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WHITE PAPER

Atopic Dermatitis –

***Health Inequities and Barriers to Care   
Across the Patient Journey***

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# Background

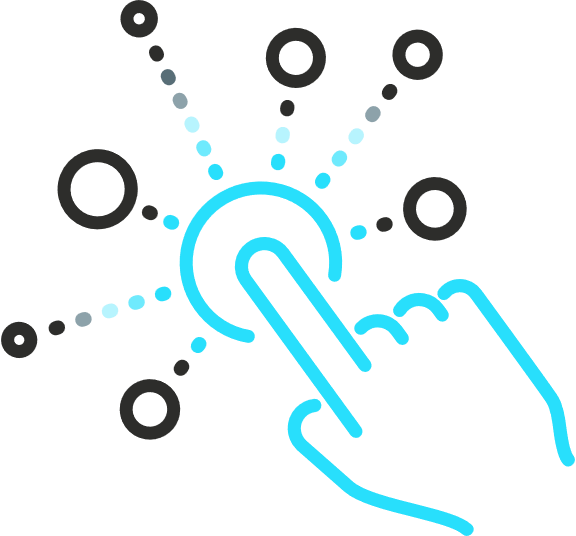
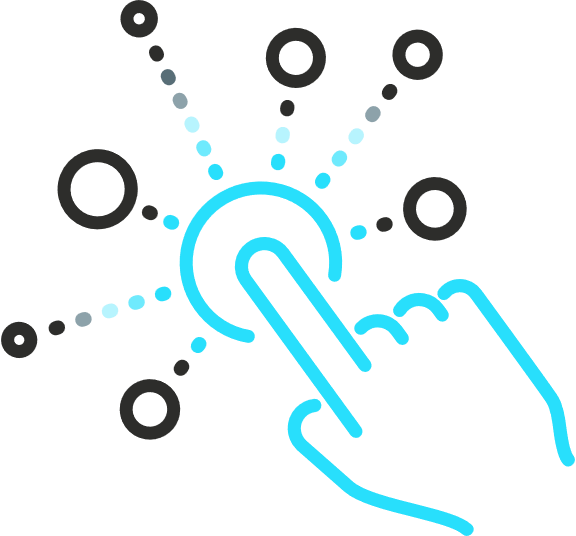
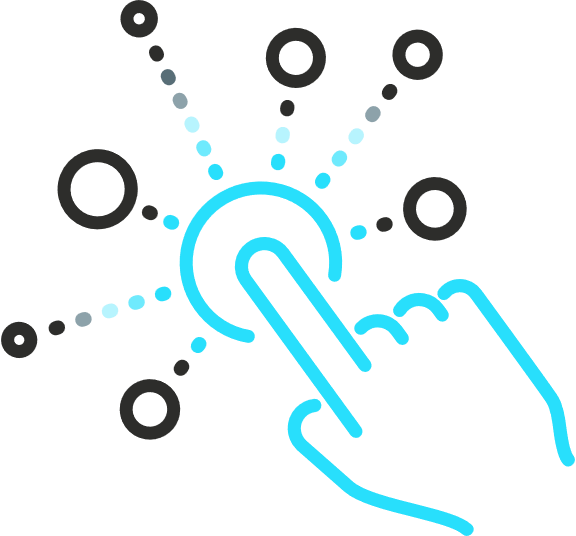
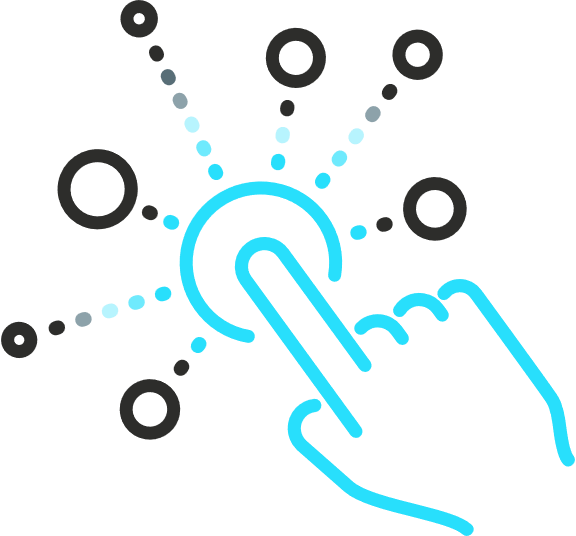
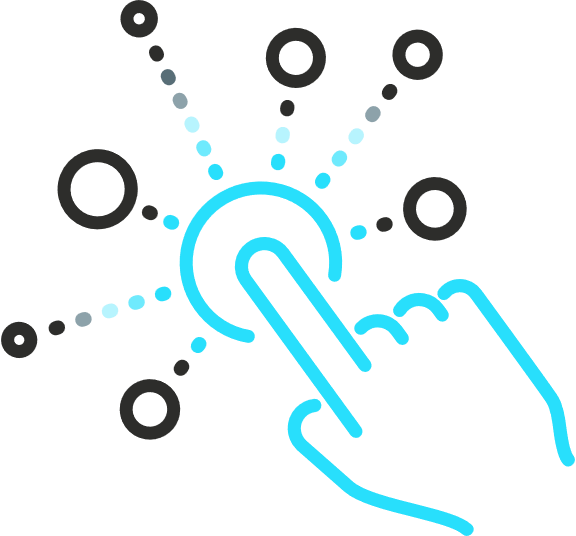
**~16.5M** **adults**   
 in the US have atopic dermatitis—**6.6M** having moderate to severe disease.1-3

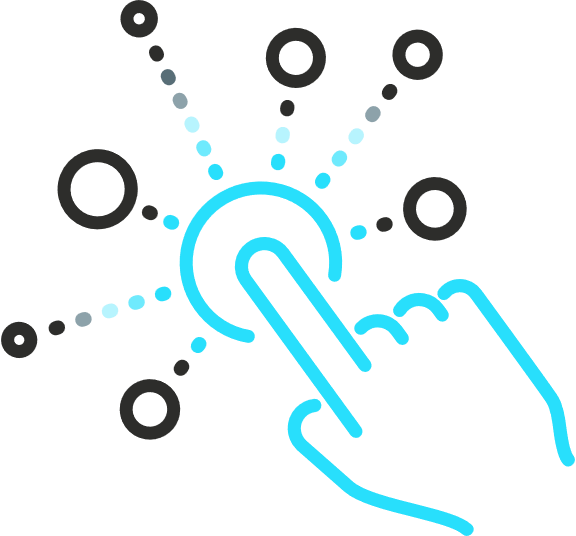
**9.6M** **children**   
have the dis-  
ease—⅓ of those have moderate to severe disease.1-3

**~80%** of   
 people with atopic dermatitis experience **symptom onset before age 6**.7

**>55%** of adults with  
 moderate to   
 severe atopic  
 dermatitis **do not have adequate control** of their disease.13-15

Annual **economic burden** of atopic dermatitis … estimated   
**>$5B**.22-24



Atopic dermatitis is the most common form of eczema, characterized by itching, skin redness, skin pain, and a burning, tingling, or stinging sensation. Approximately 16.5 million adults in the US have atopic dermatitis, of whom 6.6 million have moderate to severe disease. In children, about 9.6 million have the disease, and one-third of those have moderate to severe disease.1-3 People of all skin colors, races and ethnicities can develop atopic dermatitis. In the US, children who are African American or Black are more likely to develop the disease, and they tend to have more severe disease than White children,4,5 yet they are often underrepresented in clinical studies.6

… all skin colors, races and ethnicities can develop atopic dermatitis. … US children who are African American or Black are more likely to develop the disease … tend to have more severe disease than White children4,5 … often underrepresented in clinical studies.6

About 80% of people with atopic dermatitis experience symptom onset before age 6.7 Those with a family history of eczema, asthma, or allergies have a higher risk of disease development,8,9 and children who live in an urban environment have a higher risk for prolonged disease.10,11 Pollution, climate, and exposure to irritants can also contribute to disease development.12 Socioeconomic status (SES) may also play a role, and one systematic review indicates that higher SES is associated with an increased prevalence of disease, whereas lower SES is associated with an increased severity of disease.4

More than 55% of adults with moderate to severe atopic dermatitis do not have adequate control of their disease.13-15 Even with treatment, patients are concerned about long-term use and side effects, and many have experienced ineffective treatment.15-17 Managing medical appointments, treatment initiation and adherence, and insurance prior authorization and approval processes requires time and financial considerations for patients and their families.18-21 The annual economic burden of atopic dermatitis, including direct and indirect medical costs, is estimated to be more than $5 billion.22-24 Inpatient costs are nearly $8.3 million per year for adults and more than $3.3 million per year for children,25 while annual out-of-pocket costs for disease management range from $600 to $5,000 or more.26,27 Atopic dermatitis also contributes to increased healthcare utilization due to more outpatient doctor visits,28-30 more visits to urgent/emergency care,31 and more hospitalizations.32,33

A cross-sectional study indicated that half of people with moderate to severe atopic dermatitis experience significant effects on their lifestyle,34 and nearly one-third have challenges at school or work, with 14% indicating their academic and/or career progression has been hindered.35 Children with severe atopic dermatitis have fewer friends and spend more time alone,18 and 20% to 40% experience bullying because of their disease.36,37 Two-thirds of people with atopic dermatitis indicate their mental health is negatively affected,38 with adults having a 2.5 to 3-fold higher risk and children having a 2- to 6-fold higher risk for anxiety or depression, respectively.2,39-41

Premier Inc., a technology-driven healthcare improvement company, partnered with Henry Ford Health in Detroit, Michigan, and Eli Lilly and Company to obtain learnings and insights from clinicians about the socioeconomic drivers of health disparities for patients with atopic dermatitis. These findings will help us better understand the social, physical, economic, and political contexts that influence poor health outcomes for these patients.

# A hand with red spots on it AI-generated content may be incorrect.Objective and Method

PATIENT POPULATION CHARACTERISTICS

|  |  |
| --- | --- |
|  | Adult patients often have unusual presentations of common conditions, rare genetic deficiency diseases or manifestations that did not grow out of childhood skin conditions. |
|  | Exposure to environmental allergens that may contribute to skin conditions (wet or chemical environments) |
|  | Pediatric patients often have warts, acne and eczema |
|  | A diverse population of race, skin type, age and socioeconomic status |

Henry Ford Health and Premier conducted 1-hour in-depth interviews (IDIs) with two patients who had atopic dermatitis, as well as three dermatologists and a nurse practitioner who care for this patient population. Interview questions addressed patient access to care and treatment, resources and programs available to patients, health literacy and communication and clinicians’ role in addressing socioeconomic barriers.

Interviews were recorded and transcribed. Project team members also took notes. Premier’s medical writer scanned and synthesized text from the interview transcripts and generated a thematic qualitative analysis of concepts and topics for this white paper.

# Findings

## Patient Population Characteristics

Clinicians noted that among their patient populations, adult patients often have unusual presentations of common conditions or manifestations that did not grow out of childhood skin conditions. Some of these patients likely have regular exposure to environmental allergens that may contribute to skin conditions. For example, one clinician described seeing several patients who have dermatitis on their hands due to exposure working in wet environments or environments with direct chemical contact. In the pediatric population, clinicians said they mostly see patients with warts, acne and eczema. Specifically with eczema, patients are generally 5 years old or younger, although some will present to healthcare at older ages including through adolescent or college years.

All clinicians stated they see a diverse population of race, skin type, age and socioeconomic status, with one clinician adding that most patients they see with atopic dermatitis are African American. Further, they indicated many patients in their population are on government insurance and are from the inner city. While this observation may insert a bias into the assessment, it also represents our aim of highlighting the needs of underserved and less represented populations in this study.

## Patient Journey

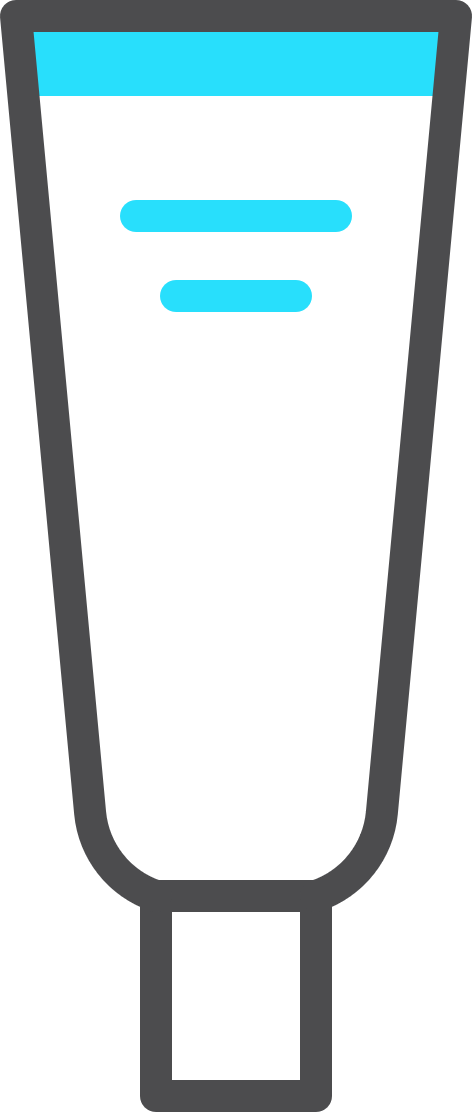
*Patient Perspective*

Patients noted various symptoms they’ve experienced with atopic dermatitis including rashes located in arm and leg creases, a strong urge to scratch, bloody hands, thick and leathery patches, redness, flaking, bumps, burning skin when in the sun for too long or from being in ocean salt water, and overall body soreness. As one described it, “*If I'm having a really bad flare-up itching, it doesn't matter what I'm doing, I will stop what I'm doing and scratch it to death and make it worse. It's very disruptive.”*

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**—Patient**

One patient discovered she had eczema at a young age, and although her doctors thought she would outgrow it, the symptoms got worse over time. Despite using over-the-counter (OTC) treatments and other prescriptions, her case was severe, was not seasonal, and was not well managed. She said she had to research the condition more than her clinicians did. The other patient started experiencing symptoms around 7 years old, with severe flare-ups starting in 2020. She sought help from urgent care, and initial suspicions of clothing or detergent allergies proved unfounded.

Over-the-counter treatments the patients tried included hydrocortisone cream, calamine lotion, and oatmeal baths. However, all participants stated that nothing seemed to help with strong skin flare-ups. Prescription treatments included topical medications that were ineffective or only temporarily effective, as well as injections of Kenalog® (triamcinolone acetonide), a steroid that provided temporary relief, and Dupixent® (dupilumab). Overall, even clinician-directed treatments provided little relief, and as one patient said, *“I was willing to try anything they gave me because nothing was working as the years went on. They didn't have anything else to give me to help relieve my symptoms. It might work for a little while, but you develop a tolerance to it, and then it doesn't work anymore. I never got advice on how to manage that.”* The patients also said some treatments exacerbated their conditions instead of improving them. They mentioned the high costs of some treatments, such as a one-month supply of a treatment that cost $5,000. The patients said some medications did provide rapid and significant improvement, but they were only prescribed for a limited time.

The patients said they understood they have to continue some form of treatment long-term, as stopping would cause symptoms to reappear or worsen. However, they expressed frustration over their struggles with their skin conditions and the toll it takes on their mental health and daily living. One said, “*It has impacted my mental health for as long as I can remember. I still feel like I can't wear what I want to wear - it was so hard to put on a pair of shorts or a shirt. It's affected my life in a lot of ways. I can't do the things I want to do because of this. Before I received treatment, I would cry constantly. I would say, ‘Why is this happening to me?’ My mom would do anything to not let me go to school or my sports because I felt so insecure, and I felt so out of place. I didn't look like everyone else. I didn't feel like me. It was visible, and I just felt insecure and ugly.”*

*“It has impacted my mental health for as long as I can remember. I still feel like I can’t wear what I want to wear – it was so hard to put on a pair of shorts or a shirt. It’s affected my life in a lot of ways. I can’t do the things I want to do because of this.”*

**—Patient**

*“I have to look up Black skin in my search because it doesn’t pop up if you just look up eczema. I have to do extra work to try to find what’s for me or what looks like me. Even though we all have eczema, we’re not the same, so don’t give us a one-size-fits-all type of thing.”*

**—Patient**

They are also frustrated with the lack of effective solutions, guidance, or answers to their questions. One said, “*I've been a test dummy for a lot of things. Some people think I have neuro dermatitis. I don't know what to believe. I don't know who to trust. I don't know if they're just throwing stuff at it. This doesn't have a cure, so I know they don't have a 100% answer, and I can't fault them for that. I don't know what could be done. I wish people were more willing to dive deeper with people with eczema and try to find a solution.”*

The patients pointed to the scarcity of accessible information and the limitations of primary care physicians (PCPs) to accurately diagnose and treat patients with skin conditions or refer patients to specialized dermatologists. As one stated, “*From the forums I've joined, other people said the same thing. They feel like they get the runaround because nobody knows why you're seeing this flare up. Even the doctors are just as lost as us. They can do all the testing they want, but at the end of the day, we still end up getting the runaround.”* One patient also said she spent a lot of time seeing different doctors to try to get answers and better care. *“There wasn't a deeper dive into how to help. I didn't get an in-depth explanation, and it bothered me. It felt extremely dismissive, and I understand they don't really know what's going on, but I was expecting a little more. I jumped around to a lot of people, just to get a second opinion, third opinion, fourth opinion, just to see if anybody has something different to say.”*

One patient also described experiences with clinician bias due to her skin color, and she said it was difficult to find information about skin conditions related to Black skin, stressing that treatments need to be customized rather than one-size-fits-all, as people with similar conditions may have different symptoms. *“I have to look up Black skin in my search because it doesn't pop up if you just look up eczema. I have to do extra work to try to find what's for me or what looks like me. Even though we all have eczema, we're not the same, so don't give us a one-size-fits-all type of thing.”* Further, the patient said it was important for healthcare clinicians to recognize their potential unintended bias toward people of color, as it may lead to misdiagnosis and inadequate or ineffective treatment.

*Clinician Perspective*

Clinicians noted that patients may consult family members for advice on health issues before exploring other options, especially when there is a family history of a specific condition. They often rely on what relatives have done to address the problem or what they hear or see on social media, regardless of whether those methods are effective. Additionally, patients often use home remedies or OTC products for skin issues, sometimes exacerbating symptoms. Despite trying various ointments, creams, and other remedies, many patients still struggle with dryness, itchiness, and other symptoms. Patients with moderate to severe conditions may even miss work or school.

Often, children may be diagnosed with a skin condition during a wellness check. Conversely, many PCPs might not recognize skin conditions in adults, which may lead to delays in diagnosis. Even if patients start treatment with PCPs or pediatricians, they are often given topical steroids with restrictions on their use. While pediatricians are generally well-versed in eczema and other skin conditions often seen in childhood, adult PCPs may lack that depth of knowledge and may only be able to offer limited management. Consequently, patients frequently experience many uncontrolled flares before being referred to dermatologists. About 10% of adults develop chronic atopic dermatitis, which often started in childhood, and therefore, clinicians noted that adults with a history of the condition may have received more consistent healthcare attention at least through their childhood years.

Understanding a patient's history is crucial for accurate diagnosis and treatment before prescribing any medications. Clinicians mentioned gathering information on symptoms, treatments used, and responses, as well as physical examination. Dermatologists may also refer patients to allergists for additional patch testing and to screen personal care products or ask about pets to identify potential triggers. One clinician mentioned a combined multidisciplinary clinic at their site where patients can have an appointment with several specialties at once.

## Patient Awareness of and Access to Clinical Trials

The patients mentioned participating in clinical trials for their skin conditions. They haven't noticed any worsening of symptoms since starting the trials, and the treatments seem to be helping better manage symptoms. They expressed a desire to help others with skin conditions by finding more effective treatments via clinical trials that investigate new treatment paradigms.

Although clinical trials may be useful for patients to access newer treatments as well as potentially have lower or no medication costs that insurance typically won’t cover, clinical trials still present challenges. There are few clinical trial options for younger children, for example, as most studies focus on adults. Additionally, patients may not be able to commit to regular appointments due to busy lives, and trials usually have strict regulations for keeping appointments and are often limited to specific locations, which means accessibility may be an issue for patients unable to travel far.

One clinician said patients may not be aware of the availability of clinical trials for their health issues. *“I don't think a lot of people are aware that we [Henry Ford Health] have a robust clinical trial section in our department. Often, I've had a patient with a severe condition, and I want to prescribe a certain medication, and there's no way insurance will cover it. And I'll say, ‘Did you know we have a clinical trials section in dermatology?’ I've had patients get into a clinical trial where they can get cutting-edge effective treatment because their insurance can't provide it for them due to the drug being not yet approved or because an effective drug is provided as part of the study whereas insurance would not cover it.”* It’s important that patients are screened to ensure they meet study criteria, and that they understand the process and requirements, such as regular visits, as well as potential side effects. Referrals for trials mainly come from other dermatologists or through community support groups, as well as from institutional advertisements, allowing outreach beyond the health system. Both doctors and nurses play crucial roles in identifying candidates for trials, ensuring they meet study criteria, providing study information, and providing enrollment assistance.

## Socioeconomic Barriers to Care

Patients did not mention difficulties accessing dermatology care, but instead indicated they faced issues obtaining effective care, even from dermatologists, as described earlier. However, the clinicians we interviewed discussed a range of barriers that patients experience when trying to access care. For example, there can be significant wait times for appointments, especially in rural areas where few specialists are available. As one clinician put it, *“There's not a million dermato-logists all over the place, and the wait time to see a dermatologist is long, no matter where you are. So if you live in a rural area, there's not many dermatologists serving these communities. It might take you six months just to see the doctor.”*

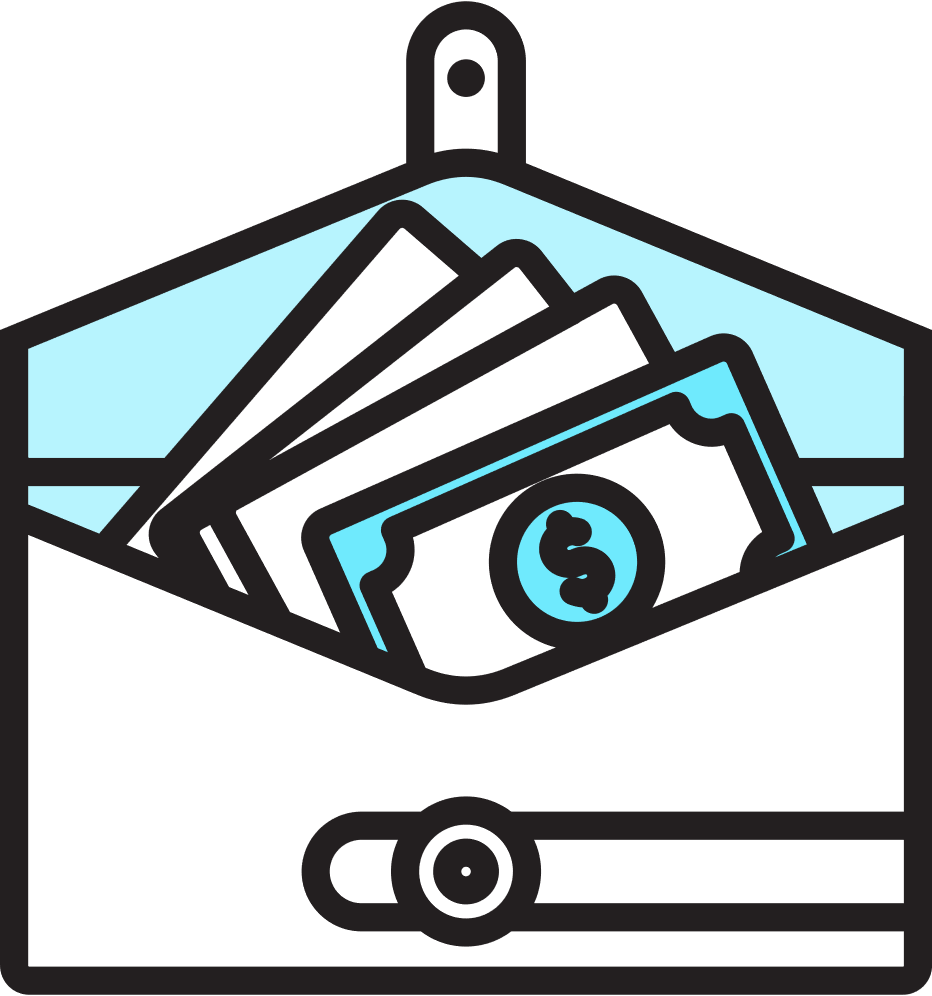
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**—Clinician**

Patients often assume they need to see a dermatologist and can make appointments without referrals, which leads to a congested clinic schedule, as many come in for minor issues. Practices may struggle to accommodate urgent cases while managing a busy patient load, resulting in long delays for those who need more timely care. One clinician said, *“Everybody thinks they need to see a dermatologist, so it's not like you have to be referred. You might be perfectly fine, but you want a full skin check. They're not prescreened, and we don't say no, you can't come in. So people come in with minimal issues, and they come in with significant issues. And there's no way of weeding out. If somebody calls, and it sounds significant, we'll add them into our schedule.”* Furthermore, patients frequently run into complications when they have flares and can't secure timely appointments. Another clinician observed, *“What I see from an access standpoint is they come see us once, and they get topical steroids. Typically, we talk about dry skin care, and they flare in winter. Then they go away and all of a sudden, it's September, and after Labor Day it gets cold, and they're flaring, and they panic, and they can't get in to see us.”*

Patients also may have limited or poor insurance coverage, which then affects their treatment options. Many patients do not have a steady income, leading to difficulties in affording medications and necessary skincare products. Although newer and more effective treatments exist, such as biologics, their high costs and insurance limitations can make access difficult. *“We talk about non-steroidal new medications that are promising and very good, even injections of biologic-type drugs,”* one clinician said. *“But then there's cost involved with those newer medications, and sometimes, I may have a patient, and I'm thinking, ‘This might be great for you to try. But insurance won't cover it.’”* Patients may be compelled to settle for inferior treatments that are covered. One clinician described it as, *“The economics of the patient - even if they have insurance, the insurance might be a type or plan that does not have a broad formulary and restricts prescribing what I think they need, and sometimes, you feel like you're playing a game. Let me prescribe something I know is inferior, but I have to play the game to get through that to say, ‘OK, this person is really suffering; you need to approve something else for them.’”*

Prior authorization for expensive medications is seen as a barrier insurance companies impose to encourage the use of cheaper alternatives*.* This process is time-consuming for clinicians, who must thoroughly document patients' treatment histories, including all medications used, their dosages, durations, and outcomes, to justify the need for more expensive prescriptions. Clinicians often struggle to find the time to gather and compile this information, yet proper documentation is crucial, as it helps prove a patient has failed other, less effective treatments and facilitates the approval of potentially more effective systemic medications.

Although new medications are emerging, one clinician was concerned that new treatments are tested against placebo controls rather than against cheaper alternatives. *“They test these new medicines against a blank placebo like Vaseline, which is fine. But what I really want to know is, do they work better? The stuff that cost $5 a tube vs the stuff that cost $500.*” In addition, the clinician pointed to the costs for non-prescription treatments, *“There is expense not just with your medication, but also with soaps or lotions or creams to moisturize your skin. They aren't always cheap, and we try to keep that in mind with what we recommend, but there is expense just with the general maintenance of your skin that's non-prescription.”*

Some of the clinicians mentioned using GoodRx and specialty pharmacies in the community for lower out-of-pocket costs if patients’ prescriptions are declined by insurance. Others use patient assistance programs from pharmaceutical companies, as they provide direct access to medications, although they typically have a limited duration. These kinds of financial constraints not only affect treatment accessibility, but they also exacerbate health disparities for economically disadvantaged populations, limiting their ability to manage their chronic conditions effectively. These issues underscore the daily frustration clinicians experience trying to provide optimal care in a restrictive healthcare landscape.

Patients may also not know which type of clinician to consult for skin conditions. One clinician said patients may not understand the specific training required for specialty care like dermatology, and therefore they may assume any doctor can answer their questions and provide appropriate care. Consequently, they may go to urgent care facilities or emergency rooms, where staff may have limited experience in dermatology. This choice can lead to mismanagement of non-emergency issues. “*Some patients have been in and out of healthcare institutions where they go to the emergency room, and they use that as their primary care doctor, and they go in when they're flaring. But they don't get a chance to find a continuous relationship with a dermatologist where they can get in front of their disease.”*

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**—Clinician**

Clinicians also encounter health literacy issues with patients, such as misconceptions and reliance on ineffective remedies. One clinician said, *“There's a lot of misinformation on the Internet - a lot of parents spend thousands of dollars trying to find the food that's causing it.”* Another noted that individuals may hold unconventional beliefs, such as using raw milk for eczema treatment.

*“I didn’t realize until they started a clinic staffed by African American doctors in our group how much that meant to patients. When you saw someone who looked like you and talked like you, you became much more adherent to the suggestions being made. That was a really interesting life lesson for me.”*

**—Clinician**

Cultural and social factors may also influence patient beliefs and behaviors. One clinician observed that patients tend to show greater adherence to medical advice when they see clinicians who share similar backgrounds, stating, *“I didn't realize until they started a clinic staffed by African American doctors in our group how much that meant to patients. When you saw someone who looked like you and talked like you, you became much more adherent to the suggestions being made. That was a really interesting life lesson for me.”*

There is a noted lack of educational resources on atopic dermatitis, and clinicians recognized the need to address this gap to better educate patients about their chronic conditions and the ongoing need for compliance with treatment. *“Are they aware of this disease? How to manage it? I feel like as a nurse practitioner, I really focus on educating my patients.”* Compliance issues may also stem from patients’ fear and disappointment from past treatments, making them hesitant to try new therapy options to better manage their conditions. One clinician gave the following example - *“I suggested to a patient about going on a systemic therapy, and she was so scared. She said so many things haven't worked for her in the past, and she's scared to try something else. Past experience weighs heavy on these patients, and they wonder, ‘How do I know that this is going to be different? I've been disappointed in the past, so how do I know I'm not going to be disappointed again?’”*

Technology may be a barrier because patients may need to use computers and online resources to connect to and to update their healthcare clinicians. Yet clinicians pointed out that patients may not have Internet access or access to smartphones. Transportation may be another issue for patients. Many people do not own cars and rely on buses, which may not be timely or reliable. As a result, some patients miss appointments, especially if they have to take multiple buses or travel long distances, particularly in rural areas. Additionally, issues such as having to pay for parking at clinics further complicate attendance. While some insurance plans may offer reimbursement for transportation, the requirement to arrange this in advance can be yet another barrier.

Finally, time and scheduling requirements may play a role. One clinician said, *“People who have less control of their lives can't often take a day off. Or they forgot the appointment. They switch their phone numbers, so we don't have it to give them a reminder. Or life just they threw them a screwball that morning, and they suddenly couldn't get the clinic.”* In addition, when parents can’t take time off work, it complicates follow-up visits and ongoing care for their children. Non-traditional hours may help, but many still struggle to maintain consistent treatment and care for their children.

## Communicating with Patients

Aside from some brief education, the patients we interviewed did not receive materials or resources from their healthcare clinicians and had to do their own research. They found online forums and groups helpful, and one emphasized the importance of communicating with clinicians and fellow patients when trying to understand the condition, as the diagnosis can be overwhelming. *“They taught me a lot of new terms. Of course, I didn't know about the human body and what happens when you have eczema. But yeah, it's very scary learning stuff about that.”*

Clinicians noted that patients often don’t understand the chronic nature of their conditions. *“We have to make it clear to them that their medications are not a cure, and patients are surprised by that. They'll be on a biologic medication, and their skin is clear. And when they go off the biologic medication, let's say because they lost their insurance, they're surprised their condition comes back.”* Another clinician added, “*Adherence is related to how clearly we can give our message to the patient.”*

*“Adherence is related to how clearly we can give our message to the patient.”*

**—Clinician**

Assessing a patient's comprehension during medical consultations by noting their level of understanding of questions and responses can help ensure a patient thoroughly grasps the information. This may necessitate providing translated materials and involving bilingual staff to facilitate communication with non-English speaking patients. Using printed visit summaries and annotating these documents during discussions can also help gauge comprehension, and nurses and medical assistants can help reinforce education on managing treatments and understanding skin care. Despite attempts to facilitate effective communication with these methods, time constraints in clinical settings may limit clinicians’ ability to perform detailed "teach-back" or other comprehension evaluations. Therefore, building trust and ensuring information comprehension as part of communication between patient and clinician may require multiple appointments.

*“Hairdressers are looking at scalps. They see a lot of things we don’t see and could be a referral source, a screening source. It’s marvelous, those kind of really interesting linkages.”*

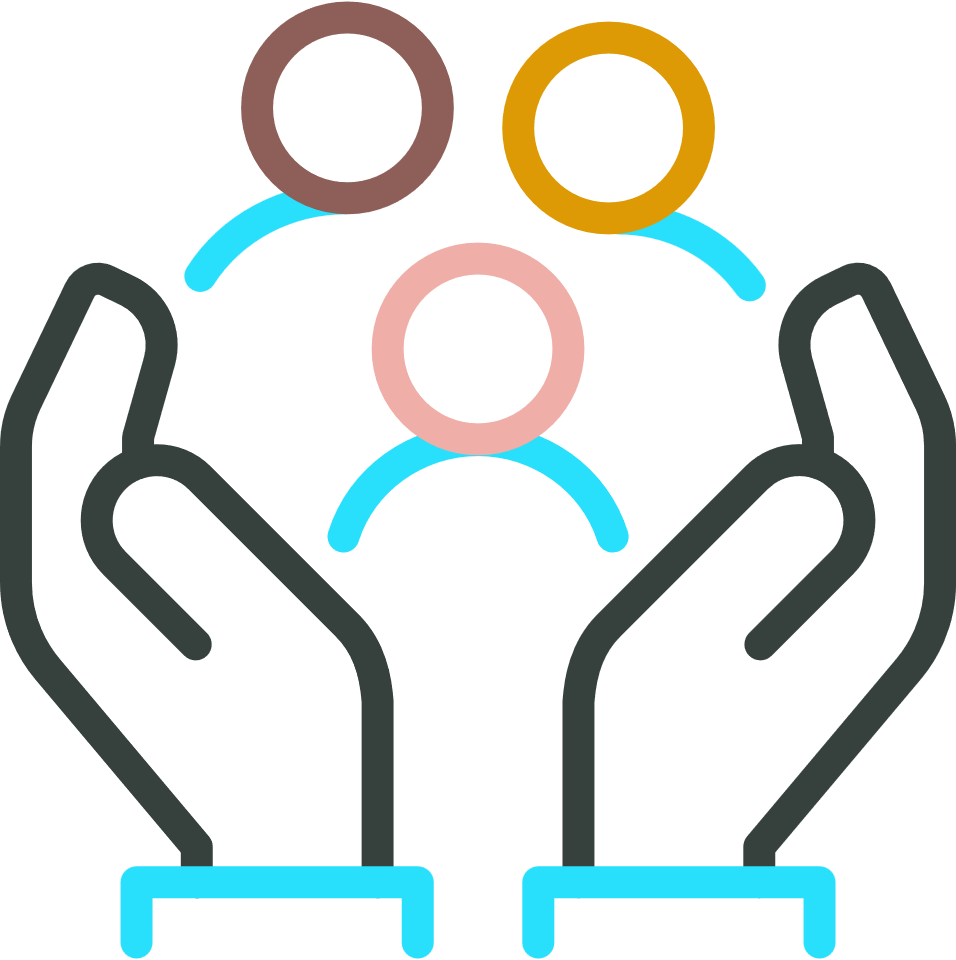
**—Clinician**

## Current Resources and Programs

Patients said they had limited awareness of resources or programs related to atopic dermatitis. One said, “*There's not a lot of exposure for people who have eczema. There aren't programs, or maybe there are, but they aren't being promoted very heavily, and we don't know about them.”*

Clinicians were aware of a few external resources, such as Camp Discovery, which is a summer camp for children with severe skin diseases that helps them connect with peers, as well as organizations like the National Eczema Association, which provides educational materials, a symptom tracker app, and skin product recommendations. They agreed there is a need for better awareness and education for patients and physicians about equity-focused initiatives to enhance their use.

Regarding community resources, one clinician mentioned hair stylists, noting their ability to identify skin and scalp issues. These connections in the community, especially within the Black community, are significant, and people like hair stylists may be an untapped resource to effectively communicate important health messages. “*Hairdressers are looking at scalps. They see a lot of things we don't see and could be a referral source, a screening source. It's marvelous, those kind of really interesting linkages.”*

Clinicians agreed on the importance of staying up to date on new treatment options that have emerged in recent years. They point out that clinicians may hesitate to recommend these treatments due to unfamiliarity with them, resulting in failure to provide potentially beneficial care. One said, *“We have this wealth of new treatment options that have come over the past eight years. And if you are not up to date on new treatments, if you're not comfortable with them yourself, you're certainly not going to offer them to your patients.”* Continuing medical education support from institutions can help clinicians stay informed about innovations and practices in the field, and several clinicians noted the variety of educational opportunities available, such as in-person conferences from the American Academy of Dermatology and online webinars. One clinician also described their clinic's monthly meetings at which the clinicians discuss challenging cases and noted the diverse perspectives that may improve patient care.

Another clinician emphasized the need for additional education for PCPs, and described their department’s courses on common dermatologic conditions, even offering credits for participation. The initiative aimed to not only enhance PCPs’ education, but also to enable them to more effectively handle the initial management of dermatology cases. The training emphasized recognizing and diagnosing atopic dermatitis, especially in patients with skin of color, and addressing implicit bias toward these patients.

## Opportunities

The patients emphasized the importance of promoting self-advocacy for people suffering from skin conditions, and that if something feels wrong or painful, one should pursue further testing. *“I would suggest - advocate for yourself. If you feel like something's not right, or if you are in pain because of it, advocate for yourself. Make them test you if you have the means to do so, make them do a deeper dive into what's going on. Make them find resources to help you because if you don't, nobody else will.”* They also highlighted the need for allergy testing and giving practical advice to patients, such as avoiding hot showers, using heavy moisturizers, and wearing gloves at night to prevent scratching.

They recommended seeking support groups as well. While online forums are not certified, the patients said they can provide valuable insights and recommendations from others experiencing similar issues – *“Find support groups - you are hearing the opinions of people who suffer from the same thing you suffer from.”* Clinicians agreed and noted there are patient support groups for conditions like vitiligo, alopecia areata, eczema, and scleroderma, and there’s a similar need for support systems for other conditions like atopic dermatitis, as well as for clinicians themselves to make a point of referring patients to these groups.

Clinicians acknowledged the need to better promote and provide patient education on the advanced treatment options available for atopic dermatitis and to showcase expertise and access to new medications that community dermatologists might not have. There are also specialized clinics that address psychiatric dermatological issues, which may not be readily available elsewhere. They emphasized the importance of quality care and research opportunities, suggesting that patients with complex needs or low socioeconomic status might benefit from these offerings. Thus, improved communication within and across departments is needed to ensure both patients and clinicians are aware of care options that may help meet individual needs.

Patient education also needs to focus on the chronic nature of atopic dermatitis and correcting misinformation, as well as on providing such education in a variety of formats and languages. Translators and support staff can help reiterate main points and ensure patient understanding, and written materials need to be tailored to lower literacy levels to broaden access to this information. Simplified handouts, educational videos, and practical skin care tips tailored to individual patient needs may also be useful.

Efforts are needed to address the staffing shortage and improve appointment availability to better meet patient needs. More support in the health system is needed with transportation coupons and pharmacy assistance. More administrative help is needed for the authorization process and other tasks, so healthcare clinicians can focus more on direct patient care and meaningful patient interaction. Additional resources to support PCPs at initial diagnosis and care of patients with atopic dermatitis as well as guidance on dermatology referral navigation can also help improve patient health outcomes and access to disease-specific expertise. More coordinated multidisciplinary care is also warranted, such as workflows that facilitate collaborating with allergists for patients with severe disease who also suffer from seasonal allergies or asthma. Clear communication and detailed visit summaries can help ensure continuity of care and effective referrals, especially for complex cases.

Addressing the financial burden of treatment is crucial. This might be done via the pharmaceutical industry providing more patient assistance programs, coupons, and other resources as well as recommending lower-cost OTC products and generic versus high-end therapies when able. Processes and templates that make the documentation process for prior authorization of medications easier may also be helpful, as would greater policy advocacy to expand insurance coverage for atopic dermatitis treatments and for collaboration with insurance clinicians to better support patients' needs.

Alternative appointment options may be useful, and appointments could be staffed by alternative clinicians like physician assistants or nurse practitioners for initial consultations as well as a nurse triage process to prioritize appointments. A triage video visit could provide early guidance and help patients secure timely appointments. It is also important to emphasize to patients that they need regular appointments for ongoing care and to manage flare-ups, and that they should schedule them well in advance, such as scheduling the next appointment at the end of the current visit and providing appointment reminders if possible.

# Conclusions

The diverse patient experiences identified in the interviews highlighted several opportunities for improvement. The main domains of focus include patient education on the disease, treatment options, and healthcare navigation; healthcare clinician education to ensure timely and effective treatment, including processes around healthcare navigation and consultation engagement; workforce-related barriers to care such as access limitations in seeing a dermatologist, staying up to date on new treatment options, and support infrastructure for patients to engage in optimal healthcare practices; and in community engagement targeted at overcoming social determinants of health, access to effective yet costly contemporary therapies, and building trust between clinicians and the communities they serve.

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# Abbreviations

OTC – over the counter

PCP – primary care physician

SES – socioeconomic status

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