

## **Adult Atopic Dermatitis Patient Engagement Strategy: a Tertiary Care Case Study**

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**Introduction:** Patient engagement is widely acknowledged to enhance patient satisfaction, physician satisfaction, and healthcare overall<sup>1</sup>. While multiple patient engagement initiatives exist across Canada, little is known about best practices and impacts of meaningful patient engagement in atopic dermatitis. Atopic dermatitis (AD) affects many but to various capacities and degrees over time; the heterogeneity of this chronic condition coupled with the heterogeneity of its quality-of-life burden affirms the need for true patient engagement in bettering AD care<sup>2</sup>.

**Purpose:** To describe and evaluate the evolution of the Eczema Quebec clinic as the first patient-centered, community-based, adult atopic dermatitis tertiary care clinic and support network in Canada.

**Methods:** Using the Strategy for Patient-Oriented Research (SPOR) Patient Engagement Framework<sup>3</sup>, Eczema Quebec was evaluated through the following 6 outcome measures: 1) Inclusive Mechanisms and Processes; 2) Multi-Way Capacity Building; 3) Multi-Way Communication and Collaboration; 4) Experiential Knowledge Valued as Evidence; 5) Patient-Informed and Directed Research; and 6) Shared Sense of Purpose.

**Results:** 1) Inclusive Mechanisms and Processes were ensured via the creation of a Patient Advisory Committee, in response to: a) the clinic's need to establish an official, meaningful patient partnership; and b) the need for patient partners to identify topics of interest and priorities for improved AD healthcare and health delivery. 2) Multi-Way Capacity Building took place through the clinic's multi-disciplinary board, including representatives from all major AD care stakeholders: patients, dermatologists, primary care doctors, nurses, medical students, and basic science researchers. Capacity building took place through bidirectional skills-based workshops and trainings held amongst stakeholder groups. 3) Multi-Way Communication and Collaboration are explicit goals during monthly Eczema Quebec meetings, with focus on creating a supportive, safe environment that promotes honest interactions, cultural competence, and patient empowerment. 4) Experience Knowledge Valued as Evidence is honoured via regular social media outreach to patients and patient families for testimonials, stories, and feedback. Eczema Quebec also hosts support groups for patients living with eczema, and holds focus groups to elicit perspectives from its patient population community. 5) Patient-Informed and Directed Research takes place via multiple active research projects that are informed and directed by patients. Two examples include a) a case series on AD presentation in skin of color informed by patients, and b) the creation of an AD mobile app (co-led by a hired, full-time patient partner), currently under development with patient engagement via feedback focus groups and surveys. Finally, a 6) Shared Sense of Purpose is regularly expressed by all members of the clinic team, working towards the common goal of improving AD research and care quality for people living with AD, not only for the Quebec context but also for the larger national and international community.

**Discussion:** The evolution of Eczema Quebec offers an example of a specialty AD clinic that has successfully and meaningfully engaged patients according to the SPOR Patient Engagement

framework in the design, implementation, and interpretation of AD care. Establishing patient partners and advisory committees ensures sustainable longitudinal partnership with patients at the decision-making level. It is important to continue analyzing the progression and evolution of this patient partnership, and to quantify the impact that Eczema Quebec is having for AD patients and providers alike.

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