


A tool for enabling policy conversations on psoriatic disease: the Psoriatic Disease Response Index

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Despite burdening millions of people worldwide, psoriatic disease is far from a priority for health systems around the world. To enable policy conversations and highlight best practices for optimal management of psoriatic disease, the International Federation of Psoriasis Associations and the Global Psoriasis Coalition launch the Psoriatic Disease Response Index, an analysis of health systems' response to psoriatic disease on an international scale.

Psoriatic disease, a condition affecting more than [60 million people worldwide](#) [1], is so much more than red, scaly patches on the skin and stiff joints: it is a significant burden on mental health, it increases the risk of developing other non-communicable diseases (NCDs), and it's a significant cost for both individuals and health systems*[i]* [2]. Nevertheless, psoriatic disease is rarely considered a priority in health policy agendas.

The [Psoriatic Disease Response Index](#) [3], a product of the International Federation of Psoriasis Associations and the Global Psoriasis Coalition, aims at enabling policy conversations around the complex impact of psoriatic disease management while underlining the benefits of a stronger health system response. It is the first effort to analyse health systems' responses to psoriatic disease on an international scale: barriers and enablers of health care system responsiveness to psoriatic disease were identified in five countries – Denmark, France, Germany, Sweden and the United Kingdom. In addition to highlighting gaps in psoriatic disease management, the Psoriatic Disease Response Index offers solutions and best practices to ultimately improve the lives of people living with psoriatic disease.

A holistic care of psoriatic disease is still a mirage

The clinical manifestations of psoriatic disease, namely skin symptoms with joint inflammation present in one third of the cases, are accompanied by an increased risk of developing other NCDs. The most common comorbidities in psoriatic disease are cardiovascular disease, diabetes, and metabolic syndrome*[iii]* [4]. Moreover, many people living with psoriatic disease carry a heavy burden on mental health: embarrassment, anxiety, and an increased rate of depression in those with a visible disease such as psoriatic disease can compromise social life and work*[iiii]* [5].

As the Index reports, “patient needs, outside of those related to the skin or joints, are often not comprehensively managed”. Even when national guidelines incorporate the screening of co-morbidities in the care of psoriatic disease, a holistic care of psoriatic disease is more likely to be achieved only in specialised centres rather than on a broader scale. Moreover, the lack of specialists relevant to psoriatic disease co-morbid conditions and the low awareness of psoriatic disease among general practitioners, identified in all countries included in the Index, complicate a comprehensive care of the disease. In-country experts interviewed for the Index highlighted that “psychological symptoms [of psoriatic disease] are largely overlooked”. In all five countries analyzed, the time that doctors allocate per patient was found to be too short, therefore not being enough to ensure that all issues related to psoriatic disease are addressed.

The long road to treatment

According to interviews with disease experts from the five countries included in the Index, the patient journey to receiving care for psoriatic disease usually begins in primary care, with an assessment by the general practitioner that informs a referral to specialist care. After diagnosis, ongoing disease management is mainly carried out in primary care for people affected by a mild form of psoriatic disease, whereas a moderate-to-severe form requires further interventions by specialists (dermatologists). The first obstacle to care for people living with psoriatic disease is the number and distribution of specialists in the area: the Index shows that three of the five countries included – Sweden, Denmark, and the UK – have a low density of dermatologists relative to the population. Moreover, specialists tend to be concentrated in urban areas to the detriment of rural areas. Consequently, it can take anywhere from a few weeks to months before a person living with psoriatic disease is able to get an appointment with a dermatologist and start the treatment journey, and it can even take years for people affected by severe psoriatic disease to access more advanced - and costly - treatment options.

Psoriatic disease to measure health system performance

Psoriatic disease is a model condition to evaluate health system performance. It is a complex chronic condition that requires life-time care, spanning from primary to specialist care. It is also associated with a variety of co-morbid conditions that are best managed in a holistic way, and it necessitates consistency in care even in times of unprecedented health emergencies.

In addition to highlighting gaps and barriers in the management of psoriatic disease, the Psoriatic Disease Response Index offers solutions and best practices to improve the lives of people living with the disease.

“Patient engagement within all levels of a health system is key to success in the patient journey”, as meaningful engagement of people living with psoriatic disease improves every step of the way, from achieving the best standard of care at the individual level, to developing better care guidelines at the national level.

Increased awareness on psoriatic disease at the primary care level is also identified as an effective measure that will benefit people living with psoriatic disease. Informed general practitioners can identify psoriatic disease and its co-morbid conditions at an early stage, including those related to mental health, thus avoiding disease progression and lessening its burden. Increased awareness could be achieved if psoriatic disease carried a greater emphasis in medical education, especially for general practitioners, and through training courses accessible to primary health care physicians as part of the continuing medical education.

One more tool in the toolbox of the psoriatic disease advocate

The Psoriatic Disease Response Index is a precious tool for those of us advocating on the importance of integrating psoriatic disease management, prevention, and treatment into national and global health policy. Emphasis on access to adequate diagnosis, early, adapted and appropriate treatment as well as an affordable long-term supply of medicines and treatments would reduce the burden of psoriatic disease and also favours social and economic inclusion, generating important return on investments for society overall.

About the author

Elisa Martini is Program Officer for Advocacy and Policy at the International Federation of Psoriasis Associations (IFPA). She is responsible for development and implementation of IFPA's advocacy and policy strategies at a global level, as directed by the Board and Executive Director. She has previous experience in advocacy at the local level as secretary and then president of a local branch of the Italian Association for Organ Donation. She holds a Master's degree in pharmaceutical sciences and has obtained a PhD. in medicine with a project on psoriasis. [@PsoriasisIFPA](#) [6]; [@PSOCoalition](#) [7]

[i] [8] Al Sawah et al. (2017). Healthcare costs in psoriasis and psoriasis sub-groups over time following psoriasis diagnosis, J Med Econ; 20(9):982-990

[ii] [9] Takeshita et al (2017) Psoriasis and comorbid diseases: epidemiology, J Am Acad Dermatol; 76(3):377-390

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