

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

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INTRODUCTION

- Patient engagement enhances patient satisfaction, physician satisfaction, and healthcare overall¹
- The heterogeneity of the atopic dermatitis (AD) disease coupled with the heterogeneity of its quality-of-life burden affirms the need for true patient engagement in bettering AD care²
- Little is known about best practices for meaningful patient engagement in AD

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 Framework³, Eczema Quebec was evaluated through the following six 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
- 6) Shared Sense of Purpose

RESULTS

1) Inclusive Mechanisms and Processes

- Creation of a Patient Advisory Committee, in response to:
 - Clinic's need to establish an official, meaningful patient partnership
 - Need for patient partners to identify topics of interest and priorities for improved AD healthcare and health delivery

2) Multi-Way Capacity Building

- Multi-disciplinary clinic board, including representatives from all major AD care stakeholders:
 - Patients
 - Dermatologists
 - Primary care doctors
 - Nurses
 - Medical students
 - Basic science researchers
- Capacity building through bidirectional skills-based workshops and trainings between stakeholder groups

3) Multi-Way Communication and Collaboration

- Communication and collaboration are explicit goals during monthly Eczema Quebec meetings
- Focus on creating a supportive, safe environment that promotes honest interactions, cultural competence, and patient empowerment

4) Experiential Knowledge Valued as Evidence

- Regular social media outreach to patients and patient families for testimonials, stories, and feedback
- Host support group events for patients living with eczema
- Hold focus groups to elicit and understand perspectives from Eczema Quebec's patient population community

5) Patient-Informed and Directed Research

- Multiple active research projects:
 - Informed by patients:
 - Atopic dermatitis presentation in skin of color
 - Directed by patients:
 - 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

6) Shared Sense of Purpose

- Shared sense of purpose is regularly expressed by all members of the team: working towards the common goal of improving AD research and care quality for people living with AD, not only for Quebec but also the larger national and international AD community

DISCUSSION

- Eczema Quebec offers an example of a specialty tertiary AD care clinic that has successfully and meaningfully engaged patients according to the SPOR Patient Engagement framework
- Establishing patient partners and advisory committees ensures sustainable longitudinal partnership with patients at the decision-making level
- Future directions include:
 - Analyzing the progression and evolution of this patient partnership
 - Quantifying the impact that Eczema Quebec is having for AD patients and providers alike

REFERENCES

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