ECONOMIST
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Beyond skin-deep: tackling gaps in psoriasis care

Commissioned and supported by Bristol Myers Squibb®

Contents

About this report

Beyond skin-deep: tackling gaps in psoriasis care commissioned and supported by Bristol Myers Squibb. The report examines the challenges and opportunities across the psoriasis care pathway in eight countries spanning Europe, North America and Asia (the United Kingdom, France, Italy, Spain, Germany, the United States, China and Japan), with a view to uncovering how health systems can better meet patients' needs.

The report brings together the findings of a primary research programme – consisting of an evidence search, expert interviews and a series of focus groups. Ultimately, the research aims to highlight the existing gaps and available opportunities that could drive much needed change along the care pathway.

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Executive summary

Psoriasis is a serious, chronic, non-communicable autoimmune disease. It is a painful and stigmatising disease that affects not only the skin, but is also associated with many systemic comorbidities. The disease has a significant detrimental impact on quality of life and overall health. In its most common form (comprising about 90% of cases), psoriasis manifests as patches of scaly, dry skin—plaque psoriasis.[1] Once the disease spreads beyond the skin, it can cause painful inflammation of the joints and connective tissue; as a result, approximately 30% of psoriasis patients suffer from psoriatic arthritis.[2]

Psoriasis carries an elevated risk of many comorbidities, such as metabolic syndrome, cardiovascular disease and inflammatory bowel disease.[3,4] It also has significant physical, psychological and quality-of-life consequences for millions of people worldwide.[2] Over 80% of patients cite personal and professional impacts, including societal stigmatisation.[5]

Psoriasis arises from an interplay of genetic, environmental and immune factors. Genetic factors account for 66-90% of disease susceptibility, while smoking, obesity and, to a less conclusive extent, alcohol use are all associated with disease incidence.[6,7,8] Infections also increase the risk of psoriasis.

Mild psoriasis is predominantly treated using topical creams and ointments, as well as targeted phototherapy; however, some mild cases are treated with systemic treatments or receive no treatment at all (the latter is true for 12-29% of mild-moderate cases, depending on the extent of skin involvement, according to a cross-sectional survey[(a)] published in 2022).[1,10,11] Moderate to severe cases are treated using systemic medications that work throughout the body, sometimes alongside topical treatments.[3] Many patients often report feeling dissatisfied with their treatment and find existing treatments burdensome. A cross-country survey of psoriasis and/or psoriatic arthritis patients showed that

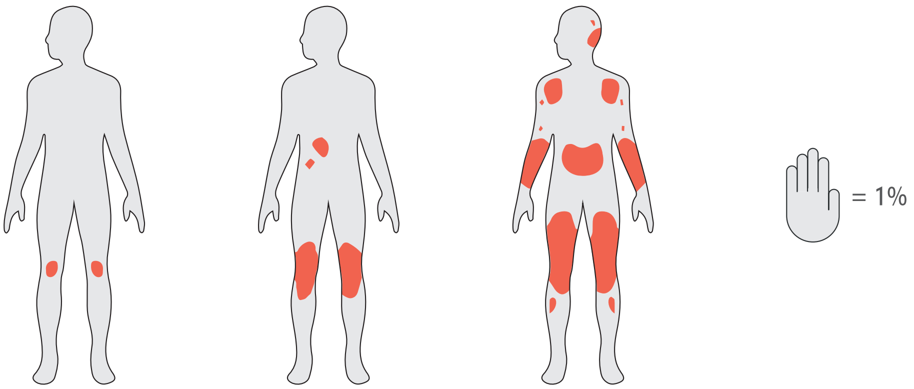
[(a)] The survey was conducted in Canada, France, Germany, Italy, Japan, Spain, the UK, and the USA.

topical medications (75%), oral treatments (66%) and injectable treatments (84%) were considered burdensome by the majority of patients. Approximately one in four patients with psoriasis symptoms reports not receiving any treatment for psoriasis and/or psoriatic arthritis. Patients who rate their disease as "moderate", based on level of body surface area (BSA) involvement (assessed by number of palms), report receiving only topical treatments (23%) or no treatment at all (16%). On the other hand, patients who rate their disease as "severe" report receiving only topical treatment (24%) or no treatment at all (12%).[11]

The past two decades have seen a shift forward in the treatment of psoriasis with the arrival of injectable biologic treatments and new oral treatments.[12] The patient response rates to biologic treatments are high, ranging from 49-59% within 12-24 weeks, measured as an improvement of 75% or greater on the Psoriasis Area and Severity Index (PASI) score.[1,13,(b)] Conventional oral treatments offer good levels of response and are favoured by some patients owing to the convenience of dosing.[15] Although dependent on the specific drug, the advent of newer oral treatments has seen response rates in line with first-generation biologic treatments. Yet, new oral and biologic treatments are viewed as costly, which limits access and uptake. However, cost-effectiveness studies using real-world data may help decision-makers look beyond treatment costs and better elucidate the value of these treatment options.

Despite its widespread impact, psoriasis is misunderstood, under-resourced, underdiagnosed and undertreated. With this in mind, Economist Impact, supported by Bristol Myers Squibb, conducted a research programme across eight countries—the United Kingdom, France, Italy, Spain, Germany, the United States, China and Japan—to stimulate discussion among key stakeholders on how care can better meet patient's needs. Drawing on pragmatic literature searches, expert interviews and focus group discussions, Economist Impact assessed the care pathway from the perspective of patients, caregivers, clinicians, academics and advocacy groups. Economist Impact's findings and calls to action are compiled in this report, ***Beyond skin-deep: tackling gaps in psoriasis care***.

Figure 1: Psoriasis coverage and severity[9]



Mild psoriasis
Less than 3% of the body has psoriasis

Moderate psoriasis
3% - 10% of the body has psoriasis

Severe psoriasis
More than 10% of the body has psoriasis

(b) The Psoriasis Area and Severity Index (PASI) score is a tool used to measure the severity of psoriasis. A numeric score is produced between zero (no disease) and 72 (maximal disease). A score between five and 10 is considered to indicate moderate disease, and a score over 10 is considered as severe.(14)

Looking forward

Address stigma, misdiagnosis and undertreatment by improving awareness and health literacy.

Psoriasis care is held back by knowledge gaps among patients, clinicians and the wider public. Health literacy efforts must therefore seek to increase patient knowledge and reduce stigmatisation. Primary care providers should be better equipped to recognise the signs of psoriasis, be able to administer first-line treatments for mild to moderate manifestations, and make referrals to specialist care when appropriate. Furthermore, specialists must be better prepared to help patients manage the full range of disease effects, including the many potential physical and mental comorbidities. There is a documented disconnect between patients and dermatologists when it comes to perceptions of disease severity. Typically linked to the use of conventional measures of severity, especially body surface area involvement, this disconnect often leaves patients dissatisfied with the level of care that they receive.[11] Improvements in patient-provider communication (and generally more patient-centric approaches) are needed to address the perceived disparity between psoriasis treatment and patient satisfaction.

Support the adoption of technology to improve equity of access to care and—hand-in-hand with screening—facilitate early diagnosis of comorbidities.

Unequal access to adequate care hinders treatment initiation and adherence, and leads to poorer patient outcomes. Regulatory, reimbursement and administrative barriers need to be addressed. These barriers may vary on a regional level within countries, depending on local policies, urban/rural divides, socioeconomic factors and the availability of resources. Screening for psoriasis comorbidities should become routine.

Technology has a role to play not only in improving access to care (including follow-up visits), but also in facilitating early diagnosis of psoriasis and its comorbidities. Policymakers should support the adoption of telehealth and the development of virtual platforms that facilitate patient-centric, integrated access to care, and a smooth journey along the care pathway.

Improve data collection, quality and use, especially in terms of disease burden and registries.

There are vast epidemiological and economic disparities in psoriasis data. Even in high-income, Western countries, where most of the research on psoriasis has been undertaken, there is a lack of up-to-date data and information on the state of psoriasis. In addition to national and regional-level data gaps, the lack of global-level data makes it difficult to access reliable information for assessment and surveillance, and to accurately design studies in order to help address existing policy issues. International and national organisations, industry and policymakers all have a role to play in driving the progress of psoriasis research.

Disease registries need to become more widely established, in order to provide a more comprehensive view of disease impact and treatment effectiveness. Existing databases such as the Global Psoriasis Atlas (GPA), led by the International Federation of Psoriasis Associations (IFPA), the International League of Dermatological Societies (ILDS) and the International Psoriasis Council (IPC), must be supported and regularly updated on a country-level by all relevant stakeholders.[16]

Make care and research more patient-centric; support the use of multidisciplinary teams and shared decision-making.

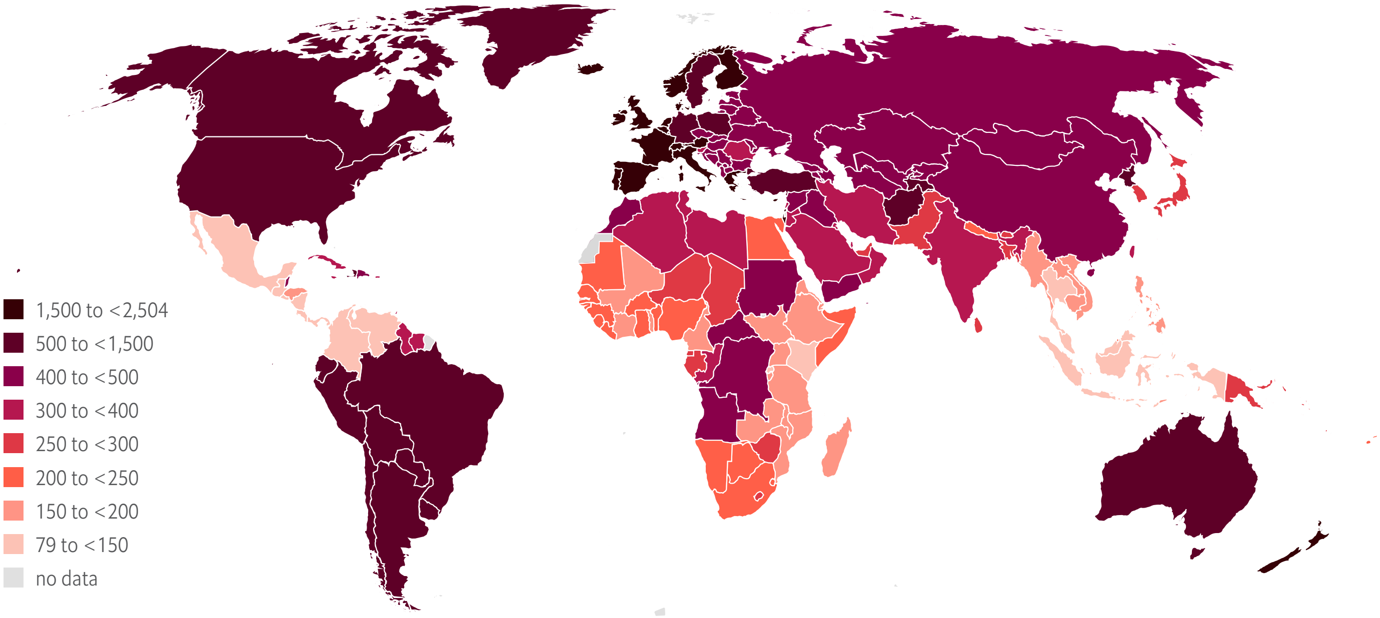
Better communication is necessary between providers and patients to align treatment goals and preferences, and thereby enable shared decision-making. Patient organisations can play an important role in empowering patients to define personalised treatment goals, as well as establish and implement a treatment plan alongside their provider. Integrated, multidisciplinary care is necessary to ensure that all patients receive the care they need; access to trained specialists and clearer referral pathways will help. This will enhance the impact of care holistically throughout the patient care pathway, improving treatment adherence and leading to better patient outcomes.

The impact of psoriasis

Epidemiology

One of the most striking aspects of psoriasis is the lack of demographic and epidemiological data. Only 19% of countries in the world—predominantly wealthier countries in North America and Europe—have good documentation of psoriasis prevalence; estimations of the total disease burden vary wildly, ranging, in the cases of the Global Burden of Disease (GBD) data and the GPA respectively, from about 40.8m people to 60m people.[16,17,18] Incidence data are also sparse,

Figure 2: National age-standardised prevalence rate of psoriasis (per 100,000), 2019 [17]



although GBD data estimate that there were 4.6m new cases globally in 2019.[17,19] Reported incidence is higher among lighter-skinned individuals and older people, although misdiagnosis could be a factor among darker-skinned individuals and children.[19]

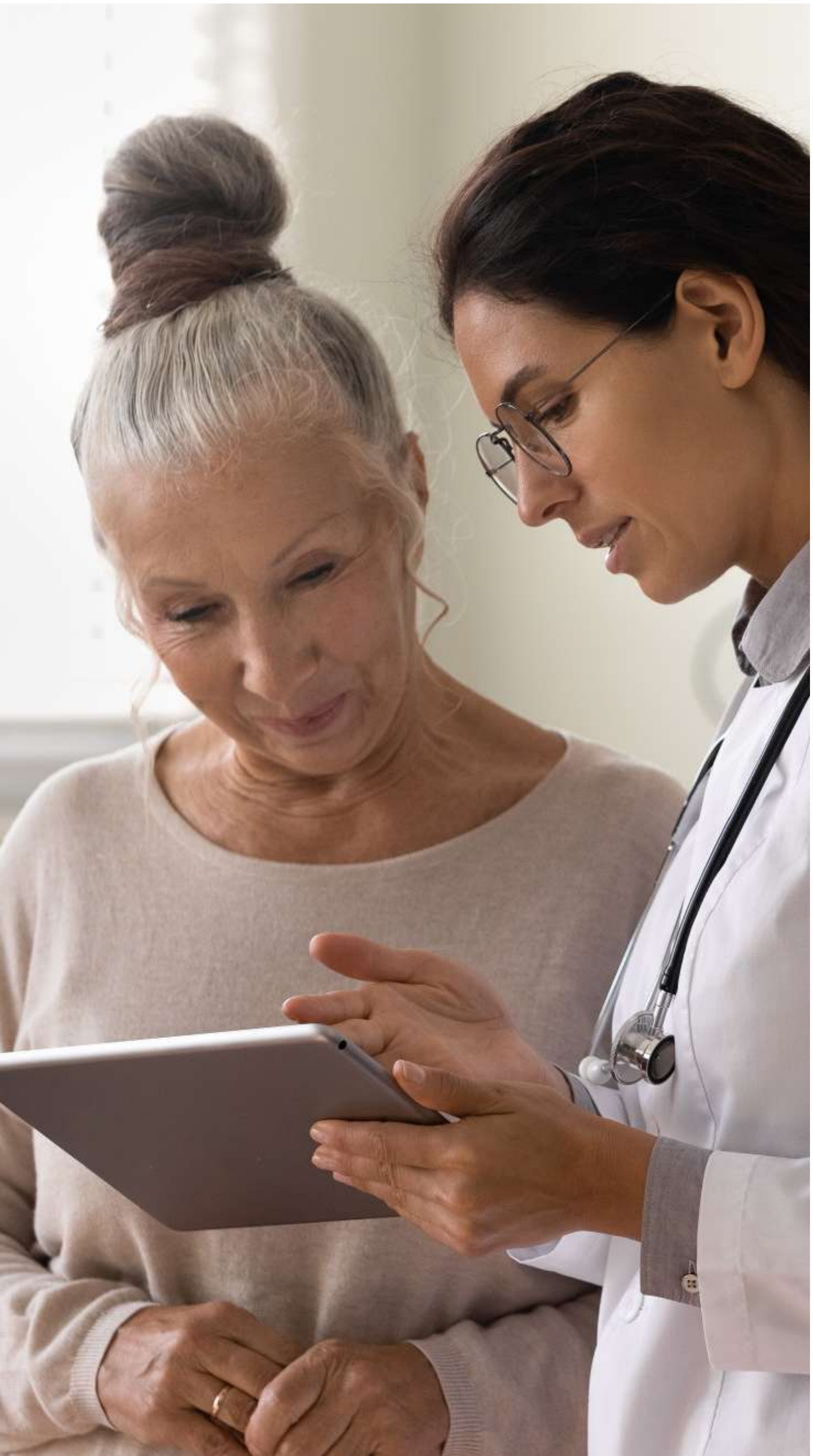
The available data on psoriasis are sparse even when it comes to European and North American countries.[19] For example, prevalence estimates in France range from approximately 1-2% of the population to nearly 5%, and the most recent community-based estimates are from 2002.[20,21] A systematic review conducted in Italy in 2017 found only four studies evaluating the prevalence of psoriasis and one study evaluating incidence; the methods used varied greatly.[22]

What the data do suggest is that psoriasis is more common in high-income countries, where age-standardised incidence is almost double the global average (57.8 per 100,000), at 112.6 per 100,000.[17] There is a clear difference in prevalence between European and North American countries (in this study, the United States) and Asian countries (China and Japan). Estimated prevalence is 0.21% in China and 0.34% in Japan, versus more than 1-5% in the US or Europe.[20,23-25]

There is also ample evidence that psoriatic patients tend to suffer from one or more comorbidities. Data show that up to 30% of patients are estimated to have psoriatic arthritis.[28] A study from the United Kingdom estimates the standardized incidence of psoriatic arthritis at 0.37% of the population, whereas a Japanese survey found that approximately half of psoriasis patients surveyed had comorbid metabolic, cardiovascular or cerebrovascular diseases.[26,27]

There is also limited information on paediatric psoriasis. A German study estimated the prevalence of psoriasis among children at 0.45%.[29] A 2015 US study noted increasing prevalence with age in childhood.[30]

While paying attention to the trends identified by the existing data, strengthening data collection systems, particularly by creating robust new registries where they are lacking, as well as expanding, integrating and updating current registries, needs to be prioritised. Expanding the collection of data and formalising data-sharing are the first steps to accurately estimating the disease burden, in addition to better understanding the impact of the various treatments.



The economic and societal burden of psoriasis

The direct health costs of psoriasis are staggering, and are even more pronounced when comorbidities are involved. A US study found that all cause healthcare costs for psoriasis patients in the first year of treatment average US$10,862, and are almost three times higher (US$28,104) among patients affected by psoriatic arthritis.[31] Costs rise in line with the number of comorbidities, increasing by as much as four-fold.[32]

Another factor leading to the increase in costs is the advent of modern therapies (such as newer biologics and targeted small molecules), which are more expensive than conventional topical and systemic treatments. Although research indicates that patients with psoriatic arthritis receiving biologic treatment have lower hospital costs and fewer hospital days per admission, these subsequent savings only slightly offset the increase in upfront treatment costs.[33] Given the chronic nature of psoriasis, limited predictive markers for treatment response and the occurrence of side effects, treatment-switching is common, which can further increase costs.[34,35,36] Persistence with biologic therapy has been shown to reduce non-drug medical costs and ambulatory care costs.[37]

The indirect costs of psoriasis are also significant, although data are scarce.[39] Work-related impacts—unemployment, absenteeism and presenteeism (working while ill)—are the most cited drivers of indirect costs.[38] One study found that the annual indirect costs per patient due to work productivity losses range from US$3,742 in Spain to US$9,591 in the US.[39] The average hours of total work productivity loss (as a percentage of work hours) for patients with mild, moderate and severe presentations of psoriasis were 10%, 19% and 29%, respectively.[39]

Figure 3: Mean and median all-cause healthcare costs per patient per follow-up year among patients with psoriasis, patients with psoriatic arthritis, and a control group. United States, US$ [31]

From claims data 2009 to 2020

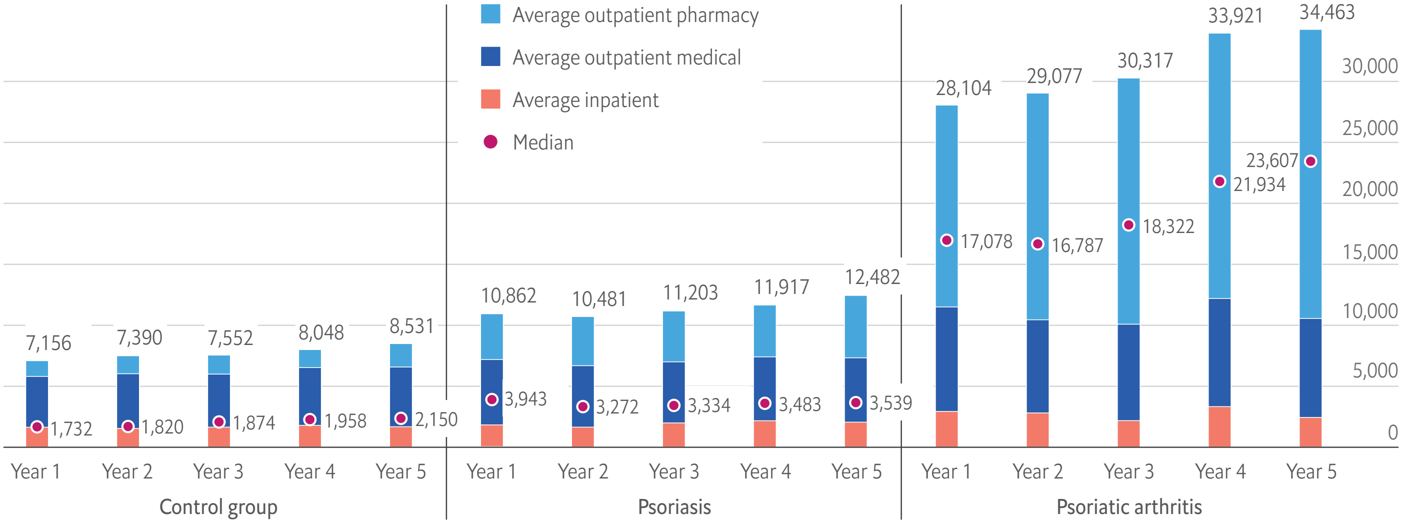


Figure 4: Direct mean total healthcare costs depending on the number of comorbidities in patients with psoriasis, United States, US$ [32]

Data between January 2010 and March 2017, per patient per year in 2017 US$

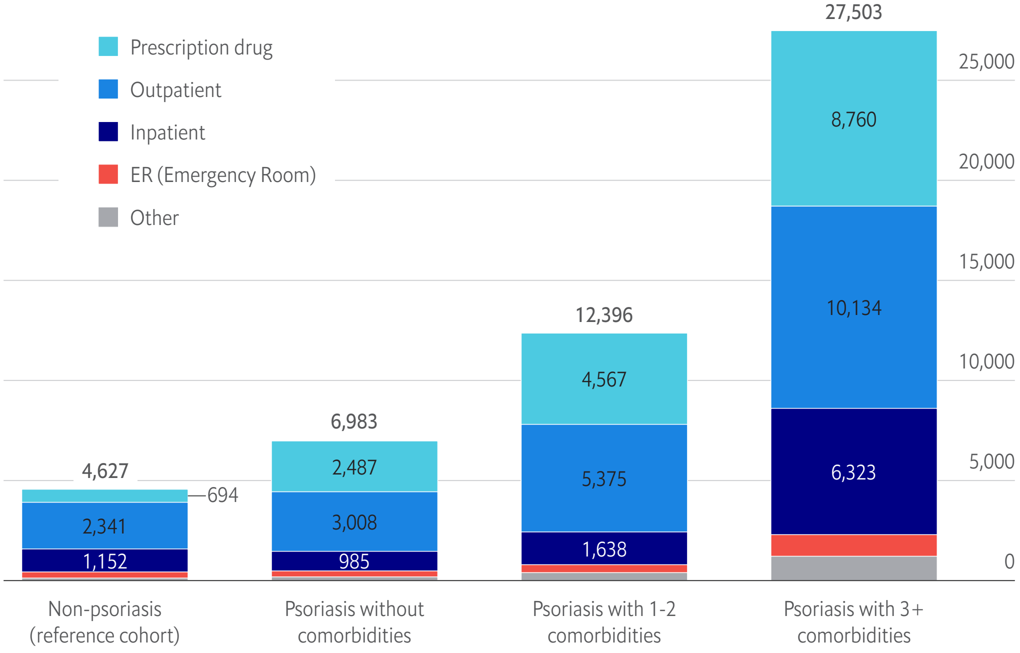
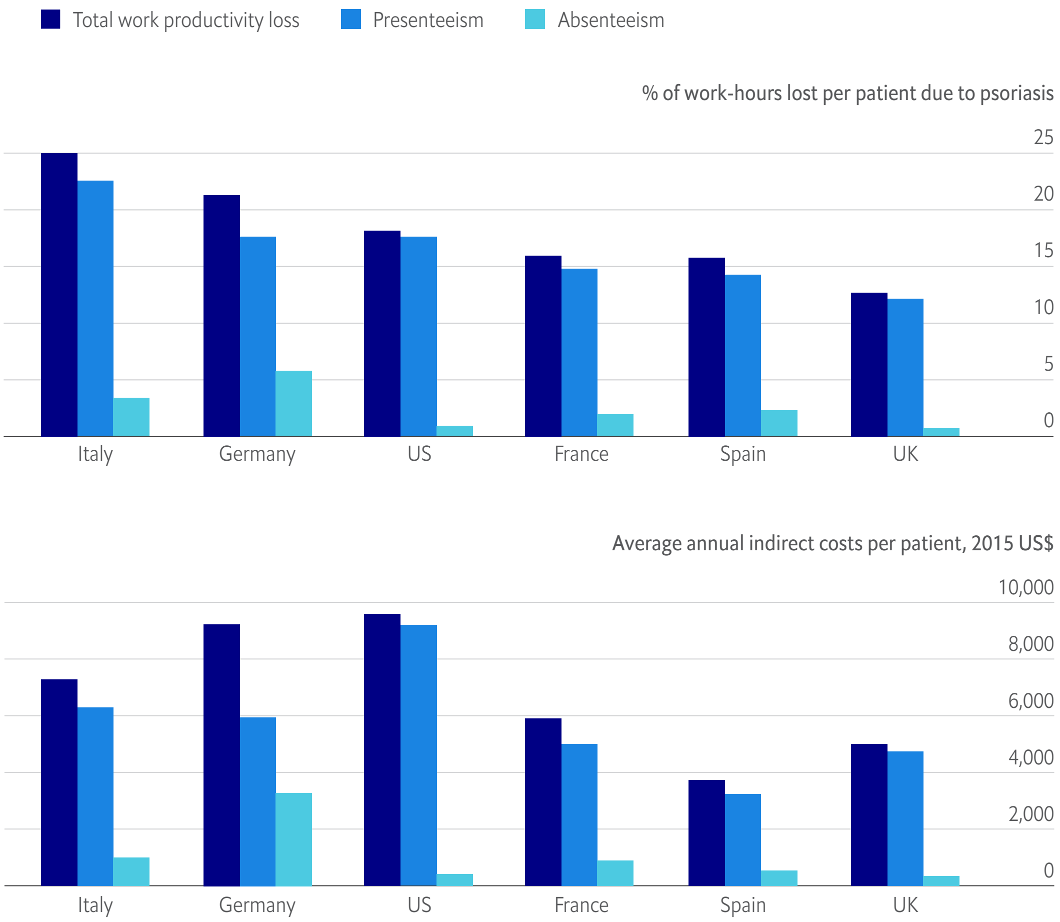


Figure 5: Percentage of work-hours lost and annual indirect costs per patient due to absenteeism, presenteeism and total work productivity loss by country, 2015 [39]



The impact of psoriasis on society has increased over time – for instance, the disability-adjusted life years (DALYs) number and crude rate due to psoriasis rose by 73% and 22% between 1990 and 2017.[2,40] High-income countries tend to have the highest rates of years lived with disability (YLD).[17]

About half of patients with plaque psoriasis experience substantial fatigue, which correlates with pain and depression.[41] The disease also poses relationship challenges with family, friends and colleagues; 18% of psoriasis and psoriatic arthritis patients report being unable to participate in social activities and 16% even report that psoriasis prevents them from having a sex life.[42]

Patients with psoriasis are more likely to suffer from mental health issues.[43] Depressive symptoms

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(c) DALYs is a universal metric of disease burden that allows for comparisons across populations in both reduction in life expectancy and quality of life.(40)

are reported in 28% of patients; patients with psoriasis are also four times more likely to take antidepressant medication.[44] Suicidal ideation is twice as common among psoriasis patients as compared to the average population, and both attempted and completed suicide are more likely; younger patients with severe disease are at higher risk.[45] On a more positive note, anxiety can decrease with the treatment of psoriasis.[46]

Patients can face several barriers across their care journey. Delays in referral—and, thus, diagnosis and treatment—are common, and factors like insurance coverage, patient acceptance of, and compliance with, treatment regimens often affect whether (and how quickly) patients benefit from treatment. In addition, low numbers of dermatologists per capita and urban/rural disparities can limit access to specialist and on-site care, which often leads to suboptimal access to care and, in many cases, undertreatment. The significant mental health impacts of psoriasis are often inadequately addressed, if at all.

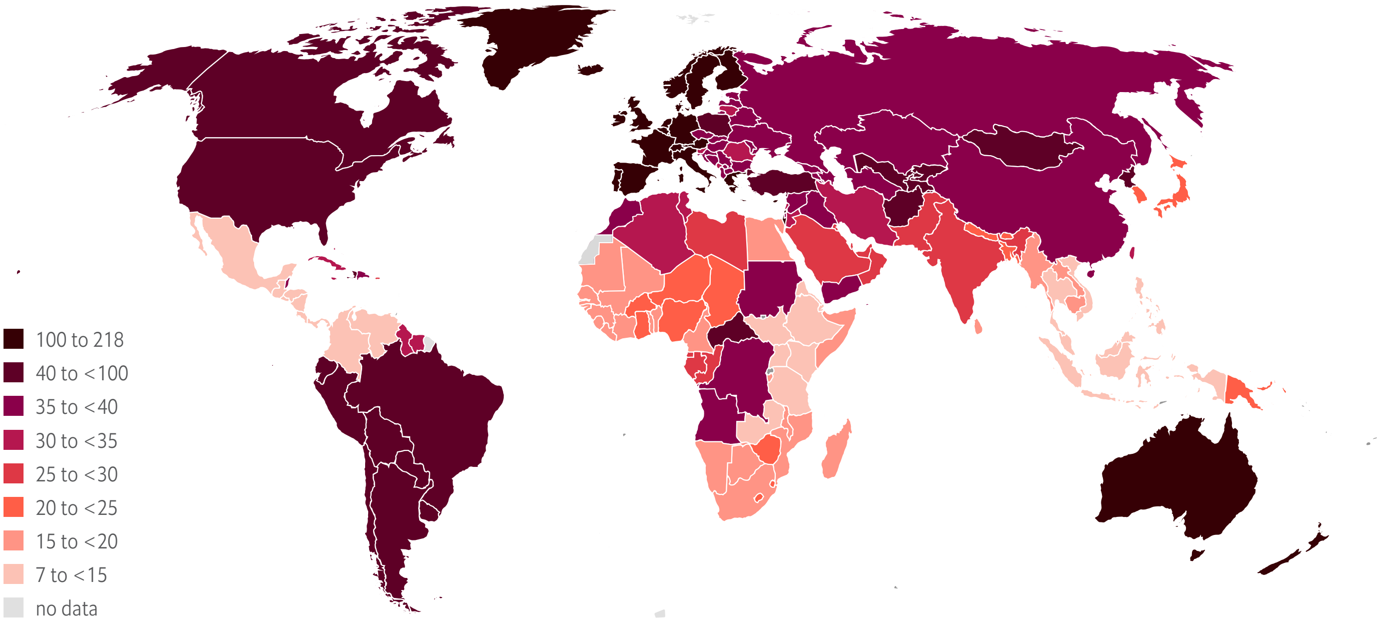


Figure 6: National age-standardised years lived with disability (YLD) rate of psoriasis (per 100,000), 2019[17]

Overview of the care environment – assessing the patient's journey

The impact of psoriasis is protracted and varies greatly depending on a range of factors, including disease severity, the presence of comorbidities, treatment impact (positive and negative), and the overall social and healthcare environment in which individual patients find themselves.

Awareness and knowledge gaps around psoriasis

Stigma and a general lack of awareness remain pervasive, but patient advocacy efforts have true value.

Awareness and knowledge of psoriasis are relatively low in the countries studied.[47] Low patient awareness can directly impact treatment-seeking behaviour and treatment adherence, as well as potentially prevent people from coming to terms with their diagnosis and living normal lives despite their condition.

A broader lack of social awareness, meanwhile, can give rise to misconceptions and stigmatisation. In a France-based survey, half of respondents demonstrated discriminatory behaviour, with about one-third expressing reluctance to shake hands, and 44% reporting that they would be reluctant to have a sexual relationship with someone affected by psoriasis.[48]

"One of the main things is to destigmatise psoriasis, tell people that it is not contagious and to give patients a good living environment," says Xingxiang Shi, Head of the Mutual Assistance of Psoriasis Patients Website and Secretary-General of the Chronic Skin Disease Fund of the China Primary Health Care Foundation. "Because psoriasis is an outwardly ‘visible’ disease, there is a certain amount of psychological pressure on the patient.”

When it comes to care provision, both primary health care providers, such as general practitioners (GPs), and specialists would benefit from greater awareness. “Even some dermatologists don’t fully understand psoriasis, let alone primary care physicians,” explains Mr Shi. Ensuring that providers, both at the primary care and specialist level, are properly trained to recognise and treat psoriasis and its systemic manifestations is critical to better patient outcomes.

Across all eight countries in this study, patient organisations are a key awareness-raising force and are vital drivers of de-stigmatisation efforts and effective policymaking. The experts interviewed for this study shared that although general knowledge and understanding of the disease are improving, policymakers and clinicians need to work more collaboratively with patient advocacy groups to create more impactful public awareness initiatives.

At the heart of this work by patient organisations is empowering patients to have active input about their care and treatment options. “There is a need for patients to raise their voices, as has happened with other pathologies such as multiple sclerosis, or for patients to become spokespersons and mobilise, as happened years ago with HIV,” says Santiago Alfonso Zamora, Director of Acción Psoriasis, a patient advocacy group in Spain. “[Advocacy groups] remain at your disposal, but the patient can also do much more for [their] disease. That is also why all the training, all the empowerment, is essential.”

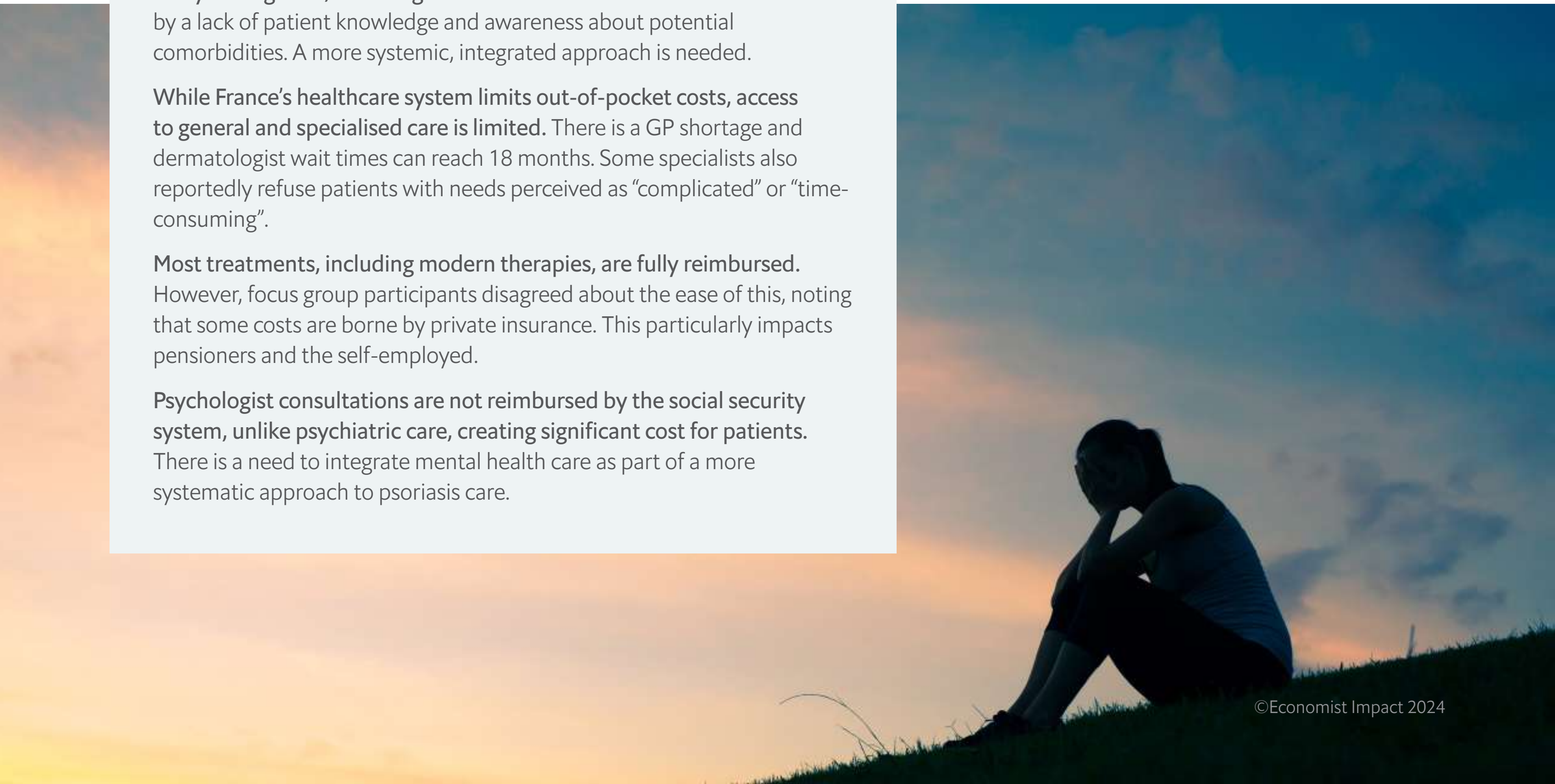
FRANCE FOCUS GROUP
Key takeaways from participants

GPs lack proper training to detect psoriasis, leading to misdiagnosis and delayed diagnosis, including of comorbidities. This is further exacerbated by a lack of patient knowledge and awareness about potential comorbidities. A more systemic, integrated approach is needed.

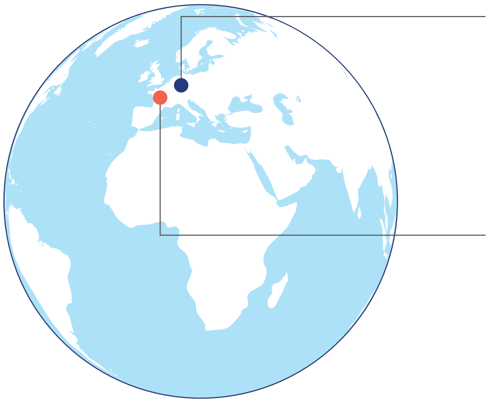
While France’s healthcare system limits out-of-pocket costs, access to general and specialised care is limited. There is a GP shortage and dermatologist wait times can reach 18 months. Some specialists also reportedly refuse patients with needs perceived as “complicated” or “time-consuming”.

Most treatments, including modern therapies, are fully reimbursed. However, focus group participants disagreed about the ease of this, noting that some costs are borne by private insurance. This particularly impacts pensioners and the self-employed.

Psychologist consultations are not reimbursed by the social security system, unlike psychiatric care, creating significant cost for patients. There is a need to integrate mental health care as part of a more systematic approach to psoriasis care.



Insight 1: Awareness and knowledge gaps

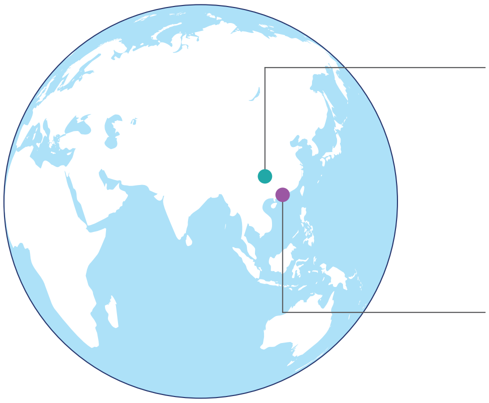


Germany

A study (n=2,001)* indicated that there is a lack of understanding of the disease, contributing to prejudice and stigmatisation towards people with psoriasis. 27% of study participants indicated that they did not want a personal relationship with someone with psoriasis, 23% did not want to utilise the same swimming pool, and 10% did not want to live in the same house with someone affected with psoriasis.[49]

France

An online survey (n=1,005)* found that psoriasis was thought to be a contagious disease by approximately 16.5% of respondents, while 6.8% believed that the illness was related to personal hygiene. About 50.0% of the population surveyed exhibited discriminatory behaviour towards psoriasis patients, indicating reluctance to maintain friendship ties (7.6%), to have a meal with a person with visible manifestations (17.9%), to give a kiss on the cheek in greeting (29.7%), to shake hands (28.8%) and to have sexual relations (44.1%) with someone with psoriasis.[48]



China

A recent study (n=497)* showed that 89% of patients reported mental stress, 78% of patients had experienced discrimination, 34% of patients had suicidal thoughts due to psoriasis, and 5% had committed suicide. However, only 11% of patients had sought psychological treatment, and 51.5% of patients chose to close themselves off from society, friends and even family members in order to reduce psychological pressure, which poses great hidden dangers to their health and social development.[50]

Hong Kong

A survey (n=124)* found that 87% of patients with psoriasis living in Hong Kong had faced some degree of discrimination in public, including being stared at (65%), being asked if they were contagious (50%), or people avoiding physical contact with them (47%). 60% of patients had experienced denial of service or difficulties in the service industry due to their condition, the most common being swimming pools, fitness studios and sports venues (40%). Besides public places, 77% of patients also experienced discrimination in the workplace, including being taunted by colleagues/cleaners for dropping dander (36%). 45% of patients choose to reduce going out, more than half of whom, because of psoriasis, have been diagnosed with anxiety and depression.[51,52]

* n refers to the study or survey's sample size, or the number of participants or observations included in a study or survey, respectively.

"People with the disease have experienced stigmatisation in various places... receiving funny looks, or having to hear comments [like] – "go and have a wash". ...I think in terms of public awareness it's still difficult to spread the word that it's not communicable, not contagious, that it has nothing to do with poor hygiene. "

Anette Meyer, patient advocate, Germany.

"Awareness has to be raised. We have made some progress in destigmatising the disease, but awareness has yet to reach the point where we are paying attention to comorbidities, complications, and psychological issues – this is still a work in progress. "

Xingxiang Shi, patient advocate, China.

"One of the things we do is advocate for genuine awareness because when there is awareness, it is more likely that people will know about care and treatment, and that will improve their lives and reduce suffering. "

Hoseah Waweru, patient advocate, Global.

"Unfortunately, most Japanese people have not ever heard of psoriasis, even its name, so many patients are not aware of it. "

Masanori Okuse, patient advocate, Japan.

Difficulties and inconsistencies with referral

Referral pathways can vary, often revealing accessibility barriers and inequities in care.

Once a patient has made contact with the health system, the referral pathway to specialist care can be convoluted and complex. Often, there is no singular referral pathway, and the patient's treatment route varies depending on the individual clinician that they see, both at the primary care level and when seeing a specialist such as a dermatologist or rheumatologist. For example, where some primary care providers may refer a patient directly to a specialist, some may prescribe an ointment, which, if ineffective, only delays access to specialist care treatment. Even after referral, delays are common. "If it's a severe case, with a referral to a dermatologist, it takes at least three months to half a year until an appointment takes place," explains Anette Meyer, an Advocate and Press Contact for the German Psoriasis Association (DPB). "And it's not easy at all anymore to get an appointment with a dermatologist, or with specialist doctors in general."

In many countries, there is a shortage of trained specialists, a problem that is exaggerated for rural residents and others affected by barriers to accessibility (such as socioeconomic status, age and race, for example).[53,54] Access to specialists is a domain that reveals significant differences between public and private healthcare, even in the relatively wealthy countries that we studied. For example, in Germany, private patients can wait less than three months for an appointment with a specialist, as compared with the six months it takes in the public health system, explains Ms Meyer.

"We have an over-stretched secondary care system [in the UK]," says David Chandler, Chief Executive of the Psoriasis and Psoriatic Arthritis Alliance, an advocacy organisation in the UK, referring to the months-long delays attributable to an under-supply of dermatologists. "There's perhaps not enough incentive for people to become dermatologists. There's a disconnect between what can be achieved and what the government is prepared to pay for." In France, too, echoes Bénedicte Charles, President of Association France Psoriasis, recruitment of dermatologists is a problem – "a real catastrophe".

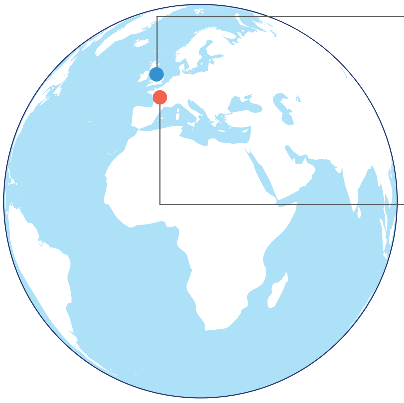
GERMANY FOCUS GROUP
Key takeaways from participants

Dermatologists tend to focus on general psoriasis and do not sufficiently address comorbidities. There is uncertainty about which comorbidities should be screened (for example, some may suggest that psoriatic arthritis should be prioritised). Comorbidities are assessed in consultations inpatient visits; however, they are not the main focus.

Rural patients face difficulties accessing the latest therapies due to the lack of dermatologists and their inability to manage biologic therapy. Cost is also a barrier, and the absence of proper transportation and electronic medical records make treatment access even more challenging.

Prejudice against people with psoriasis still exists, despite advancements in awareness. Some still believe psoriasis is contagious, for example. Although prejudice may not be as common as it once was, it still exists.

Insight 2: Difficulties and inconsistencies with specialist referrals

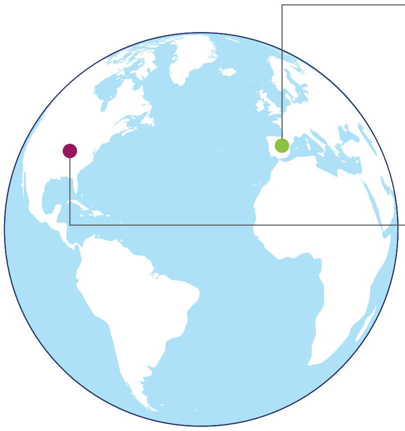


United Kingdom

A study (n= 10,832)* exploring the referral rates found that approximately 18% of newly diagnosed patients with psoriasis in the UK were referred to dermatologists. Evidence indicates that 25% to 44% of patients with psoriasis are moderate-to-severe and would likely benefit from specialist attention, thereby suggesting underutilisation of specialist services.[56]

France

A survey (n= 2,329)* observed that only 50% of French respondents were treated by a dermatologist and 22% were treated by a general practitioner. Among the rest, 25% reported not consulting any doctor for their psoriasis. Among patients with severe psoriasis, 58% were treated by a dermatologist, and 29% reported not being treated by any healthcare professional.[55]



Spain

A study (n= 503)* found a diagnostic delay of four years on average was reported in Spain. Approximately 80% of patients with psoriatic arthritis had seen a primary care physician, 34% an orthopedic surgeon, and 30% the emergency department before a diagnosis was made. Only 3.5% of referrals originated from the emergency room (ER), showing a significant gap in awareness and care.[57]

United States

A study (n= 162)* observed that, on average, patients with psoriatic arthritis experience a diagnostic delay of 2.5 years, of which 23% receive a diagnosis within six months of symptom-onset, 35% receive a diagnosis within one year, and 45% receive a diagnosis by two years.[58]

* n refers to the study or survey's sample size, or the number of participants or observations included in a study or survey, respectively.

> **"The US is quite complex because there are a lot of different ways people access healthcare and then a lot of different ways people pay for it, and so part of it really depends on how you come into the system...there's no one entry point into the healthcare system in the US. And so there's no singular referral pathway. "**
>
> Leah McCormick Howard, patient advocate, US.
>
> **"So for many [cases], the referral criteria is not clear. There are diseases like diabetes or hypertension that give you a number [score used for referral]. Psoriasis does not have that "number"... Then the referral is based on the physician's [subjective] criteria and some affected areas of the individual's health... So there are many patients who are under-diagnosed or under-referred because they don't get to the proper specialist since the primary care physician does not refer them correctly. "**
>
> Santiago Alfonso Zamora, patient advocate, Spain.
>
> **"And once again we come up against the problem of medical demography. Young doctors don't necessarily have a rolodex yet. Doctors with a bit of experience have been able to build up a rolodex here over the years, and take it upon themselves to contact their specialist colleagues. "**
>
> Bénedicte Charles, patient advocate, France.

Diagnosis

Challenges with diagnosis can lead to misdiagnosis, inappropriate referral and delays in care.

Diagnosing psoriasis can be challenging because it often depends on the level of experience that healthcare providers have with the disease; misdiagnosis is especially prevalent among people of colour, owing to differing disease presentation and a lack of representation in the learning materials for providers.[59] Significant delays in the diagnosis of psoriasis and psoriatic arthritis are common across this study's eight countries of interest. A UK-based study showed that the diagnosis of psoriasis can be delayed by up to five years in some primary care settings.[60]

At the primary care level, healthcare providers are not always adequately trained to recognise psoriasis. In addition, they may not be aware of the systemic nature of psoriasis (or the potential for comorbidities), which often means that they prescribe a treatment, such as a topical cream, for skin-based symptoms, when it would be more appropriate to refer the patient to specialist care early where they can be treated with more advanced therapies.

"The dermatology education for primary care workers is insufficient," says Mr Chandler. "There is often a very basic understanding of dermatology conditions and there's also little incentive to learn. I can understand that, because primary care providers have a broad group of diseases and conditions to look for and there are priorities," he adds.

The consequences are two-fold: at the population level, there is a risk of underdiagnosis (psoriasis is assumed to be far more widespread than data suggest), and at the individual level, even patients who eventually receive a correct psoriasis diagnosis face delays in treatment, often starting with suboptimal decisions around referral.

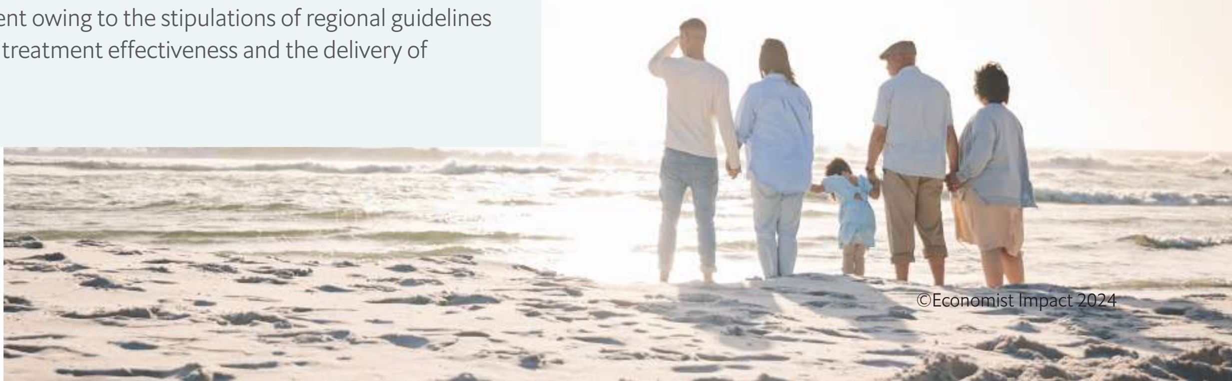
Delayed diagnosis and undertreatment are also significant issues due to the reluctance of patients to visit healthcare providers, owing to a lack of awareness of available therapies, mismatched treatment goals and accessibility barriers. One study found that as many as half of psoriasis patients in North America and Europe had not seen a healthcare provider in the preceding 12 months; among patients with psoriatic arthritis, 85% in North America and 77% in Europe had seen a healthcare provider, 30% of whom had not seen a healthcare provider felt the healthcare provider could not help.[61]

ITALY FOCUS GROUP
Key takeaways from participants

While strong advocacy efforts exist on a regional level, there is a lack of widespread, national awareness campaigns. This has left the public, including patients, unaware about psoriasis and treatment options.

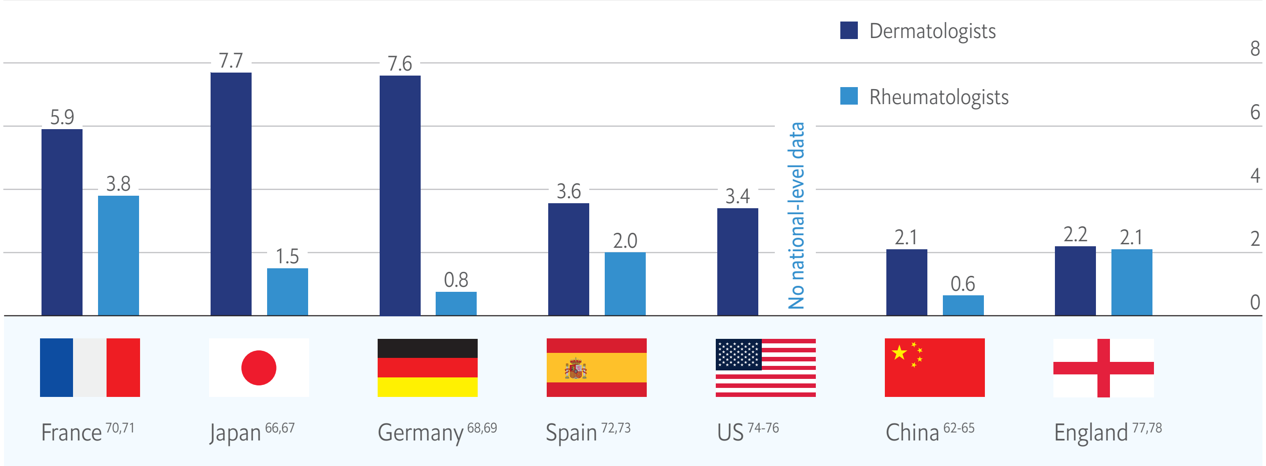
Patient advocate-led efforts to lobby government for greater recognition of psoriasis in public health policy are a step in the right direction; however, participants note that this is an uphill battle involving competition for finite resources. A public perception of psoriasis as not being a "serious" disease (in comparison to other chronic diseases) may jeopardise efforts.

Regional and national treatment guidelines are often not aligned. This has significant impact on care delivery. Cost sometimes precludes or delays high-cost treatment owing to the stipulations of regional guidelines has knock-on effects on treatment effectiveness and the delivery of personalised care.



Insight 3: Challenges with diagnosis

Number of dermatologists and rheumatologists per 100,000 population*



France

Regional differences in the number of dermatologists: in mainland France, Île-de-France has the highest density (8.6), while Limousin, at 2.9 per 100,000, has the lowest.[70] Regional differences in the number of rheumatologists: in mainland France, Île-de-France has the highest density (5.3), while Picardie, at 2.3 per 100,000, has the lowest.[71]

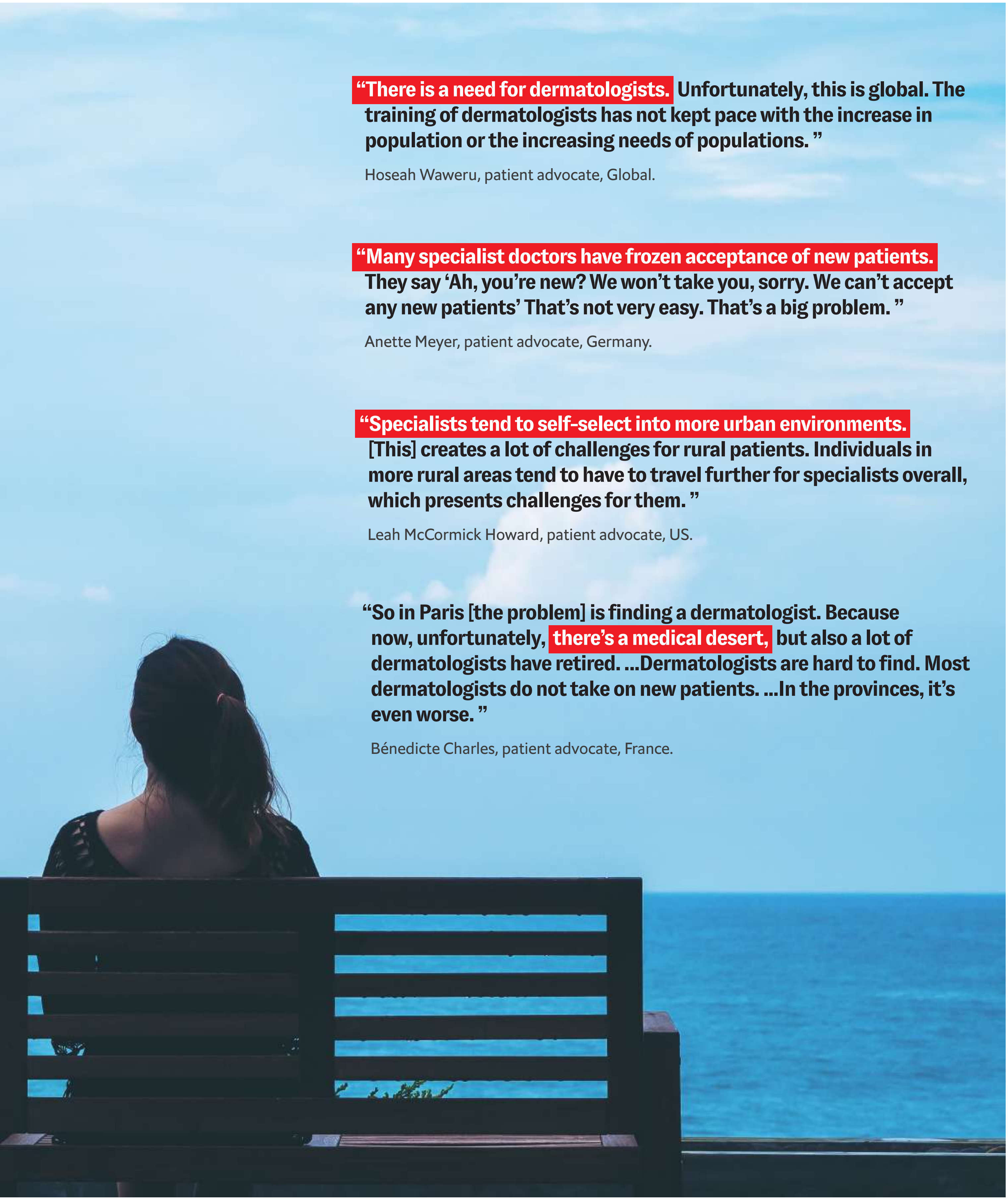
Spain

Regional disparities in the number of rheumatologists: the ratio is lowest in Castilla y León (0.6) and highest in Comunidad de Madrid (4.8).[72,73]

US

The number of dermatologists per 100,000 persons was estimated at 3.4 in 2017.[74] In 2015, the number of adult rheumatologists per 100,000 adults estimates differed across regions in the US, ranging from 3.07 in the north-east of the US to 1.28 in the south-west.[75] Likewise, in 2015, the number of paediatric rheumatologists per 100,000 children differed, ranging from 0.83 in the north-east to 0.17 in the south-west.[76]

*Year of data varies (2015-2023), see reference number by country name for source and year of data



“There is a need for dermatologists. Unfortunately, this is global. The training of dermatologists has not kept pace with the increase in population or the increasing needs of populations. ”

Hoseah Waweru, patient advocate, Global.

“Many specialist doctors have frozen acceptance of new patients. They say ‘Ah, you’re new? We won’t take you, sorry. We can’t accept any new patients’ That’s not very easy. That’s a big problem. ”

Anette Meyer, patient advocate, Germany.

“Specialists tend to self-select into more urban environments. [This] creates a lot of challenges for rural patients. Individuals in more rural areas tend to have to travel further for specialists overall, which presents challenges for them. ”

Leah McCormick Howard, patient advocate, US.

“So in Paris [the problem] is finding a dermatologist. Because now, unfortunately, there’s a medical desert, but also a lot of dermatologists have retired. ...Dermatologists are hard to find. Most dermatologists do not take on new patients. ...In the provinces, it’s even worse. ”

Bénedicte Charles, patient advocate, France.

Treatment

Access to treatment is affected by socioeconomic and geographic factors.

Factors such as a patient's location can constrain access to specialist care, as can socioeconomic barriers. "It's the waiting time and the travel time," says Ms Meyer when speaking about the German experience. Geographical difficulties in accessing specialist care are particularly pronounced in larger countries such as the US and China.

Barriers related to socioeconomic status are not only demonstrated by the differences in access to care between the public and private healthcare sector, but also play out where local health services are less resourced, as well as among low-income populations – through the demand for out-of-pocket payments, for example. "If you were to divide up the population of people living with psoriasis in the US, you would find differences in how people are treated and the outcomes they're achieving," says Leah McCormick Howard, President and CEO of the National Psoriasis Foundation. "Where they live, what their income is, what their race or ethnicity is, what their age is, what type of insurance they have … these factors vary greatly."

Policymakers need to reassess the comprehensiveness and equity of reimbursement frameworks, particularly given the rise of innovative treatments, which are more expensive than traditional first-line treatments such as conventional systemics. In Italy, for example, patients can contribute up to 20% of their own money towards consultations and treatments, says Valeria Corazza, President of APIAFCO – the Association of Italian Psoriasis Patients Friends of the Corazza Foundation, an advocacy group.

In Japan, too, "some patients cannot afford the best treatment, because of out-of-pocket payments," says Masanori Okuse, Chairman of INSPIRE Japan WPD – The Japanese Association for Public Awareness of Psoriasis. "Every patient is responsible for 30% of the total medical cost." Even within countries, coverage can vary – different regions can afford different levels of spending. "Where local finances are not good, reimbursement may be lower, or you have to be hospitalised to get it," explains Mr Shi about the situation in China.

There are positive examples, especially in Europe. In France and the UK, for example, reimbursement is comprehensive, covering 100% of the treatment costs for long-term illnesses.

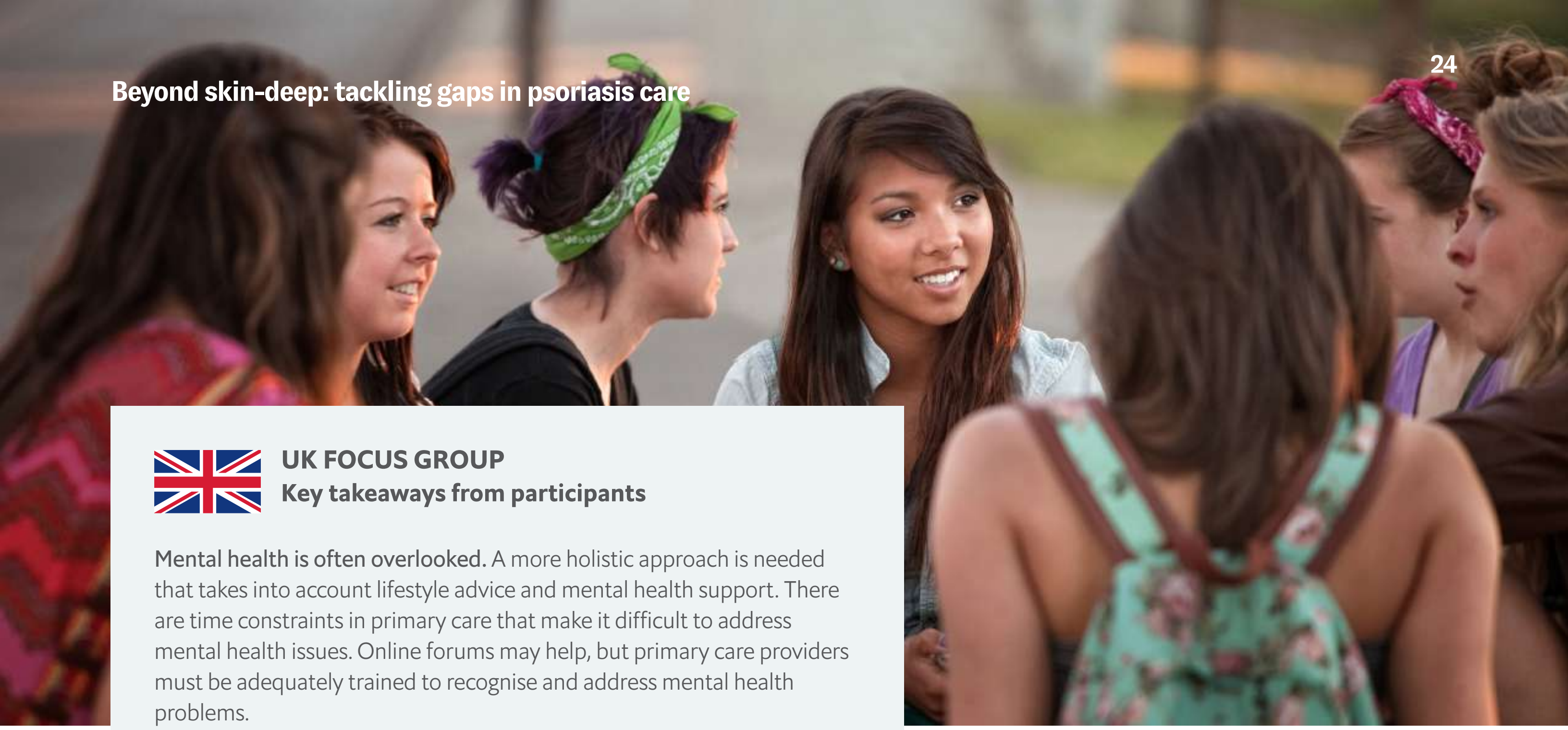
Yet even where coverage is universal, variations in quality and access exist, cautions Anna López Ferrer, Associate Professor of Dermatology at the Hospital de la Santa Creu i Sant Pau in Spain. As indicated by French focus group participants, costs are also sometimes borne by private insurance, which can particularly disadvantage pensioners and the self-employed. In addition, indirect costs such as productivity losses, lack of opportunities and the need to travel for treatment create barriers for people in all countries.

SPAIN FOCUS GROUP
Key takeaways from participants

The lack of national policy and treatment guidelines negatively impacts care. Given the fragmented nature of Spain's health system, the treatment that patients receive highly depends on the region in which they live. There is a need for more unified national policy.

There are significant discrepancies when it comes to access to specialised care. Patient experience challenges in getting an appointment, especially in the public sector. Whereas private-sector wait times reportedly range from same day to up to a month, they are much longer in the public sector.

Access to treatment, especially innovative, high-cost therapies, is often highly dependent on each autonomous region's health funding. This has significant impact on care delivery, as often the most cost-effective line of treatment is prioritised over newer and more advanced therapies. Patient's socioeconomic status may also influence treatment access.



UK FOCUS GROUP
Key takeaways from participants

Mental health is often overlooked. A more holistic approach is needed that takes into account lifestyle advice and mental health support. There are time constraints in primary care that make it difficult to address mental health issues. Online forums may help, but primary care providers must be adequately trained to recognise and address mental health problems.

Improving patient care requires a multifaceted approach. Public awareness, national and international guideline groups with patient involvement, and local education programmes are all needed to improve care. The use of AI, robotics and wearables could improve patient care. More must be done to attract medical professionals to the field and make training more attractive.

Factors such as cost, insurance coverage and age limit access, contributing to undertreatment. High demand and limited supply of rheumatology services have created barriers to access. Generally, access is not as good as it should be, and waiting times can be lengthy.

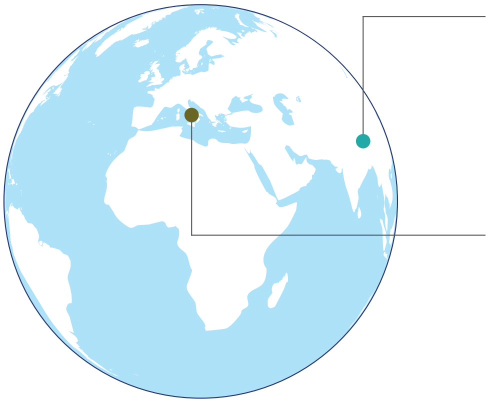
Regulatory and administrative factors can also limit patient access to biologics and advanced oral treatments, meaning that only a small fraction of patients are using them. In Spain, for example, biologics can only be provided via the public health system. “Private physicians are unable to prescribe biologics because insurance does not cover it,” says Associate Professor López Ferrer. “Therefore, patients with moderate to severe psoriasis must be treated in public hospitals. This is a significant restriction.” The ability to prescribe and administer treatment is dependent on local healthcare reimbursement systems. In Spain, biologics are exclusively administered by hospital-run pharmacies and financed by the regional public health system.[79]

Many patients report feeling dissatisfied with their treatment, and often find existing treatments burdensome. A cross-sectional, cross-country survey of psoriasis and/or psoriatic arthritis patients showed that topical medications (75%), oral treatments (66%) and injectable treatment (84%) are considered burdensome by the majority of patients. Additionally, approximately one in four patients with psoriasis symptoms reports not receiving any treatment for psoriasis and/or psoriatic arthritis. Of patients who rate their disease as “moderate” or “severe”, based on level of body surface area (BSA) involvement (assessed by number of palms), 16% and 12% respectively receive no treatment; in both groups, just under a quarter receive topical treatment.[11]

In addition, some patients are not, or only partially, responsive to treatment, while others find their response diminishes over time; some only have a partial response or discontinue treatments because of intolerance and side effects. For example, in one 2022 study, 57% of patients had discontinued conventional oral treatment, with 50% of them citing lack or loss of treatment effectiveness.[11] Symptom improvement, safety issues and needle fatigue were among the leading reasons that a similar proportion of patients (57%) had stopped undergoing injectable treatment.

Clearly, given the differing nature of countries’ health systems, approaches to psoriasis care will need to vary; however, many lessons may be transferable. National guidelines must be designed to best facilitate access to treatment in the context of the specific health system—including by accounting for regional differences and countering regional and socioeconomic inequity where possible.

Insight 4: Access to treatment is affected by socioeconomic and geographic barriers

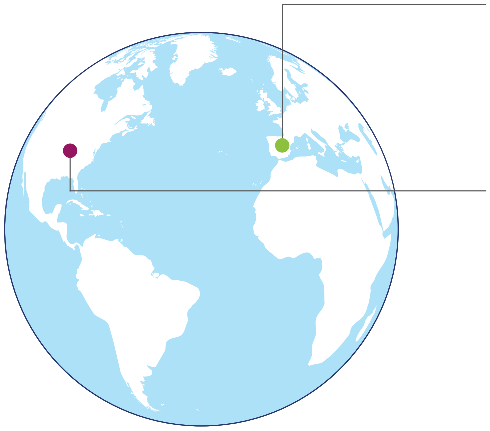


China

A study (n=236)* performed to assess patient preference for biologics in China used a discrete choice experiment comparing benefits and costs. Over 50% of patients considered cost as the most important factor for determining the choice of therapy. These data suggest that there are accessibility barriers and reimbursement challenges with new, modern therapies in China.[83]

Italy

A study (n=300)* conducted in Bologna, Italy, discovered a negative relationship between socioeconomic status and the level of severity of psoriasis. Patients who had lower educational and income levels, as well as were employed in manual or office work, had a significantly greater incidence of moderate-to-severe psoriasis.[82]



Spain

A study (n=1,265)* observed that 73% of patients had access to some sort of treatment, but only 4% received modern systemic therapies (apremilast, dimethyl fumarate); 18% were receiving biologic treatments; and, of those with moderate-to-severe cases, 49% received only light therapy or topical treatment.[84]

United States

A literature review revealed a significant lack of culturally competent psoriasis care in the US, in addition to limitations and challenges in access to care and diagnosis among non-white individuals.[80] In support of this finding, another study (n=27,691)* reported discrepancies in access of care due to racial and ethnic differences, as well as insurance status.[81]

* n refers to the study or survey's sample size, or the number of participants or observations included in a study or survey, respectively.

"The cost of treatment is still a burden for some low-income patients... The cost of treatment with biologics or targeted drugs is currently between 15,000 yuan and 30,000 yuan a year... This is still very difficult for some low-income or rural families to afford...because China is so big, the gap between the economic developments of various regions is also very big. The ease of reimbursement can be said to be completely linked to the economic development of the region... where local finances are not good, the reimbursement may be lower or you have to be hospitalised to get it. "

Xingxiang Shi, patient advocate, China.

"A given drug that was approved by AIFA (Agenzia Italiana del Farmaco-Italian Medicines Agency) a year ago can, in some way or another, be found in all regions but it may have a different price in the different regions. "

Valeria Corazza, patient advocate, Italy.

"Access to treatments has become more and more challenging for patients. So, on the one hand, you've got more options to work with your provider. On the other hand, the access challenges and the barriers people face in getting on those treatments seems to continue to grow... If you slice up the psoriasis population in the US, what you would find is that there are differences in how patients are treated and the outcomes they're achieving based on different characteristics of the patient. So where they live, what their income is, what their race or ethnicity is, what their age is, what type of insurance they have. "

Leah McCormick Howard, patient advocate, US.

Multidisciplinary and patient-centred care

Multidisciplinary and patient-centred care is necessary, but is not always well formalised.

Given the systemic nature of the condition, its varying severity and its many comorbidities, psoriasis care is far from a one-size-fits-all package. A variety of specialists may be needed to provide integrated, multidisciplinary and patient-centred care, based on shared decision-making and individual patients' needs. In collaboration with the patient, the multidisciplinary team may include dermatologists, rheumatologists, physiotherapists, mental health specialists and nurses.

Yet such holistic care is often not the reality for patients, with disparities in approach proven to be an issue both between and within countries. In Germany, for example, dedicated outpatient psoriasis clinics generally offer integrated multidisciplinary care, says Ms Meyer, but this is not the case outside of such clinics. In the US, while some centres give patients integrated access to whichever specialists they need, in many others, access to specific experts is reliant on a case-by-case consultation process, explains John Murray, Professor of Dermatology at Duke University School of Medicine. While many countries are seeing a shift towards multidisciplinary care, the focus is often on large hospitals and clinics in cities, limiting access to such care for those in more remote and rural areas.

USA FOCUS GROUP
Key takeaways from participants

Lack of culturally competent care and language barriers pose significant challenges. There is a need for interpreters to communicate with patients who speak different languages. Patients prefer to see physicians who look like them, and there is historical distrust of the medical community among certain communities. Additionally, the different presentations of psoriasis lesions on different skin colours pose diagnosis and treatment challenges.

Several factors contribute to the undertreatment of psoriasis and psoriatic arthritis. One is cost, while changes in insurance coverage or turning 65 can also cause patients to lose access to medications. Doctors may also be hesitant to treat very young or very old patients.

Patients and caregivers are willing to share data to facilitate accessible and effective care. The lack of available information highlights the need for data sharing to improve diagnosis and treatment. Patients are willing to do anything to make it easier to manage their conditions, and sharing data can help to achieve this.

"The challenge when you are talking about multidisciplinary teams is that you are talking about a physician, you are talking about dermatologists, you are talking about rheumatologists, you are talking about psycho-dermatologists or psychologists, a physiotherapist, a nurse, etc.," says Hoseah Waweru, President of the International Federation of Psoriasis Associations (IFPA). "It's often very, very difficult to put this team together in many places, even in developed countries."

There are several examples of notable efforts to further multidisciplinary care for psoriasis and psoriatic arthritis. In Spain, the NEXUS 2.0 project, launched in 2017, is a collaborative effort between dermatologists and rheumatologists that aims to establish national standards and quality indicators for multidisciplinary care for psoriatic arthritis;[84,86] similarly, the US National Psoriasis Foundation has made patient-centric research a priority agenda.[85]

While these are strong examples that highlight initiatives targeted at integrated care, more concerted efforts are needed to improve collaboration and to ultimately optimise the patient experience and quality of life.

CHINA FOCUS GROUP
Key takeaways from participants

Patient advocacy groups need to improve their outreach efforts to effectively engage with (i) patients to improve their knowledge of the disease and its treatment possibilities and (ii) the general population to improve awareness and help reduce stigmatisation and prejudice, especially in rural areas.

The financial and psychological burden of psoriasis could be reduced by **improving medication reimbursement and providing adequate mental health care** as part of standard treatment protocols.

China needs to improve the provision of specialised training and licensing for the workforce, especially because most dermatologists come from other countries and don't meet the requirements of Chinese medical organisations to prescribe certain treatments.

Screening

Screening for comorbidities can aid in decision-making and mitigate disease severity.

Screening for disease progression and secondary conditions is a valuable decision-making aid that is already widely in use in some countries. Screening can not only confirm common comorbidities, but also help to reduce the number of misdiagnoses of comorbidities. For example, a survey of patients in North America, Europe and Japan found that 58% of psoriasis patients experienced joint discomfort and 63% of those also had symptoms consistent with oligoarthritis.[11]

Primary care providers in the US screen for comorbidities through indicators such as weight, glucose intolerance, diabetes, high blood pressure and abnormal lipids, and more dermatologists are becoming aware of these practices, says Professor Murray. Similarly, in Germany, clinical guidelines include detailed guidance on the screening and management of comorbidities.[87] Whereas in Spain, dermatologists are recommended to screen for cardiovascular comorbidities and recommend referral for rehabilitation for those with joint deformity.[88] "I think the trend now is that people are being informed to screen for those comorbidities that can be associated with severe psoriasis," says Professor Murray. "Namely, pay attention to things like weight, glucose intolerance, diabetes, high blood pressure and abnormal lipids."

In Japan, based on Economist Impact's interviews and analysis, screening for comorbidities is far more limited, often being undertaken only in large hospitals. To be truly effective, screening must become routine and standardised. Only then would patients be able to effectively manage their disease and mitigate its progression.

JAPAN FOCUS GROUP
Key takeaways from participants

There is insufficient public knowledge and understanding on psoriasis; patient advocate associations need to be more active in leading national awareness campaigns and disease education. **Stigma and discrimination can be addressed by creating the social awareness** that psoriasis is not a contagious disease.

Specialist workforce is strong in Japan, albeit regional differences in supply of dermatologists and rheumatologists.

With a continuously shifting treatment landscape, **there is a need for national guidelines on psoriasis** to ensure consistent treatment approach.

Patient experience and treatment burden

Stigma can prevent patients from seeking help with mental health challenges; flare-ups and limited progress can impact treatment adherence.

For any condition, the patient should be at the centre of the decisions and processes that constitute care. This is especially true of psoriasis, a condition that affects individuals in widely different ways. Yet, improvements in patient-provider communication (and a more patient-centric approach in general) are urgently needed to address the perceived disparity between psoriasis treatment and patient satisfaction.

There is a documented disconnect between patients and dermatologists when it comes to perceptions of disease severity, suggesting that measures of severity traditionally used by physicians do not fully capture the impact of psoriasis on patients' lives and mental health.[11]

"It is the visual part that makes the physician decide whether [psoriasis] is severe, moderate or mild," says Mr Alfonso. "Therefore, many people are not [receiving the appropriate] level of care, and sometimes the seriousness for the patient is not the same as for the physician."

Mental health, in particular, is a factor that could be neglected if care providers, patients and policymakers do not fully consider the potential systemic and quality-of-life impacts of psoriasis. "Suicide is a topic that is often not discussed," says Mr Alfonso. "[Patients] have been through very, very traumatic episodes… Psoriasis affects and traumatises a lot of people, and we don't give solutions or tools. The public system does not provide tools for the improvement of emotions," he adds.

Even before a patient with psoriasis embarks on their care journey, factors such as stigmatisation and discrimination can make an already painful experience even more difficult, sometimes driving them to forgo treatment altogether.

Once treatment begins, if a patient does not feel adequately cared for—for instance, if the treatment that they are receiving does not seem to work for them—treatment adherence can deteriorate, in turn worsening outcomes and further solidifying the impression that the care they are receiving is inadequate.

“Patients who have been suffering for a few years may feel confident at first that the disease can be treated,” says Mr Shi. However, after extended periods of treatment, punctuated by flare-ups, patients may “become disillusioned with the medicine and their compliance will decline.” A negative experience, whether with treatments or other care support, may drive a patient to abandon treatment altogether.

With both the psychological and physical aspects of psoriasis, there is continuing unpredictability. This means that the course of treatment assigned to a patient will need to be continually reviewed and evaluated to ensure that it remains appropriate and effective. “You have to consider that this is a chronic illness—there are always highs and lows,” says Ms Meyer. “Psoriasis that has been kept under control can always flare back up, and then you have to reconsider what to do next, what the right treatment is now, and because of that it’s necessary to always deal with your illness,” she explains.

Conclusion and calls to action

Psoriasis is a chronic, systemic autoimmune disease that is frequently accompanied by serious comorbidities. It is painful and can have major physical, mental and quality-of-life impacts on those affected by it. Yet, it is also an eminently treatable condition. In some cases, the symptoms of the disease can even be managed using topical creams and ointments, and advances in systemic therapies have expanded the ability to treat the condition more comprehensively and effectively.

To fill the gaps in current care pathways, several factors need to be considered. Firstly, the disease is beset by low levels of awareness and knowledge, both among the public and healthcare providers. This contributes to delayed diagnosis or misdiagnosis, undertreatment or complete lack thereof. Access to care is further impacted by regulatory, administrative, socioeconomic and geographic factors. Along with the many challenges that patients face in seeking treatment, available treatments are underutilised. To top it off, reliable data on the burden of psoriasis, and the effectiveness of treatments, are sparse. Put simply, psoriasis is a misunderstood, under-resourced and undertreated condition that imposes significant costs on patients and society at large.

To tackle these challenges, Economist Impact has identified the following areas for immediate action.

Address stigma, misdiagnosis and undertreatment by improving awareness and health literacy.

Psoriasis care is held back by knowledge gaps that impact patients, clinicians, policymakers and the wider public. Better education of patients and physicians about psoriasis, comorbidities, disease management and treatment (including risks, benefits, side effects and realistic expectations when it comes to treatment plans) will help to improve treatment access, uptake, adherence and impact. Patient organisations are critical to this effort. For example, the US National Psoriasis Foundation has strategically taken steps to help people understand the patient's experience with psoriasis and psoriatic arthritis. Under the banner of a global, patient-led online research network, called Citizen Pscientist, the Foundation allows people living with psoriasis to share their experiences and contribute to data collection anonymously. By understanding the challenges patients encounter with their quality of life and treatment, the Foundation seeks to advance the knowledge of psoriasis beyond the clinical setting.

Policymakers, in collaboration with patient advocacy organisations, must work to ensure that individuals are better informed about the potential impact of psoriasis and the benefits of treatment. To ensure that countries are on the same page, and that the best knowledge and practices are shared, there should be an increased focus on policy making and public discussion at the local/national level, regionally (across the European Union, for example) and internationally.

Health literacy efforts aimed at the general public must effectively communicate that psoriasis is a non-communicable disease that has significant impact on quality of life, and that it is treatable, especially given the rise of effective systemic treatments. Increased awareness of the nature of psoriasis will also drive down stigmatisation, thus increasing people's willingness to seek treatment, thereby improving the chances of early diagnosis—and helping people to accept and overcome the challenges that living with psoriasis brings.

When it comes to healthcare providers, education on psoriasis should be routinely reassessed to ensure that primary care providers are better equipped to recognise the signs and symptoms of the condition, and are capable of distinguishing it from other (chronic and short-term) conditions, in order to reduce the chances of misdiagnosis and delayed treatment. Medical universities and training programmes should also formally engage with patient groups to ensure that shared decision-making and patient centricity become cornerstones of psoriasis care. Providers also need to be equipped with the knowledge that the disease manifests in different ways, both locally and systemically, and to different extents, because a one-size-fits-all approach will leave many patients short-changed.

Co-operation and collaboration between healthcare providers and patient organisations is yet another way to achieve more effective care and better patient outcomes. As seen in Germany, collaboration between dermatologists and patient advocates can lead to better understanding and management of the condition. As Ms Meyer explains, "We're very close and co-operate and understand one another and where each other's competencies are… and that works very well." Such partnerships should be facilitated and nurtured by policymakers.

Additionally, better understanding of the multifaceted nature of referral and treatment will help patients receive effective care more quickly. Specialists must be better prepared to help patients manage the broad range of disease impacts outside of their own specialties, whether that be skin issues, comorbidities, or strains on mental health, and should escalate therapy when not achieving patients' goals.

Support the adoption of technology to improve equity of access to care and—hand-in-hand with screening—facilitate early diagnosis of comorbidities.

Unequal access to adequate care, especially when it comes to multidisciplinary and specialist treatment, hinders patients' progress along the treatment journey, affecting treatment effectiveness, adherence and outcomes. Regulatory, reimbursement and administrative barriers to access must be addressed comprehensively. These barriers may vary on a regional level within countries, depending on local policies, urban versus rural divides, differing socioeconomic realities and the availability of resources.

Technology has a role to play not only in improving access to care (including follow-up visits) but also in facilitating early diagnosis of psoriasis and its comorbidities. For example, telehealth may enable access to specialist consultations for those who live long distances away from specialist hospitals and clinics; in the US, for example, advocacy groups seized upon the acceleration of telehealth services during the covid-19 pandemic to drive a roll-out of telehealth for psoriasis, demonstrating the impact that such patient advocacy groups can have.

Additionally, mobile health applications are on the rise for symptom-monitoring, early identification of psoriatic arthritis, and for providing psychosocial support to patients.[89,90] In Italy, APIAFCO is working on a digital "patient journey" platform that connects patients with all of the specialists that they need, explains Ms Corazza. At the same time, machine learning and big-data solutions are being explored for early diagnosis of psoriatic arthritis and its differentiation from rheumatoid arthritis.[91]

Screening for psoriasis comorbidities should also become routine. Dermatologists should screen psoriasis patients for comorbidities, particularly psoriatic arthritis, as one-third of patients may develop joint symptoms. Cardiovascular comorbidities should be checked during the first dermatology visit, and any issues should be referred to an appropriate care provider for further investigation and management.

Improve data collection, quality and use, especially in terms of disease burden and registries.

There are vast disparities in psoriasis data, especially when it comes to the epidemiology and economic burden of the condition. The US and the European countries included in this study benefit from the fact that research has long been focused on high-income, Western countries. Yet, even in these countries, there is not a significant body of research or data, particularly when compared with other non-communicable diseases. International and national organisations, industry and policymakers all have a role to play in increasing the level of research resources directed towards psoriasis, its impact on people's lives and the effectiveness of treatment.

A key area to focus on would be the high variability in the epidemiological and economic cost estimates of psoriasis, which is attributed to gaps in data, especially in low- and middle-income countries, differences in methods of ascertainment of diagnosis (physician-reported versus self-reported) and diverse data sources (claims, electronic health records or population-based surveys, for example). Disease registries must also become more widely established as they provide a more comprehensive overview and understanding of the disease burden and treatment effectiveness.

The GPA, established in 2019 through the collaborative efforts of IFPA, is a worthy attempt to bridge these gaps. The GPA works in collaboration with the dermatology group of the GBD study and various countries to collect data on the epidemiology of psoriasis, develop a better understanding of the health and economic burden of the disease, and facilitate early diagnosis through better training and diagnostic tools.[92] Such efforts must be supported on a national level by relevant stakeholders.

Additionally, more granular, patient-centric outcomes research is needed. In Spain, says Associate Professor López Ferrer, different psoriasis research groups focus on very specific issues, which range from the impact of treatments on cardiovascular comorbidities, the probability of preventing psoriatic arthritis in patients receiving biologics therapy, to the detection of arthritis risk factors in psoriasis patients. Facilitating such research opportunities in other countries will increase the depth of knowledge about psoriasis and its impact on patients, which can only help make care more responsive to individuals' needs.

Make care and research more patient-centric; support the use of multidisciplinary teams and shared decision-making.

Better communication between physicians and patients to more closely align treatment goals and preferences is needed, as is a true commitment to shared decision-making.

The patient's voice is vital, especially when treatment is not achieving its goals. Shared decision-making correlates with improved treatment satisfaction—yet it is often neglected in psoriasis care, raising the risk of patient dissatisfaction and disillusionment with treatment.[93] A cross-country survey conducted in 2020-21 revealed that 44% of patients with concomitant psoriatic arthritis made shared decisions with their provider, 42% never discussed treatment goals with their provider, and 13% had care decisions made for them by their provider.[5]

Patient organisations have a critical role to play in advancing the patient's care journey—policymakers should ensure that the voices of these groups are heard so that care can be designed to better respond to the needs of all patients. Additionally, healthcare providers should be better trained and equipped to improve their communication with patients and caregivers.

Integrated, multidisciplinary teams can also ensure that patients receive the care that they need across multifaceted domains. The NEXUS 2.0 project in Spain is an early-stage example of how collaborative efforts can help to establish standards and quality indicators for multidisciplinary care.[86] More clearly defined referral pathways are also needed to help primary care providers and specialists to grant patients early access to the varied types of care that they may require, particularly in the presence of comorbidities. This will enhance the impact of care, improving treatment adherence and outcomes, and ultimately enhancing psoriasis patients' quality of life.

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