Poster #1149

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International Alliance of Dermatology Patient Organizations

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The patient voice in atopic eczema guidelines: How do we make it standard practice?

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Learning objectives

- **To understand the important role that patient and caregiver input can have to clinical guideline development and implementation in atopic eczema (AE)**
- **To explore the barriers that need to be overcome to facilitate more patient and caregiver involvement in AE guidelines**
- **To learn the key steps that need to be taken to improve the rates of patient and caregiver involvement in AE guideline development and implementation**

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Key Takeaways

1. **Owing to the high disease burden of atopic eczema (AE), it is vital that clinical guidelines incorporate the patient perspective and reflect the priorities of individuals with the condition. However, only a minority of current AE guidelines do so**

2. **While much general guidance on patient involvement (PI) is applicable to AE, there are disease-specific factors that require particular attention including its heterogeneity and psychosocial impact. These need special consideration**

3. **All relevant stakeholders need to work together to overcome barriers to PI and ensure the development of guidelines that are culturally, racially, socially, and geographically appropriate for the population they serve**

Patient and caregiver involvement in guidelines

Introduction

Patient and caregiver involvement in developing clinical guidelines is widely recommended. However, among current atopic eczema (AE) guidelines, only a minority incorporates the patient perspective.

- There are specific factors to consider in order to embed sustainable PI in the AE guideline development process.
- These include the selection of patients and caregivers to represent the heterogeneity of the disease and of the patient experience.
- AE patient priorities and feedback can differ from those of healthcare professionals (HCPs) and are central to shaping the recommendations, research and implementation that form part of the guideline cycle.

The context: A political will to improve dermatological conditions

- In May 2025, the World Health Assembly (WHA) passed a resolution mandating a global action plan on skin diseases that encompasses prevention, treatment and care, equitable access to services and the integration of skin health into broader health systems [1].
- Clinical guidelines are likely to play an important role in the formation and implementation of such a plan, providing evidence-based recommendations that support optimal patient care.
- It is broadly agreed in clinical guideline standards that patient and caregiver involvement is an essential element of the development process [2-5]. The patient community likewise advocates for patients to have a voice in the decisions that shape the healthcare they receive [6].

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The value of patient involvement in guidelines

Patients and caregivers add important knowledge, context and insights to help shape guidelines

- In 2019 an estimated **171 million people globally were living with atopic eczema (AE):** a disease characterised by itching and scratching, poor sleep quality, occupational limitations, low self-esteem, social isolation, and depression and anxiety [7-10].
- **Patients and caregivers bring a first-hand account of the disease**, its physical and psychological impact, the practical adaptations necessary in daily life and of the care they receive. Their views may complement healthcare professional (HCP) experience and the published evidence or may offer insights and perspectives that enable recognition and better understanding of aspects that are not evident to medical specialists [3, 11].
- **Priorities and preferences of patients with AE can differ from those of the clinicians** who are treating them [12,13].
  - Patients surveyed in the Asia–Pacific region placed greater emphasis on the prevention of exacerbation, minimising adverse treatment effects, and improvements in mental health than dermatologists did [12].
  - Divergent emphases between parents of children with AE and their GPs in the UK included a parental focus on the psychosocial impact whereas GPs focussed on the appearance of the skin [13].
- **A guideline developed with PI can take the patient perspective into consideration when forming recommendations**. The 2023 Joint Task Force on Practice Parameters (JTFPP) guideline, which was developed with PI, cites patient preference as a factor that shaped several recommendations: against adding topical ruxolitinib over continued usual care alone, for example [14,15].

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Considerations for patient involvement in AE guidelines

Barriers to PI in terms of resources or healthcare policy need to be addressed so that patients and caregivers can be active participants in developing guidelines that are culturally, racially, socially, and geographically appropriate

Patient and caregiver recruitment

AE is clinically heterogeneous with considerable variation in severity and patient experience [16]. While patient representatives may not be able to represent the entire patient population, **criteria are required to select appropriate patients to be members of a guideline development group** (GDG)

Support and enabling patient involvement

As with any patients and caregivers involved in guideline development, **those living with AE require support to facilitate their participation** [17,18]. This includes the provision of role descriptions, training to increase understanding of research methods, clear communication at the outset around expected workload, time and location of meetings [19-21]. Patients may require support that gives them confidence to make their voices heard.

Patient involvement in research

Patient knowledge cannot be translated into clinical practice by PI-informed guidelines alone. PI is also central to the research on which the guideline is based and to the implementation process [22]. **Without PI in the research base, a guideline may fail to reflect patient priorities and experience**.

Communication at all levels to support implementation

Communication between patients, caregivers and HCPs is essential for effective guideline implementation. A joint implementation and dissemination plan between the medical society and patient advocate community may help with access and provision of patient education resources that use plain language to support key guideline recommendations. Establishing a patient feedback loop can serve to address confusion or omissions.

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Call to action

In support of the WHA mandate for a global action plan on skin diseases, we call on all members of the AE community to work together to identify and address barriers to PI, creating a climate where the contribution of patients and caregivers to AE guideline development becomes standard practice

Work to increase awareness of the patient perspective in AE and secure resources for guidelines with patient involvement

- **Instigate training modules** to prepare patient partners for work on guideline committees
- **Clear and timely calls to the patient community for 'expressions of interest'** to be involved in guideline development
- **Ensure diversity among patient partners and in guideline development groups** (age, background, ethnicity, gender, AE experience, rural/urban). Communicate requirements of patient partner involvement in terms of time and travel. Offer financial and other support (IT, training) as required
- **A mentor/liaison to work with patient partners** and answer any questions they have, ensuring they are aware of the scope of their involvement prior to the start of the project
- **Meetings structured with clear ring-fenced agenda points** to gain the patient perspective
- **Ongoing evaluation of the collaborative process** with a prompt response to any changes required
- **A joint implementation/dissemination plan** between the medical society and patient advocate community, post guideline publication, along with a plain language summary of/resources to support key guideline recommendations

Declaration of conflict of interest

- **Bernd Arents** has no relevant financial or non-financial interests to disclose
- **Korey Capozza** Korey Capozza has received advisory board payments from Incyte, Amgen, Pfizer, and Astria and is employed by Global Parents for Eczema Research
- **Ncoza C Dlova** has no interests relevant to this poster to disclose
- **Melanie Funk** Melanie Funk is Managing Director of Eczema Support Australia, a national patient organisation that is mentioned in this poster. The organisation has received grant funding from the Alliance of Dermatology Patient Organizations (GlobalSkin) to support patient education and advocacy projects, including a grant for activities surrounding World Atopic Eczema Day. Melanie received no personal financial compensation for participation in this work
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