

# CROWDSOURCING THE WISDOM OF PATIENTS:

## FINAL REPORT TO THE NATIONAL ECZEMA ASSOCIATION

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### **Executive Summary**

Patients report significant distress associated with living with moderate to severe eczema, which has a very negative impact on quality of life. Patients with difficult eczema often experiment with a wide range of treatments, which may be a reflection of the limited number of effective therapies available. However, the results of their isolated experimentation are unlikely to be shared more globally with a wider audience of clinicians, researchers, or other patients.

Social media provides a channel for patients to share their experiences across a broader community. For this project, we sought to tap into this “wisdom of the crowd” by culling patient and caregiver chatter from online social networks using a Natural Language Processing technique called topic modeling. A key advantage of this approach is that it capitalizes on technology and analytics designed to make sense of “natural”, inconsistent language. This approach allows for open-ended inquiry whereas typical qualitative approaches are limited to answers to pre-defined questions and do not capture behavioral data that does not fit this structured questioning.

We used this computer modeling approach to structure and analyze the free-form, patient commentary so that it could be analyzed thematically. We applied the same approach to recently published research on eczema extracted from the PubMed database.

In so doing, we aimed to describe topics and issues of importance to patients, and to catalogue the range of treatments used or tried by eczema sufferers. Additionally, we

sought to compare and contrast topics discussed by patients to those mentioned in research literature, and to highlight topics that may warrant future research attention.

Our project produced two sets of results. First, the analysis of patient comments alone yielded 37 final topics that emerged from the more than 10,000 online posts. Patients discussed a wide array of issues, and the most commonly raised topics dealt with issues related to topical treatments, concerns with steroid treatments and diet (in that order). Patients and caregivers discussed treatments commonly recommended by clinicians (steroids, creams, ointments), but also a wide range of alternative treatments which were less prevalent in the overall comments, but reflect the diversity of treatments currently used by patients with eczema.

Second, when we combined the patient comments with research literature culled from PubMed, we found that published articles focus on a more narrow group of topics that each have higher prevalence rates in comparison to the topics discussed by patient communities which highlighted a much wider array of topics. The most salient topics from the research literature include: skin immunology, research on risk factors, and genetic markers and variants. In contrast, these topics were rarely mentioned by patients. Similarly, the topics most salient in the online patient comments (for example, concerns about the side effects of steroid treatments and dietary intervention) were less prominent topics covered in the research literature.

NLP techniques like topic modeling can highlight novel patient insights, experiences, and priorities associated with living with a difficult-to-treat dermatological condition and offer direction for future patient-centered research.

## **Introduction**

Approximately 10-20% of children in the U.S. have been diagnosed with eczema in the first decade of life (Shaw, Currie, Koudelka, Simpson, 2003; Krakoski, Eichenfield, Dohil, 2008). Childhood eczema is associated with serious morbidity for the patient and family. Intense discomfort, sleep disturbance, depression, and difficulty in school have been documented among children with the condition (Beattie & Lewis-Jones, 2006). In turn, parents of children with eczema report high levels of psychological stress and difficulty managing the disease (Su, Kemp, Varigos, Nolan, 1997).

Moderate to severe eczema is not well understood. Standard therapies alone often fail to resolve symptoms and research science is lacking due to the small number of

patients -- approximately 2% of children with eczema fall into this non-responsive group (McAleer & Irvine, 2012).

As a result, caregivers of children with moderate to severe eczema commonly experiment with a wide range of therapies – some with a basis in research science; many with little evidence to support efficacy. A survey of 80 caregivers to children with atopic dermatitis found that 43% had tried an alternative therapy (herbal, homeopathic, or complementary medicine) (Hughes, Ward, Tobin, Keegan, and Kirby, 2007). A separate survey found that 54% of patients reportedly used complementary medicine because conventional treatment was not working (Johnston, Bilbao, Graham-Brown, 2003). However, little is known about the full range of treatments used by patients in the “real world”.

Over the past two decades, use of social media sites and online health communities has exploded. The allure of these sites for patients is a chance to connect with others facing similar challenges, to learn about treatment and management options, and to find social support. Comments posted online often document patients’ experience with specific treatments and strategies – conventional, experimental, and alternative. The use of web-based technologies to compile and analyze vast amounts of patient-generated data, allows for the aggregation of these unstructured, individually-driven insights into a more powerful view. It may also provide leads for future directions in clinical research.

## **Methods**

Using topic modeling and machine learning techniques, we aggregated and analyzed patient comments (or “posts”) from 7 publicly-accessible, US-based, online patient communities posted between April 2011 and October 2014. These sites were selected because they had 30+ comments related to eczema. We prioritized Web sites that had the highest traffic rates, and then categorized the sites by disease/condition by running a selection of our models across each site. Some websites contain data that are heavily skewed toward a particular topic, thus biasing the data, which is in part because of the inherent lack of restriction and control over what patients can discuss. By combining data from a range of healthcare websites, our approach reduced the potential bias that may exist on an individual website.

Initially, we included the site “Eczema Voice” which has the largest number of postings of any site we found (18,427). However, we later decided to exclude the site as it was hosted by an organization in the United Kingdom, and many comments appeared to be specific to the UK health system (National Health Service), and possibly reflective of practice patterns in that country. Ultimately we culled comments from the following 7 Web sites:

Inspire Community: <http://www.inspire.com/groups/national-eczema-association>

Topix Forum: <http://www.topix.com/forum/health/eczema>

Experience Project: <http://www.experienceproject.com/groups/Have-Eczema/107>

Baby Center: <http://www.babycenter.com/>

OnHealth: <http://www.onhealth.com/eczema/patient-comments-78.htm>

MedicineNet: [http://www.medicinenet.com/atopic\\_dermatitis/patient-comments-122.htm](http://www.medicinenet.com/atopic_dermatitis/patient-comments-122.htm)

eMedicineHealth: [http://www.emedicinehealth.com/eczema/viewer-comments\\_em-147.htm](http://www.emedicinehealth.com/eczema/viewer-comments_em-147.htm)

We applied this same methodology to 1,817 abstracts retrieved from PubMed using the criteria: a) title contains the words "eczema" or "atopic dermatitis" and b) the publication date occurred April 1, 2011- Oct. 1, 2014.

We trained a supervised learning model on a set of 375 manually annotated posts to teach the program how to identify relevant posts. The training achieved an accuracy of 96.6%. We applied the revised model to a total of 12,820 posts obtained from the 7 websites, and 10,216 (80%) of them were classified as relevant posts. We then applied a topic modeling tool (unsupervised learning) on the relevant posts to obtain topics, pulling to top 2 most salient topics from each post (most posts cover multiple topics). From this approach, we identified a list of stable topics, or salient themes. We manually reviewed this list of stable topics and refined the topic list to exclude irrelevant topics. We then manually summarized topics and combined similar topics where appropriate.

We catalogued, categorized, and then displayed these topics using a basic Web application. We will compare this data with the findings of a literature review of published articles describing treatments for eczema. Finally, we quantified the overlap, noting commonalities and differences and highlighting promising areas for future research.

## Results

### *A. Patient/Caregiver Comments Alone*

No single topic dominated the comments within the sample of posts culled from the 7 online patient communities. Instead, patients and caregivers discussed a wide array of topics (60). Of these 60 topics, 37 were determined to be relevant to management and treatment of eczema after manual review by the research team. The following results emerged from the data.

First, it's worth noting that the online patient community for eczema is supportive and oriented towards helping peers navigate and cope with the disease. This is consistent with survey research that has shown patients use social media to find peer support, help with daily management issues, and to derive a sense of community. (Pew Research Center, 2011) The social and supportive nature of online patient communities was reflected in the words of support, well wishes, and good luck such as, "good luck", "hope", "helps", and "well wishes" which were highly common among the more than 10,000 comments analyzed.

Likely reflecting the most common treatment for eczema, the most prevalent topic that emerged from the data was related to the use of prescription creams, lotions and ointments, and particularly steroids. This category dealt with types of treatments used or recommended and their reported efficacy. For example:

***"My son got eczema at about 6 weeks of age, he's now 3 years old. It covers his whole body...when he was younger we used aquaphor on his face due to the drool factor. Now that he's older it's Cetaphil all the way the cream is the best seems not to sting."***

Many comments in this category also included mention of concerns about steroid addiction and withdrawal, which emerged as a very salient issue for patients, and was the second most prevalent topic. Patients and caregivers expressed great concern with issues such as "steroid withdrawal" and "steroid addiction". Comments in this topic highlighted difficulty with controlling flares with topical steroids and the rebound effect associated with stopping such treatment. For example:

***"Here is what I can tell you from my experience and many others. STOP USING TOPICAL STEROIDS. They are poison.... I kept being prescribed stronger and stronger creams as I got older because the old ones didn't work anymore. Then I found out about topical steroid addiction and withdrawal...Please do yourself a favor and look into topical steroid withdrawal."***

Another stated:

***"I don't think doctors do enough to warn about the possible side effects of steroid creams. They just prescribe the cream. I've been prescribed increasingly stronger creams since I was a baby. I stopped steroid creams in November 2011 and the rebound has been horrific. Red, burning rash all over my body caused by dilated blood vessels. Nobody warned me that this could happen."***

Diet and food sensitivity was the next most prevalent topic, which centered on issues such as gluten intolerance, and foods that commonly cause allergy or sensitivity (soy, nuts, wheat, tomatoes, eggs, dairy), as well as opinions of and experience with elimination diets. For example one post stated:

***"I recently cut out all dairy and wheat products and within 2 weeks my eczema has totally cleared up. I tried incorporating these foods into my diet again and my eczema has returned. It has been an adjustment not to have wheat and dairy but I have been free of eczema since I cut these two foods out of my diet."***

Somewhat surprisingly, the next most prevalent topic dealt with topical treatment with oils, coconut oil being the most dominant oil discussed. As one patient stated:

***"I have been using "Extra Virgin Coconut Oil" found in health food stores as a moisturizer since June, and haven't touched a steroid, antibiotic, antihistamine etc..."***

Another recounted:

***I bought a big tub of organic, non-GMO, extra virgin coconut oil to take internally and topically. It's supposed to have antibacterial and antimicrobial properties, has Lauric Acid. It also balances the PH level on the skin, which is apparently super important for us because eczematous skin tends to be too alkaline, as opposed to being acidic. Acidic skin allows the skin to protect itself from bacteria and infections. Super excited to see results.***

Preliminary research on coconut oil and olive oil as a topical treatment for eczema suggests that it can reduce dryness and Staphylococcus aureus colonization (Verallo-Rowell, 2008). This is an interesting area for further exploration.

Bleach baths, and other bath-related treatments including cider vinegar and oatmeal additives, were the next most prevalent topic. Also included in this category was discussion of the benefits of swimming in a chlorinated swimming pool. As one comment stated:

***"Within the last year I read an article related to using bleach in the treatment of eczema, having 2 daughters effected by it and my mother I decided to try, so placing a cap full of bleach (Milton sterilizing fluid) in my kids baths for a couple of weeks (just 2-3 weeks), we saw a huge difference, their skin was back to normal, occasionally they have the odd reoccurrence, but one bath with the cap full of bleach and they are back to normal once again."***

Allergies, and allergy testing, especially patch testing, and what it means were the next most discussed issues. As one patient commented:

***“Had the tests a few yrs ago and showed no reaction. My Md explained that you can't test for everything. The allergist said that "I had sensitivity to the environment". I became more than a little disenchanted with the allergy specialist!”***

Another stated:

***“I wish there were more research going into the interaction of food allergies and eczema...”***

Sleep disturbance caused by discomfort associated with scratching and itch was the next most prevalent topic. Examples of comments in these categories include:

***“Sleeping is definitely an issue. My daughter has difficulty getting to sleep due to the excessive itching. Once she falls asleep it is difficult to wake her up. Sleep deprivation has affected her ability to attend school. Many times I have been called to school to pick her up due to her not being able to function due to being tired or itching excessively. While we sleep she is up scratching. Many nights she wakes me up to help her apply cream or rub her back.”***

Patients and caregivers also commonly discussed issues related to hand and foot eczema. An example of the discussion in this category is as follows:

***“For my hand and foot eczema I use vaseline and cotton gloves and cotton socks over my feet. I tried Toctino but could not handle the side effects so quit after one day. I am a tennis player so you can imagine the cracks and bleeding on the hands is a distraction to say the least. But it is 'manageable' as long as I use the vaseline for say 4 or 5 hours a day, plus I sleep with them at night.”***

A separate category of comments related to eczema flare ups and particularly areas of the body that represented “problem areas”, such as the eyelids, back of the knees, and elbows:

***“Hi! I'm 11 and I have eczema ... The rashes are on my arms (right in the elbow crease), my legs (behind my knees), and on my wrist, on top of my hands, and has spread to my fingers. The rashes on my arms are the worst. I wear long sleeves every day to school because I am scared people will not like me or wants to be friends with me if they see the eczema on my arms.”***

The final topic on the top ten list related to itch and how to find “itch relief”. Below is an example of the type of comments in this topic category. The following comment is from an adult with eczema giving advice to a parent whose child suffers with itch:

***“Really, sometimes ya have to scratch. As an adult, I know it can hurt me, I know if I create sores on my feet I might not be able to walk or dance without pain, and I can promise that it is not something***

***that people with eczema want to do. Itching is a miserable feeling. If I were a kid, I would want my parent to do anything physically to help quiet the itch, be it soaks, lotion, medicine, ice, anything to make me feel better. And I would want a hug, and some understanding that I feel so horrible. Because anyone that is scratching themselves to bleed is very uncomfortable, even if they aren't really aware of it. So don't yell at someone who feels like that, or scold them. They hurt enough already."***

Another adult patient offered this advice for itch:

***"One thing I have found that has never failed me at anytime is: get a gallon bag which seals securely put ice in it. Sometimes I wrap a cover over or not. Place the bag where the intense itching is and keep it there for about 15 min. Check skin as it warms up the itching should be gone if not place ice back on for a few more minutes. You will be surprised how the cold will keep the itching at bay. I prefer using this method to trying to use ointments and creams that just sits on my skin doing nothing."***

These were the top ten most prevalent topics identified by the model. The full 37 topics are listed in Appendix A in rank order of prevalence.

### *B. Researcher Topics Compared with Patient Topics*

A total of 87 stable topics were generated from the combination of online patient comments and PubMed abstracts. After manually reviewing, merging similar topics and deleting irrelevant ones, we obtained a list of 60 stable topics.

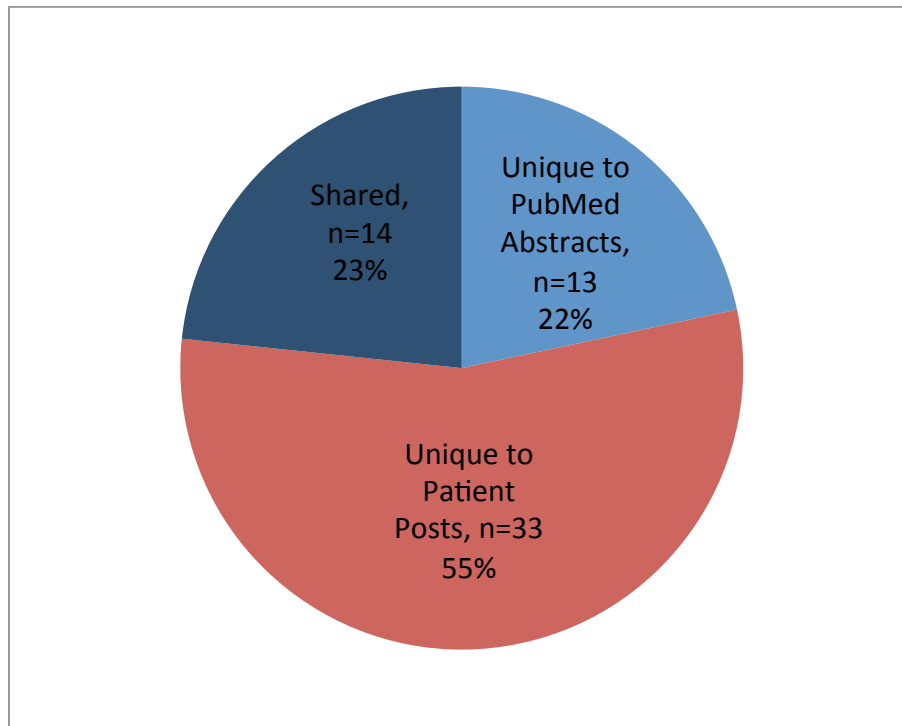
Of these topics, 13 (22%) were unique to the research abstracts, meaning they occurred in the patient posts at a prevalence less than 1%. In contrast, 33 (55%) were unique to the patient posts and rarely (<1%) mentioned in the abstracts. Another 14 topics (23%) were shared by both sources.

Three of the five most mentioned topics by patients were shared topics, whereas only one of the five most mentioned topics in research abstracts was "shared" with the patient posts. This difference perhaps points to the way information currently flows between these two groups; while patient communities with eczema discuss research findings, researchers may not be pursuing topics communicated as "of interest" by patients.

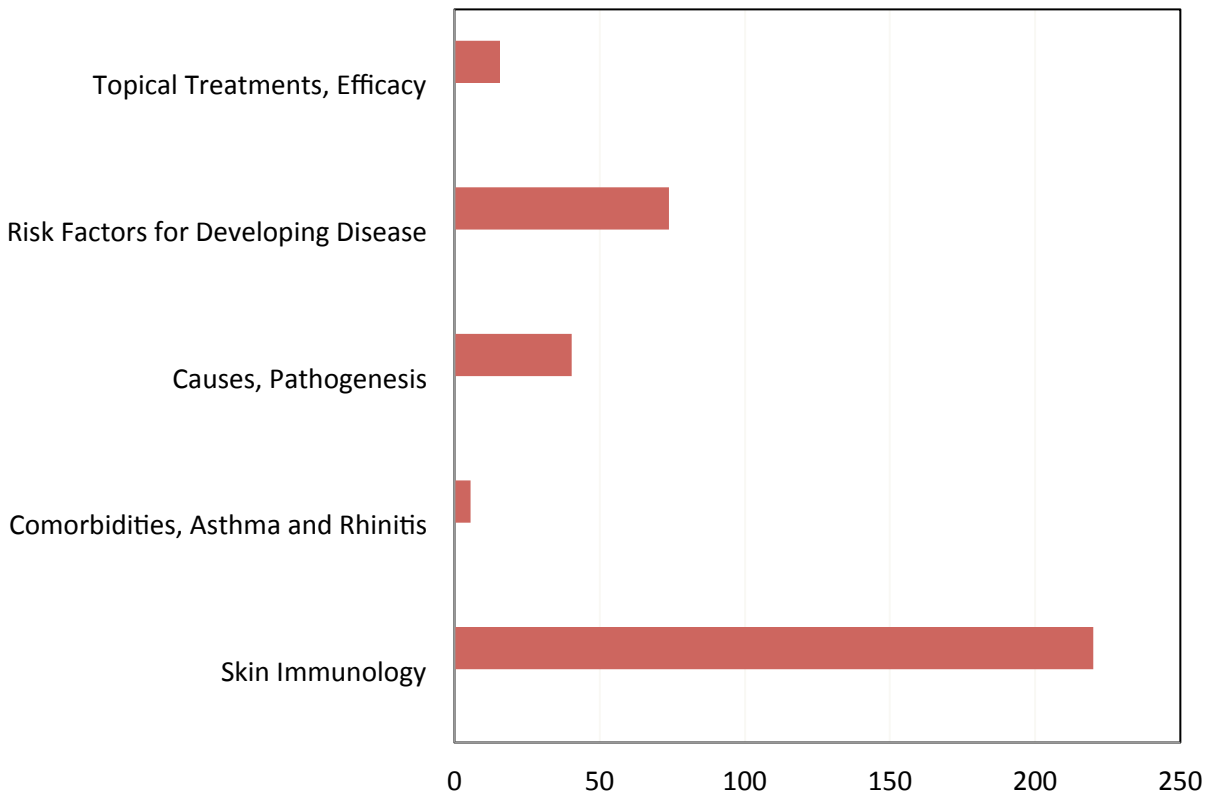
Published articles are concerned with a narrow group of topics (27) that each has higher prevalence rates in comparison to patient communities which discuss a much wider array of topics (47).



**Figure 1: Stable Topics by Category, n=60**



### Most Prevalent Topics in Research Abstracts with Prevalence Ratio (Research/Patient Posts)



#### Discussion:

Patient comments posted in online patient communities are concerned with a broad range of topics, most of which are not captured in recently published research literature. The findings suggest that patient concerns about side effects associated with current treatments, especially topical and oral steroid treatment, may not be adequately addressed in the clinical or research setting. Our findings would suggest a patient-centered education effort is needed around this topic.

Patients and caregivers discuss treatments most commonly prescribed by clinicians (steroids, creams, ointments), but also a wide range of alternative treatments which were less prevalent in the overall comments, but reflect the diversity of treatments currently used by patients with eczema. Patients with eczema also discuss a number of

lifestyle and non-medical interventions: the impact of weather and climate, frequent swimming in the ocean or pools, environmental triggers, and especially diet. These topics were virtually absent from the research literature.

Natural language processing techniques can highlight novel patient insights, experiences, and priorities associated with living with a difficult-to-treat dermatological condition and offer direction for future patient-centered research and clinical practice

#### *Publication/Dissemination:*

We are in the process of undergoing Institutional Review Board review and hope to publish a full paper in an academic journal in 2015. Additionally, we hope to place an article in a national magazine targeted to consumers. Partial/preliminary findings were presented at the 2014 Medicine 2.0 conference as a research poster (see Appendix B). A rudimentary Web site was created featuring a summary of the themes identified by the analysis with patient comments relevant to those themes visible within the next layer of browsing. A more user-friendly, accessible resource for a broader audience could be created with supplemental funding.

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## APPENDIX A: TOPICS BY PREVALENCE RANK (PATIENT/CAREGIVER COMMENTS)

