



Atopic Eczema workshop report 2020

Engaging the **Community**



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International Alliance of
Dermatology Patient
Organizations

OVERVIEW

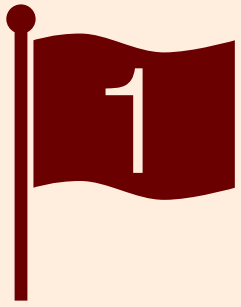


In October/November 2020, GlobalSkin organised a series of virtual workshops for the global atopic eczema community. The focus of these workshops were to develop an approach and stimulate ideas for engaging the community on issues and campaigns around atopic eczema.

The workshops were designed and facilitated by Neil Bertelsen, a former patient advocate with several decades of experience engaging communities on a variety of healthcare subjects. The workshop was split into three separate sections covering:

1. Identifying and analysing your challenge
2. Selecting and understanding the communities to work with
3. Planning an approach to engage the community

Two parallel streams of this workshop were held to accommodate time-zone differences, and this report brings together the main learning points and the outputs of both streams.



Identifying and analysing your challenge

CHALLENGES IDENTIFIED

Each working group were asked to identify particular challenges for the atopic eczema community that could form the focus of the workshop activities. The groups first developed a long-list of potential challenges which were then prioritised to find the main challenges that would be explored further in the workshop. Below is a combined summary of the challenges identified from both of the working groups:

Challenge	Who does this affect?
Atopic eczema undervalued: By both medical profession and some patients/parents	Impact and severity of atopic eczema are undervalued by multiple healthcare stakeholders Patient and parents are not believed by medical professionals - disengage from medical services Some parents don't accept that it is a chronic condition and wait for symptoms 'to be over'
Difficult to reach medical communities: With some suspicion from medical societies and clinical groups on the role of patient groups	The medical community and advocacy community both suffer from a lack of collaboration
Getting through to the community we need to help: Those not already connected to patient groups	People affected by atopic eczema are not receiving the support they could be cause they are not connected to the patient community
Reaching people in rural areas: Those not reachable by bus or car, and those without electricity (e.g. rural Kenya)	Isolated communities that are far from healthcare systems and support
Overcoming stigma for people with eczema: Particularly affects men in some communities (Kenya)	People and children with eczema Family (to overcome tension caused by stigma)
Lack of training materials: Need materials with local information and appropriate localised pictures	Advocacy - training materials HCPs – need more training Patients - need education on eczema
Impact of COVID: Chronic diseases not addressed, so diagnosis, care and appointments missed	All people with eczema (diagnosed and undiagnosed) People unwilling to go to healthcare environments
Access to treatments: Some of the newer treatments have limited or no access	All people with atopic eczema whose condition is not being controlled by current approaches
No patient-centric approach to research: So a lot of patient-relevant issues are missed	The dermatology research community needs to bring patients into the design of their studies
Misinformation in social media: Blurred boundaries between credible medical information and some of the advice offered on social media	Affects all people with atopic eczema and their families as they look for trusted sources of information

Main challenge identified:

Atopic eczema is undervalued by both the medical profession and some parents/families

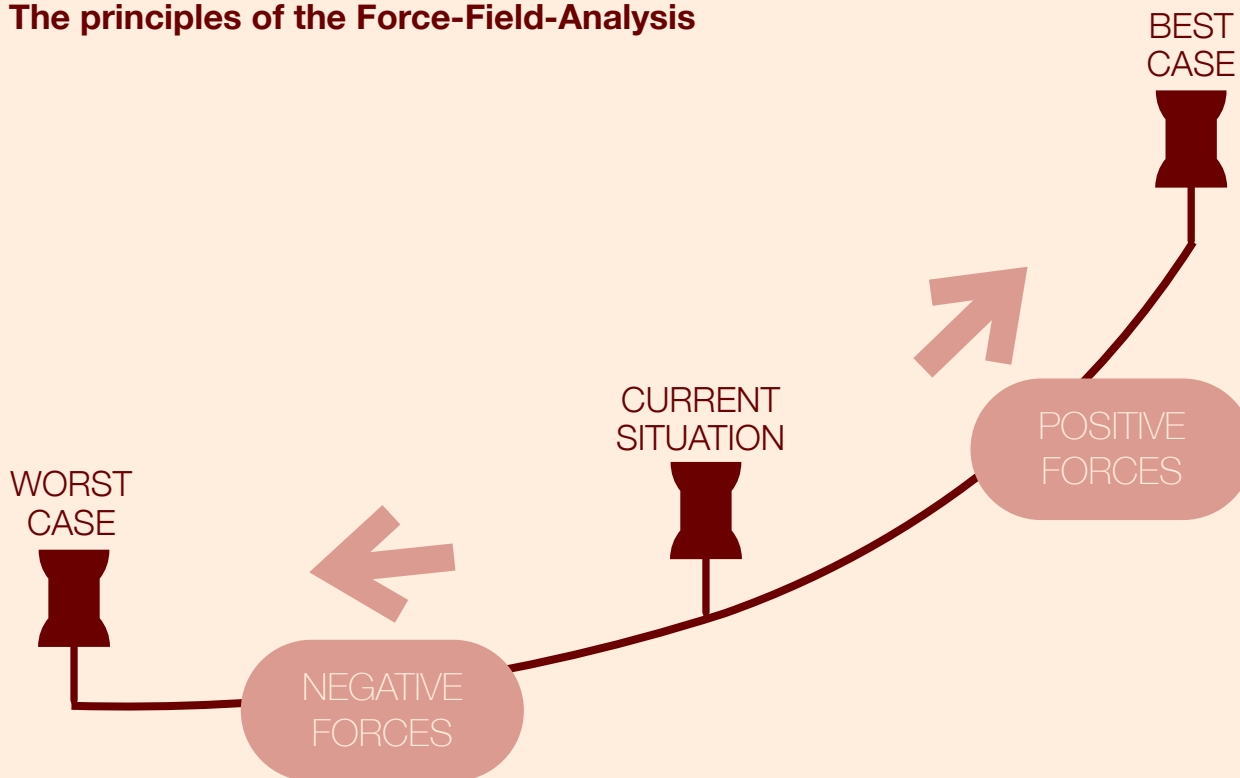
Sub-challenge:

Difficult to reach medical communities must also be addressed to meet this challenge

FORCE-FIELD ANALYSIS

Participants were shown a technique called the 'Force-Field Analysis', a way of looking at a challenge in terms of the 'situation' and the 'forces that affect that situation'.

The principles of the Force-Field-Analysis



Instructions

1. Describe the current situation - focus on the facts and what actually happens today in relation to the challenge identified
2. Describe the best-case future situation - what is the aim - what would actually happen in the future if this challenge were solved (i.e. what would the ideal future look like?)
3. Describe a potential worse-case situation - what are you trying to avoid? (i.e. If we do nothing and the situation gets worse, what would that mean for people affected by this challenge?)
4. Identify the positive forces: What are the positive trends, attitudes, actions and policies in the environment that could be leveraged to push towards the best-case situation
5. Identify the negative forces: What are the negative trends, attitudes, actions and policies in the environment that could pull back towards the worst-case situation

Analysis

The positive forces identify the trends and attitudes that can already be leveraged to help get to the goal. Different communities such as medical professionals, policy makers or the industry are often the drivers of these positive forces. The negative forces show the attitudes and trends that need to be overcome to avoid falling back. Again, these negative forces are often driven by members of the community.

ANALYSING THE CHALLENGE

Both work streams agreed that the main challenge to focus on was: **Atopic eczema is undervalued by both the medical profession and some parents/families**

RECOGNITION

Eczema completely unrecognised recognised as a chronic and debilitating disease

POOR / NO TRAINING

No specific training provided for medical professionals - leading to poor diagnosis

GUIDELINES & ADVICE

Current guidelines not followed and no patient input into new ones

FINANCIAL IMPACT

Patients expected to take an even higher burden of treatment costs

PARTNERSHIP CARE

Deterioration in relationships between patients, families and the medical profession

RESEARCH

Little or no research into atopic eczema leading to a lack of attention by the medical and scientific community

RECOGNITION

Eczema often not recognised as a chronic and debilitating disease that needs prioritisation in healthcare delivery

TRAINING / DIAGNOSIS

Takes years to be properly diagnosed due to poor training by medical professionals

Incorrect medication and creams prescribed due to poor diagnosis

GUIDELINES & ADVICE

Poor understanding of and use of current guidelines, and no route for patient advocates to be involved in developing guidelines

FINANCIAL IMPACT

High out of pocket costs incurred by patients and families with often no subsidies for these extra costs

In some countries it is expensive to see a dermatologist

PARTNERSHIP CARE

Strained relationship between physician and patients/families due to inconsistent advice and lack of belief that patients are using treatments as directed

RESEARCH

Still a lack of research priorities for eczema

RECOGNITION

Eczema recognised as a chronic and debilitating disease that needs prioritisation in healthcare delivery

TRAINING / DIAGNOSIS

More training provided (leading to better and quicker diagnosis and better care and management)

GUIDELINES & ADVICE

Clear guidelines followed so that patients know what to expect (including steroid usage)

Patient perspectives are integrated into guidelines development

FINANCIAL IMPACT

Receives same subsidies and support as for diabetes patients

PARTNERSHIP CARE

Patient centric approach to care established and practiced

RESEARCH

Centralised repository of information / research which patients and patient groups can access

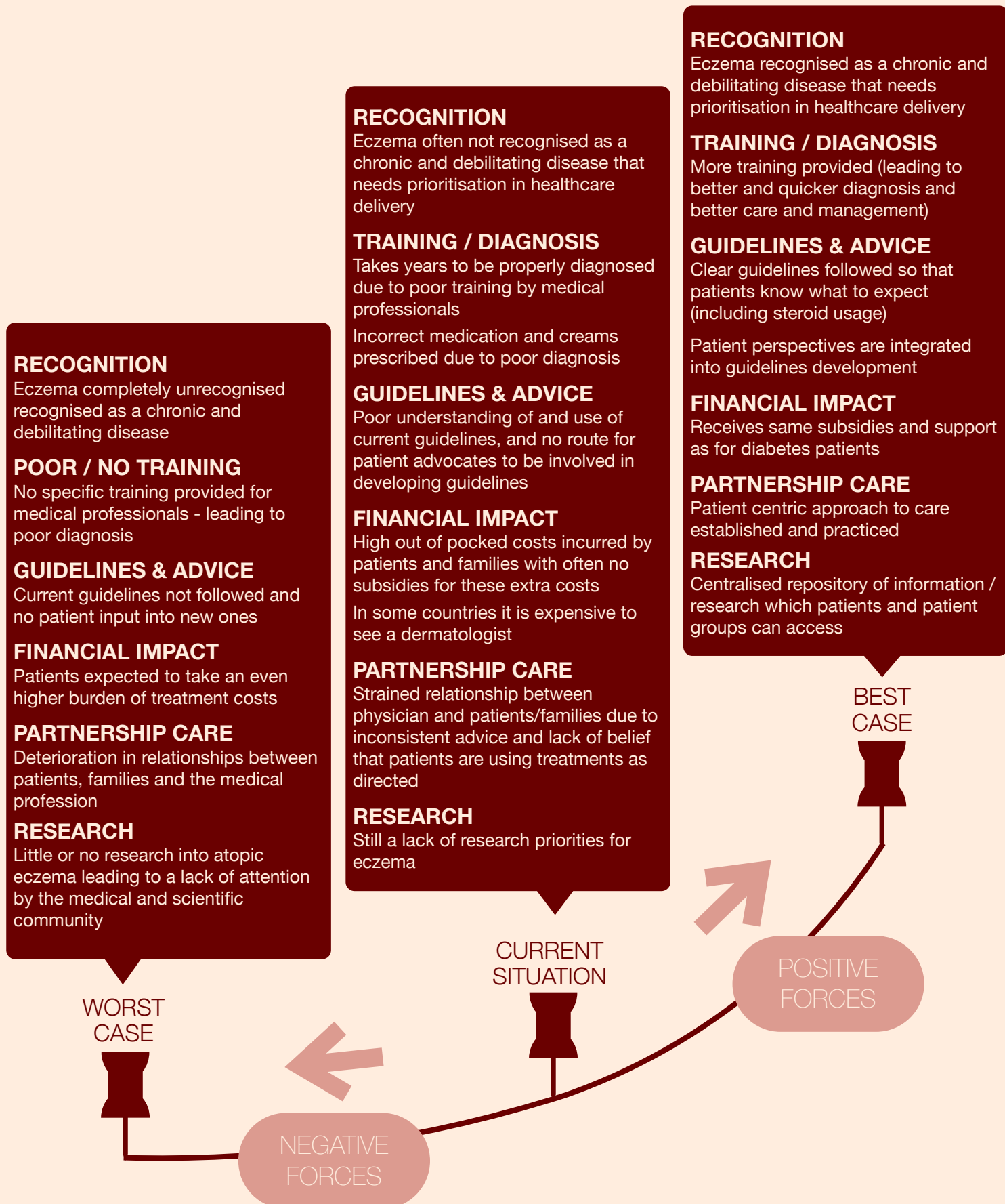
WORST CASE

CURRENT SITUATION

BEST CASE

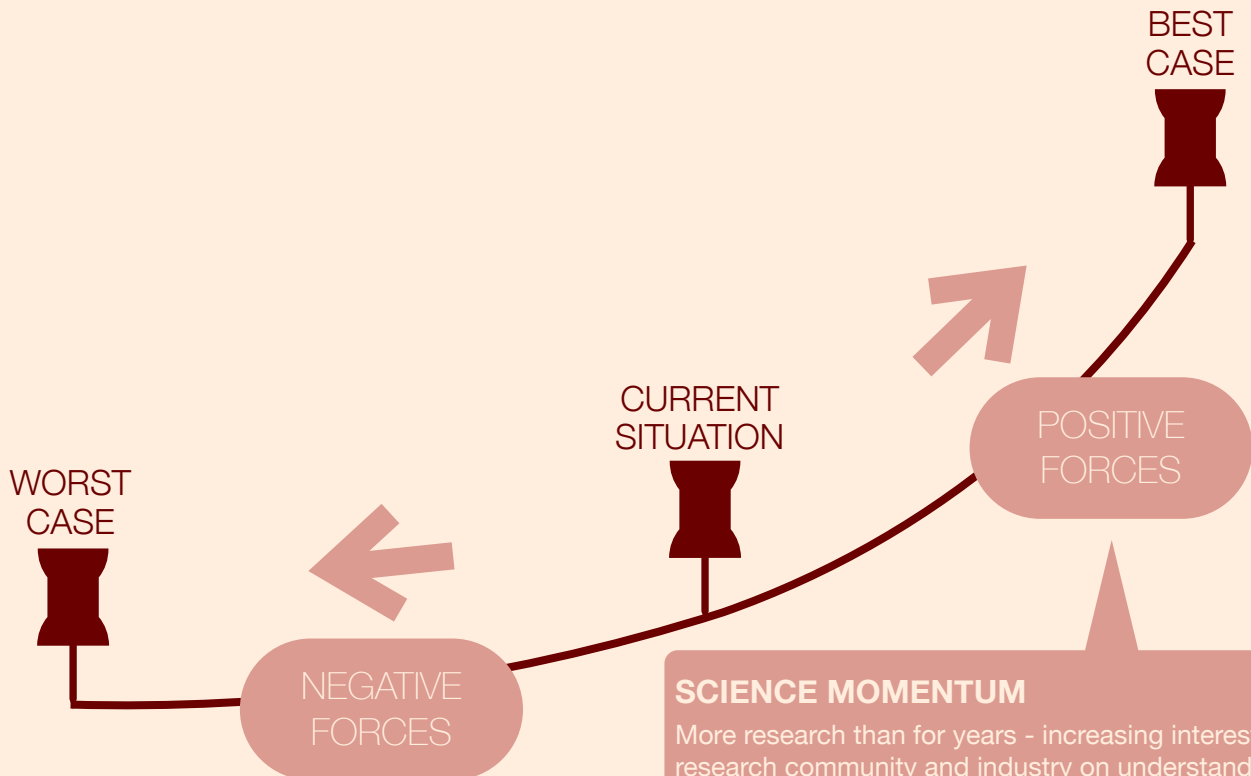
NEGATIVE FORCES

POSITIVE FORCES



ANALYSING THE CHALLENGE

Both work streams agreed that the main challenge to focus on was: **Atopic eczema is undervalued by both the medical profession and some parents/families**



HEALTHCARE SYSTEM CHAOS

- Increased fragmentation of healthcare delivery
- Move to more centralised and less personalised approach to healthcare in some countries
- Decreasing access to dermatologists and growing waiting times to see specialists
- Reducing access to treatments in some cases
- Increasing co-pays for patients

MEDICAL PROFESSION ATTITUDES

Old-fashioned attitudes from dermatologists stifle innovation and new ways of working

TRUST IN MEDICAL PROFESSION

Growing mistrust of healthcare system by some patients and parents that have been disappointed by their care

SUSPICIOUS OF PATIENT GROUPS

Suspicion from medical community (in some quarters) as patient voice increases

MISINFORMATION

Rise of social media where “Everyone is an ‘expert’” – alternative and unproven remedies

HEALTH POLICIES

Increasing lack of interest from health policy makers as diseases such as COVID and cancer are prioritised

SCIENCE MOMENTUM

More research than for years - increasing interest from the research community and industry on understanding atopic eczema and its potential treatment

Atopic eczema is becoming a ‘hot topic’

CONNECTED COMMUNITY

Becoming more connected globally with GlobalSkin taking a lead role in bringing people together

Growing body of evidence of the value of multi-stakeholder collaborations driven by work in other disease areas

NEW GENERATION OF DOCTORS

The younger generation of doctors seem more motivated to embrace the patient groups and to work collaboratively to make change happen

TREND FOR INDIVIDUALISED CARE

In some countries and internationally there is a growing recognition of the value of personalised care

HEALTH EQUITY

Within nations and across borders, there is a growing focus on reducing health inequalities, especially for children and the poorer members of society

GUIDELINE DEVELOPMENT

Moves by scientific societies such as Guidelines International Network (GIN) to promote patient involvement in guideline development



Community identification & mobilisation

PRINCIPLES

Workshop participants explored the principles of community mobilisation and the critical success factors that are needed for successful partnership with other members of the healthcare eco-system and society.

Why do we need to engage with communities?



Principles of engagement

1

BE CLEAR ON WHO YOU NEED TO ENGAGE

Define the problem you are trying to solve

Identify the stakeholders involved in the problem and potential solutions

Select the communities that can most impact the solution

2

UNDERSTAND WHAT WILL MOTIVATE THEM

Understand their goals to determine where there are shared goals

Be respectful of their barriers or challenges

Clearly define areas and roles that help both sides achieve success

3

MAKE IT EASY TO TAKE PART

Make the 'ask' simple, clear and actionable

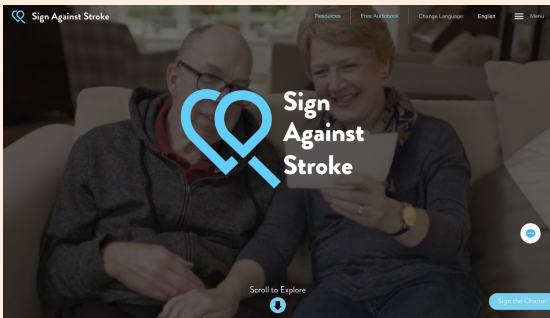
EXAMPLES

A range of real-world examples of activities., driven by patient groups, to engage with and mobilise different communities were explored:

1

SIGN AGAINST STROKE

<https://en.signagainststroke.com>



Target community: General public

Learning from this example: The general public want to do good things, but want it to be easy. In three words, 'SIGN', 'AGAINST' and 'STROKE' this campaign explained exactly what the ask was and made it as easy as a few clicks to take action

2

IN MY SHOES

<https://www.ittakesguts.org.uk/share/in-my-shoes-app>



Target community: Family of someone with Chron's disease

Learning from this example: Family members are prepared to devote more time and effort to understand what a loved one is going through. This example helped family members to understand a chronic condition by being reminded of its effects over a 24 hour period. The technique could be applied to other chronic conditions

3

CHAMPIONS OF CHANGE

<https://www.tht.org.uk/our-work/community-projects/champions-change-bristol-based-project>



Target community: Black and ethnic minorities

Learning from this example: Sometimes even national charities learn that the best way to make change happen is locally. This example took a city-wide approach to identify and provide skills to community leaders in one city. This allowed them to leverage existing communities and individuals rather than try to build a new community

POTENTIAL COMMUNITIES

Participants explored all the stakeholders that could be involved in solving the challenge: **Atopic eczema is undervalued by both the medical profession and some parents/families.** The first task was to build a long-list of potential communities to work with:

Community	Rationale
Patients and families	Intimately affected by this challenge Can act as a multiplier to reach others
Healthcare professionals: <ul style="list-style-type: none">• Dermatologists• Paediatricians• Allergists• General family doctors• Nurses• Pharmacists	Are the stakeholders that need to take action Can provide training to other healthcare professionals Can make connections to other healthcare professionals Connected to policy makers
Policy makers / government members	Can raise the issue up the agenda Have the power to change policies Can control funding for training
Hospital administrators	Can provide the right conditions for change Can provide better pathways for patient care Have the power to reduce waiting times
Pharmaceutical industry	Have more resources to affect change Have the science knowledge for new innovations Are connected to multiple stakeholder groups Are already working with the patient community

Both working groups were tasked with reducing this list of communities to a maximum of two communities. This was to ensure that focused and targeted approaches could be developed in the workshop that would key into the needs and motivations of target stakeholder communities.



MOTIVATING COMMUNITIES

Before determining an activity or campaign, it is important to understand what motivates the community you plan to partner with. In the workshop, the working groups developed a list of motivators for the identified stakeholders that should be considered when designing an approach:



- Want a better relationship with patients
- Genuinely want to deliver better outcomes
- Want to overcome frustration in being unable to deliver meaningful benefits to patients
- Want to overcome misinformation / myths
- Need better materials to give patients
- Want to educate their peers
- Want to be seen as an expert amongst peers
- Want to be at the forefront of new science

- Care about their loved ones
- Want to learn more about the condition
- Want to 'do the right thing' in terms of support
- Want to avoid unintentional insensitivities

Those also with atopic eczema themselves

- Want to feel less isolated - part of the community
- Want a better quality of life for their children
- Want to overcome stigma

Families of those with atopic eczema looking to support their loved one more



In the workshops the groups discussed these motivators and decided that a separate approach was needed to engage the medical professionals than the families and those living with atopic eczema. Each group worked independently, but came up with very similar project ideas that could be considered and taken forward.



Project ideas to engage communities

IDEAS FOR PATIENTS/FAMILIES

1

LISTEN - SUPPORT - ADAPT

Guidance for families of people with atopic eczema built from real-life experiences of those with atopic eczema to educate families on how to offer support that builds confidence and quality of life

LISTEN

A resource and guidance using videos and real life experiences that encourages families to:

- **Listen** to the people they care about
- **Pay attention** to their needs daily
- **Understand** how a person with AE would like to be supported

SUPPORT

Detailed guidance and examples of everyday situations that helps families and carers to avoid common mistakes:

- **Library of common experiences** where people with AE feel unsupported or stigmatised
- **Examples** of how to show support in a way that is valued by a person with AE

ADAPT

Guidance and real examples on how to adapt environments to ensure that people with AE have a better quality of life:

- **Reduce stress** in the home
- Choose **household products** that reflect the needs of someone with AE
- **Examples** of how to change the environment for the better

2

ATOPIC ECZEMA STARTER-PACK

A trusted source of information, advice and general tips for living with atopic eczema. To be given by doctors to newly diagnosed patients or family members and developed in partnership with medical professionals

DEVELOP

Work with dermatologists and paediatricians to develop the trusted and credible content

- **Disease knowledge:** So that patients and families understand the chronic nature of the condition
- **Myth busting:** To overcome some misconceptions about atopic eczema
- **Self-care:** To ensure that patients and families understand how to care for themselves or their loved one

STRENGTHEN

Through co-developing the resources, strengthen the relationship between the patient group community and the healthcare professionals

Through providing resources that give credible and trustworthy information, strengthen the trust between the patient/family and the treating healthcare provider

REFER

Use starter-pack as a route to have patients signposted to and referred to patient groups.

Physicians cascade the materials through their networks and the patient groups do the same.

Each person receiving a starter pack is given the information and contact details of the relevant local patient group in the materials

IDEA FOR HCPs

1

TRAINING FOR GENERAL FAMILY DOCTORS & PHARMACISTS

A training course delivered jointly with dermatologists and paediatricians and developed jointly with the patient community to encompass both the clinical and the patient quality of life aspects of treating AE

The working group spent much time fleshing out this training idea, building an action plan of steps to implement it. The main goal was to overcome poor clinical knowledge at the family doctor practices and in the pharmacists and to ensure that doctors understood the needs of patients and the frustrations of managing AE when supporting them.

LOCAL APPROACH*

Identify a city where a training approach can be developed and piloted.

Identify a dermatologist and paediatrician in that city to partner on the development of the training materials

Build an advisory board of those whom would receive the training (family doctors and pharmacists) from the city in question

Jointly develop the training approach and content with advice from the advisory board to steer the content

ROLL OUT

Before roll-out benchmark the patient experience in that city using a survey

Roll-out the training locally in the city, perhaps in a district by district approach to ensure local networks of both pharmacists and family doctors are strengthened

Assess the impact of the course with a post-training survey of patients against the original benchmark set at the start of the project

EXPAND

Take the materials and learnings from the pilot to other cities

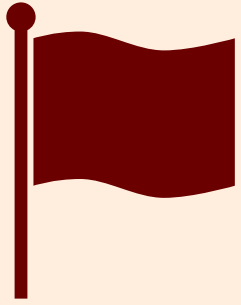
Work once again with local dermatologists and paediatricians to revise materials and format for local needs

Engage target stakeholders of family doctors and pharmacists at the local city level to ensure that the format and content of training still meets local needs

Build case studies across several cities before considering to spread nationally

Ensure paediatricians and dermatologists are promoting this work in the professional networks nationally too

* **LOCAL versus NATIONAL:** The working group debated the merits of starting nationally with this type of activity and then pushing this down to the local level. It was noted that this has been attempted several times, and it has proved hard to get traction at the local level using this approach. Hence this is the reverse idea - starting very locally and expanding from there by leveraging local networks of HCPs to co-develop the solutions and co-deliver it with the patient group community



Report Ends