

# Uncovering Psoriasis

## Introduction

The winter months can mean dry air, less sunlight, indoor heating, and heavy clothing – not the best conditions for people living with psoriasis. As part of our continuing seasonal series, we conducted a survey of our psoriasis community between October and March, receiving responses from over 500 patients. Members in more than 15 countries responded, signaling our survey is really starting to go global!

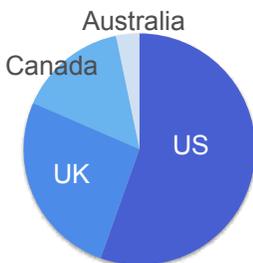
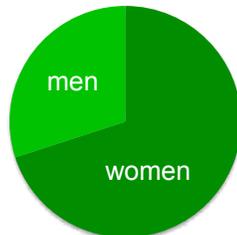
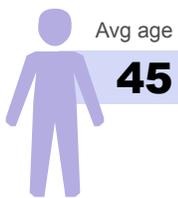


### About the Uncovering Psoriasis series



This is the third in a series of psoriasis-focused surveys that PatientsLikeMe has conducted since building out our psoriasis community in 2012. Every three months, we'll deliver the information and tips from patients like you that will help you get the most out of the season, whatever the state of your psoriasis or the weather. Look for our next survey to add your voice and help uncover psoriasis.

## Who Responded?



One or two people responded each from: Belgium, Brazil, India, Indonesia, Ireland, Italy, Jordan, Mexico, New Zealand, Pakistan, the Philippines, and Portugal.

## What Will I Learn About in This Report?

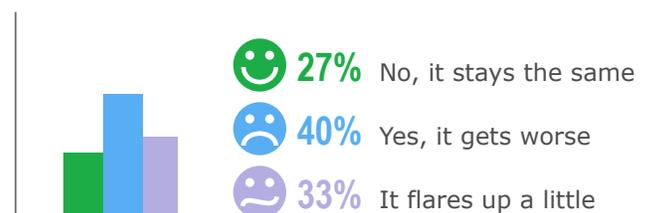
- How winter really affects those with psoriasis
- Helpful tips from other members for making it through the season
- How to assess your quality of life with psoriasis
- More about BSA, or Body Surface Area, a way to measure your psoriasis

## How Does Winter Affect Psoriasis?

Winter often means sniffles, coughs, and the dreaded flu. (Learn why [here](#)) This year the season seemed to hit hard with colds, an aggressive strain of the flu, and even stomach bugs (yuck!). In fact according to the [CDC](#), the 2013 "flu season" was a particularly bad one. We asked our members if getting sick affected their psoriasis. Most people (40%) said that it had an effect, 33% said it affected their psoriasis "a little", while 27% said it had no effect.

Bundling up is important to stay warm during colder weather, but what's the best way for people with psoriasis to dress? The majority (67%) said that multiple layers was the way to go for the winter; around 24% said they use cotton clothing for winter, while 8% use only sweaters. These data match up with the [advice given via Twitter](#) by the National Psoriasis Foundation. "Wear soft layers in breathable fabric. Avoid wool, denim & other fabrics more likely to irritate your skin."

## Does Getting Sick Affect Your Psoriasis?



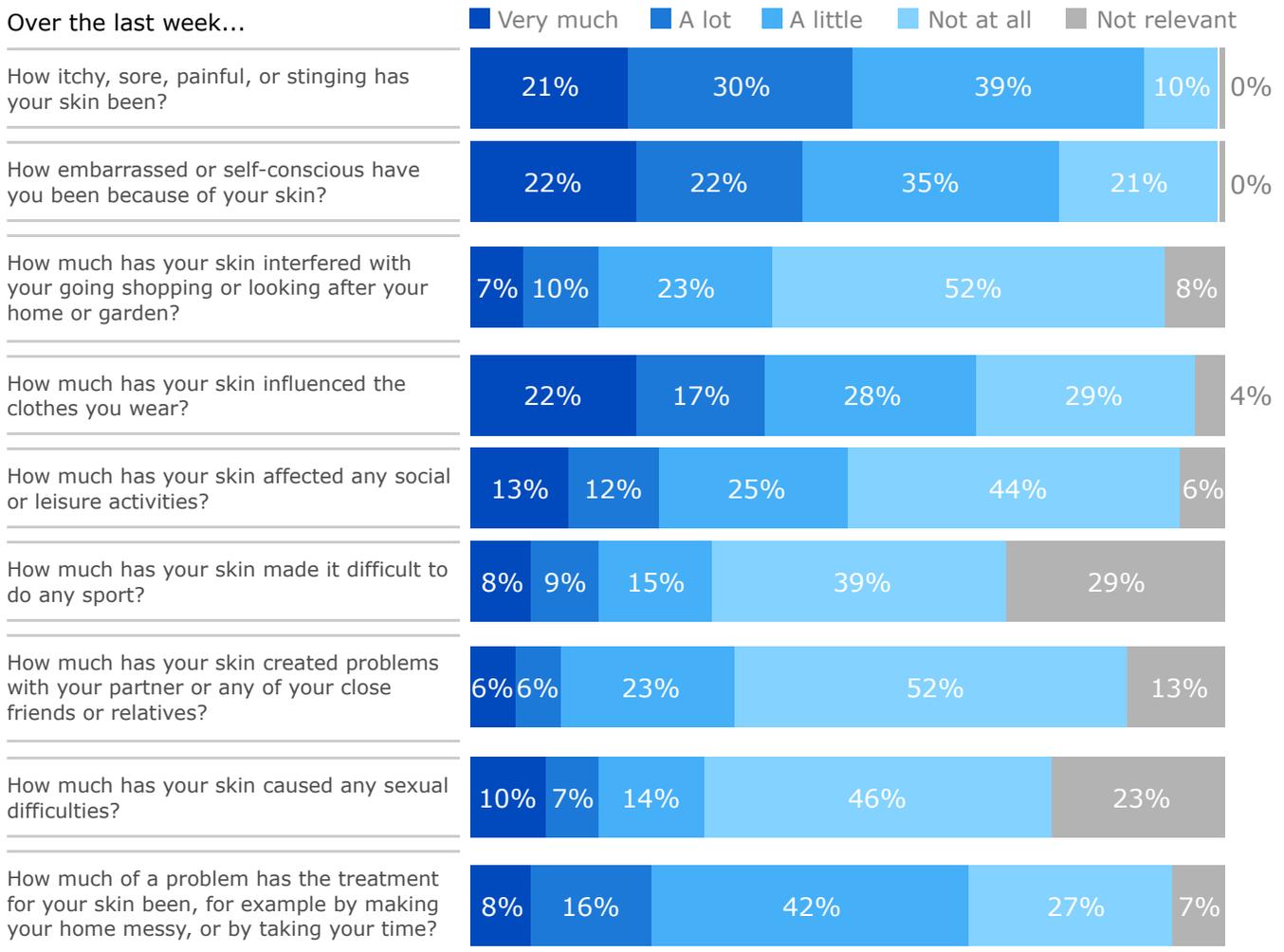
## How's Your Skinpact?

The Dermatological Life Quality Index (DLQI) is used to measure the “skinpact” that psoriasis can have on patients. It asks questions like “How self-conscious are you because of your skin?”, “How much has psoriasis interfered with your personal activities?”, and “Does your skin condition affect your ability to do sports?”

The questionnaire runs from a low score of 0 (no impact) to a maximum of 30 (extremely large impact). This season the average skinpact in our winter survey was around 9. Men’s averages were slightly lower than women’s (8.6 versus 9.3, respectively).

Here are all the data from this season’s Skinpact questionnaire.

## Here’s how our 518 survey respondents answered the skinpact questions. How do you compare?



**Table 1:** Dermatologic quality of life (DLQI), known internally at PatientsLikeMe as “skinpact”

## What affects psoriasis in the Winter?

We asked our R&D team to find out which of the questions we asked this season seemed to be having the biggest impact on your quality of life. They found, in order, that what affects quality of life most is:

- Total percentage of the body covered by psoriasis
- Psoriasis on the feet
- Psoriasis on the genitals
- Being younger
- Having illness that affected psoriasis

Then they looked at the question “Over the last week, how itchy, sore, painful, or stinging has your skin been?” They found three top things that respondents said contributed most to skin irritation: psoriasis on the scalp or feet, and having an illness that affected the psoriasis.

Psoriasis isn’t just about the skin though, it’s about what’s underneath too. We asked “Over the last week, how embarrassed or self-conscious have you been because of your skin?” There were three leading reasons behind the feelings: psoriasis on the back, on the genitals, and having an illness that affected the psoriasis.

## Feeling any different since the Fall?

This season there were 70 patients who completed both our Fall and Winter surveys. How are they doing now? If you look at just the group average, BSA coverage dropped from an average of 16% in the Fall to 11% by the Winter. But these gains were not evenly divided; there was an almost even split between those who reported improvements (43%) and those who got worse (40%).

Of the 43% who reported their psoriasis got better, nine patients (13%) reported achieving a reduction of 15% or more, which is a great improvement. Within those who reported their psoriasis worsening though, their psoriasis worsened by 6%, on average.

## How much of your body is covered by psoriasis?

Every season we also field another important measure, which is how much of a person’s body is covered by psoriasis. A trained dermatologist might tell you, but you can also use a validated technique to find out for yourself. The trick is to take the flat palm of your hand, illustrated above, and work out how many whole palms the psoriasis covers. One whole palm (including fingers) is roughly 1% of the surface of your skin. This measurement is called “Body Surface Area,” or BSA%, and PatientsLikeMe features a [tool](#) that allows you to track this score over time so you can learn more about what influences your psoriasis. This season the average body surface area score was 17.7%, and was slightly higher for women (18.3%) than men (16.6%).



## #1 Effect on Quality of Life: % of Body Covered



### Calculating Your BSA



One palm of your hand is equal to about 1% of your body surface area. If your psoriasis is only scattered small dots, try to imagine combining them together into one patch. Please remember to include your scalp and back if affected. Do not include areas in which psoriasis has faded, leaving only changes in the color of the skin.

## What do other members do to improve their condition in Winter?

Some of the tips patients offered in the survey:



"I flare up most during highly stressful times, but reducing your stress levels is easier said than done!"

"I use moisturizer just to make it a little soft and stay away from the plaques developing cracks."

"I try to drink one liter of water to keep my immune system running."

"I do not use any natural remedies, but when a flare up occurs, I use a topical ointment containing a small percentage of 'coal tar'."

"Vaseline with Cocoa Butter, olive oil baths and apple cider vinegar when itchy."

"A warm shower makes me feel better."

## More about PatientsLikeMe

PatientsLikeMe ([www.patientslikeme.com](http://www.patientslikeme.com)) is the leading online health community for patients with life-changing conditions. PatientsLikeMe creates new knowledge by charting the real-world course of disease through the shared experiences of patients. While patients interact to help improve their outcomes, the data they provide helps researchers learn how these diseases act in the real world. PatientsLikeMe endeavors to create the largest repository of real-world disease information to help accelerate the discovery of new, more effective treatments.