

Clear about Psoriasis survey



Introduction

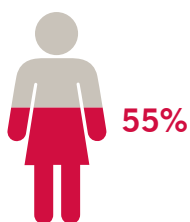
The Clear about Psoriasis survey is the largest global survey to date of people living with psoriasis, involving 8,338 people from 31 countries^{*,1}. It is the first survey to focus on treatment aspirations and what clear skin[†] really means to people with psoriasis. The purpose of the survey is to identify areas where support can be provided to patients so they can live life to the fullest with clear skin.

A global collaboration

Launched in June 2016, the survey is a truly global project supported by 25 patient groups from around the world[‡] and a global steering committee of ten leading experts, including dermatologists, general practice physicians, patient representatives and a journalist. The survey marks the largest ever patient group collaboration for Novartis, who initiated and funded the survey.

Who took part?

GENDER



Mean age 43

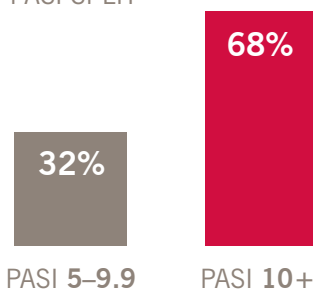


Mean age 45

PASI

The average PASI score of participants:
14.3

PASI SPLIT



A robust methodology

The survey was co-developed with patient groups and validated with the help of a global steering committee. Participants were recruited via online panels and patient organizations, and remained anonymous throughout. To take part, people had to be aged over 18, have a medical diagnosis of moderate-severe plaque psoriasis, and be affected by plaque psoriasis at the time of answering the survey. Four validated scoring methods were used to assess severity of the disease and health-related quality of life, the PASI index, Sleep Scale MOS, WHO-5 Quality of Life and Stanford Presenteeism Scale. Moderate-severe psoriasis was defined as patients either having a PASI score of 10 or above, or alternatively they had a PASI score between 5 and 9.9, with psoriasis plaques on either their face, palms, hands, fingers, genitals, soles of feet or nails.

Participants completed the survey primarily online with some face-to-face interviews in selected countries, 44 questions were asked in total, allowing for a mix of both qualitative and quantitative responses. The research was conducted by the independent market research company, Gesellschaft für Konsumforschung (GfK) Switzerland.

Survey themes

In order to fully understand how people's lives are affected by this distressing, non-contagious skin condition the survey investigated a number of themes:

Daily life: How the everyday lives of people with psoriasis are affected by the condition, and most importantly how this made them feel. Discrimination, humiliation and feelings of shame were common experiences that arose from the participants.

Treatment goals and expectations: Patients were asked about their treatment aspirations and if they are receiving the support they need. The results identified a distinct lack of treatment expectation, especially when it came to the belief of clear skin as a realistic goal of treatment.

Relationships: Psoriasis places a huge emotional stress on people's personal lives. The survey took an in depth look at the true impact of psoriasis on relationships and dating. The difficulties people with psoriasis have when it comes to forming intimate relationships were very apparent from the results, as were feelings of inadequacy as a spouse or partner.

Working lives: Given the distressing nature of psoriasis, it is perhaps to be expected that people's work life is likely to be affected. The results revealed that this affect included limited career opportunities and diminished productivity. This clearly has implications beyond just the individual suffering with the condition.

Mental health: Psoriasis is not simply a cosmetic problem, its impact on someone's life goes far beyond just their physical health. The results from this survey reveal many people have even been diagnosed with anxiety and depression as a direct result of their condition.

In summary

The Clear about Psoriasis survey highlights the need to reset expectations for psoriasis treatment and increase understanding of the condition and its burden in order to reduce discrimination against those living with it.

Clear skin is an achievable treatment goal and people with psoriasis should work with their dermatologist to achieve this.

To find out more

Visit www.skintolivein.com, an online hub from Novartis with social media channels across Facebook, Twitter and Instagram that is dedicated to educating and supporting patients with severe skin conditions, such as psoriasis.

Further information

*Countries include: Argentina, Australia, Austria, Belgium, Brazil, Bulgaria, Canada, Czech Republic, Denmark, Finland, France, Germany, Hungary, India, Ireland, Israel, Italy, Japan, Mexico, Netherlands, Norway, Portugal, Romania, Russia, S. Korea, Sweden, Switzerland, Taiwan, Turkey, UK and USA

† clear or almost clear skin

‡ AEPSo, APAA, Asociación Mexicana Contra la Psoriasis, Canada Psoriasis Network, Finnish Psoriasis Association, France Psoriasis, GIPSO, Irish Skin Foundation, National Psoriasis Foundation, Psoríase Brasil, Turkish Psoriasis Patient Association, PsO Austria, Psoriasis Liga Vlaanderen /Psoriasis-Contact, Psoriasis Federatie Nederland, PSO Portugal, Psoriasis Vereniging Nederland, Swiss Psoriasis and Vitiligo Association, Psoriasis - og eksemforbundet, Psoriasisforeningen, Hungarian Psoriatic Patient Clubs', Association / Szeged Psoriasis Association, Israeli Psoriasis Association, Psoriasis Association Taiwan and EUROPSO.

References:

1. Novartis. Data on File. June 2016