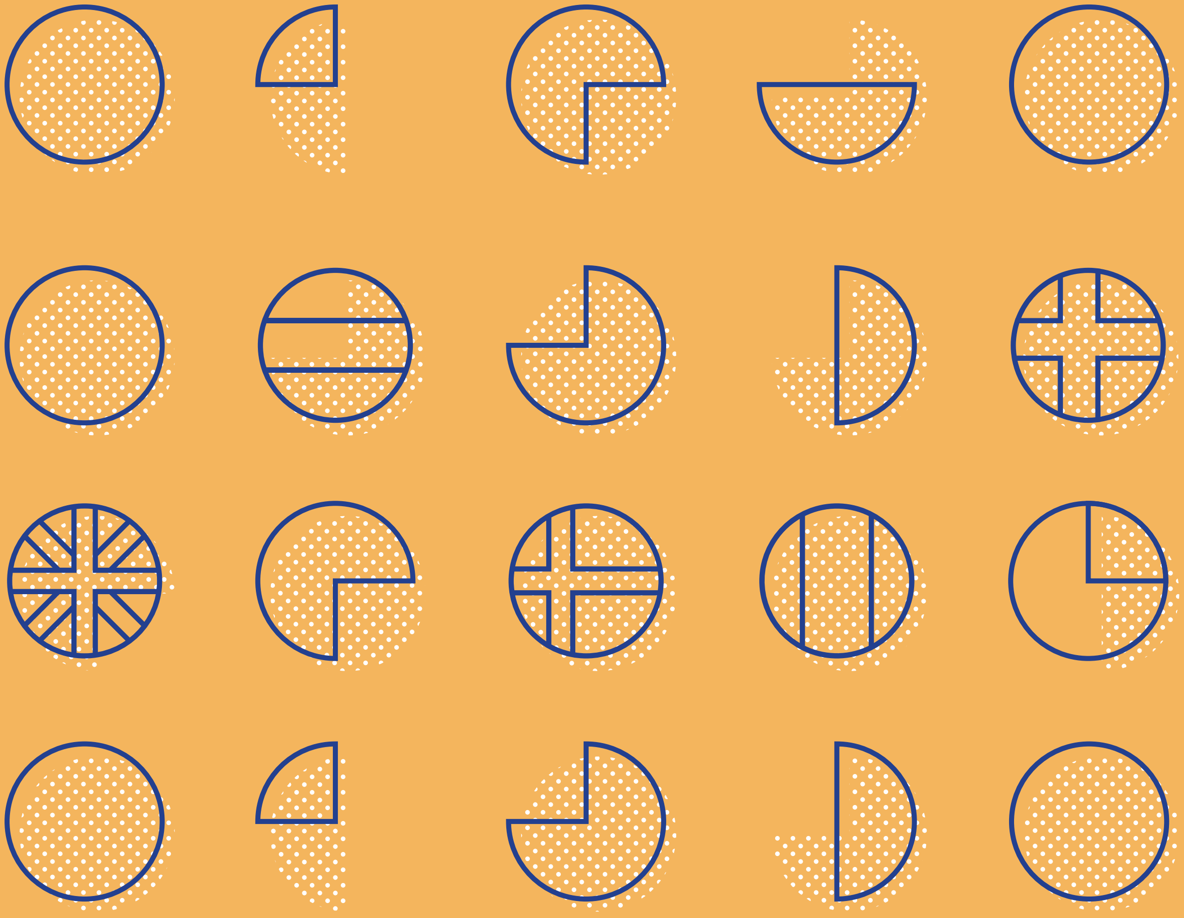


Psoriatic Disease Response Index

GLOBAL
PSORIASIS
COALITION

IFPA
INTERNATIONAL FEDERATION
OF PSORIASIS ASSOCIATIONS

Contents

Preface

The International Federation of Psoriasis Associations and the Global Psoriasis Coalition are pleased to present the Psoriatic Disease Response Index—the first-ever effort to comprehensively survey, quantify, and analyze health systems' responses to psoriatic disease on an international scale.

The purpose of the Index is to enable a policy conversation, serving the goal of educating policymakers, health system leaders, and other relevant stakeholders about the complex impacts of psoriatic disease and the potential benefits of a stronger health system response. Psoriatic disease is recognized by the World Health Organization as a serious noncommunicable disease,[1] and governments need to deliver on the WHO recommendations to ensure proper care. Our aspiration is that this tool could be used to shape national and global policy understanding and raise the international profile of psoriatic disease.

Complementing efforts at the international level, the Index may help raise the case for enriched psoriatic disease management within regional or local environments by defining criteria to measure national health systems' psoriatic disease efforts, assessing the performance of select health systems, and outlining key recommendations for improvement. As psoriatic disease constitutes a complex and burdensome health condition, access to treatment and care can be seen as indicators for the overall well-being of a healthcare system as patients with complex chronic condition(s) must navigate challenging environments.

This Index is intended to clarify the barriers to and enablers of healthcare system responsiveness and, from those learnings, identify opportunities to adopt supportive approaches across the diverse needs of people living with psoriatic disease. For the purposes of this Index, we have considered both psoriasis and psoriatic arthritis in our analysis. Through interviews with experts in the fields of public policy, advocacy, medicine, industry, and science, and alongside evidence-based data sources, we have identified five umbrella categories that contribute to the status quo of people living with psoriatic disease in five European countries: Denmark, France, Germany, Sweden, and the United Kingdom. Utilizing these rich resources we have identified key opportunities to drive long-term progress for psoriatic disease that can be implemented at the local, regional, and national levels. We believe that igniting these important conversations can help systems provide better care to long-term, chronic, non-communicable diseases using psoriasis and psoriatic arthritis as the focal-points of the dialogue to galvanize international collaboration in the fight against psoriatic disease.

Made possible through sponsorship by:

abbvie
AMGEN
Bristol Myers Squibb™
LEO
janssen
NOVARTIS
ucb

Acknowledgements

We are grateful to the more than a dozen experts that contributed their time and valuable insights to the Index, and we thank them for their enduring support in improving the lives of those with psoriatic disease. We would like to recognize the following organizations and individuals for providing their knowledge and insights.

Jonathan Barker MD FRCP FRCPath
Professor of Medical Dermatology
& Honorary Consultant Dermatologist
St John's Institute of Dermatology,
King's College London & Guy's and St Thomas's
NHS Foundation Trust, United Kingdom

Julien Pepiot
Project Director
France Psoriasis, France

Dr. Andreas Pinter
Consultant Dermatologist
Department of Dermatology,
Venereology and Allergology
University Hospital Frankfurt, Germany

Prof. Dr. med. Ulrich Mrowietz
Head of the Psoriasis Center
Clinic for Dermatology, Venereology & Allergology
University Medical Center Schleswig-Holstein,
Campus Kiel, Germany
Physician and Editor-in-Chief of the Archives
of Dermatological Research
International Psoriasis Council, Germany

Marcus Schmitt-Egenolf, MD, PhD
Professor & distinguished teacher
Dermatology, Dep. of Public Health
& Clinical Medicine
Umeå University, Umeå, Sweden

Dr. Lone Skov
Professor, Consultant
Department of Dermato-Allergology
Gentofte Hospital, Faculty of Health Sciences
University of Copenhagen, Denmark

Lars Werner
Chief Executive Officer
Danish Psoriasis Association, Denmark

Methodology

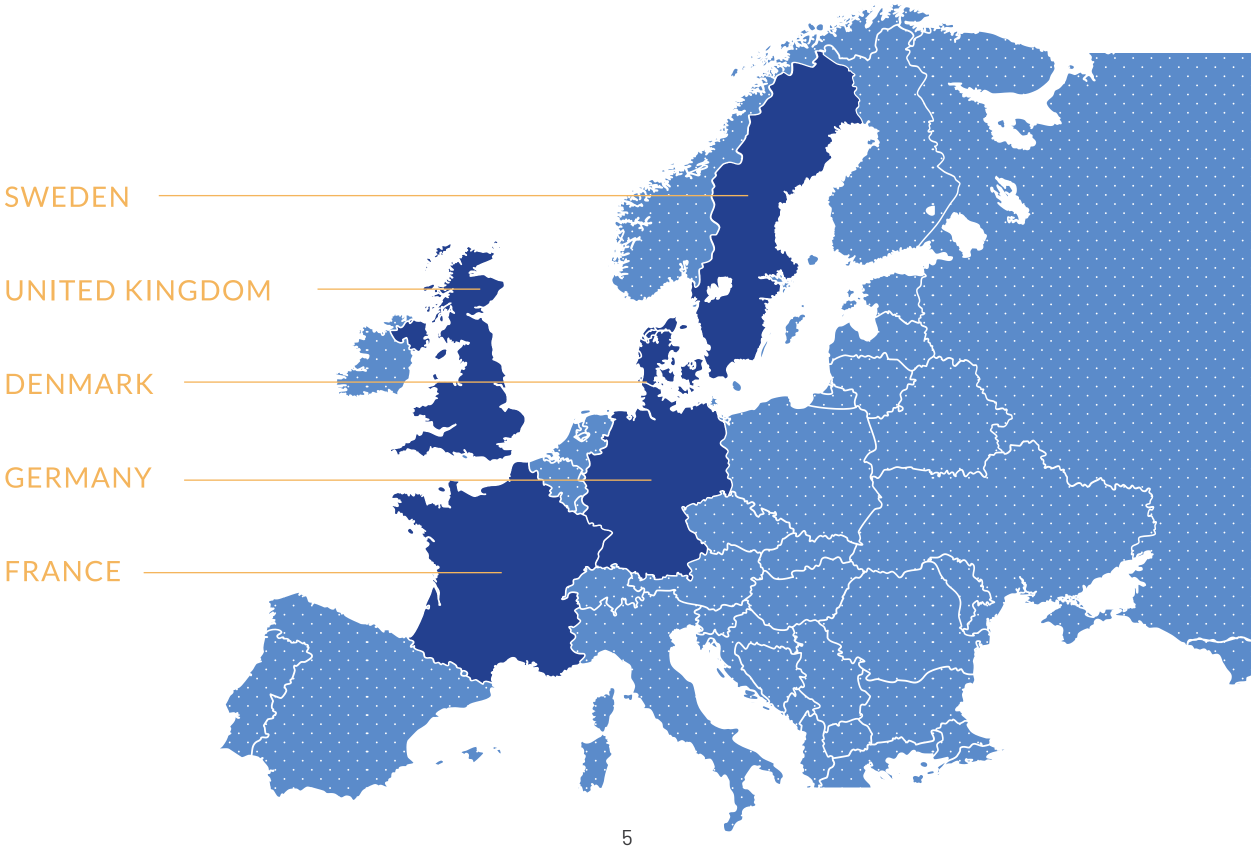
FRAMEWORK

The 2020 Psoriatic Disease Response Index was developed based on primary and secondary data sources collected and analyzed by the Global Psoriasis Coalition, powered by High Lantern Group.

Primary data sources consist of interviews and surveys with key opinion leaders and subject matter experts (including scientists, advocates, researchers, clinicians and business leaders), as well as expert input from Global Psoriasis Coalition members. Secondary data sources consist of existing research gathered from global authorities including academic researchers, national governments, non-profit reports, and other publicly available sources (see Appendix B for a full list of resources). For the purposes of the Index, we will utilize the term psoriatic disease to include both psoriasis and psoriatic arthritis. Psoriatic disease is a chronic, systemic inflammatory condition with various manifestations in diverse anatomical sites. Although historically the medical community has treated and researched psoriasis and psoriatic arthritis as two separate diseases handled by siloed specialties, the Index Steering Committee selected the term Psoriatic Disease to best encapsulate the full burden of disease.

GEOGRAPHIES

Countries were selected as the geographical boundaries for analysis as data is traditionally better captured at national levels. European countries were chosen due to health system similarities—and differences—and to ensure a baseline of available data and experts that could speak to the current status of psoriatic disease. This focus was agreed upon by the Index's Steering Committee. The countries that were then agreed upon were:



CATEGORIES AND INDICATORS

Psoriatic disease response is defined in this Index as the level to which each country can identify, treat and support people living with psoriasis and/or psoriatic arthritis, including mitigating the negative individual, societal, and economic costs of the condition(s). The categories of psoriatic disease response investigated for this Index cover a broad range of issues related to living with the condition(s) and the health systems in which they live. Indicators help to identify the mechanisms that support opportunities or gaps that are drivers of their experiences.

The Index evaluates psoriatic disease response across five categories:

Public Awareness

Provider Awareness

Patient Engagement

Health System

Enabling Environment

As described, each category is comprised of a number of qualitative and quantitative indicators. The categories and indicators were developed based on insights from existing data, as well as an assessment of the current psoriatic disease landscape through the research of evidence-based sources and other credible sources. In each category, indicators are shown using an ideogram system that delineates performance. A full list of categories, indicators, and criteria by which they were evaluated is included in Appendix A.

SCORING

The methodology of this Index combines qualitative and quantitative data to score weighted indicators across five categories. Each category comprises several indicators, and the score for each category is calculated based on the score of that category's associated indicators (a weighted score). In cases where data is not available for a specific indicator, the total score is calculated based on the points assigned to the other indicators in the same category.

The Psoriatic Disease Response Index Steering Committee identified psoriatic disease experts that contributed to survey and interview data, with a minimum of one expert per country. Secondary data helped inform this Index and relevant references are available in Appendix B.

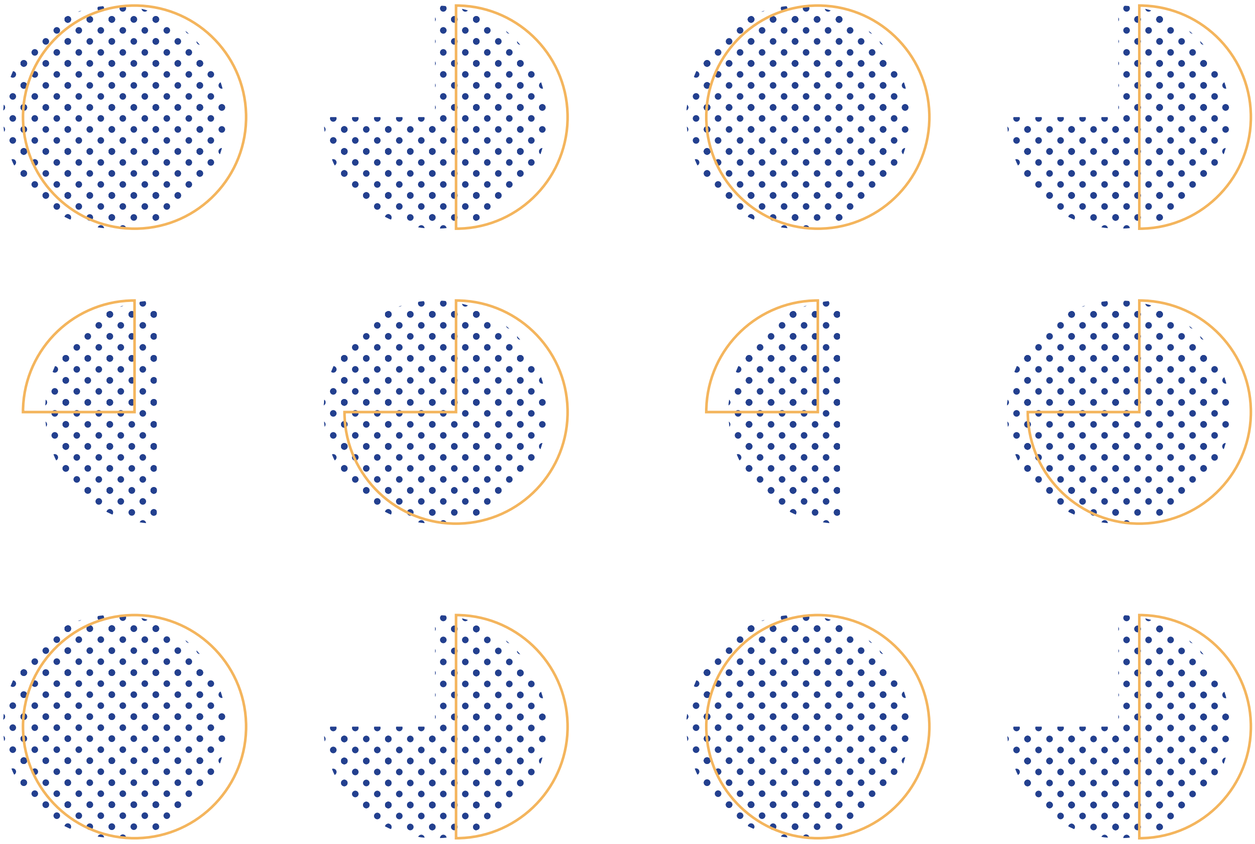
Indicators are scored either by a rating scale based on expert insights or secondary data (the rating for each indicator is available in Appendix A) or based on a "distance to frontier" calculation.* Next, each set of indicators is weighted appropriately for each indicator, based on its overall importance to the categories as agreed by the Psoriatic Disease Response Index Steering Committee.

*"Distance to Frontier" refers to normalizing data on a range where the best observed performance is the "frontier" or top score.

ASSUMPTIONS AND LIMITATIONS

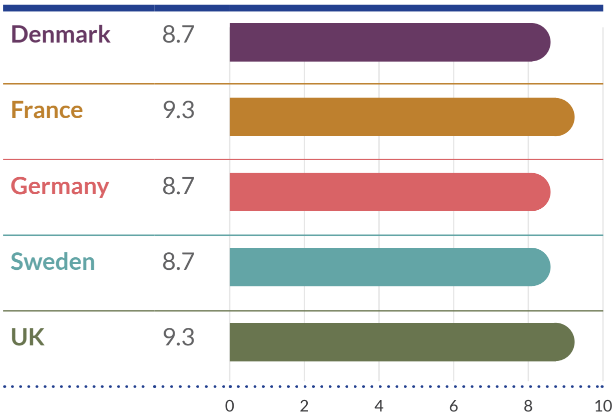
The scope of this Index is psoriatic disease response, as defined above, and the research is focused on pinpointing the barriers and enablers to identify, treat, and support people living with psoriatic disease. The goal for this Index is to identify areas of opportunity for countries to better understand the impacts related to psoriasis and psoriatic arthritis on patients, communities, health-systems and economies, and to improve support.

Where reliable secondary data was not accessible due to resource limitations or language barriers, or does not exist or for which the source cannot be validated, self-reported data shared by experts via surveys or interviews is used for scoring, and scoring assumes the reliability of these experts. Interviews and data collection were conducted in Q2 and Q3 of 2020. As such, this Index represents a snapshot of each country's response to identifying, treating, and supporting people living with psoriatic disease.



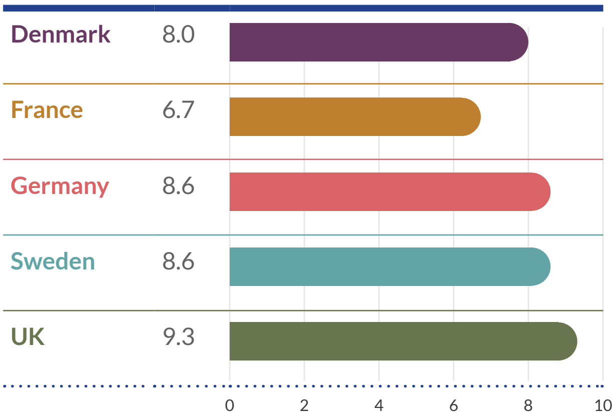
Index Snapshot by Category

PUBLIC AWARENESS



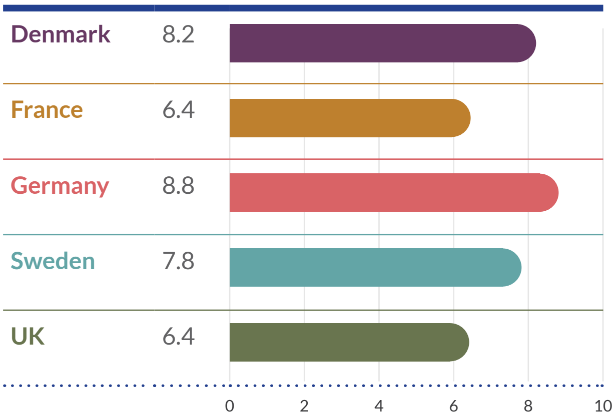
Public awareness campaigns for psoriatic disease are a consistent feature in all countries with World Psoriasis Day as the central point for advocacy. These campaigns remain core strategies of advocacy organizations and comprise of a range of activities, inclusive of digital campaigns, educational lectures, and distribution of psoriatic disease information through newsletters and brochures.

PROVIDER AWARENESS



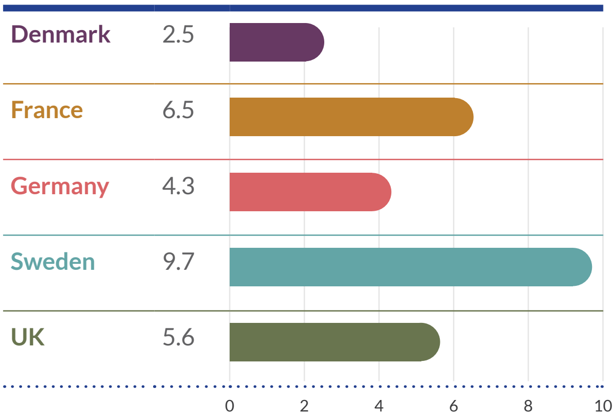
The general trajectory of care is similar throughout all 5 countries where patients first approach a general practitioner (GP) and are then triaged to a dermatologist, usually after several attempts of treatment have been made. France scored the lowest due to cultural and systematic barriers that do not incentivize GP to refer psoriatic disease patients to specialists.

PATIENT ENGAGEMENT



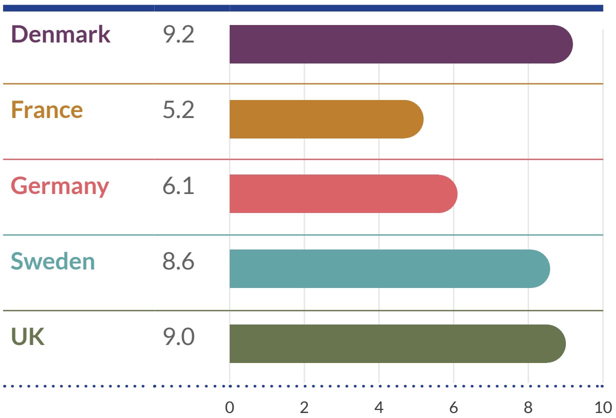
Patient engagement within all levels of a health system is key to success in the patient journey. Non-adherence to treatment and medical recommendations are leading causes of treatment failure, poor clinical outcomes, and increased healthcare utilization. France and the United Kingdom scored the lowest due to high DALY scores and direct and indirect costs to the individual.

HEALTH SYSTEMS

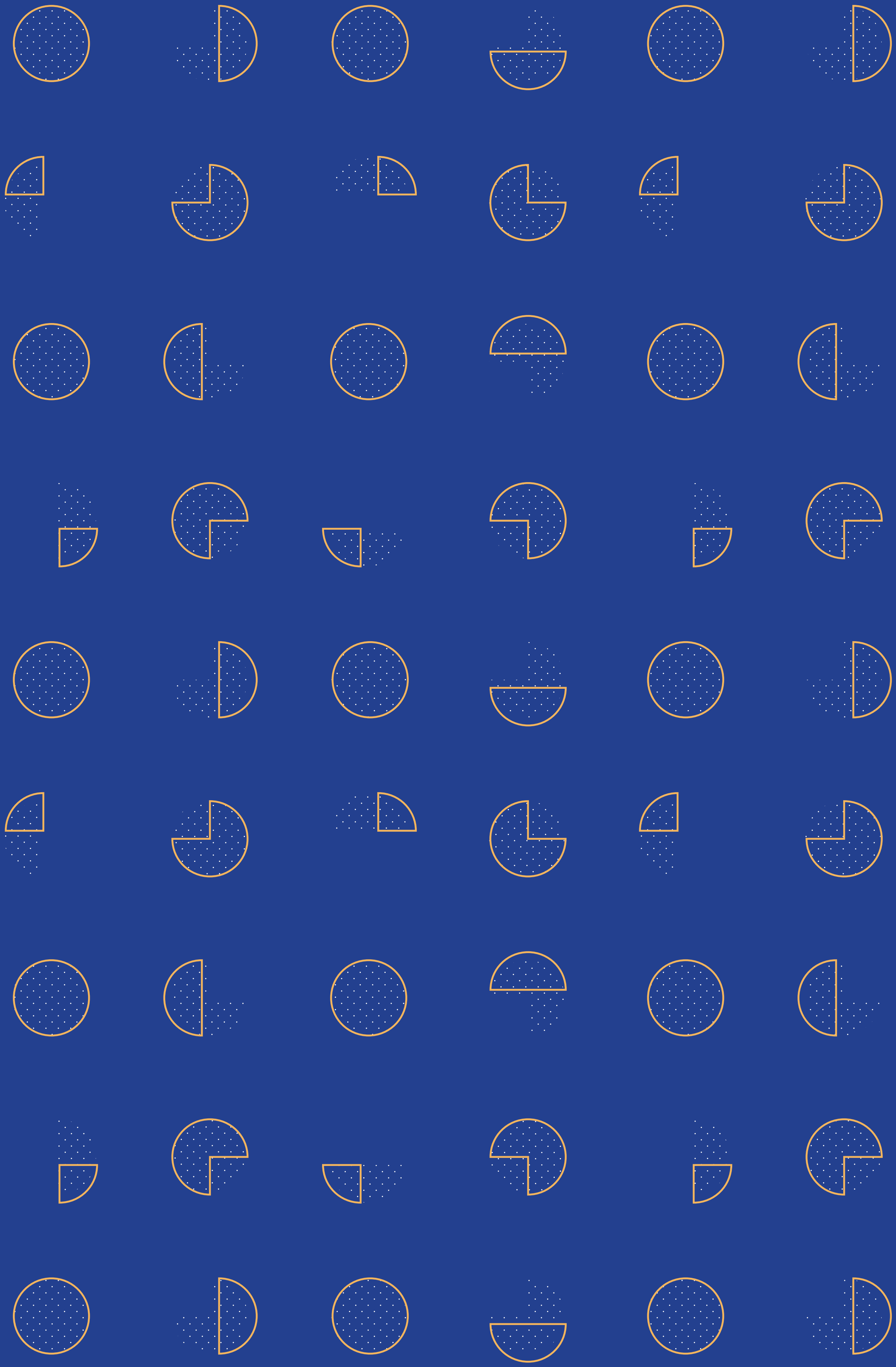


Differences in health systems exist mainly due to reimbursement schemes and access or availability of specialists. Sweden has very low barriers for medication and high access to specialists, whereas Denmark has diversified reimbursement schemes and less specialists available.

ENABLING ENVIRONMENT

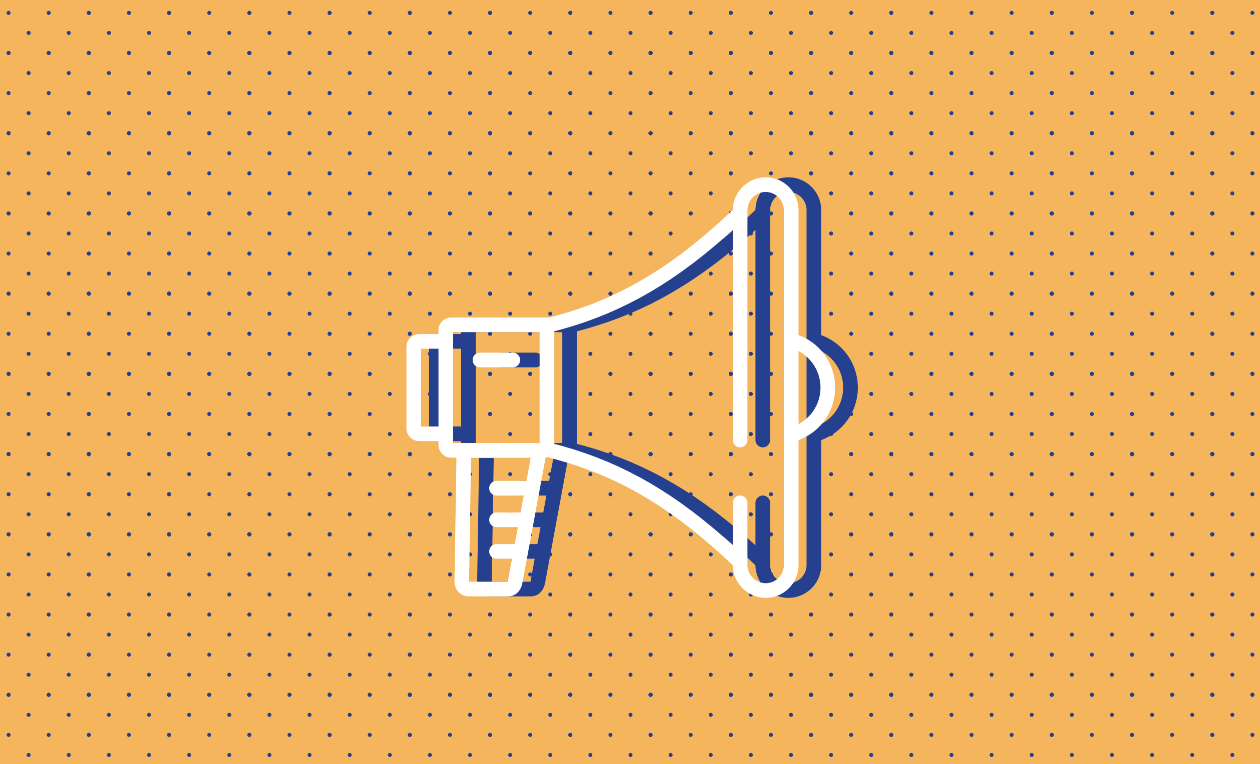


The United Kingdom scored the highest due to its continuous implementation of guidelines from the National Institute for Health and Care Excellence, with specific approaches for both psoriasis and psoriatic arthritis, even though they do have the highest per patient cost. Data for direct and indirect costs to the economy were not available for Sweden, as well as unavailable figures for health system spending on psoriatic disease for both Sweden and Denmark.



Narrative by Category

Through our valuation of our selected enablers and barriers, we identified opportunities of how each country can identify, treat, and support people living with psoriasis and/or psoriatic arthritis, including mitigating the negative individual, societal and economic costs of the condition(s). The following summary by category provides an indicator-level assessment of the five countries' performance in each category.



Public Awareness

All countries participated in periodic awareness campaigns for both people with psoriatic disease and the general public with World Psoriasis Day as the central point for advocacy. These campaigns remain core strategies of advocacy organizations and comprise of a range of activities, inclusive of digital campaigns, educational lectures, and distribution of psoriatic disease information through newsletters and brochures. Presently, social media campaigns are seen as a powerful ways to connect with others to build awareness, communicate authority within the psoriasis and psoriatic arthritis space, show authenticity, encourage engagement, and provide support. However, the reach and the extent to which increased knowledge or behavior change has occurred is unclear.

Informing the general public was considered by all experts as a priority so as to help destigmatize psoriatic disease, with a special emphasis on the visual nature of psoriasis. However, many campaign circuits travel within medical centers, hospitals, and pharmacies making the impact on the broader public difficult to discern.

Public awareness campaigns for psoriatic disease remain core strategies of advocacy organizations.

In Denmark, advocacy groups provide support and counseling services for individuals with psoriasis alongside advocacy targeting decision makers in health policy and healthcare.[2] Efforts have been made to better understand patients' experience of treatments for psoriasis to find ways to improve communication with physicians, satisfaction with treatment and improve patient understanding of treatment options. According to Danish experts, those with psoriasis alone were able to cope with the disease with limited impact on their quality of life, whereas those with psoriasis and psoriatic arthritis reported a high impact on their quality of life.[3,4] Similarly, Germany has led satisfaction surveys to gauge the quality of life for psoriasis patients[5] with stigma continuing to be a main theme in their advocacy (ECHT Campaign and Bitte Beruhren). Surveys were also used by the Swedish Rheumatism Association, Swedish Psoriasis Association and health portal company NetDoktor, to implement a web-based awareness campaign, that consisted of five lessons that provided participants with increased knowledge about psoriatic arthritis, and a survey about their experience in the healthcare environment.[6] However, though some progress has been made, people living with severe forms of psoriasis or psoriatic arthritis continue to carry the heaviest burden to their quality of life and may not be aware of all disease management options.

Attempts to sensitize the political authorities in France for better knowledge and recognition of the disease are underway by the advocacy community, leveraging the resolution of the 2014 World Health Organization (WHO), through meetings and presentation of WHO objectives.[7] With this initiative, the WHO has confirmed the need for action both on the level of awareness, the fight against stigmatization, and improve access to treatments in its member states. Overall, the medical community continues to be cautious when engaging industry in patient education and thus supports their influence via intermediaries such as medical societies and advocacy groups.

RECOMMENDATIONS & BEST PRACTICES

- Non-traditional events such as those at embassies have shown to reach different audiences and engage government stakeholders.[8]
- National advocacy efforts aimed at reaching the general public are limited; tailored local level education and identification of community support systems may encourage greater outreach to individuals that have not accessed care.

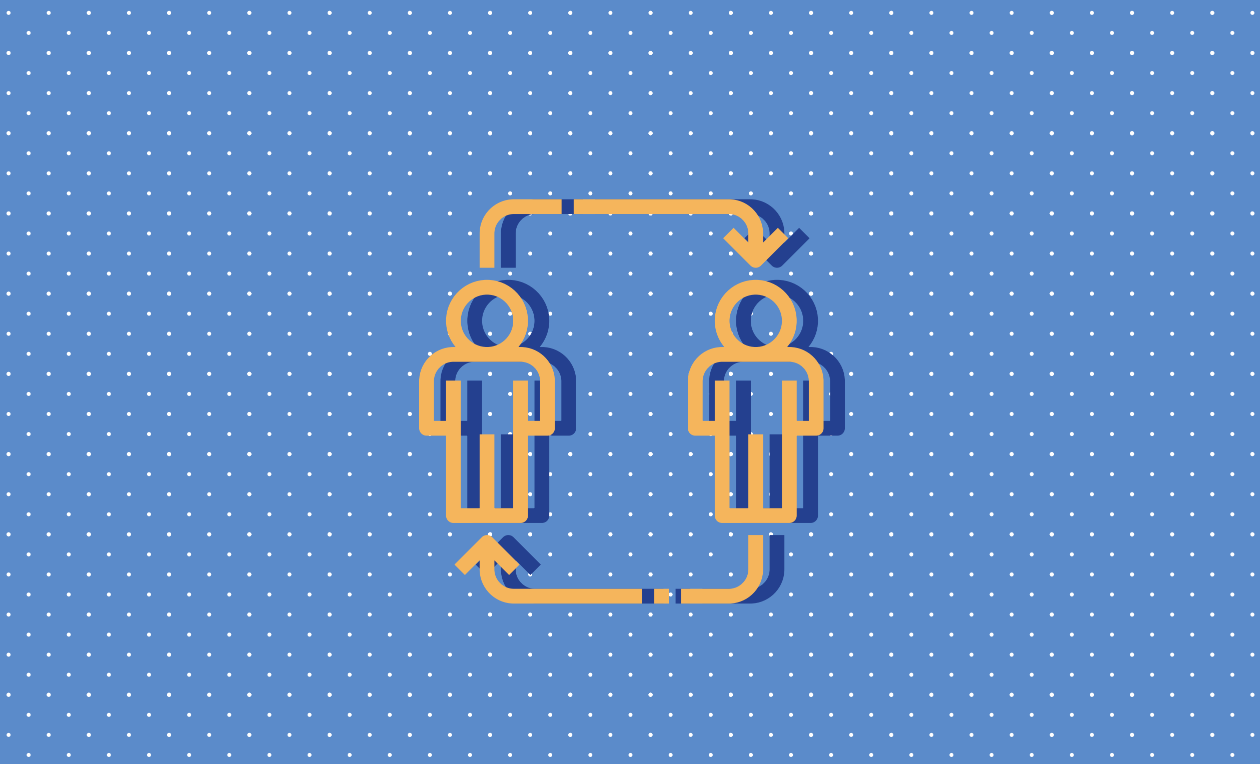
- There is an opportunity to bring greater focus to common comorbidities, especially mental health; the Psoriasis Happiness Report indicates that depression or other mental disorders are especially related to the large happiness gap and have a significant impact on subjective well-being.[9] Collaborative efforts with other associations of related dermatological diseases could create a louder voice as well as make best-use of limited funding.

- Digital communications offered by centers of excellence and university hospitals should leverage their patient focused information in the form of webinars and open meetings on social media so they may extend their reach.

- Political leaders, even at local levels, are important stakeholders to engage in educational campaigns.

- Education in schools, as psoriasis can start in early childhood, would be helpful for earlier diagnoses and to accelerate access to treatments and help reduce stigma and humanize the condition.

“Psoriatic disease is a multifaceted and progressive disease that needs tailored messages depending on the severity and known comorbidities. Patients with more severe forms become better informed over time and rely more heavily on the healthcare system and not on advocacy organizations.”



Provider Awareness

The general trajectory of care for people with psoriatic diseases is similar throughout all five countries. Patients raise their concerns with a general practitioner (GP) and are then referred to a dermatologist, for diagnosis and treatment, though, often, ongoing disease management reverts back to the GP. Should topical treatments not lead to significant improvements, patients may seek additional specialty care. However, depending on the location of the patient, appointments to visit a dermatologist or other specialist may take anywhere from weeks to months. Thus, many patients rely heavily on GPs who may lack the knowledge, skills or ability to provide more advanced treatments.

In all of the countries studied, layering on screening for comorbidities complicates the network of care even further. Patients with severe psoriasis requiring biologicals must go to specific providers approved to prescribe this form of treatment and several years may pass until they can finally access the treatment they need. Care management is largely patient-led, and the burden of accessing more advanced treatment grows with the severity of the disease. In other words, patients with more severe forms of the disease are more motivated to seek care and push for treatments that may give them the best outcome. However, reaching those with mild to moderate psoriatic disease is just as important and should be prioritized from the provider's side.

Each of the five countries have clinical treatment guidelines and use the Dermatology Life Quality Index (DLQI) to monitor and treat patients living with psoriatic disease. The Danish Health Ministry has developed National Clinical Guidelines that include assessment for psoriatic arthritis and the assessment for risk factors for comorbidities, like the development of cardiovascular diseases. In France, decision-making algorithms for the diagnosis of adult patients with moderate-to-severe psoriasis[10] are targeted for use in by health professionals involved in the management of patients including rheumatologists, general practitioners, nurses, and pharmacists.[11] In 2019, the Swedish National Board of Health and Welfare presented the first ever national guidelines for the treatment and care of psoriasis.[12] Though there have been guidelines created for the treatment of psoriasis by different shareholders in the past, this was the first time the that guidelines have been published by The National Board of Health and Welfare demonstrating positive political and healthcare leadership will. The guidelines contain recommendations in the following areas: living habits and complicity, investigation and follow-up, topical treatment, treatment for specifically localized psoriasis, light-spectrum therapy and climate care, and systemic treatment. However, experts noted that in Germany, doctors are disincentivised from prescribing more costly treatment options in psoriasis due to the personal liability embedded in the healthcare system reimbursement scheme.[13]

The general trajectory of care is similar throughout all 5 countries where patients first approach a general practitioner and are then triaged to a dermatologist, usually after several attempts of treatment have been made.

Moreover, the United Kingdom has one of the world's leading safety registry for patients receiving biologic drugs for psoriasis—the British Association of Dermatologists Biologic and Immunomodulators Register (BADBIR).[14] The United Kingdom's NICE Guidelines are used for the assessment and guidance for all those that treat patients. These are regularly updated and implemented by all healthcare providers for psoriasis and psoriatic arthritis.[15,16] Psonet, a surveillance network to monitor the long term effectiveness and safety of systemic agents in the treatment of psoriasis and / or psoriatic arthritis is also a resource used by providers. However, though these resources are available, their exact implementation in clinical practice varies as physician training and awareness varies.

Alongside clinical guidelines, advocacy organizations provide resources on the diagnosis of psoriasis and psoriatic arthritis that are available for providers.[17] Experts point to the Danish Dermatological Society example as a leading practice, providing training for specialists including competence assessments, care-based discussion guides and a course series on many dermatological topics including chronic inflammatory skin diseases.[18] The Swedish Dermatological Society has a training group that monitors and promotes dermato-venereological specialist training with the goal to instill a solid and basic education in dermato-venereology that follows the National Board of Health and Welfare's regulations and recommendations for Skin and Venereal Diseases.[19] There is also information available regarding psoriasis and co-morbidities, including the presence of somatic comorbidities and the development of psychiatric illnesses.[20]

Provider education varies among each indexed country though there is general consensus that GPs are not well informed about psoriatic disease. Advocacy organizations and larger European bodies such as the European Academy of Dermatology and Venereology organize online and in-person training courses but these resources are generally not consumed by GPs if they do not have a specific interest in the field. Additionally, though national guidelines are in place, specialized centers are the most likely to approach psoriatic disease holistically linking patients to a larger network of specialists they may need.

RECOMMENDATIONS & BEST PRACTICES

- Psoriatic disease and the associated comorbidities should carry a greater emphasis in medical education, especially for GPs.
- Allied healthcare workers should be leveraged to expand the reach of access to care for patients.
- A problem recognized by all health systems—providers should be able to allocate more time for each patient to ensure that all issues are addressed during their visit.

» Implement a checklist for patients visiting their physicians so they are able to cover all open issues.

- Patient-reported outcomes are beneficial to better understand the scope of the disease and identify gaps in care.

» Implement shared decision-making with patients and incorporate the safety aspects of drug interventions emerging from patient surveys.

- Continued education for providers through online classes or other interactive digital forms may help decrease the pressure on providers' time, allowing them more flexibility.
- Encourage physician training in dermatology, not related to a esthetics or cosmetology, due to shortages of professionals in the field.

- Collaboration between government, medical societies, and advocacy organizations leads to the development and better implementation of care guidelines.[21]
- Specialized centers of care can facilitate holistic treatments and required specialists are available “in house” for patients.
- Psonet is a valuable resource to conduct analyses and assessments for different systemic agents among other objectives, and could be expanded in its use.
- The normalization of psoriatic disease would help people with psoriasis or psoriatic arthritis feel empowered to disclose the disease and get treatment as early as possible.

Patient Engagement

Patient engagement within all levels of a health system is key to success in the patient journey. Non-adherence to treatment and medical recommendations are leading causes of treatment failure, poor clinical outcomes, and increased healthcare utilization.[22] Most countries do research and investigate adherence issues, but a universal solution has not been identified.

However, progress has been made in Denmark through the use of reminders and daily communications through a smartphone app that was found to improve adherence and reduce psoriasis symptoms compared with standard treatment.[23] In Sweden, patients are able to access benefits such as "climate therapy" (traveling to a temperate to tropical climates such as the Canary Islands) alongside treatment, a potential incentive for patients to engage in disease management.[24] Here they are supported by dermatologists, nurses and other healthcare professionals to ensure they are adhering to treatment in the islands and in Sweden. However, a limitation of most tools available for adherence is the requirement for patients to be self-motivated to seek this tool in the first place. As psoriatic disease comes in varying severities, so do the needs of patients; adherence to treatment is higher for biological therapies than conventional systemic drugs and topical treatments[25] as patients are much more engaged with their providers and the treatment schedule.

Patient engagement within all levels of a health system is key to success in the patient journey.

Experts reported in all countries studied that patients' needs, outside of those related to the skin or joints, are often not comprehensively managed. These co-occuring symptoms, especially psychological symptoms, are largely overlooked. The DLQI is implemented in each of the five countries and gives insights into the overall well-being of a patients, though usually in specialized psoriatic disease centers within universities or hospitals. The DLQI questionnaire is designed to measure the health-related quality of life of adult patients suffering from a skin disease and upon completion is used by clinicians to assist the consultation, evaluation, and decision-making process on how to move forward with the most appropriate treatment.[26] In each of the five countries investigated, there are centers of care that address the comprehensive needs of patients though a network of affilated specialists, but the capacity of these facilities is a fraction of the number needed for people living with psoriatic disease.

DALYS FOR PSORIASIS

	DALY Rate per 100,000	Percent of Total DALY	DALY
Denmark	219.45	0.78%	12,579.34
France	257.00	1.01 %	168,883.00
Germany	185.22	0.60%	154,276.85
Sweden	165.64	0.63%	16,638.46
UK	182.27	0.66%	121,457.66

To better understand the patient perspective, a Disability-Adjusted Life Year (DALY) metric is used to measure the loss of one health year of life. The sum of DALYs across a population represents the burden of disease and helps assess the gap between current health status and an ideal health situation where the entire population lives to an advanced age, free of disease and disability.[27,28] DALYs may be affected by a myriad of issues such as depression, ability to work and maintain a fulltime job, sexual dysfunction and others, all relevant comorbidities linked to psoriatic disease.

As outlined in the figure, DALYs affected by psoriasis are lowest in Sweden and highest in France. These values indicate, that on average, 201.92 DALYS are lost per 100,000 population and when compared to a well-known dermatological condition, such as acne vulgaris with a DALY value of 91.9 per 100,000 population[29] shows its significant impact on those living with psoriasis.

RECOMMENDATIONS & BEST PRACTICES

- Psoriatic disease symptoms and the increased risk of comorbidities should be addressed regularly with patients, especially mental health issues. Self-stigmatization can have the same or even greater negative impact as external stigma for patients.

- Prejudices and misconceptions about psoriatic disease bar many from seeking care at first onset, delaying treatment and increasing the number of lost healthy years of life (DALYs). Patients with a family history of psoriatic disease should have access to resources that discuss treatment options as early as possible.

- The funding and development of specialized centers are needed and are proven ways for patients to be allocated more time and attention to their psoriasis and psoriatic arthritis along with the other facets of their disease.

- Patients must be supported in understanding psoriatic disease as a systemic condition and that finding the correct balance of medications can be a long journey. National plans should incorporate care decision-making choices that include the voice of the patients using patient survey outcomes to develop strategies tailored to each country.

  » Patient-reported outcomes would help elucidate ways to address barriers related to patient engagement and thus ways to overcome them.

  » When trying to improve treatment adherence a personalized approach is usually the best fit.

Health Systems

As outlined by the World Health Organization, health systems are responsible for delivering services that improve, maintain, or restore the health of individuals and their communities.[30] Services include the entire spectrum of care from prevention to health promotion, to addressing the social determinants of health, and providing care in wide range of locations such as clinics, hospitals, health centers, and schools. For each of the countries studied, the national health system provides universal coverage and access to care for people living with psoriasis, but strengths and barriers for each health system are evident in the differences in health systems-funded medicines, diagnosis rates, access to specialist care, and the approach to chronic disease management in times of unprecedented crisis, like during the COVID-19 pandemic.

Experts shared that in the Danish health system, patients are reimbursed for drug expenses depending on annual consumption and choice of drug. For people with psoriasis, topical corticosteroids with antimicrobials are not reimbursed, which may, to some extent, explain their limited use. Yet, the majority of biologics are provided by the hospital free of charge.[31] Additionally, Denmark is one of the few countries where almost no one has the cost of treatment fully covered by insurance, and similarly the country with the second largest proportion of patients paying the full price for prescribed medicines.[32] Meanwhile in Germany, physicians are restricted to prescribing budgets for drugs without practice-specific regulation (Praxisbesonderheiten) status (different by regions) and are incentivized to fulfill quotas for preferred drugs set by "sickness funds."[33] In Sweden, prescriptions are free of charge (regardless of condition) after fulfilling a deductible of around $250 USD in annual expenses.[34]

The vast majority of people with psoriarsis in Denmark and Germany are diagnosed in specialist care settings (most often by dermatologists) whereas in the United Kingdom and France, nearly half are able to be diagnosed in primary care.

Access to several different types of specialists is also an important consideration within a health system for ongoing disease management for people with complex conditions like psoriatic disease. Specialist healthcare providers tend to be concentrated in urban geographies, leaving a significant gap in care for rural patients, as noted by experts. Low numbers of dermatologists, relative to the population, are evident in Denmark, Sweden and the UK. Additionally, the lack of other types of specialists relevant to psoriatic disease presents additional challenges for integrated and coordinated care.

DIAGNOSIS SUMMARY

	Physician Diagnosed Lifetime Prevalence Rates*	**Age of Diagnosis**
Denmark	1.5-2.0%[35] 75% diagnosed by a dermatologist[36]	47.7-58.7[37] years old
France	1.5-2.0%[38] 58% diagnosed by dermatologist[39]	N/A
Germany	2.20%[40] 71% diagnosed by a dermatologist[41]	Between 20 and 50 years old with approximately 80% of patients being less than 65 years old[42]
Sweden	2.0-2.5% [43]	Three peaks of onset: at puberty, at the age of 30, and at the age of 50[44]
UK	2.0%[45] 46% diagnosed by a dermatologist	N/A

*Note: Diagnosis rate is a ratio generally reported as a percentage indicating the number of people with a formal diagnosis of a psoriatic condition divided by the estimated prevalence of psoriatic conditions. Data for all people with psoriasis or a formal diagnosis was unavailable.

ACCESS TO SPECIALISTS PER 100,000

	DERMATOLOGIST	PSYCHOLOGIST	RHEUMATOLOGIST	DIETICIAN	IMMUNOLOGIST	ENDOCRINOLOGIST	TOTAL
Denmark	3.1	15	6.9	12.1	4.6	3.6	**33.2**
France	6.0	84	4.0	9.7	3.9	2.8	**110.4**
Germany	6.5	50	1.17	N/A	1.1	0.8	**59.1**
Sweden	3.8	146	N/A	14.6	5.2	2.5	**172.1**
United Kingdom	3.7	57	1.8	10.7	2.1	2.6	**77.9**

Each health system in the five countries investigated has advised patients to take extra precautions until COVID-19 risk and people with psoriatic disease is more fully understood. In each country, and not unique to patients with psoriasis, the use of teleconsultations with healthcare providers has been deployed where possible. The Danish Dermatological Society supported the International Psoriasis Council (IPC) statement advising physicians to counsel all their patients on how to prevent transmission of SARS-CoV-2 and for psoriasis patients diagnosed with COVID-19 disease, the IPC recommends physicians discontinue or postpone use of immunosuppressant medications.[46] Germany also included general recommendations that all patients with psoriasis on systemic therapy should take extra care with necessary preventive measures in hygiene and behavior.[47]

The French Dermatological Society launched the COVIDSKIN survey to collect and document skin manifestations that may be associated with COVID-19, in order to confirm or refute these associations and specify any links.[48] Additionally, to assess the impact of the pandemic on the psoriasis symptoms of young people, and better understand the difficulties encountered, the Psoriasis Research Group (GrPso), the French Society of Pediatric Dermatology (SFDP), and the 'France Psoriasis Patient Association' sent a call to action for all young people with psoriasis to answer a short online questionnaire, the results of which are set to be published in late 2020.[49] The Swedish Dermatological Society provides recommendations and information on the pandemic and developed measures to return to consultations and emphasis that fear of becoming infected should not cause patients to stop their treatment.[50]

Collaborative, cross-border resources have also been developed and launched to help all people with psoriasis regardless of location, in response to COVID-19. PsoProtectMe sent out a call to action to the international psoriasis community during the COVID-19 pandemic by asking people to self-report how they feel, even if asymptomatic, to help researchers understand how the pandemic is affecting people with psoriasis.[51] As referenced previously, Psonet, a surveillance network to monitor the long term effectiveness and safety of systemic agents in the treatment of psoriasis and / or psoriatic arthritis is also a resource used by providers and has been emphasized during the pandemic.[52]

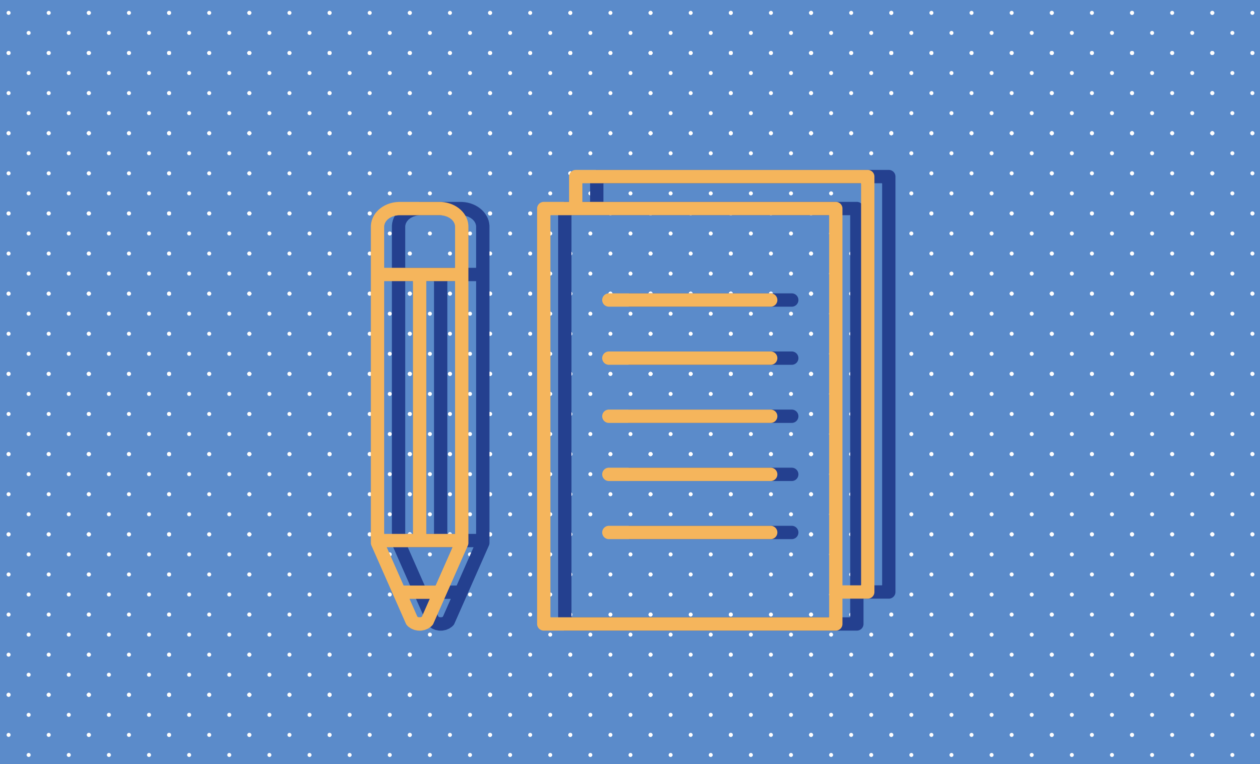
RECOMMENDATIONS & BEST PRACTICES

- In many cases, living with psoriasis requires over the counter ointments and lotions that are not prescribed and are not covered by health systems. These treatment management measures are out-of-pocket cost burdens on patients. Health systems could benefit from greater support of this form of preventative care since patients would be able to treat their skin before the condition progresses to requiring more advanced treatments.

- Health System infrastructure should push for digital solutions such as teleconsultations, e-prescriptions, and at home treatment delivery systems. This can be achieved through collaborative approaches between clinicians, psoriatic disease advocacy networks, and governments and can lead to the removal of many barriers and decrease the stigmas surrounding psoriatic disease.

- Though diagnosis settings and availability of specialists vary, there is a need for a greater number of health care providers as most health systems are reported to have long wait times and short consultations that do not allow patients to build relationships with the providers to discuss their patient journey in detail or explore potential treatment options.

» Within each country reviewed there are regional differences (rural areas vs urban centers) that affect access to care.



Enabling Environment

Creating an enabling environment for people living with psoriatic disease requires many components that reach beyond care settings and truly shape the experience of living with the condition. At the highest level it requires policies and regulations, with aligned budgetary allocations and financing. Health interventions must also be available and accessible with the corresponding health management systems in place to provide accurate and reliable services. Lastly, the capacity of the medical workforce needs safeguarding for a holistic and inclusive approach to psoriatic disease.

For all five countries, only Sweden has national guidelines for the treatment and care of psoriasis. However, clinical guidelines and recommendations were available and actively used in all nations. Germany did have a National Program on Psoriasis from 2005-2015 with the aim to improve health care for optimize outcomes for psoriasis countrywide and the plan was adopted by the Association of Scientific Medical Societies in Germany.[53] Enabling environment differences start to emerge in regard to research funding, indirect and direct costs to the economy, and health system spending. For example, a Danish collaboration between industry and university hospitals partnered to better understand prevention and treatment of skin diseases with positive results.[54] Additionally, the Psoriasis Association of France and their Health Democracy project aims to associate all the actors of the health system, not only professionals, but also patients, in the development and implementation of health policy.[55]

Greater emphasis might be put on psoriatic disease if there was greater awareness of the direct and indirect costs of the conditions.

Interestingly, in Germany, 28 regional psoriasis networks have been established since 2008 that include core elements such as their commitment to qualified care, their willingness to cooperate in an interdisciplinary approach, and the participation in health care research projects.[56] As previously discussed, the United Kingdom utilizes their NICE guidelines for medical care which include psoriasis and psoriatic arthritis. Notably, the ABPI Dermatology Initiative, in collaboration with the NHS, is focused on optimizing the treatment and care of people with long-term skin conditions in England.[57]

Greater emphasis might be put on psoriatic disease if there was greater awareness of the direct and indirect costs of the conditions. The results of a systemic literature review[58] showcase costs of generalized psoriasis and total costs to society, as outlined in the tables below. The annual cost of managing a patient with psoriasis is variable but within the context of our five countries, Denmark has the lowest annual direct costs per patient in psoriasis and Sweden is the country with the highest. In regard to total cost on society which includes elements such as lost productivity, the United Kingdom bears the lowest costs to their society where as France has the highest. Unfortunately, specified data for Sweden wasn't available. As expected across geographies, costs are proportional to the severity of disease with those with a more severe form of the disease incurring higher costs and in particular with the use of biologic treatments.

COSTS OF PSORIASIS

Current Costs Adjusted for PPP (Patient-Year, PPP USD 2015)

	Direct	Indirect	Total
Denmark	5,406	4,799	10,205
France	8,925	4,207	13,132
Germany	8,129	2,209	10,339
Sweden	14,172*		14,172
United Kingdom	20,061	N/A	20,061

*Note: Data for direct and indirect.

TOTAL COST ON SOCIETY

	Per 100,000 people in employment	As % of GDP	Overall
Denmark	$20.2m	0.20%	$574,000m
France	$74.8m	0.71%	$20,497m
Germany	$38.5m	0.38%	$15,985m
Sweden	NA	NA	NA
United Kingdom	$8.1m	0.09%	$2,638m

RECOMMENDATIONS & BEST PRACTICES

- Emphasis on access to adequate diagnosis, early, adapted and appropriate treatment as well as affordable long-term supply of medicines and treatments would reduce the burden of psoriasis and would in turn favor social and economic inclusion, generating important return on investments for the overall society.

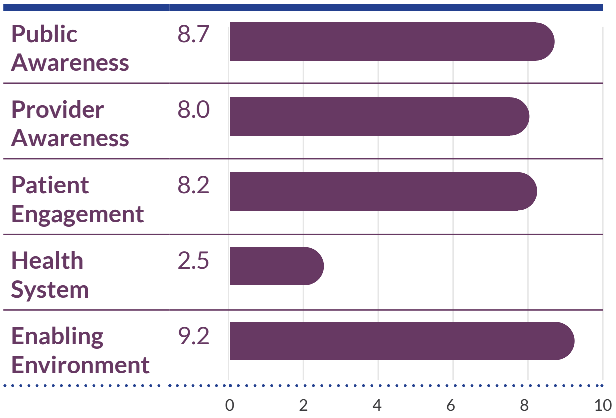
- Promote care management models that incentivize the:
  - » Support of dynamic professional, lifelong training and educational systems that includes empathy and understanding of the diseases social implications;
  - » Emphasis on patient-centered care to approach all facets of the disease(s);
  - » Distribution of responsibility across stakeholders differently and use psoriatic disease as a model for effectiveness;
  - » Integration of technology and innovation as a core competence for the health workforce and supports the adaption of cost-effective innovations;
  - » Adaptation to patient needs while delivering value- based outcomes;
  - » Usage of validated patient reported outcomes instruments;
  - » Development of interventions in partnership with end-users; and
  - » Embedding of a culture of trust and approach patents with consistent and credible resources.

- Incentivize governments to enact national policies as outlined in the 2014 WHO resolution by emphasizing the larger scope of the disease such as the burden on economies and overall detriment to health.

Index Snapshot by Country

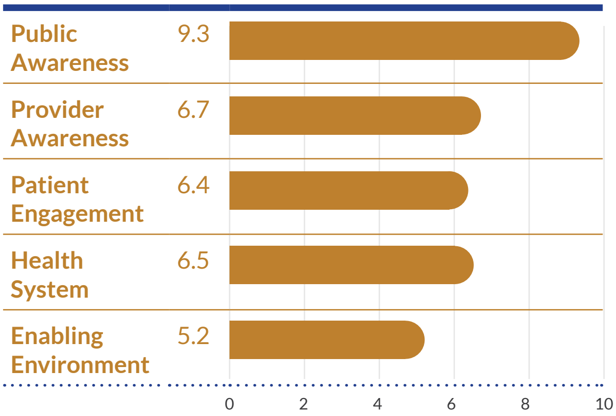
Though previously outlined by categories, the below analysis shows each country's score for the selected indicators in aggregate for an overall representation of how they identify, treat, and support people living with psoriasis and/or psoriatic arthritis. The following brief assessment is meant to applaud beneficial contributions currently being done and encourage growth and implementation of best practices for improvement.

DENMARK



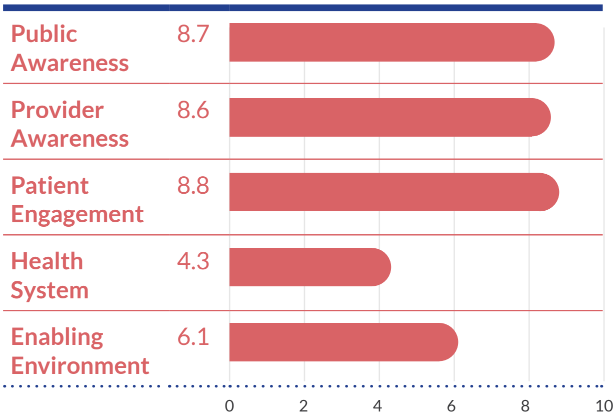
Denmark has a strong enabling environment that supports people living with psoriatic disease. This is achieved through recognition of psoriatic disease through the non-communicable disease initiative,[59] strong patient engagement groups, and relatively low cost to the patient and society as outlined above. However, as previously mentioned, Denmark is one of the few countries where almost no one has the price fully covered by their insurance, and similarly the country with the second largest proportion of people going with a prescription and paying the full price.[60]

FRANCE



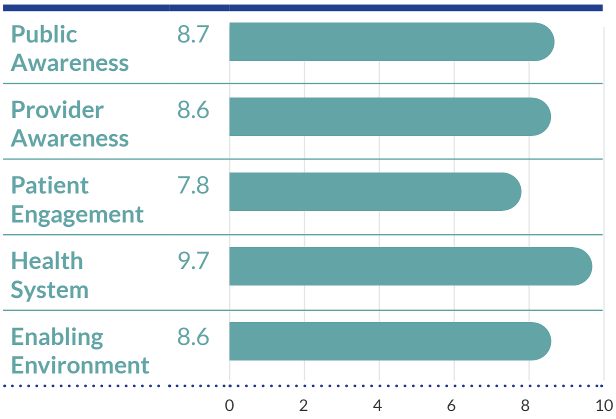
Though a national strategy is still awaiting endorsement by the government, historically, France has made strides in addressing public awareness of psoriatic disease through communication campaigns centered around stigma and prejudice.[61] Likewise, patient engagement is highlighted as an important part of care. However, cultural and systematic barriers do not incentivize GP to refer psoriatic disease patients to specialists. Thus, the reliance on training and knowledge of these GP is greater. Additionally, the annual costs to society in France are highest when compared to the other four countries.

GERMANY



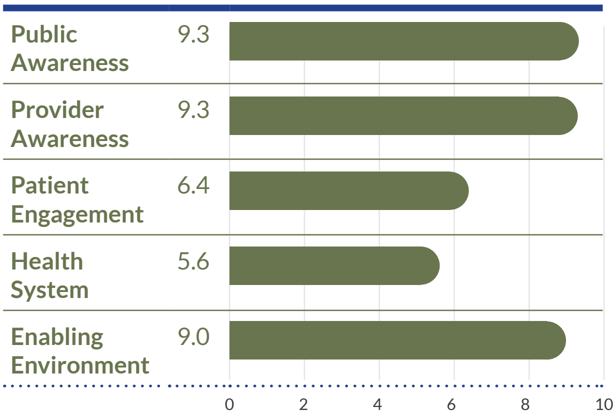
Germany has robust patient engagement groups, awareness campaigns, and guidelines for treatment and care of psoriatic disease. Patient engagement is achieved through various avenues such as advocacy groups and through their treating physician the application of individualized treatment approaches to ensure proper adherence.[62] Additionally, centers of care, usually in university hospital setting are able to provide holistic approaches for patients that include care for co-morbidities, should they have any. However, physicians are restricted to prescribing budgets for drugs without practice-specific regulation (Praxisbesonderheiten) status (different by regions) and are incentivized to fulfill quotas for preferred drugs set by “sickness funds.”[63]

SWEDEN

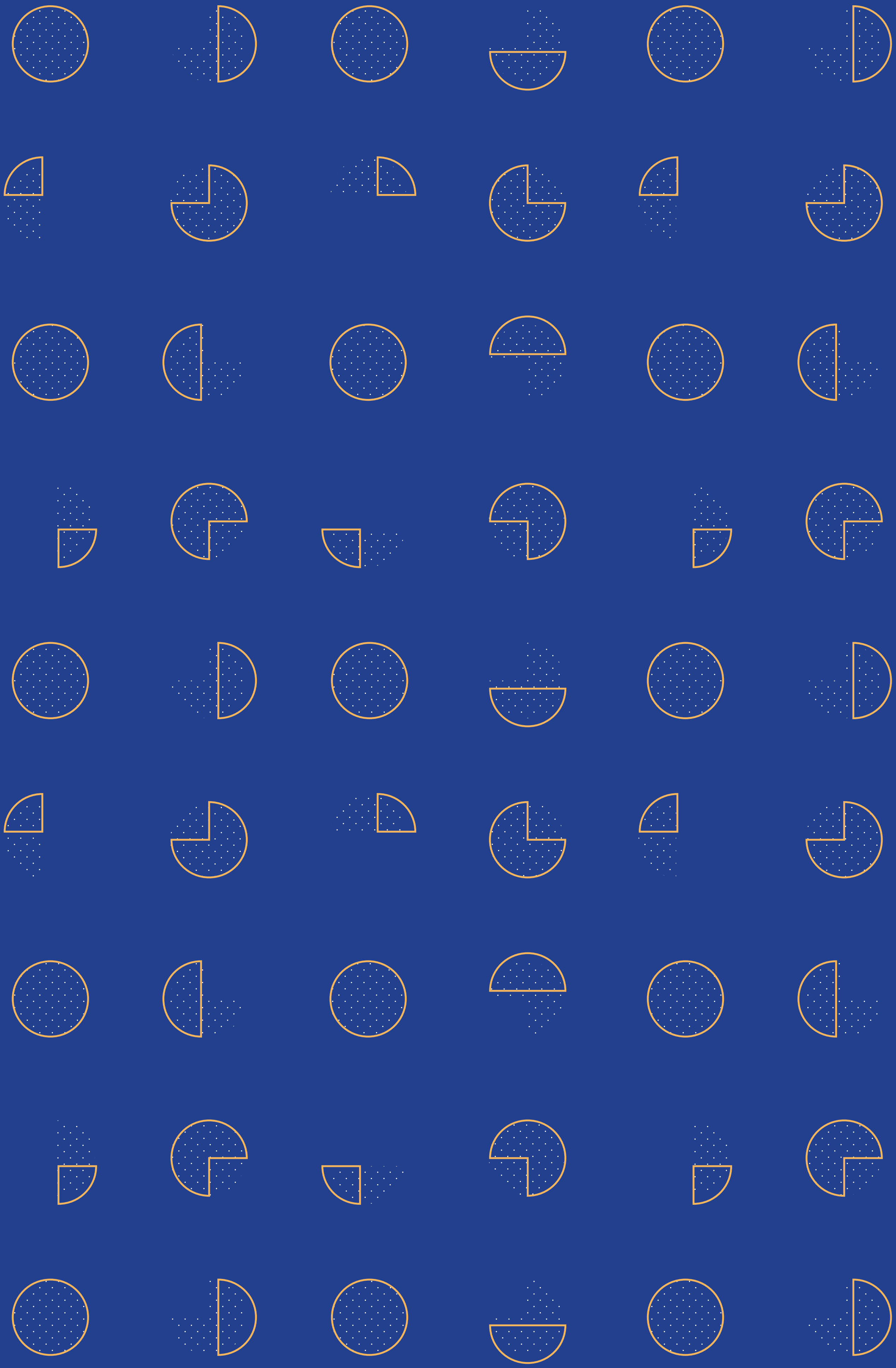


Sweden, the highest scoring country from our group, is also the only one that has national guidelines for the treatment and care of psoriasis.[64] The guidelines contain recommendations for living habits and complicity, investigation and follow-up for clinicians and patients, topical treatment guidelines, climate care, and systemic treatment. The guidelines were achieved through a consorted effort between multiple stakeholder but always emphasizing the importance of the patient voice. Additionally, their patient advocacy and engagement groups are active in implementing educational campaigns. Likewise, these organizations work alongside health professionals to provide patients with support during treatment. As medicines are free of charge their health system and their physicians are trained for early detection of co-morbidities, the barriers for treatment and care for those living with psoriatic disease are low.[65]

UNITED KINGDOM



The United Kingdom demonstrates a unified approach to people living with psoriatic disease, mainly through their implementation of NICE guidelines,[66] supportive patient advocacy and engagement efforts, and the relatively low cost of psoriatic disease on society. However, availability of specialists such as rheumatologists, immunologists, and dermatologists is low when compared to the other four countries. Additionally, direct costs for patients is the highest among all studied countries.[67]



Conclusion

The Index revealed inequalities and opportunities in health system’s disease responses across all five countries. In order to realize the WHO’s resolution and vision of better psoriatic disease care, all stakeholders need to take action.

Introducing national plans could increase the incentive to treat the patients holistically, and mandatory psoriatic disease training program for GPs, and allied healthcare workers, can be a response to the limited access to specialists. In all countries studied, patient needs, outside of those related to the skin or joints, are often not comprehensively managed. These co-occurring symptoms, especially psychological symptoms, are largely overlooked. There is an opportunity to bring greater focus to common comorbidities, especially mental health. Collaborative efforts with other associations of related dermatological diseases could create a louder voice as well as make best-use of limited funding. As such, advocacy efforts aimed at reaching the general public need to be expanded and tailored to the local level while also identifying community support systems to encourage greater outreach to individuals that have not accessed care. In parallel, policymakers need to support awareness campaigns and anti-discrimination initiatives to reduce the negative impacts making patient feeling less empowered. Normalizing the disease can increase the patient’s self-motivation and engagement in the treatment.

Leveraging digital communications can also benefit psoriatic disease patients by enabling them to access care more effectively and in this same breath offer health systems a source of patient reported outcomes to better understand the scope of the disease and identify gaps in care, thus empowering patients. Emphasis on access to adequate diagnosis, early, adapted, and appropriate treatment as well as affordable long-term supply of medicines and treatments would reduce the burden of psoriasis and would in turn favor social and economic inclusion, generating important return on investments for the overall society.

We believe that psoriatic disease is a model condition to gauge the overall well-being of a health system. In this Index we have outlined best practices and recommendations that are implementable at local, regional, national levels. Our goal for the Index is that it serve as an advocacy tool to educate stakeholders on the importance of integrating psoriatic disease management, prevention, and treatment into national and global health policy.

Appendix A: Categories & Indicators with Weighted Values & Scoring

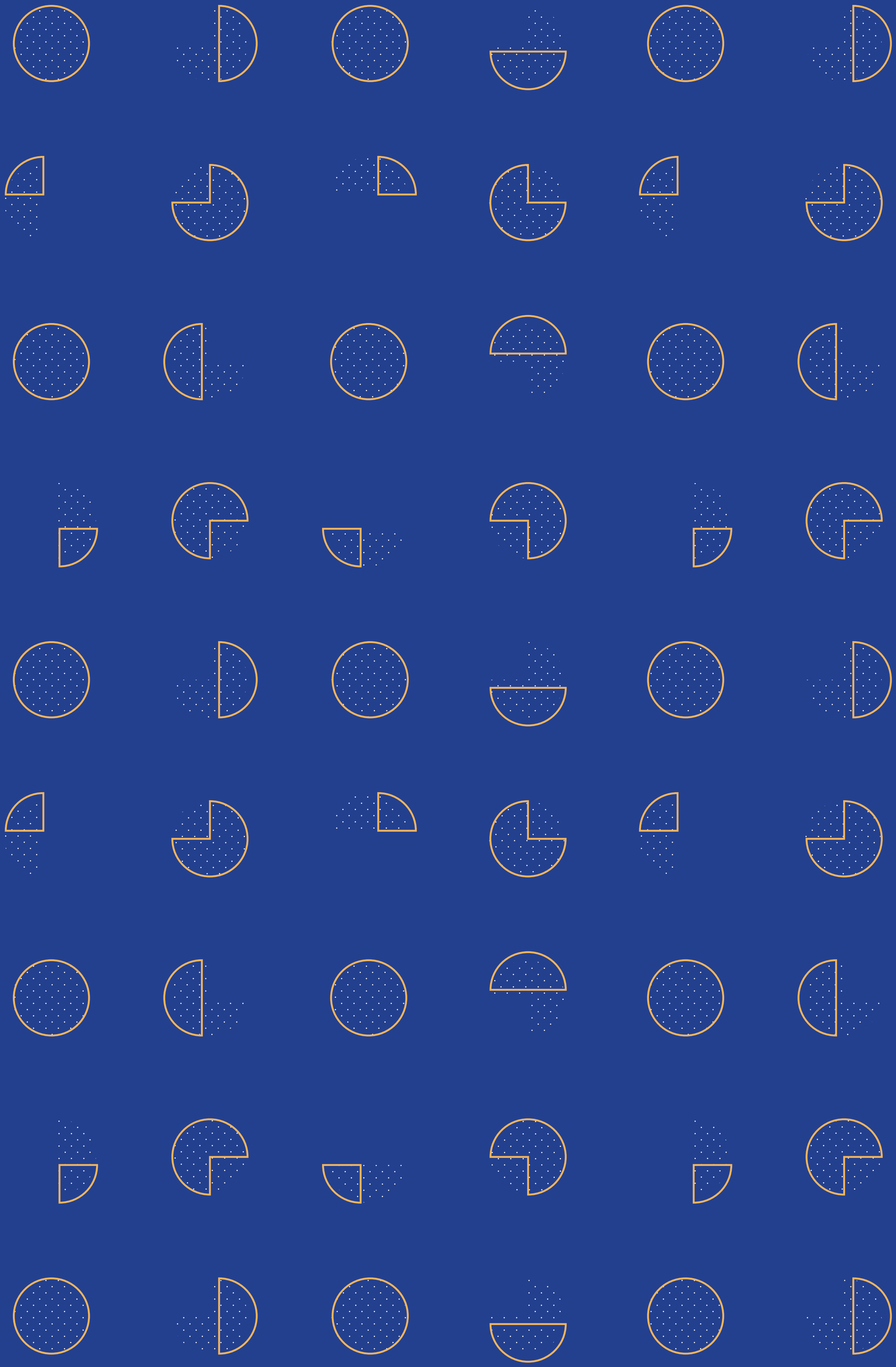
	Indicator	Indicator Score	Weighted Value	Denmark	France	Germany	Sweden	United Kingdom
PUBLIC AWARENESS	Existence of public awareness campaigns	1. A public awareness campaign does not exist 2. There has been a campaign, but it is not current 3. There is a public awareness campaign that is currently running	1	2	3	2	2	2
	Patient group engagement (based on expert insights)	1. There is no patient advocacy group 2. There is a small or ineffective patient advocacy group 3. There is an active and effective patient advocacy group	3	9	9	9	9	9
	Patient engagement surveys and other tools	1. Patient engagement surveys or tools were not used for patients living with psoriasis 2. Patient engagement surveys or tools were used previously for patients living with psoriasis, but not currently 3. Patient engagement surveys or tools are currently being used for patients living with psoriasis	1	2	2	2	3	3
	Total Score Possible for Category: 15	CATEGORY SCORE		13	14	13	14	14
		NORMALIZED SCORE		8.7	9.3	8.7	8.7	9.3

	Indicator	Indicator Score	Weighted Value	Denmark	France	Germany	Sweden	United Kingdom
PROVIDER AWARENESS	Availability of diagnostic training for PCPs	1. There is no training available for PCPs on psoriasis 2. Dermatological societies provide resources and training for PCPs on psoriasis available 3. There is training for PCPs on psoriasis as part of the core professional curriculum	2	4	4	6	4	6
	Availability of training for allied healthcare workers	1. There is no training available for allied health professionals on psoriasis 2. There is optional training available for allied health professionals on psoriasis 3. There is training for allied health professionals on psoriasis as part of the core professional curriculum	2	2	4	2	4	4
	Availability of information on co-morbidities	1. No information on co-morbidities 2. There is information available, but it is limited or out of date 3. There is information available and it is current	3	9	6	9	9	9
	Treatment guidelines	1. No treatment guidelines available 2. Treatment guidelines are non-specific to medication pathway 3. Treatment guidelines recommend a multi-pronged, patient centered approach inclusive of a medication pathway (progression of treatment: topicals, oral systemic, then biologics)	3	9	6	9	9	9
	Total Score Possible for Category: 30	CATEGORY SCORE		24	20	26	26	28
		NORMALIZED SCORE		8.0	6.7	8.6	8.6	9.3

	Indicator	Indicator Score	Weighted Value	Denmark	France	Germany	Sweden	United Kingdom
PATIENT ENGAGEMENT	Tools or support for medication adherence	1. No support exists for medication adherence exists 2. Support for medication adherence exists, but it's not specific to psoriasis 3. There is support specifically for medication adherence for people with psoriasis	2	6	4	4	4	6
	Disability-adjusted life years for psoriasis	Distance to frontier	2	2.6	2	5	6.4	5.2
	DLQI: Dermatology Quality of Life Index	Distance to frontier	3	13.2	9.3	13.2	7.8	3
	DLQI: Dermatology Quality of Life Index	1. DLQI has never been used in a clinical setting 2. DLQI has been used in a clinical setting 3. DLQI is currently being used in a clinical setting	1	3	2	2	3	3
	Total Score Possible for Category: 54	**CATEGORY SCORE**		21.8	17.3	24.2	21.2	17.2
		NORMALIZED SCORE		4.0	3.2	4.4	3.9	3.2

	Indicator	Indicator Score	Weighted Value	Denmark	France	Germany	Sweden	United Kingdom
HEALTH SYSTEMS	Access to specialist care (specialist by type: dermatologists / rheumatologists / psychologists etc.)	Distance to frontier	3	5.1	17.4	9.3	2.7	12.3
	Health-system funded medicines	1. No treatments are reimbursed by the health system 2. Some treatments are reimbursed by the health system 3. All treatments are reimbursed by the health system.	2	2	4	4	6	6
	Chronic Disease Management in times of Unprecedented Crisis (i.e. COVID-19 pandemic)	1. COVID-19 has affected the management of psoriatic disease and patients are not receiving care 2. COVID-19 has delayed the management of psoriatic disease for patients but they are still receiving care 3. COVID-19 has not affected the management of psoriatic disease for patients	1	2	2	2	2	2
	Total Score Possible for Category: 36	CATEGORY SCORE		9.1	23.4	15.3	35	20.3
		NORMALIZED SCORE		2.5	6.5	4.3	9.7	5.6

	Indicator	Indicator Score	Weighted Value	Denmark	France	Germany	Sweden	United Kingdom
ENABLING ENVIRONMENT	Existence of a national strategy	1. There is no national strategy 2. There is no psoriasis national strategy, but there is an NCD strategy 3. There is a national strategy for psoriasis	3	6	6	9	6	6
	Existence of national policy initiatives from key stakeholders Advocacy groups—not implemented by the government	1. There are no policy initiatives 2. There are policy initiative related to NCDs of dermatology 3. There policy initiatives specifically related to psoriasis	3	9	6	9	9	9
	Direct and indirect costs to the economy	Distance to frontier	3	26.3	3	6	N/A	23.4
	Research funding for psoriasis	1. There are no research foundations or advocacy groups that dedicate funding for psoriatic disease research 2. There are research foundations or advocacy groups that dedicate funding for psoriatic disease research, but there are barriers to access 3. There are research foundations or advocacy groups that dedicate a substantial amount of funding for psoriatic disease research, with negligible barriers to access	1	3	2	2	3	3
	Health System Spending for Psoriatic Disease	Distance to frontier	2	N/A	17	14.4	N/A	18
	Total Score Possible for Category: 66	CATEGORY SCORE		44.3	34	40.4	18	59.4
		NORMALIZED SCORE		9.2	5.2	6.1	8.6	9.0



Appendix B: References

1. World Health Organization. “Global report on psoriasis” October 2016. Available at: https://www.who.int/publications/i/item/global-report-on-psoriasis

2. “Psoriasis—Psoriasisforeningen.” Psoriasisforeningen. 2020. Available at https://www.psoriasis.dk

3. K.S. Tveit et al. “Treatment use and satisfaction among patients with psoriasis and psoriatic arthritis: results from the NORdic PAtient survey of Psoriasis and Psoriatic arthritis (NORPAPP).” Journal of the European Academy of Dermatology and Venereology. 2018. Available at https://onlinelibrary.wiley.com/doi/full/10.1111/jdv.15252

4. A. Duvetorp et al. “Quality of life and contact with healthcare systems among patients with psoriasis and psoriatic arthritis: results from the NORdic PAtient survey of Psoriasis and Psoriatic arthritis (NORPAPP).” Archives of Dermatological Research. 2018. Available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6546664/

5. “Deutscher Psoriasis Bund e.V.” Deutscher Psoriasis Bund e.V. 2020. Available at https://www.psoriasis-bund.de/

6. N. Unesi et al. “Survey results from a nationwide online awareness campaign suggest a clear difference in treatment and perception of quality of healthcare for patients diagnosed with psoriasis arthritis, psa, versus patients with symptoms similar to psoriasis arthritis i.e. psoriasis and joint pain.” Annals of the Rheumatic Diseases. 2018. Available at https://ard.bmj.com/content/77/Suppl_2/1874.3

7. “France Psoriasis.” Association France Psoriasis. 2020. Available at https://francepsoriasis.org

8. “World Psoriasis Day held at the embassy.” Ministry of Foreign Affairs in Denmark. 2012. Available at https://kina.um.dk/en/about-us/news/newsdisplaypage/?newsid=c653cdb7-dc95-4964-bf2e-ea7b1bee2a15

9. “France—World Psoriasis Happiness Report.” LEO Innovation Lab & The Happiness Research Institute. 2018. Available at https://psoriasishappiness.report/static/documents/world-psoriasis-happiness-country-report-2018-france.pdf

10. F. Amatore et al. “French guidelines on the use of systemic treatments for moderate-to-severe psoriasis in adults.” Journal of the European Academy of Dermatology and Venereology. 2019. Available at https://onlinelibrary.wiley.com/doi/10.1111/jdv.15340

11. F. Amatore et al. “French guidelines on the use of systemic treatments for moderate-to-severe psoriasis in adults.” Journal of the European Academy of Dermatology and Venereology. 2019. Available at https://onlinelibrary.wiley.com/doi/10.1111/jdv.15340

12. “Swedish National Board of Health and Welfare present the first ever national guidelines for the treatment and care of psoriasis.” International Psoriasis Council. 2020. Available at https://www.psoriasiscouncil.org/blog/Swedish-National-Board-of-Health-and-Welfare-present-the-first-ever-national-guidelines-for-the-treatment-and-care-of-psoriasis.htm

13. U. Theidel et al. “Benefit assessment in Germany: implications for price discounts.” Health Economics Review. 2016. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4970987/

14. “Patient Involvement.” PSORT. 2020. Available at http://www.psort.org.uk/patient-involvement/

15. “Assessing psoriasis and comorbidities.” National Institute of Health and Care Excellence. 2020. Available at https://pathways.nice.org.uk/pathways/psoriasis/assessing-psoriasis-and-comorbidities

16. “Assessing psoriasis and comorbidities.” National Institute of Health and Care Excellence. 2020. Available at https://pathways.nice.org.uk/pathways/psoriasis/assessing-psoriasis-and-comorbidities

17. “Psoriasisgigt Diagnose.” Psoriasisforeningen. 2020. Available at https://www.psoriasis.dk/psoriasisgigt-1/diagnose

18. “Speciallægeuddannelsen.” Dansk Dermatologisk Selskab. 2020. Available at https://dds.nu/speciallaegeuddannelsen/

19. “ST-utbildning.” Svenska Sällskapet för Dermatologi och Venereologi. 2020. Available at https://www.ssdv.se/utbildning/st-utbildning

20. “Association of Skin Psoriasis and Somatic Comorbidity With the Development of Psychiatric Illness in a Nationwide Swedish Study.” JAMA Dermatol. 2020. Available at https://jamanetwork.com/journals/jamadermatology/article-abstract/2766771

21. M. Augustin et al. “The German National Program on Psoriasis Health Care 2005–2015: results and experiences.” Archives of Dermatological Research. 2016. Available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4940437/

22. C. Ahn. Et al. " Adherence in dermatology." Journal of Dermatological treatment. 2016. Available at: https://www.tandfonline.com/doi/abs/10.1080/09546634.2016.1181256?src=recsys&journalCode=ijdt20

23. M. T. Svendsen et al. "Dermatology nurses view on factors related to Danish psoriasis patients' adherence to topical drugs: a focus group study." Journal of Dermatological Treatment. 2019. Available at https://pubmed.ncbi.nlm.nih.gov/31664863

24. "Sweden: The relation between patient, patient organization, and dermatologist." Psoriasisforbundet. Available at https://www.spindermatology.org/IMG/pdf/Annika_Rastas_presentation_Bucharest_EADV_Spring_Meeting.pdf

25. " Study on the Therapeutic Adherence by Patients with Psoriasis in France: A study of 181 patients." European Academy of Dermatology and Venereology. 2019. Available at https://cdn-membre.carenity.com/docs/20190919-EADV-Study-on-the-therapeutic-adherence-by-patients-with-psoriasis-in-France-1571822726.pdf

26. Cardiff University. "Dermatology Quality of Life Index" Available at: . https://www.cardiff.ac.uk/medicine/resources/quality-of-life-questionnaires/dermatology-life-quality-index

27. World Health Organization. "Health Statistics and information Systems." https://www.who.int/healthinfo/global_burden_disease/metrics_daly/en/

28. The Lancet. "Global, regional, and national disability-adjusted life-years (DALYs) for 359 diseases and injuries and healthy life expectancy (HALE) for 195 countries and territories, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017." 2018. Available at: https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(18)32335-3/fulltext

29. The Lancet. "Global, regional, and national disability-adjusted life-years (DALYs) for 359 diseases and injuries and healthy life expectancy (HALE) for 195 countries and territories, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017." 2018. Available at: https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(18)32335-3/fulltext

30. World Health Organization. "Health Systems" Available at: https://www.euro.who.int/en/health-topics/Health-systems/pages/health-systems

31. M.T. Svendsen. "Use of topical antipsoriatic drugs in Denmark: a nationwide drug utilization study." British Association of Dermatologists. 2018. Available at https://onlinelibrary.wiley.com/doi/abs/10.1111/bjd.17074

32. "Denmark—World Psoriasis Happiness Report." LEO Innovation Lab & The Happiness Research Institute. 2018. Available at https://psoriasishappiness.report/static/documents/world-psoriasis-happiness-country-report-2018-denmark.pdf

33. "Market Access / Pricing & Reimbursement." DataMonitor Healthcare. 2016. Available at https://pharmastore.informa.com/wp-content/uploads/2016/10/Psoriasis-Pricing-Reimbursement-and-Access-_163776.pdf

34. P. S. Calara et al. "Regional Differences in the Prescription of Biologics for Psoriasis in Sweden: A Register-Based Study of 4168 Patients." BioDrugs. 2017. Available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5258782/

35. R. Parisi et al. "National, regional, and worldwide epidemiology of psoriasis: systematic analysis and modelling study." BMJ. 2020. Available at https://www.bmj.com/content/369/bmj.m1590

36. "Denmark—World Psoriasis Happiness Report." LEO Innovation Lab & The Happiness Research Institute. 2018. Available at https://psoriasishappiness.report/static/documents/world-psoriasis-happiness-country-report-2018-denmark.pdf

37. A. Egeberg et al. "Incidence and Prevalence of Psoriasis in Denmark." Acta Derm Venereol. 2017. Available at https://pubmed.ncbi.nlm.nih.gov/28417141/

38. R. Parisi et al. "National, regional, and worldwide epidemiology of psoriasis: systematic analysis and modelling study." BMJ. 2020. Available at https://www.bmj.com/content/369/bmj.m1590

39. "France—World Psoriasis Happiness Report." LEO Innovation Lab & The Happiness Research Institute. 2018. Available at https://psoriasishappiness.report/static/documents/world-psoriasis-happiness-country-report-2018-france.pdf

40. R. Parisi et al. "National, regional, and worldwide epidemiology of psoriasis: systematic analysis and modelling study." BMJ. 2020. Available at https://www.bmj.com/content/369/bmj.m1590

41. “Germany—World Psoriasis Happiness Report.” LEO Innovation Lab & The Happiness Research Institute. 2018. Available at https://psoriasishappiness.report/static/documents/world-psoriasis-happiness-country-report-2018-germany.pdf

42. M. Augustin et al. “Health Services Research in Psoriasis—The German Approach.” Dermatology. 2009. Available at https://www.spindermatology.org/IMG/pdf/Orig_091_Augustin_M_Dermatology_218_293-301_2009-1.pdf

43. R. Parisi et al. “National, regional, and worldwide epidemiology of psoriasis: systematic analysis and modelling study.” BMJ. 2020. Available at https://www.bmj.com/content/369/bmj.m1590

44. “Psoriasis Phenotype at Disease Onset: Clinical Characterization of 400 Adult Cases.” Journal of Investigative Dermatology. 2005. Available at https://www.sciencedirect.com/science/article/pii/S0022202X15322156

45. “Psoriasis.” NHS. 2020. Available at https://www.nhs.uk/conditions/psoriasis/

46. “COVID-19 og immunsupprimerende behandling af psoriasi.” Dansk Dermatologisk Selskab. 2020. Available at https://dds.nu/covid-19-og-immunsupprimerende-behandling-af-psoriasis/

47. “Therapieempfehlungen während COVID.” Deutsche Dermatologische Gesellschaft. 2020. Available at https://derma.de/corona/therapieempfehlungen-register/

48. “Coronavirus-Covid19.” Société Française de Dermatologie. 2020. Available at https://evenements-sfd.fr/coronavirus-covid-19/

49. Journees dermatologiques de Paris Available at https://www.lesjdp.fr/

50. “Information angående immundämpande behandling och Covid-19.” Svenska Sällskapet för Dermatologi och Venereologi. 2020. Available at https://www.ssdv.se/images/Information_angaende_immundampande_behandling_och_Covid_uppdat_200416.pdf

51. PsoProtectMe. Available at https://psoprotectme.org/

52. Psonet. European Registry of Psoriasis. Available at http://www.psonet.eu/cms/

53. M. Augustin et al. “The German National Program on Psoriasis Health Care 2005–2015: results and experiences.” Archives of Dermatological Research. 2016. Available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4940437/

54. “Ambitious new research center will push the boundaries of skin disease research.” University of Copenhagen. 2018. Available at https://healthsciences.ku.dk/newsfaculty-news/2018/11/ambitious-new-research-center-will-push-the-boundaries-of-skin-disease-research/

55. Association Psoriasis France. “ Les Campagnes de Communication” https://francepsoriasis.org/lassociation/actions-et-services/campagnes-de-communication/

56. M. Augustin et al. “The German National Program on Psoriasis Health Care 2005–2015: results and experiences.” Archives of Dermatological Research. 2016. Available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4940437/

57. “Making real our shared vision for the NHS: optimising the treatment and care of people with long-term skin conditions in England.” ABPI Dermatology Initiative. 2018. Available at https://www.abpi.org.uk/media/4684/der-0080-0517-dermatology_initiative_report_rev16.pdf

58. R. Burgos-Pol et al. “The Cost of Psoriasis and Psoriatic Arthritis in 5 European Countries: A Systematic Review.” Academia Española de Dermatología y Venerología. 2016. Available at https://www.actasdermo.org/en-the-cost-psoriasis-psoriatic-arthritis-articulo-S1578219016301524

59. “Danish Government and Novo Nordisk first to partner with UN-anchored initiative on non-communicable diseases.” Ministry of Foreign Affairs of Denmark. 2018. Available at https://um.dk/en/news/newsdisplaypage/?newsid=08dbd569-4976-46c1-9cd5-eec5c9d92fea

60. “Denmark—World Psoriasis Happiness Report.” LEO Innovation Lab & The Happiness Research Institute. 2018. Available at https://psoriasishappiness.report/static/documents/world-psoriasis-happiness-country-report-2018-denmark.pdf

61. “France Psoriasis.” Association France Psoriasis. 2020. Available at https://francepsoriasis.org

62. C-H. Hong et al. “Patients with psoriasis have different preferences for topical therapy, highlighting the importance of individualized treatment approaches: randomized phase IIIb PSO-INSIGHTFUL study.” Journal of the European Academy of Dermatology and Venereology. 2017. Available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5698702/

63. “Market Access / Pricing & Reimbursement.” DataMonitor Healthcare. 2016. Available at https://pharmastore.informa.com/wp-content/uploads/2016/10/Psoriasis-Pricing-Reimbursement-and-Access-_163776.pdf

64. International Psoriasis Council. “Swedish National Board of Health and Welfare present the first ever national guidelines for the treatment and care of psoriasis”. April 2019. Available at: https://www.psoriasiscouncil.org/blog/Swedish-National-Board-of-Health-and-Welfare-present-the-first-ever-national-guidelines-for-the-treatment-and-care-of-psoriasis.htm

65. “Intressegruppen för Psoriasis.” Svenska Sällskapet för Dermatologi och Venereologi. 2020. Available at https://www.ssdv.se/intressegruppen-for-psoriasis

66. “Psoriasis: Assessment and management of psoriasis.” National Institute for Health and Clinical Excellence. 2012. Available at https://www.nice.org.uk/guidance/cg153/evidence/full-guideline-188351533

67. R. Burgos-Pol et al. “The Cost of Psoriasis and Psoriatic Arthritis in 5 European Countries: A Systematic Review.” Academia Española de Dermatología y Venerología. 2016. Available at https://www.actasdermo.org/en-the-cost-psoriasis-psoriatic-arthritis-articulo-S1578219016301524

About the Global Psoriasis Coalition

Millions of people worldwide live with psoriasis —a chronic, non-communicable disease.

(NCD) that inflicts a serious mental, emotional, social, and economic toll on both the individual and the societies they live in. Those affected have a greatly increased risk for comorbid NCDs like diabetes and cardiovascular disease, reducing quality of life and generating higher costs for health systems. Rates of psoriasis have been increasing globally, and in some countries, have doubled in the last several decades. Yet, there is no cure for psoriasis, and those living with the disease often struggle to receive an accurate diagnosis, have difficulty accessing appropriate treatment and care, and face discrimination and stigma. Additionally, up to 30 percent of people with psoriasis also develop psoriatic arthritis, which are always considered as a part of our conversation.

The Global Psoriasis Coalition is a program of the International Federation of Psoriasis Associations (IFPA), inspired by developments in the non-communicable diseases (NCD) policy agenda that calls on civil society to advocate for a people-centered and integrated response to psoriasis. We are global advocates joining medical societies, non-governmental organizations, foundations, corporate partners, and other relevant associations to cooperate across borders, across disease areas, and across sectors. We are a united front of diverse voices committed to focusing global health conversations on psoriasis, fostering behavioral change and creating opportunities for action that will change the living conditions of people with psoriasis.

For more information visit
www.globalpsoriasiscoalition.org

GLOBAL
PSORIASIS
COALITION

GLOBAL
PSORIASIS
COALITION

IFPA
INTERNATIONAL FEDERATION
OF PSORIASIS ASSOCIATIONS