis of Randomized Controlled Trials. *Evidence-based Complementary and Alternative Medicine*. 2017;6026434.

<sup>89</sup> Roekevisch E, et al. Efficacy and safety of systemic treatments for moderate-to-severe atopic dermatitis: A systematic review. *Journal of Allergy and Clinical Immunology*. 2014;133(2):429-38.

<sup>90</sup> Holm JG, et al. Omalizumab for atopic dermatitis: case series and a systematic review of the literature. *International Journal of Dermatology*. 2017;56(1):18-26.

<sup>91</sup> Luzzi S, et al. Effectiveness of sodium hypochlorite (bleach) in paediatric patients with moderate to severe eczema: A literature review. *Journal of Investigative Medicine*. 2018;66(1):220-1.

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Furthermore, there is great variation in the diagnostic and severity criteria used to define inclusion criteria in clinical trials. A 2018 systematic review of 212 randomised controlled trials found that ten different diagnostic criteria were used and over a third (37.3%) did not specify which diagnostic criteria were used.<sup>92</sup>

### Severity and quality-of-life measures

We reviewed national and regional guidelines to determine whether validated severity measures are specified across the eight countries and noted them in the scorecard (see Figure 3).

**Figure 3: Use of validated disease severity measures in AD guidelines**

Australia	Brazil	Israel	Italy	South Africa	Taiwan	UK	US
0	2	1	2	1	0	2	1

0=none recommended in guidelines; 1=non-validated measure recommended in guidelines; 2=validated measure recommended in guidelines.

Source: see Appendix.

Only Brazil, Italy and the UK received the top score of 2 each for having recommended severity measures in the guidelines. All three use a variety of measures. In Brazil and Italy, these include two widely accepted measures: SCORing atopic dermatitis (SCORAD), an index combining extent, severity and subjective symptoms, and Patient-Oriented Eczema Measure (POEM) for severity.

## THE OBJECTIVITY OF SEVERITY

What matters to a patient is not necessarily the same as what researchers consider to be a well-defined measurement. Sometimes patients who would be objectively rated as being mild or moderate, may “feel” that their AD is severe, depending on where its located (eg, neck, hands, face, ears, genitals) and when the flare takes place (eg, honeymoon, vacation, school trip, first date).<sup>93</sup>

### Quality of life

Researchers have similar qualms with quality-of-life measures.<sup>94</sup> The literature review found only between 20-30% of AD studies measured the quality of life. And among those that did, they used as many as 18 different measures.<sup>95</sup>

Only half of the countries reviewed—Israel, South Africa, the UK and the US—received full marks in the scorecard for having recommended AD-specific quality-of-life measurements in guidelines (see Figure 4). In the US and Israel, it is recommended that clinicians ask general questions about itch, sleep, impact on daily activity and persistence of disease. In South Africa and the UK, quality of life is integrated into the criteria used to assess disease severity. The other countries have not recommended quality-of-life measures in their guidelines.

<sup>92</sup> Vakharia PP, et al. Systematic Review of Diagnostic Criteria Used in Atopic Dermatitis Randomized Controlled Trials. *American Journal of Clinical Dermatology*. 2018;19(1):15-22.

<sup>93</sup> Jeon, Y, et al. The Comparison between Objective and Subjective Severity Scores of Atopic Dermatitis. *Journal of Allergy and Clinical Immunology*, 2008;121(2); Supp 1:S38.

<sup>94</sup> Drucker AM, et al. Research gaps in quality of life and economic burden of atopic dermatitis: The National Eczema Association burden of disease audit. *JAMA Dermatology*. 2016;152(8):873-874.

<sup>95</sup> Chalmers JR, et al. Report from the fifth international consensus meeting to harmonize core outcome measures for atopic eczema/dermatitis clinical trials (HOME initiative). *British Journal of Dermatology*. 2018;178(5):e332-e341.

**Figure 4: Use of quality-of-life measures in AD guidelines**

Australia	Brazil	Israel	Italy	South Africa	Taiwan	UK	US
0	0	2	0	2	0	2	2

0=no; 1=yes, generic instrument recommended/used; 2=yes, AD-specific instrument recommended/used.

Source: see Appendix.

“Quality of life is a very important [issue] and we are currently reviewing [our] guidelines,” says Dr Takaoka in Brazil. According to the scorecard, Brazil scored zero in this indicator. “It is clear that AD has a big impact on quality of life...the fact that it is not in the guideline does not mean that it is not important. Brazil has many support groups for AD patients helping them deal with quality-of-life issues.”

### **Evidence-based treatment guidelines**

Guidelines provide recommendations for the treatment and management of diseases that are usually based on a combination of evidence and the discussion of experts in the field. They aim to improve practice on-the-ground by ensuring that individual healthcare professionals are aware of what the best available evidence is around treatments.<sup>96</sup>

Our scorecard highlights the availability of evidence-based AD treatment guidelines across the eight countries studied. An additional point was given where guidelines have been developed or were updated within the past three years.

Only four countries—South Africa, Taiwan, the UK and the US—received a mark for having country-specific AD guidelines (see Figure 6). However, the UK’s AD guidelines only cover children up to the age of 12 years and lack guidance for adults. Healthcare professionals in Australia, Brazil and Italy rely on regional guidelines, while in Israel, they rely on US guidelines.

“We have no adult guidelines,” confirms Ms Warner of Allergy UK. “We have certain groups of organisations that make recommendations but there is no national consensus.”

As Taiwan is the only country in the scorecard to have national guidelines and have updated them within the past three years, it has the top score for this indicator. The Taiwanese Dermatological Association reached a consensus for managing AD in 2014,<sup>97</sup> but Dr Tsai, the corresponding author for the consensus, says there is no study to suggest that much has changed for patients with the publication of the guidelines.

**Figure 5: Presence of evidence-based treatment AD guidelines**

Australia	Brazil	Israel	Italy	South Africa	Taiwan	UK	US
1	1	1	2	2	3	2	2

0=no guidelines; 1=region-specific guidelines; 2=country-specific guidelines; + 1= guidelines developed within last 3 years.

Source: see Appendix.

<sup>96</sup> Available at: <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/types-of-guideline>.

<sup>97</sup> Chu C-Y, et al. Taiwanese Dermatological Association consensus for the management of atopic dermatitis. *Dermatologica Sinica*. 2015; 33(4): 220-30.

“Sometimes the evidence does not reflect what is done in Taiwan or what the patient can afford,” he says. “But the guideline is a model to provide care based on the recommendations and we think with this guideline...dermatologists can provide a better way to defend the right of the patient to get the optimal treatment.”

He adds that to improve national AD care, he thinks Taiwanese officials need more evidence to quantify the effect of the disease on patients’ productivity and quality of life, and the priority of medical expense from government for AD scores far behind some other major diseases, mainly cancers, viral hepatitis and so on.

Dr Takaoka explains the situation in Brazil. “[We] follow a general guideline for mild and moderate cases of AD, which recommends moisturisers, steroid creams and maybe some oral antihistamines, and this is like a universal guideline for mild-moderate cases,” he says. “I think the problem is when you are treating moderate to severe cases and each doctor will do whatever their experiences tell them to do.”

In his experience doctors follow the American and European guidelines for the severe cases rather than the European guidelines. “For the severe cases it varies and some countries will use an array of immunosuppressive drugs and I know that with the new drugs coming there is going to be a lot of discussion about that. We will have to see what will happen in terms of the new guidelines.”

### ***The provision of care and access to care***

One study finds that 4-7% of all doctor visits by adult and paediatric patients are for dermatological complaints,<sup>98</sup> and AD is the most frequent reason, after skin infections, for a new dermatological consultation in general practice.<sup>99</sup>

Due to the chronicity of AD, patients may make frequent visits to GPs and specialists each year. In one Canadian study, 42% of AD patients surveyed visited a doctor four or more times in the past two years, and 28% have seen more than three different doctors in that time for help with managing the disease.<sup>100</sup>

The experience a patient has with their local healthcare system will vary depending on age,<sup>101</sup> severity of their flares, and on their access to a robust healthcare system. And, according to our panellists, even in regions where health systems appear strong, people can often report frustration to the point of quitting when navigating a referral system, enduring long wait times and accessing effective treatments.

### ***Attention and care from primary services***

The majority of AD patients will be managed in primary care, by a GP, according to the expert panel and studies.

<sup>98</sup> Silva CS, et al. E-learning program for medical students in dermatology. *Clinics*. 2011; 66(4):619–622.

<sup>99</sup> Le Roux E, et al. GPs’ experiences of diagnosing and managing childhood eczema: a qualitative study in primary care. *British Journal of General Practice*. 2018; 68 (667): e73-e80.

<sup>100</sup> Eczema Society of Canada. Atopic Dermatitis Quality of Life Report: moderate to severe disease 2016/2017 survey results. Available at: [https://eczemahelp.ca/wp-content/uploads/2017/08/ESC\\_QUALITY\\_OF\\_LIFE\\_REPORT\\_2017.pdf](https://eczemahelp.ca/wp-content/uploads/2017/08/ESC_QUALITY_OF_LIFE_REPORT_2017.pdf).

<sup>101</sup> Strom MA, Silverberg JI. Utilization of Preventive Health Care in Adults and Children with Eczema. *American Journal of Preventive Medicine*. 2016;50(2):e33-e44.

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However, depending on where they are trained, medical students may not receive robust education about AD and other skin diseases. For example, in the US, dermatology education is about two weeks.<sup>102</sup> In the UK, medical students receive, on average, no more than about six days training in dermatology<sup>103</sup>. And in Australia, GPs have three days of dermatology training, although it can vary, according to the expert panel.

“A lot of primary care is quite good at identifying that a patient has dermatitis or eczema,” explains Ms Warner, who is based in the UK. “But they may not have the time or knowledge to realise that it might be atopic or what might trigger it. Without that deeper-level of diagnosis, the follow-up management of the disease is sometimes questionable.”

It is also clear that patients need time with their GP to discuss other issues—such as the emotional and quality-of-life impacts from the disease—as well as treatment plans and additional resources. But, in some countries, clinicians are short on time and the level of care they provide can frustrate some patients. For example, in the UK the patient might have as little as eight minutes with the healthcare provider.<sup>104</sup> In such a short time, our panellists say that patients might not feel they are “heard” and patients may not feel comfortable about asking for referrals.

Notably, a UK survey of parents of children with AD in a primary care setting found the top two complaints are the GPs’ knowledge of eczema and GPs’ level of understanding of the impact eczema has on quality of life.<sup>105</sup>

“The UK medical model right now concentrates on training GPs to make the diagnosis and give a list of treatments, but really it should be about managing the patient,” adds Dr Charlson. “This is different because it is about teaching them to use the treatment and [about] managing their psychology.”

He believes that if a GP spends more time discussing emollients and proper application, the NHS could save money in the long run. Indeed, an Allergy UK report found that 21% of UK referrals of AD patients to secondary care could have been treated in a primary care setting, which could be needlessly costing the NHS up to £29m a year.<sup>106</sup>

“If you are working in general practice then you realise there isn’t more time, so it’s simply not practical, but I think there is a worrying lack of knowledge about how to apply emollients. It does not take long, only 2-3 minutes to describe it,” argues Dr Charlson.

Many from the panel agree that not all GP referrals to specialists are necessary—some could have been managed at the GP level with greater training, thereby reducing patient suffering and saving the overall system time and resources.

And according to the British Association of Dermatologists, based in London, the UK, “[more dermatology training in the undergraduate GP curriculum] is particularly important as skin diseases are often co-morbidities to other diseases... A more able primary care workforce would reduce the pressure on secondary care.”<sup>107</sup> This conclusion may hold true for other nations regardless of the healthcare system.

<sup>102</sup> Giesey R, et al. DERM: A Four-Step Dermatology Education Digital Tool Kit for Nondermatologists. *Family Medicine*. 2018; 50(7):539-543.

<sup>103</sup> Eedy D. Dermatology: a speciality in crisis. *Clinical Medicine* 2015;15 (6):509–10.

<sup>104</sup> Allergy UK and Sanofi Genzyme. Seeing Red: Getting under the skin of adult severe eczema. 2017. Available at: [https://www.allergyuk.org/assets/000/001/411/Seeing\\_Red\\_Report\\_FINAL\\_25.04.17\\_original.pdf?1508228476](https://www.allergyuk.org/assets/000/001/411/Seeing_Red_Report_FINAL_25.04.17_original.pdf?1508228476)

<sup>105</sup> Le Roux E, et al. GPs’ experiences of diagnosing and managing childhood eczema: a qualitative study in primary care. *British Journal of General Practice*. 2018; 68 (667): e73-e80.

<sup>106</sup> Allergy UK and Sanofi Genzyme. Seeing Red: Getting under the skin of adult severe eczema. 2017. Available at: [https://www.allergyuk.org/assets/000/001/411/Seeing\\_Red\\_Report\\_FINAL\\_25.04.17\\_original.pdf?1508228476](https://www.allergyuk.org/assets/000/001/411/Seeing_Red_Report_FINAL_25.04.17_original.pdf?1508228476)

<sup>107</sup> Eedy D. Dermatology: a speciality in crisis. *Clinical Medicine* 2015;15 (6):509–10.

With these concerns in mind, the scorecard therefore considers the presence of nationwide AD training and awareness programmes for primary healthcare professionals (see Figure 6). None were identified in Brazil, Israel, Italy, Taiwan or the US, showing major gaps in this indicator. They were only strongly represented in Australia and the UK, and to a lesser extent in South Africa (around awareness).

**Figure 6: Primary healthcare professional training and awareness programmes around AD**

Australia	Brazil	Israel	Italy	South Africa	Taiwan	UK	US
2	0	0	0	1	0	2	0

0=no; +1=nationwide primary healthcare professional awareness schemes; +1=nationwide primary healthcare professional training schemes.

Source: see Appendix.

However, due to variations in healthcare systems, training at primary care level for AD is not adequately provided. For example, Dr Tsai is neither surprised nor concerned by Taiwan's score of zero in this category. He says that a referral is not mandatory and patients may go directly to same-day consultations with dermatologists, not GPs, and that children with AD immediately see a paediatrician when they have a skin issue, not a GP.

### **Specialists**

AD patients, particularly those with severe or complex cases, will be referred to dermatologists for further management. Specialists—in this case mainly dermatologists—can help identify the underlying causes of the disease and deliver personalised treatment plans.

Efficiency at this stage could contribute towards improving quality of life, and cost savings for the healthcare systems and wider economy.

To better understand the availability of specialists, the scorecard looked at the number of dermatologists in each country, and found a wide variation (see Figure 7).

At the highest density, Israel, Taiwan and the US each have around 4 dermatologists per 100,000 populations. However, the UK has just 1 dermatologist per 100,000, as posts remain vacant. The dermatologist workforce is unknown in South Africa. These numbers and data gaps suggest health systems may struggle to deliver AD care.

**Figure 7: Number of dermatologists per 100,000 population**

Australia	Brazil	Israel*	Italy	South Africa	Taiwan	UK	US
2.3	2.9	4.4*	2.0	Not available	3.9	1.0	3.6

Reported as number of dermatologists per 100,000 population. Figures do not distinguish between those in public and private practice.\*Data based on personal correspondence with the CEO of Kumi Uri, a patient support and advocacy group.

Source: see Appendix.

However, the data do not distinguish between public and private dermatology practice. And while some countries like Brazil may have a high number of dermatologists, according to the panel discussion, it would seem that work in cosmetic dermatology by a good percentage of dermatologists reduces access for clinical care patients, including those with AD.

### Shortage of specialists

“There are 6,000 dermatologists in Brazil but that does not mean it is easy to see one,” says Dr Takaoka. Indeed, the average wait times for a dermatologist vary globally. In the US, for example, this can be up to 40 days,<sup>108</sup> and access to dermatologists is limited for Medicaid-insured children with eczema.<sup>109</sup> In Canada, the median wait time is 41-42 days,<sup>110</sup> in Germany, 34 days,<sup>111</sup> and in Saudi Arabia wait times can be up to 60 days.<sup>112</sup>

According to Allergy UK, most AD patients report waiting times of 1-3 months for a secondary care appointment after being referred.<sup>113</sup> The Eczema Society of Canada reports that 69% of adults with moderate or severe AD have waited three months or longer to see a dermatologist and 27% have waited longer than six months.<sup>114</sup> It is also notable that, in some regions, average wait times for a cosmetic dermatologist appointment is often shorter than for a medical dermatologist.<sup>115</sup>

<sup>108</sup> Uhlenhake E, et al. The dermatology work force: A focus on urban versus rural wait times. *Journal of the American Academy of Dermatology*. 2009; 61(1):17-22.

<sup>109</sup> Chaudhry SB, et al. Pediatric access to dermatologists: Medicaid versus private insurance. *Journal of the American Academy of Dermatology*. 2013; 68(5):738-748.

<sup>110</sup> Jaakkimainen L, et al. Waiting to see the specialist: patient and provider characteristics of wait times from primary to specialty care. *BMC Family Practice* 2014; 15:16.

<sup>111</sup> Krensel M, et al. Waiting time and practice organization in dermatology. *JDDG: Journal der Deutschen Dermatologischen Gesellschaft*. 2015; 13: 812-814.

<sup>112</sup> Alzolibani AA. Patient satisfaction and expectations of the quality of service of University affiliated dermatology clinics. *Journal of Public Health and Epidemiology*. 2011;3(2): 61-67.

<sup>113</sup> Allergy UK and Sanofi Genzyme. Seeing Red: Getting under the skin of adult severe eczema. 2017. Available at: [https://www.allergyuk.org/assets/000/001/411/Seeing\\_Red\\_Report\\_FINAL\\_25.04.17\\_original.pdf?1508228476](https://www.allergyuk.org/assets/000/001/411/Seeing_Red_Report_FINAL_25.04.17_original.pdf?1508228476).

<sup>114</sup> Eczema Society of Canada. Atopic Dermatitis Quality of Life Report: moderate to severe disease 2016/2017 survey results. Available at: [https://eczemahelp.ca/wp-content/uploads/2017/08/ESC\\_QUALITY\\_OF\\_LIFE\\_REPORT\\_2017.pdf](https://eczemahelp.ca/wp-content/uploads/2017/08/ESC_QUALITY_OF_LIFE_REPORT_2017.pdf).

<sup>115</sup> Yadav G, et al. A Cross-Sectional Survey of Population-Wide Wait Times for Patients Seeking Medical vs. Cosmetic Dermatology Care. *PLoS ONE* 2016; 11(9): e0162767.

<sup>116</sup> Moore E, et al. Nurse led clinics reduce severity of childhood atopic eczema: a review of the literature. *British Journal of Dermatology*. 2006; 155:1242-1248

## UTILISING NURSES FOR ATOPIC DERMATITIS SUPPORT

One of the most important aspects of atopic dermatitis treatment is education. Many health systems do not provide general practitioners with sufficient time to review treatment plans with patients and show application. However, the contribution of nurse-led clinics can greatly impact in this area. In one systematic review, nurse-led clinics resulted in longer consultations and consequentially greater patient satisfaction, education and improved outcomes when compared with doctor-only visits.<sup>116</sup>

Dr Charlson thinks the dermatology posts will gradually fill, but he believes the number will largely depend on where the government wants to invest. “There was a lot of money put into cardiology a few years ago, and then there were an awful lot of people training to be cardiologists.”

To help drive down wait times and improve the quality of care at the GP and specialist level, expert panellists suggested two changes: greater education at the GP level and clearly written instructions from GPs for patients to follow to better control their AD.

Panellists suggest that national shortages could also be addressed by online consultations with dermatologists (a field known as tele dermatology). One panellist suggests that providing patients with samples of different emollients can help them trial these at home and make more informed decisions about their care, rather than re-entering the system following each therapy failure.

### **Availability of multidisciplinary care**

According to the panellists, one of the biggest changes they want to see is more multidisciplinary clinics where access to a psychologist, nurse, dermatologist and nutritionist can give people the ability to better control their disease.

In these multidisciplinary clinics, which are usually established in medical centres, a multi-pronged approach to AD care is developed in response to the interplay of psychological, behavioural and dietary factors that affect disease control. Patient-centric systems commonly include medical evaluations of triggers, educational, psychological and behavioural support, nutritional assessments, and guidance.<sup>117</sup>

This approach ultimately seeks to achieve disease control by improving knowledge about the condition, improving adherence to treatment plans, and reducing the risk or the impact of mental health disorders associated with the disease.

Results, so far, are positive. According to one report, children and adolescents with AD and their parents put in a multidisciplinary group indicated greater reductions in medical consultation and prescription costs compared with those receiving standard medical care.<sup>118</sup>

The scorecard reviews the national guidelines in the eight studied countries for recommendations about multidisciplinary care for AD patients (see Figure 8). An additional point is given for countries that include more specific recommendations for the team make-up (eg, psychologist, allergist and nutritionist).

**Figure 8: Multidisciplinary care recommendations in AD guidelines**

Australia	Brazil	Israel	Italy	South Africa	Taiwan	UK	US
1	2	1	1	0	1	0	1

0=no recommendations about multidisciplinary care; 1=multidisciplinary care recommended; 2=multidisciplinary care and team make-up included in recommendations.

Source: see Appendix.

The scorecard shows most countries do recommend “an integrated, multidisciplinary approach to care” in their AD guidelines. Brazil is the sole country to receive full marks for including a recommendation for a multidisciplinary team comprising dermatologists, paediatricians, allergists and psychologists. Only South Africa and the UK have no such recommendation.

Shulamit Burstein, founder of Kumi Uri (part of the Israeli Association for Atopic Dermatitis), says that “although the US, European and old Israeli guidelines dating from 2004 are used in Israel, a multidisciplinary approach is not occurring widely in practice.”

Healthcare systems may benefit in the long run from using co-ordinated care teams, but there are also considerable costs associated with providing multidisciplinary care, given the time and number of professionals involved, and costs associated with administration.<sup>119</sup> Funding may include payment

<sup>117</sup> Spielman SC, et al. A Review of Multidisciplinary Interventions in Atopic Dermatitis. *Journal of Clinical Medicine*. 2015;4(5):1156-1170.

<sup>118</sup> Staab D, et al. Age related, structured educational programmes for the management of atopic dermatitis in children and adolescents: multicentre, randomised controlled trial. *BMJ*. 2006; 332(7547): 933-938.

<sup>119</sup> Spielman SC, et al. A Review of Multidisciplinary Interventions in Atopic Dermatitis. *Journal of Clinical Medicine*. 2015;4(5):1156-1170.

from insurance companies, but to operate fully requires additional aid from government, health agencies, charitable donations, grants from companies and support through collaboration with patient associations.<sup>120,121</sup>

### THE POWER OF MULTIDISCIPLINARY CARE

Boston Children's Hospital's children's atopic centre is a multidisciplinary paediatric outpatient specialty clinic for patients with refractory atopic dermatitis (AD).<sup>122</sup> The programme sees patients with moderate to severe AD who have not responded to conventional treatment and experienced a significant impact on their quality of life.

"The hallmark of our programme is comprehensive, multidisciplinary patient and family education focused on improving family understanding of the disease and its management and development of coping techniques to improve quality of life," says a representative of Boston Children's Hospital.

New patient visits typically take three hours and follow-up visits take two hours. This allows for each member of the centre's team (nurse practitioner, paediatric allergist, psychologist and dietitian) to meet with the patient and family. Team members collaborate to provide

each patient and family with an individualised care and treatment plan.

The hospital adds that it is developing an evidence-based educational handbook for parents of paediatric patients with AD, to facilitate patient and family education as a routine component of care. The handbook will also be available publically on the internet as a free resource. "We will also be conducting a randomised controlled trial to evaluate the impact of the handbook on AD symptoms and quality of life," the hospital adds.

The centre routinely tracks its clinical outcomes using validated measures of skin severity, AD symptoms and quality of life.

The centre's clinical team has contributed to a number of publications including AD practice parameters,<sup>123,124</sup> reviews of multidisciplinary care for AD,<sup>125,126</sup> and quality improvement research with use of written eczema care plans.<sup>127</sup>

<sup>120</sup> *ibid*

<sup>121</sup> Stalder JF, et al. Therapeutic patient education in atopic dermatitis: worldwide experiences. *Pediatric Dermatology*. 2013; 30 (3): 329–334

<sup>122</sup> Available at: <http://www.childrenshospital.org/conditions-and-treatments/conditions/a/atopic-dermatitis-and-eczema>

<sup>123</sup> Schneider L, et al. Atopic dermatitis: A practice parameter update 2012. *Journal of Allergy and Clinical Immunology*. 2013;131(2):295-299.e27.

<sup>124</sup> Lio PA, et al. Clinical management of atopic dermatitis: practical highlights and updates from the atopic dermatitis practice parameter 2012. *Journal of Allergy and Clinical Immunology: In Practice*. 2014;2(4):361-9.

<sup>125</sup> LeBovidge JS, et al. Multidisciplinary interventions in the management of atopic dermatitis. *Journal of Allergy and Clinical Immunology*. 2016;138(2):325-334.

<sup>126</sup> LeBovidge J, et al. Atopic dermatitis: therapeutic care delivery: therapeutic education, shared decision-making, and access to care. *Seminars in Cutaneous Medicine and Surgery*. 2017;36(3):95-99.

<sup>127</sup> Rork JF, et al. Parental response to written eczema action plans in children with eczema. *Archives of Dermatology*. 2012;148(3):391-2.

## CHAPTER 3: A FOCUS ON BEST PRACTICES AND COMPLETE CARE

AD patients and their caregivers may need more support than they are currently receiving from their healthcare providers. In some countries, support groups and national organisations are helping to fill the void. These organisations are involved in supporting education, advocacy, awareness and research activities around the disease. Patient groups are also providing mental health support for AD patients that can be lost at the physician level. Furthermore, they provide opportunities for patients and caregivers to learn about the disease, connect with each other, be supported and get involved.<sup>128</sup>

The expert panel holds support for the idea that patient groups should be included on the prescription for AD.

Critically, patient groups are an important stakeholder for shaping policy and informing guidelines. And indeed, they are frequently called upon by governments and decision-makers to share their expertise and support guideline development.

However, patient organisations often rely on donations from trusts, healthcare institutions, pharmaceutical companies and individuals rather than public bodies, and the lack of a dedicated source of funding can make it difficult for patient groups to engage over a long period of time.<sup>129</sup>

<sup>128</sup> Available at: <https://atopicdermatitis.net/support-groups/>

<sup>129</sup> Rose SL, et al. Patient Advocacy Organizations, Industry Funding, and Conflicts of Interest. *JAMA Internal Medicine*. 2017;177(3):344–350.

<sup>130</sup> Sidbury R, et al. Guidelines of care for the management of atopic dermatitis: Section 4. Prevention of disease flares and use of adjunctive therapies and approaches. *Journal of the American Academy of Dermatology*. 2014; 71(6):1218–33.

<sup>131</sup> Williams HC. Educational programmes for young people with eczema: One size does not fit all. *BMJ*. 2006;332(7547):923–924.

<sup>132</sup> Available at: <https://actionagainstallergy.org/the-eczema-education-programme/>

<sup>133</sup> Ersser SJ, et al. Psychological and educational interventions for atopic eczema in children. *Cochrane Database of Systematic Reviews*. 2014;1: CD004054.

<sup>134</sup> Williams HC. Educational programmes for young people with eczema: One size does not fit all. *BMJ*. 2006;332(7547):923–924.

### **Atopic Schools**

AD educational programmes, sometimes called Atopic Schools or Eczema Schools, provide structured lessons to patients and caregivers on topics such as how moisturisers help control itch, how to properly apply them, how to address stigma and emotional challenges, and how to gain access to specialist care and treatment.<sup>130</sup> The knowledge and skills shared help people become more informed about their condition.

Atopic Schools are already being run globally, including in the US, Japan, Denmark and Germany.<sup>131</sup> Research from current models show significant improvements are observed in patients' and caregivers' quality of life and disease severity following "school".<sup>132</sup> However, due to the different methods used across the programmes, it is difficult to comparatively evaluate a programme's impact on severity, quality of life, psychological distress and cost effectiveness.<sup>133</sup> Some have also questioned the costs of training staff to run them.<sup>134</sup>

In our scorecard, we looked for education schemes for patients and caregivers and only found evidence of these in Israel and no evidence for the other seven countries (regardless of provider) (see Figure 9). Specifically, in Israel, the patient group Kumi Uri provides information, guidance and "summer camps" for people with AD to learn about their condition and treatments.

**Figure 9: Patient and education carer programmes for AD**

Australia	Brazil	Israel	Italy	South Africa	Taiwan	UK	US
0	0	2	0	0	0	0	0

0=no; +1=nationwide patient self-care education schemes; +1=nationwide parent/carer education schemes.

Source: see Appendix.

### ***Patient advocacy and support groups***

Patient support groups exist around the globe, offering opportunities for patients and caregivers to connect, learn and access support for their psychosocial needs. Local support groups are generally structured differently depending on local needs and capabilities. Some offer helplines and chat services for people grappling with their problems and the healthcare system, and can also walk patients through financial assistance programmes where they are available to them.

In Sao Paulo, Dr Takaoka explains that the Brazilian Atopic Dermatitis Association (AADA) organises monthly semi-structured support meetings for patients to discuss different topics and problems with professionals—currently there are ten such groups across the country. For example, one meeting might be about treatment and what the patient can use, and the next meeting about psychological aspects.

Dr Takaoka says that his support groups are usually monthly meetings. “We try to always have one medical doctor and one psychologist in each group, although sometimes we have a doctor and a social worker,” he says. “They invite patients and mostly talk about the disease and how it is impacting their life.”

He adds that if you don’t have one medical doctor present to moderate meetings, patients have a tendency to refer other patients to their treatments. “And having a psychologist there is good because it can get very emotional sometimes.”

The scorecard finds that each country, with the sole exception of Taiwan, has a formal patient advocacy and/or support groups (see Figure 10). These include the Eczema Association of Australasia, AADA, Italian Association for Ambulatorial Dermatologies, South African National Eczema Association, the National Eczema Society in the UK, the National Eczema Association in the US and Kumi Uri in Israel.

**Figure 10: Presence of advocacy and support groups for AD**

Australia	Brazil	Israel	Italy	South Africa	Taiwan	UK	US
2	1	1	2	1	0	2	2

0=no patient advocacy and/or support groups; +1=formal patient advocacy groups exist; +1=formal patient support groups exist.

Source: see Appendix.

### ***Early prevention services***

Early prevention is also a service patient groups can offer, reducing the symptoms of patients and pressures on their national health system. But this is only possible if patients and caregivers are aware of these services.

Allergy UK has been offering a service for over 500 babies since January 2015. “This has now become a research project,” says Ms Warner who explains that people often call their helpline to report ongoing symptoms suggestive of a food allergy in their infant, usually after going to their primary care provider numerous times with no resolution of symptoms.

Callers receive a 30-minute consultation with a registered dietician specialising in allergies, as well as a nurse adviser if they report skin issues. “Many of these babies have eczema. They receive advice on use of emollients, [the] value of testing, alternatives to dairy if cow’s milk allergy is suspected and more.”

Ms Warner adds: “We know that children with early onset eczema, particularly severe eczema, are more at risk of developing food allergies. That is a huge message for policymakers. If we do not get this right the cost implications over time is much more than getting it right at the start.”

### ***Recognising the role of support groups***

Sufficient funds to cover the cost of programmes and staff are hard won for patient groups, and this threatens the valuable services they provide. With some exceptions, patient groups are mainly charities or non-profits, and therefore self-funded.

Worryingly, many lack the resources and are often staffed by volunteers. The ability to effectively aid patients and reduce the stress on national health systems is then compromised.

“We wish we could have one support group in every city but it’s very hard to start a support group everywhere, not just in Brazil,” says Dr Takaoka. “It is very demanding on the professional and the team doing the work.” And although some countries like Germany fund educational programmes and groups, “in Brazil everybody is doing it as voluntary work. They are doing it from [the] goodness of their heart.”

With regard to Taiwan’s absence of a formal patient advocacy or support group, Dr Tsai also points to the difficulty of being recognised: “We need the voice of the patient to be heard because AD will have to make a case for funding against other areas competing for budget. It is going to be a long and difficult journey. We know activity from patient groups can make a difference but we are very weak in this respect.”

Dr Charlson says: “I think it’s a good idea to raise the profile of AD as much as possible and maybe someone in government might listen one day, you never know. If you lobby people enough you can bring about change.”

# A MISUNDERSTOOD SKIN DISEASE

## MAPPING THE POLICY RESPONSE TO ATOPIC DERMATITIS

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He adds: "If you are a gastro-surgeon saving lives it's a lot more impressive than someone who dabs cream on eczema...We see the same dismissive attitude towards people who have AD: 'it's just a rash—put some cream on it and get on with it'...It is often dismissed because you are not going to die from it, but it can cause a lot of morbidity."

## **CONCLUSION: LOOKING AHEAD: KEY ISSUES FOR POLICYMAKERS**

Unfortunately, the lack of data and consensus on AD terminology and scoring can often impede policymakers' decisions to act on AD care. And because AD is not considered life threatening—although it is linked to depression—it is not often given the same priority by healthcare systems as other high-profile, chronic non-communicable diseases.

Yet AD is a serious chronic disease that impacts on the physical and psychological wellbeing of patients and caregivers, and it needs wider recognition, further research and policy support.

Policymakers have a duty to respond to these challenges around AD, which impacts on quality of life, ability to work and school attendance. And although the costs to health systems and the economy are difficult to quantify, some estimates of direct and indirect costs show AD is far from immaterial.

With the aid of policy support and funding, the following measures can help make AD care more effective, cost efficient and greatly improve the quality of life of patients and their caregivers:

- **Re-align established guidelines for care, measurement and monitoring of AD.** At the heart of the challenges to recognise and support AD is the variety of severity and quality-of-life measurements that cannot be compared. Policymakers can work with researchers, medical societies and patient groups to create consistency in AD measurement and agree a common terminology for the disease. Consistency in data will also make it easier to present economic and quality-of-life data to stakeholders that design and fund research programmes and further AD-care policy.
- **Emphasise AD awareness at the primary care level.** Create programmes for widespread awareness of appropriate management and treatment strategies, particularly with extended educational support for primary-care healthcare professionals. Doing so would improve quality of life for patients, and reduce the referral rate to specialists and the corresponding strain on that system (eg, reduce waiting times). “It would be a small cost to educate healthcare professionals to educate patients and I think if you did the sums of that you’d work out that it’s well worth it from a health economics point of view,” says Dr Charlson.
- **Build and support integrated care solutions, patient organisations and psychological programmes.** Bridges must be built with patient support groups to raise awareness of the challenges and impact of life with AD. These groups often provide the additional support to patients and caregivers that are not directly provided by healthcare systems. By supporting these patient groups, policymakers can ensure patients are receiving better all-round quality care. And because these programmes are shown to help patients and caregivers improve their own AD treatment practices and mental health, they effectively help reduce the burden on the healthcare system from returning patients.
- **Support for general public awareness on AD and recognition from government.** All stakeholders should work together towards common messaging and a united strategy to combat AD stigma and quality healthcare issues. Awareness gives rise to appreciation for the true impact AD has on individuals and families, as well as populations and economies.

## Atopic Dermatitis Scorecard: Methodology

Scorecard summary	Australia	Brazil	Israel *	Italy	South Africa	Taiwan	UK	US
<b>Domain 1: Epidemiology</b>								
<b>1.1 Lifetime prevalence</b> Percentage of people within the population who will have AD at some point in their life	32%	14%	9%	17%	17%	24%	11%	Not available
<b>1.2 Currency of prevalence data</b> 0=>15 years to ≥10 years; 1=<10 years to ≥5years; 2=<5 years old	5-10 years	5-10 years	>10 years	>10 years	>10 years	5-10 years	5-10 years	n/a
<b>Domain 2: Monitoring and measuring</b>								
<b>2.1 Use of validated disease severity measures</b> 0=none recommended in guidelines; 1=non-validated measure recommended in guidelines; 2=validated measure recommended in guidelines	0	2	1	2	1	0	2	1
<b>2.2 Use of quality-of-life measures</b> 0=no; 1=yes, generic instrument recommended/used; 2=yes, AD-specific instrument recommended/used	0	0	2	0	2	0	2	2
<b>Domain 3: The provision of care</b>								
<b>3.1 Presence of evidence-based treatment guidelines</b> 0=no guidelines; 1=region-specific guidelines; 2=country-specific guidelines; +1= guidelines developed within past three years	1	1	1	2	2	3	2	2
<b>3.2 Availability of multidisciplinary care</b> 0=no recommendations about multidisciplinary care; 1=multidisciplinary care recommended; 2=multidisciplinary care and team make-up included in recommendations	1	2	1	1	0	1	0	1
<b>3.3 Number of dermatologists</b> Reported as number of dermatologists per 100,000 population—figure does not distinguish between those in public and private practice	2.3	2.9	4.4**	2.0	Not available	3.9	1.0	3.6
<b>Domain 4: Support for patients and carers</b>								
<b>4.1 Assessment of wider impact of AD on families/carers</b> 0=no; 1=mentioned briefly in guidelines acknowledge that AD impacts on families/carers; 2=guidelines recommend one or more specific interventions and a referral process	0	0	1	0	2	0	2	1
<b>4.2 Availability of psychological and emotional support</b> 0=no; 1=mentioned briefly in guidelines; 2=guidelines recommend one or more specific interventions and a referral process	1	2	1	1	2	1	2	1
<b>Domain 5: Awareness and advocacy</b>								
<b>5.1 Primary healthcare professional training and awareness programmes</b> 0=no; +1=nationwide primary healthcare professional awareness schemes; +1=nationwide primary healthcare professional training schemes	2	0	0	0	1	0	2	0
<b>5.2 Patient/carer education programmes</b> 0=no; +1=nationwide patient self-care education schemes; +1=nationwide parent/carer education schemes	0	0	2	0	0	0	0	0
<b>5.3 Patient advocacy and support groups</b> 0=no patient advocacy and/or support groups; +1=formal patient advocacy groups exist; +1=formal patient support groups exist	2	1	1	2	1	0	2	2

\* For indicators based on guideline recommendations, Israel's answers are based on the US guidelines, as our research indicated that these are most commonly used in Israel

\*\* Data based on personal correspondence with the CEO of Kumi Uri—a patient support and advocacy group. The Atopic Dermatitis Scorecard is colour-ranked for easy navigation; the darker the colour, the higher the score.

## Country selection

The Atopic Dermatitis (AD) Scorecard project covers eight high- and middle-income countries. When selecting countries we tried to ensure representation across World Bank income groups and the six regions of the World Health Organisation (WHO), then used global and localised prevalence estimates of AD to identify countries within these regions with the highest prevalence.<sup>135,136,137</sup> From a long list of potential countries, we made a final selection (see Table 1 below) representing a cross-section of the WHO regions, World Bank income bands and health system types.

**Table 1: Selected countries for this project**

	Country	World Bank income group	WHO region
1	Australia	High income	Western Pacific
2	Brazil	Middle income	Americas
3	Israel	High income	Eastern Mediterranean
4	Italy	High income	Europe
5	South Africa	Middle income	Africa
6	Taiwan	Middle income	Western Pacific
7	UK	High income	Europe
8	US	High income	Americas

## Literature review methods

A rapid and pragmatic literature review was undertaken to identify key themes that would form the basis of a scorecard. We searched Embase.com (which contains both Embase and Medline databases) using relevant subject headings and free text terms relating to AD/eczema. Search results were limited to reviews and systematic reviews published in the past ten years. The ~500 retrieved articles were first sifted based on title and abstract, followed by full text appraisal. A large volume of relevant articles were included after sifting (169 articles). We grouped the articles thematically (eg, diagnosis, outcome measures, treatment) then analysed the most recent reviews first. We also used supplementary searching techniques, by following up articles cited by these systematic reviews and performing additional searches to explore the emergent themes further.

## Scorecard development

The literature review identified three broad themes, from which a draft scorecard framework was developed to rate the performance of individual countries' policy and services for AD. This draft scorecard framework was presented to an expert panel of healthcare professionals, patient representatives and patients, who provided feedback to help refine the scorecard indicators and proposed measures.

Indicators were mostly scored on a 0-2 scale, with 2 being the highest score. The epidemiology section of the scorecard included an unscored indicator on prevalence—because low reported prevalence does not always mean low actual prevalence due to issues around accessing diagnosis and recognition

<sup>135</sup> Deckers IAG, et al. Investigating International Time Trends in the Incidence and Prevalence of Atopic Eczema 1990–2010: A Systematic Review of Epidemiological Studies. PLoS ONE. 2012;7(7):e39803.

<sup>136</sup> Odhiambo JA, et al. Global variations in prevalence of eczema symptoms in children from ISAAC Phase Three. (1097-6825 (Electronic)).

<sup>137</sup> Silverberg JJ, et al. Adult eczema prevalence and associations with asthma and other health and demographic factors: a US population-based study. Journal of Allergy and Clinical Immunology. 2013;132(5):1132-8.

of the disease. The epidemiology indicator measuring the currency of prevalence data was scored on a 0-2 scale but the year ranges for each country were presented in the scorecard to enable easy interpretation. The indicator measuring the number of dermatologists was given as a raw figure per 100,000 population rather than translated into a 0-2 score. The purpose of the scorecard is not to rank countries, but rather to identify opportunities for future policy development through cross-country comparisons.

### **Scorecard domains and indicators**

The five domains and constituent indicators are designed to cover the most important issues for the included countries. Each domain is made up of one or more indicators that measure each country's performance against that indicator, enabling cross-country comparison.

Where scores are based on information contained within guidelines, we used the relevant country guideline or the regional guideline if no country guideline was available (eg, in the case of Italy). For Israel, there are country guidelines but these date from 2004 and our research indicated that a blend of these Israeli guidelines, European and US guidelines are used in Israel, with the US guidelines predominating. Therefore, for guideline-based indicators we have used the US guidelines to provide answers for Israel.

The five domains and constituent indicators are as follows:

1. **Epidemiology**—to plan appropriate services and allocate sufficient resources, countries need to understand the number of people affected by AD. The literature review and expert panel indicated that many countries do not have these data and that where data do exist, they are often out-of-date. Therefore services may not reflect actual need. A number of different prevalence measures were considered, but lifetime prevalence was used because it was the most complete dataset—with data available for seven out of eight countries.

The indicators within this domain assessed:

- 1.1 Lifetime prevalence (unscored)—the percentage of people within the population who will have AD at some point in their life.
- 1.2 Currency of prevalence data (unscored)—countries were assessed based on when their prevalence data were published, >15 years to  $\geq 10$  years; <10 years to  $\geq 5$  years; <5 years old.

2. **Monitoring and measuring**—in order to effectively monitor someone's disease and how well it responds to treatment, there is a need for agreed, objective measures. The literature review and expert panel indicated that in AD there are a variety of disease-specific and generic severity measures and quality-of-life measures currently in use. The data for these indicators were sourced from national guidelines.

The indicators within this domain assessed:

- 2.1 Use of validated disease severity measures—scoring based on whether validated severity measures are not specified in guidelines (0), non-validated measure(s) are recommended (1) or validated measure(s) are recommended in guidelines (2).

2.2 Use of quality-of-life measures—scoring based on whether no quality-of-life measure is specified (0), a generic instrument is recommended (1) or an AD-specific instrument is recommended for use in guidelines.

3. **The provision of care**—variations in the care received by people with AD were reported by the expert panel and in the literature, both between and within countries. This domain explores what care is available. The data for these indicators were sourced from national guidelines and various other sources, such as professional societies and groups.

The indicators within this domain assessed:

3.1 Presence of evidence-based treatment guidelines—scoring based on whether evidence-based treatment guidelines are available covering the region (1) or are country-specific (2), an additional point was applied where guidelines were developed within the past three years.

3.2 Availability of multidisciplinary care—scoring based on whether multidisciplinary care was not included in recommendations (0), recommended in guidelines (1) or multidisciplinary care and team make-up was included in recommendations (2). A multidisciplinary team could include a dermatologist, general practitioner, paediatrician, respiratory specialist, allergologist, nurse, psychologist, nutritionist and/or a social worker.

3.3 Number of dermatologists (unscored)—reported as the number of dermatologists per 100,000 population—figure does not distinguish between those in public and private practice.

4. **Support for patients and caregivers**—the literature and expert panel indicated that beyond the provision of care to manage people's AD, it was also important to support their psychological and emotional needs. The impact of AD on families and caregivers was also highlighted as an area where support was needed as part of effective services. The data for these indicators were sourced from national guidelines.

The indicators within this domain assessed:

4.1 Assessment of the wider impact of AD on families/carer—scoring based on whether no such services were mentioned in guidelines (0), guidelines briefly mention or acknowledge the impact of AD on families/caregivers (1) or guidelines recommend one or more specific interventions to support families/caregivers and include a referral process (2).

4.2 Availability of psychological and emotional support—scoring based on whether no such services were mentioned in guidelines (0), guidelines briefly mention psychological/emotional support (1) or guidelines recommend one or more specific interventions to support people with AD's psychological and emotional needs and include a referral process (2).

5. **Awareness and advocacy**—the majority of AD care is delivered by primary care services, but the literature and expert panel highlighted that there are issues around awareness of AD, its underlying mechanisms, the full range of possible treatments—all of which can delay diagnosis and result in suboptimal care. The data for these indicators were sourced from various websites, such as professional societies and groups, patient support groups and charities.

The indicators within this domain assessed:

- 5.1 Primary healthcare professional training and awareness programmes—this indicator scored countries up to two points—one point if professional nationwide awareness schemes were available and one point if nationwide professional training schemes were available, countries with neither scored zero.
- 5.2 Patient/carer education programmes—this indicator scored countries up to two points—one point if there was a nationwide education scheme for patient self-care and one point if nationwide education schemes for parents/caregivers were available, countries with neither scored zero.
- 5.3 Patient advocacy and support groups—this indicator scored countries up to two points—one point if formal patient advocacy groups exist and one point if formal patient support groups exist, countries with neither scored zero. The distinction between patient advocacy and patient support groups was based on the organisation's stated aims.

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