



Atopic Eczema Care Priorities and Challenges

From the Perspective of Patients and Caregivers

December 5, 2020

Atopic Eczema Community

Strategic Roadmap



STRATEGIC PILLARS

Building COMMUNITY CAPACITY



A strong and cohesive atopic eczema community is a prerequisite for effective global action on atopic eczema

Galvanizing GLOBAL ACTION



Galvanizing global action on atopic eczema helps improve access to high-quality care & enhances awareness about the impact of the condition on peoples' lives

OBJECTIVES

1



Build a strong and united voice on atopic eczema

2



Collaborate with and influence other stakeholder groups

3



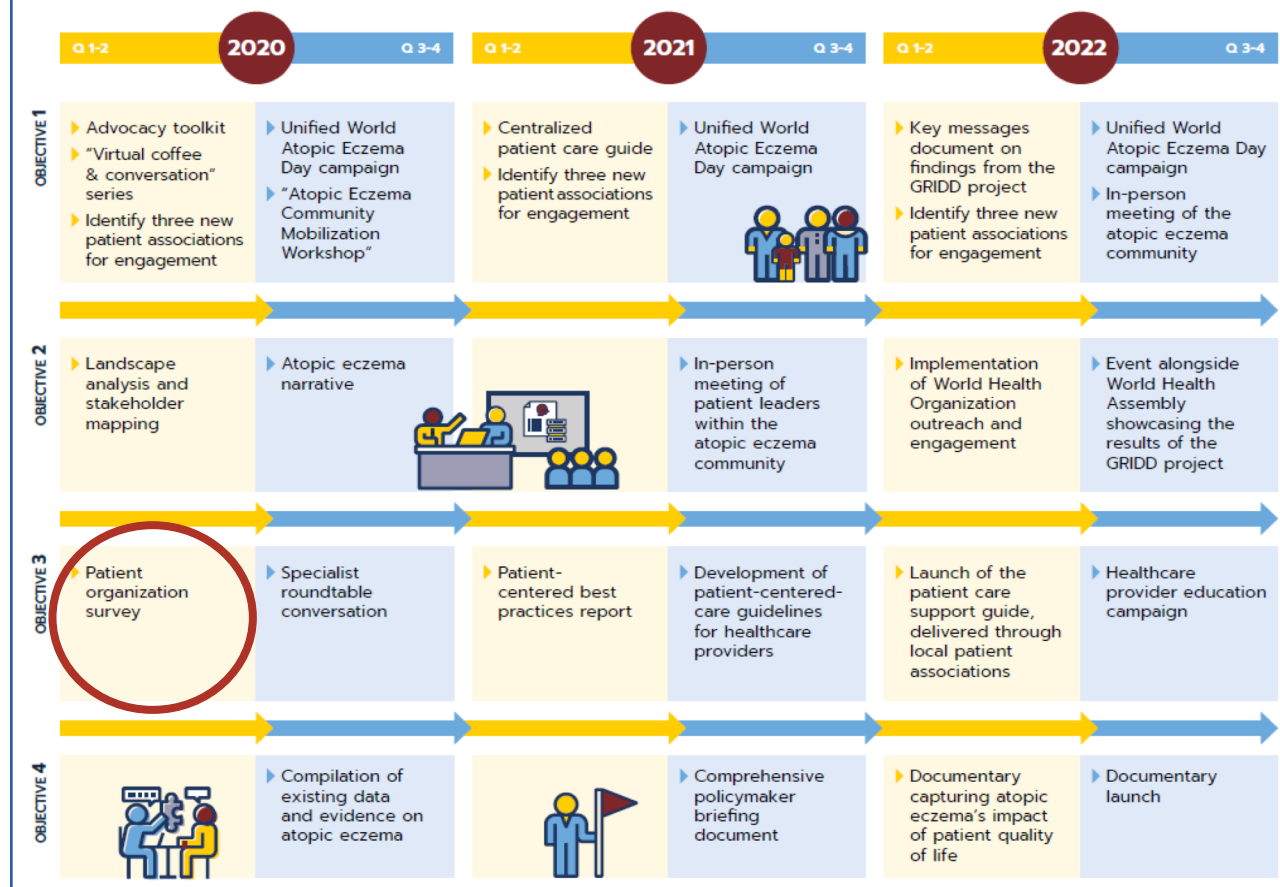
Access to high-quality, coordinated, and innovative care

4



Raise awareness of atopic eczema, its impact on patients' lives, and the needs of the patient community

Community Milestones: 2020-2022



Survey Design

Goals and Methodology



Identify patient perspectives: We surveyed 348 patients living with atopic eczema.



Identify caregiver perspectives: We surveyed 124 people providing care for atopic eczema patients.

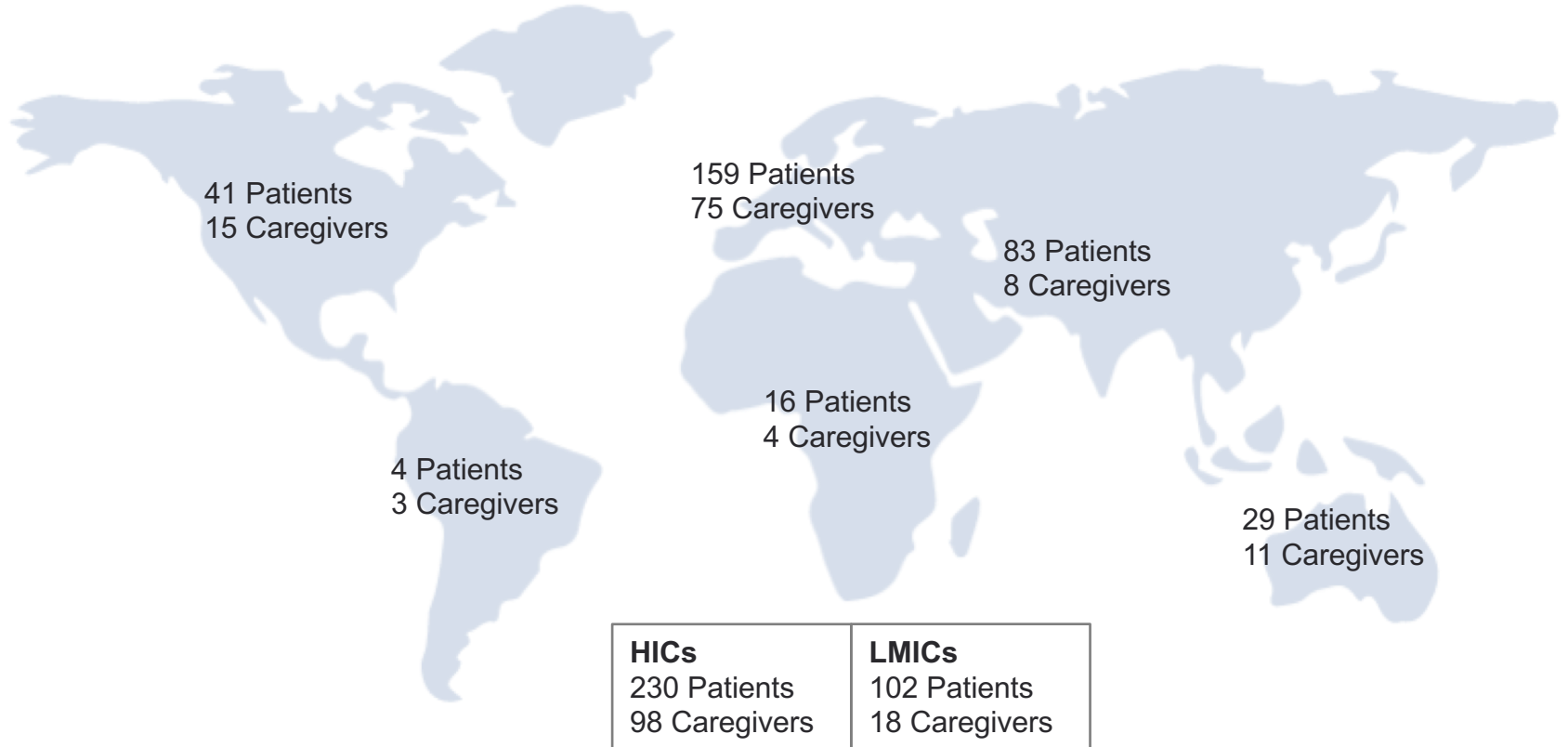


Compare patient and caregiver perspectives to identify commonalities and discrepancies



Distill the key priorities and challenges for patients and caregivers managing atopic eczema

Two Perspectives, Global Representation



Patient Survey: Demographics of Respondents



Age

18-25: 34 (10%)
26-35: 81 (24%)
36-45: 52 (15%)
46-55: 74 (22%)
56-65: 74 (22%)
66+: 27 (8%)



Gender

Female: 282 (82%)
Male: 54 (16%)
Other: 2 (0.6%)
N/A: 5 (1%)



Level of Education

No/little formal education: 8 (2%)
High school/secondary cert.: 87 (26%)
Bachelor's degree: 146 (43%)
Master's degree: 62 (18%)
Doctorate: 10 (3%)
Other: 28 (8%)

Caregiver Survey: Demographics of Patients



Age

0-4: 38 (32%)

5-12: 43 (36%)

13-17: 15 (13%)

18+: 24 (20%)



Gender

Female: 65 (54%)

Male: 52 (43%)

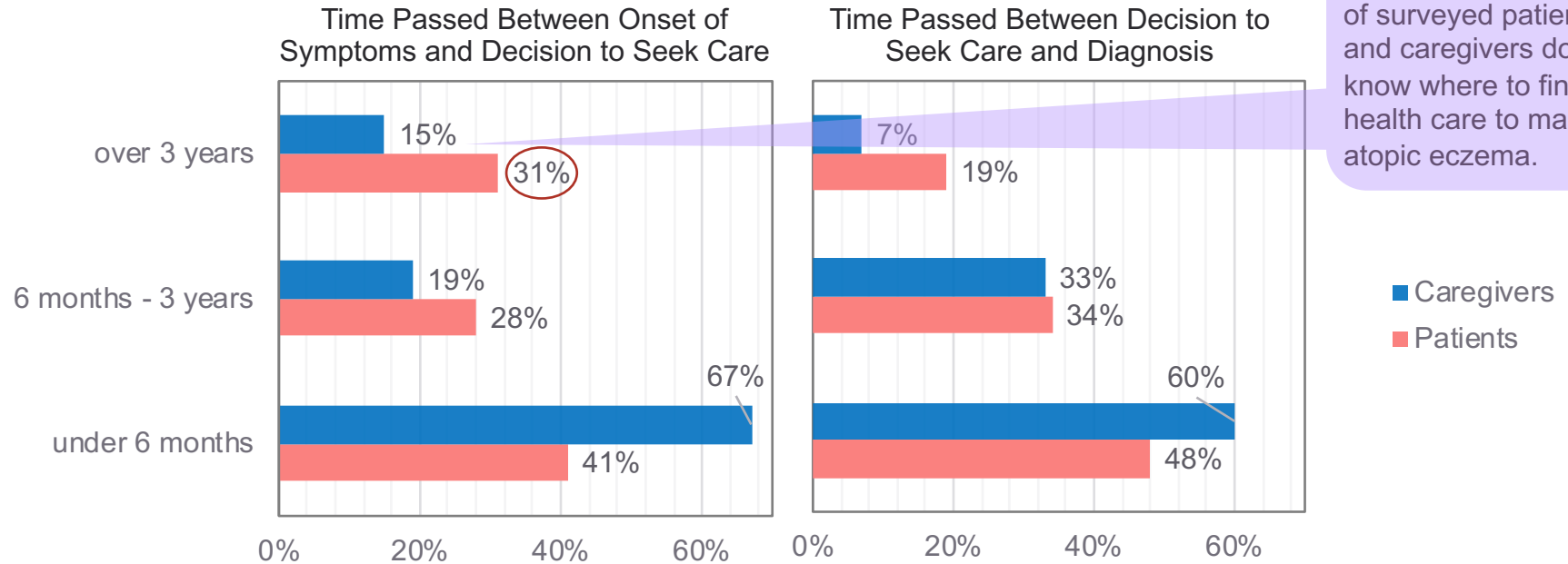
N/A: 3 (3%)

Survey Results: Atopic Eczema Care

- 1) Route to treatment
- 2) Cost of treatment
- 3) Information about treatment
- 4) Priorities and challenges concerning treatment

Survey Results: Route to Treatment

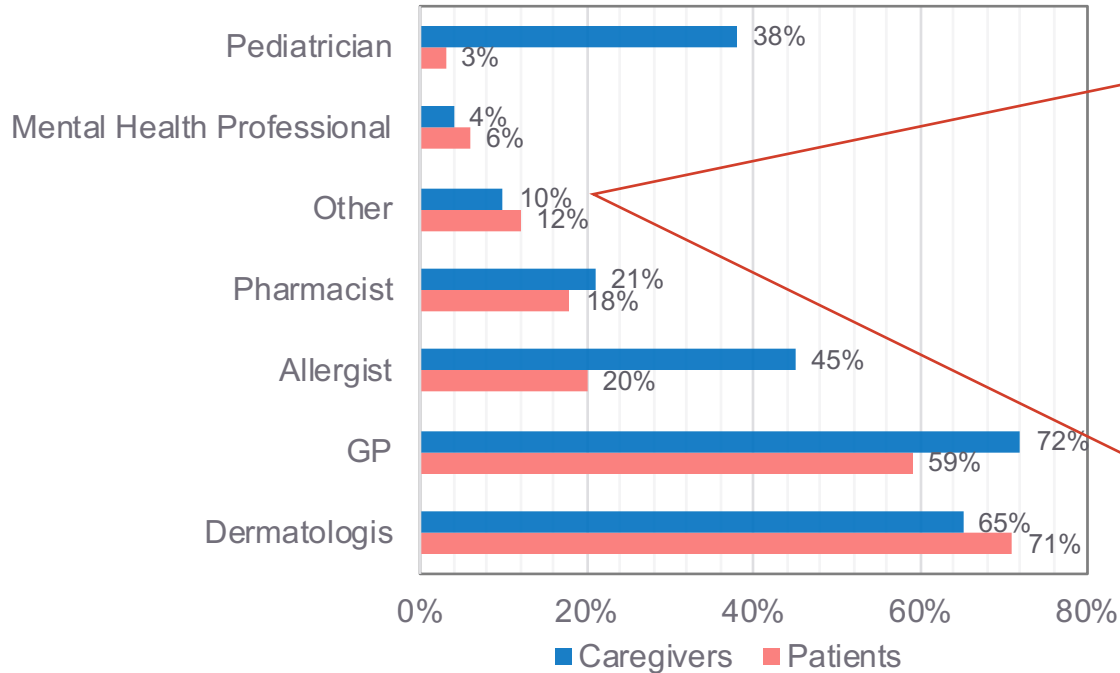
Most people are diagnosed with atopic eczema within the first year of the onset of symptoms – but there still is a need for faster routes to treatment.



Over a quarter (27%) of surveyed patients and caregivers do not know where to find health care to manage atopic eczema.

Survey Results: Route to Treatment

Patients and caregivers consult with many different health care providers to discuss and manage atopic eczema, but do not often seek out mental health professionals.



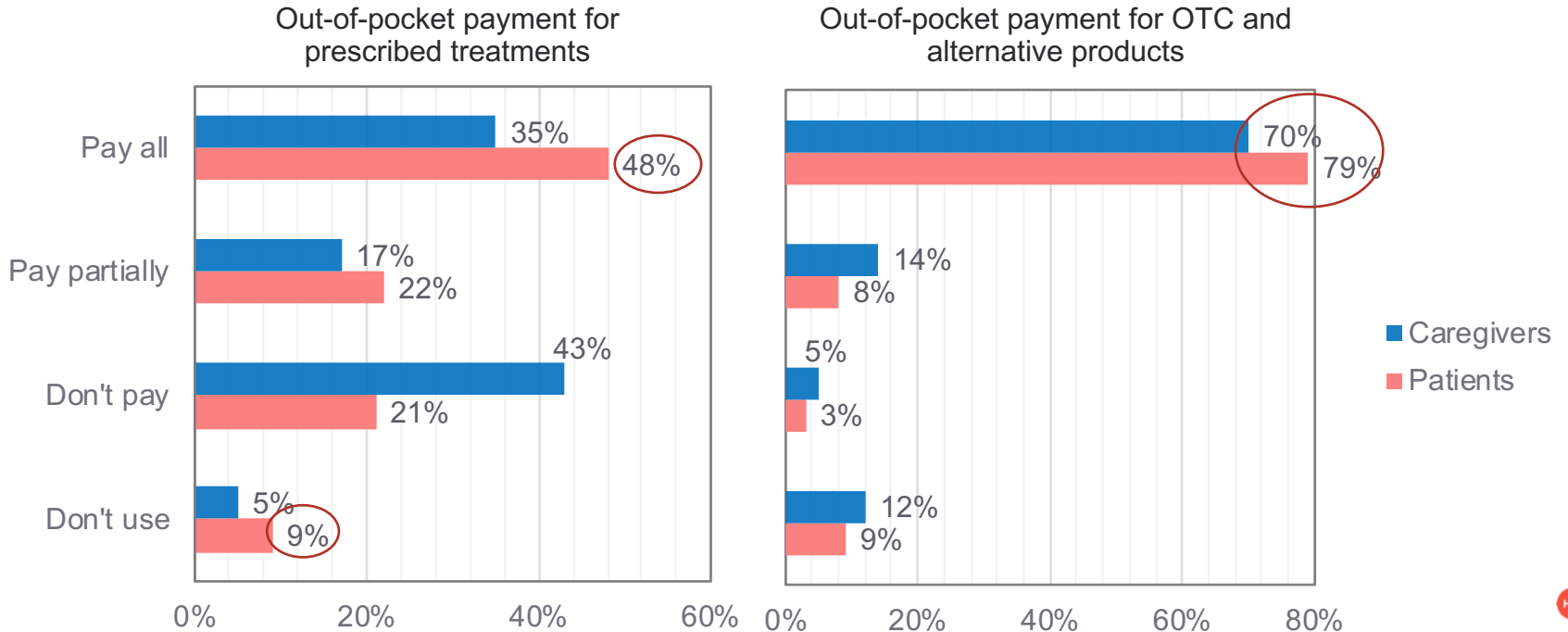
Other health professionals:*

- Herbalists
- Kinesthesiologists
- Acupuncturists
- Eczema nurse specialists (for children)
- Naturopaths

**Consulted exclusively by patients and caretakers in high-income countries, primarily the UK and Australia.*

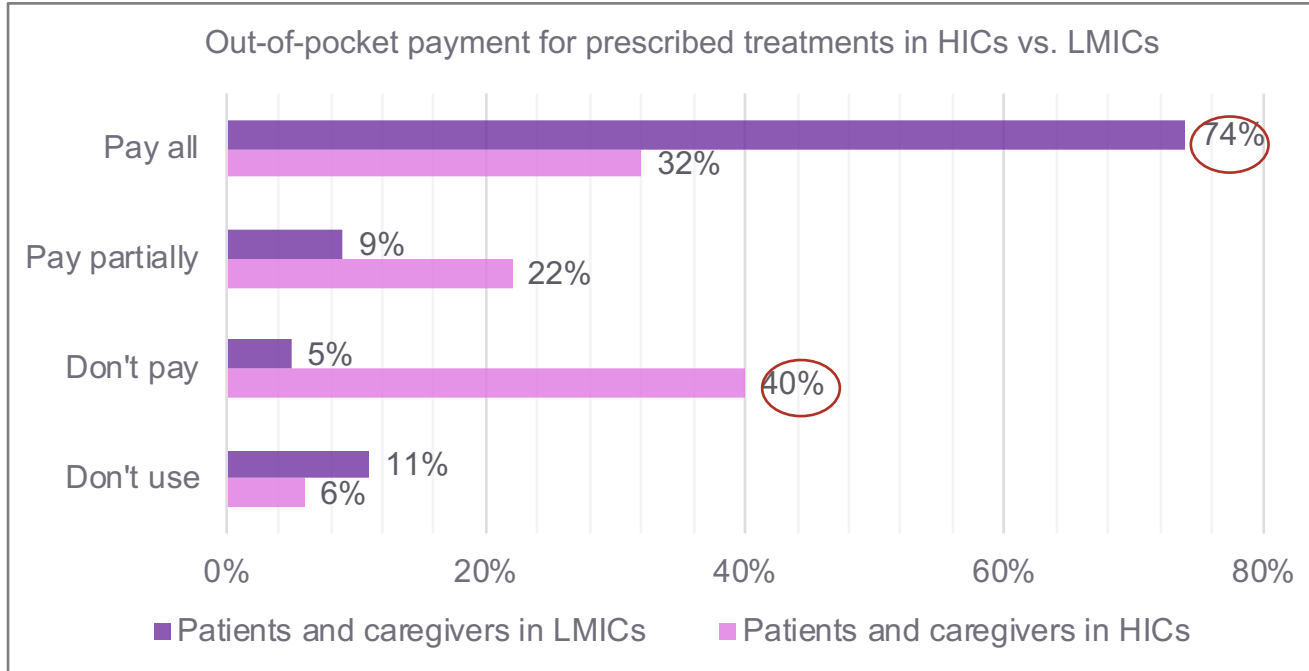
Survey Results: Cost of Treatment

Too many patients and caregivers pay for all or part of prescribed treatments out of pocket. OTC and alternative products are rarely reimbursed.



Survey Results: Cost of Treatment

Patients and caregivers in high-income countries are eight times as likely to not have to pay for prescribed treatments out of pocket. Conversely, patients and caregivers in low-to-middle-income countries are more than twice as likely to have to cover the entire cost of treatment on their own.



Over one third of respondents do not feel adequately informed about atopic eczema by their health care provider, nor know where to find educational resources to fill their knowledge gap.

35% of patients and caregivers disagree or strongly disagree that the atopic eczema care provider has clearly explained the condition to themselves and/or the person they care for



Only **37%** of patients and caregivers agree or strongly agree that their atopic eczema care provider has recommended useful resources on managing atopic eczema







Moreover, **30%** of patients and caregivers indicate that they do not know where to find useful educational resources on managing atopic eczema



Survey Results: Priorities and Challenges

Effectiveness of care emerges as top priority for both patients and caregivers concerning treatment for atopic eczema – ranked number one by 59% and 70% of respondents, respectively.

<u>Patients</u>		<u>Caregivers</u>
1	Effectiveness of care	1
2	Attitude and communication style of provider	2
 3	Cost of care	 4
 4	Convenience of visiting a care provider	 3

Availability of effective treatment and ability to see care provider emerge as top priorities concerning access to treatment

1

Availability of Effective Treatments and Medication

Over half of the surveyed patients and caregivers ranked this as their top priority.

2

Ability to see specialist in reasonable amount of time

18% of patients and 29% of caregivers ranked this as their top priority.

3

Ability to see GP or family doctor in reasonable amount of time

11% of patients and 9% of caregivers ranked this as their top priority.

4

Costs of treatment and medication do not result in financial hardship

5

Spending enough time with care provider during visits

6

Reasonable travel time to reach care provider

Survey Results: Priorities and Challenges

Availability of care provider emerges as top challenge concerning access to treatment. Patients are also challenged by the cost of treatment, caregivers more so by disagreements about best treatment plan.

<u>Patients</u>		<u>Caregivers</u>
1	Inconvenient/unacceptable wait time to see specialist	1
2	Inconvenient/unacceptable wait time to see GP	2
3	High financial burden of treatments and medication	5
4	Insufficient time spent interacting with care provider	4
5	Disagreement between different care providers on the correct plan for managing atopic eczema	3
6	Inconvenient/unacceptable distance to care provider	6

A holistic treatment plan and corresponding guidance emerge as top priority and challenge concerning diagnosis and support.

Priorities

Challenges

1 **Holistic treatment plan** that includes consideration of both atopic eczema and other physical and mental health conditions: **62%** of patients and caregivers see this as the number one patient care priority.

Unclear or ineffective guidance on prescriptions and treatment: **45 %** of patients and caregivers see this as the biggest challenge.

2 **Clear and effective guidance** on prescriptions and treatment.

Lack of attention paid to building a holistic treatment plan that includes the management of other health issues and diseases

3 **Lifestyle advice** on making changes that may improve disease

Lack of attention paid to lifestyle or behavioral changes that may impact disease

4 **Availability of educational materials** on managing atopic eczema

Lack of accessible and useful educational materials on managing atopic eczema

Key Insights and Opportunities

Key Survey Insights

Most people are diagnosed with atopic eczema within the first year of the onset of symptoms, but too many still do not receive timely diagnosis and treatment. This can be partly attributed to a lack of knowledge about where to find appropriate care.



Pave faster routes to treatment and raise awareness about where to find health care for managing atopic eczema.

The routes to treatment are numerous and sometimes unexpected. Patients and caregivers consult with many different health care providers to discuss and manage atopic eczema, but do not often seek out mental health professionals.



Engage new and different health care providers in the diagnosis and treatment of atopic eczema, and integrate mental health professionals in the treatment plan.

Too many patients and caregivers, especially in low-to-middle-income countries, have to pay out of pocket for basic treatment prescribed by a medical professional.



Develop an agenda on controlling the price and rolling out insurance for treatments of atopic eczema, with special focus on low-to-middle-income countries.

Key Survey Insights

Educational resources are underused by health care providers and patients alike.



Raise awareness about existing resources that empower people to manage atopic eczema, and make them more findable and easily accessible to health care providers, patients, and caregivers alike.

Availability of effective treatment and ability to see care provider emerge as top priority and challenge concerning access to treatment for atopic eczema.



Increase access to effective treatment by addressing wait times to see specialists, e.g., with innovative tools such as telehealth technology.

A holistic treatment plan and corresponding guidance emerge as top priority and challenge concerning diagnosis of and support for atopic eczema.



Reclassify atopic eczema as a systemic disease that requires holistic treatment as well guidance that also considers other physical and mental health conditions.

Thank You.

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