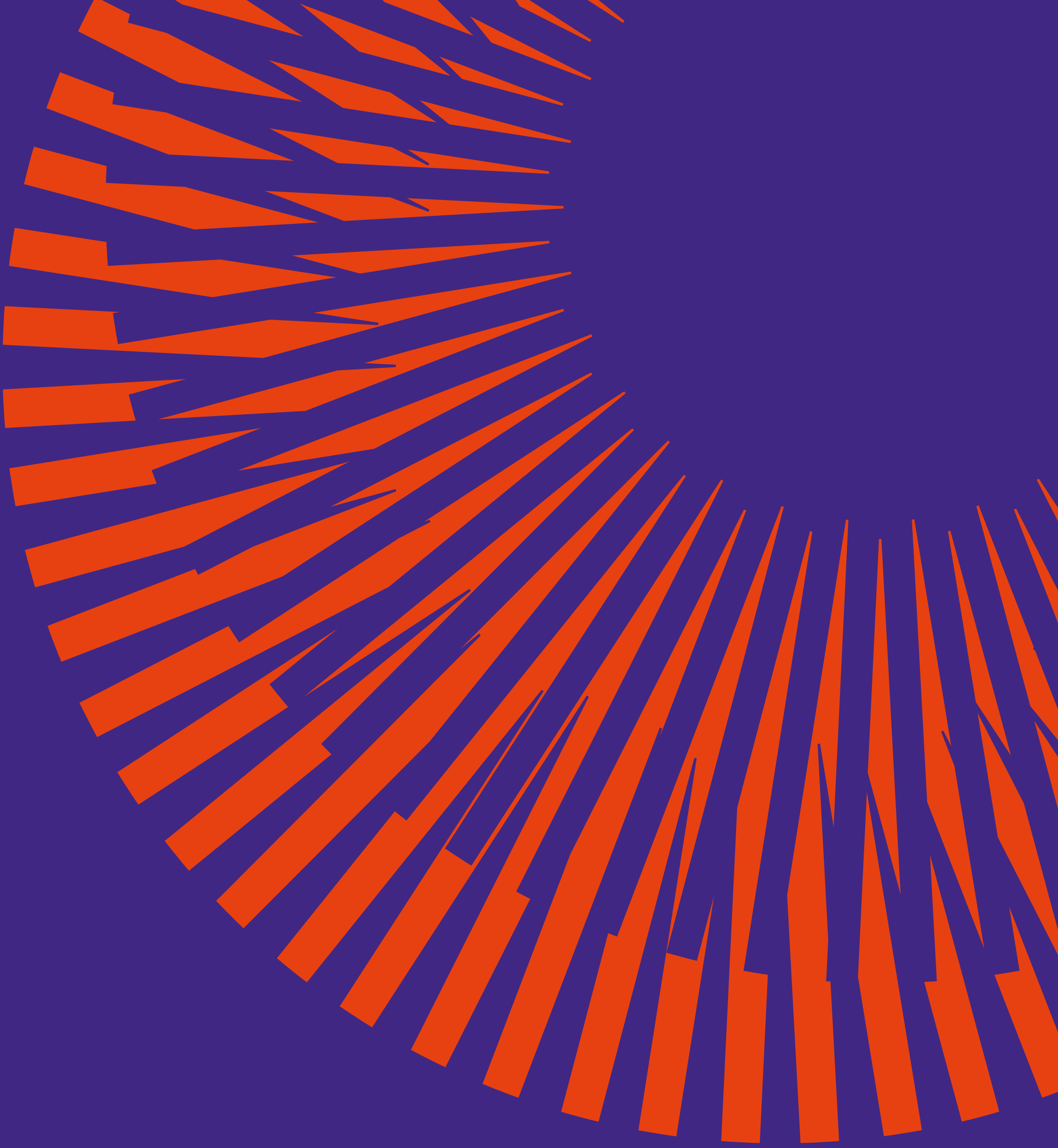


Review of progress since the 2014 WHA Resolution on Psoriasis

IFPA
GLOBAL LEADER IN FIGHTING
PSORIATIC DISEASE

Executive summary

Authors

Nicholas Norton, Aiman Afaque, Elisa Martini

Acknowledgements

We are deeply grateful to each of the following key opinion leaders for providing their experienced perspectives, guidance, and time:

Paolo Gisondi, MD Dermatologist, University of Verona, Verona, Italy
Alice B Gottlieb, MD, PhD Dermatology, Rheumatology, Icahn School of Medicine at Mt Sinai, New York, New York
Christopher Griffiths, OBE, MD, FMedSci Emeritus Professor of Dermatology, King's College London, London, United Kingdom

We would also like to thank all the participating IFPA member organizations for lending their support in conducting the patient survey. Lastly, we owe a debt of gratitude to the survey respondents who volunteered their time to provide their perspective on living with the disease in their respective countries.

Preface

Psoriatic disease is a systemic condition affecting multiple body sites, predominately the skin, the joints, or both. In addition to skin and joint symptoms, psoriatic disease is characterized by increased risk of developing related noncommunicable diseases. The number of people affected and the risk of developing life-threatening comorbidities calls for urgent action. But despite the numbers, psoriatic disease is not a priority for health systems.

In 2014, World Health Organization (WHO) member states adopted the resolution on psoriasis (WHA 67.9). This resolution officially recognizes psoriatic disease as a serious noncommunicable disease that can lead to immense, needless suffering due to insufficient access to healthcare. Two years later, recommendations were laid out in the WHO Global Report on Psoriasis, and empowered policymakers with practical solutions to improve the health care and social inclusion of people living with psoriatic disease.

Ten years later, the psoriatic disease community unites to celebrate the achievements of the past ten years, and to set the agenda for the next decade. To that end, it is paramount to know what changed in the past ten years of efforts from diverse stakeholders in improving the lives of people living with psoriatic disease, and what instead did not change. This report provides an overview of these changes, and the challenges that people still face despite the milestones achieved, to set priorities for the years to come.

Frida Dunger
Executive director
IFPA

Executive summary

Psoriatic disease is a chronic disease that affects the skin (psoriasis), joints (psoriatic arthritis), and sometimes other organs of the body (1). The prevalence of psoriatic disease varies around the world, with recent estimates ranging from 0.14% in East Asia to 1.99% in Australasia, and greater prevalence in higher-income countries with older populations (2). Those living with psoriatic disease often experience significant economic and quality-of-life (QoL) burden throughout their lifetimes.

In 2014, the World Health Assembly (WHA) put forth a resolution to address the current major concerns and risk factors for people with psoriatic disease and encourage further advocacy efforts by member states (3). The resolution was then succeeded by the 2016 Global Report on Psoriasis (4), intended to "empower policy-makers with practical solutions to improve the health care and social inclusion of people living with psoriasis in their populations." IFPA decided to conduct a review of evidence assessing psoriatic disease care and awareness progress across the globe in the last 10 years since the 2014 resolution, using the context of the metrics included in the resolution.

> A majority of those surveyed found that the disease and treatment information they received from their healthcare provider was lacking.

Methods

The review of progress consisted of three data collection approaches: a literature review, a patient survey and a series of expert interviews with key opinion leaders (KOLs). Each approach was structured to focus on the main metrics included in the WHA resolution. The literature review included published records, grey literature and any relevant materials provided by IFPA. The interviewers followed a discussion guide to keep data collection consistent across KOL interviews. The patient survey was sent to all IFPA member organizations, with the goal of at least one patient per member organization providing their perspective based on a set of pre-specified questions. Endpoints for each metric were established the protocol phase, and a narrative synthesis of the collected data was conducted.

Results

A total of 138 out of 757 collected records were included in the review. The most common regional categories for the included records were the European region, the Americas, or did not have a specific region. In addition, 3 KOLs were interviewed and 31 people with psoriatic disease responded to the voluntary patient survey (1 respondent per organization and country).

Metric 1:
Providing access to treatment and healthcare education

The most evidence was found for the first metric. A majority of those surveyed found that the disease and treatment information they received from their healthcare provider was lacking. The evidence collected suggested that many countries around the world are still lacking up-to-date guidelines. Even in high-income countries, there is evidence of clinicians still using older guidelines in spite of newer ones, which lack the latest recommendations for treating psoriatic disease. In addition, for people with the disease, there is a risk of being subjected to misinformation through social media and other online sources. However, there is evidence that progress has been made in some areas over the past decade.

> The evidence collected suggested that many countries around the world are still lacking up-to-date guidelines.

Metric 2:
Understanding of the features of psoriatic disease

There is still a limited understanding of the disease, and its features in the general public, regardless of region. Providers are being educated more and more in regions with more developed systems but may lack the time or resources to act on the new information, while in less developed areas, there are higher risks for misdiagnosis or delays to treatment. Thus, the interviewed KOLs recommended additional education for primary care providers and specialists, to allow them to maximize their impact, while referring to other providers for aspects outside their focus areas. Patient advocacy groups can also partner with celebrities who live with the disease to help spread awareness.

Metric 3:
Social and work-related stigma

Most people around the world who live with psoriatic disease still experience stigma, which impacts mental health, relationships and even employment opportunities. According to KOLs and collected evidence, stigmatization is slowly improving, but it is still a major issue. Most of those surveyed experienced negative reactions from people around them, with a frequency between 'occasionally' and 'very often'. It is recommended that psychological assessments be carried out by providers to minimize the mental health impacts of the disease and encourage patients to seek help when needed.

> "
> It is recommended that psychological assessments be carried out by providers to minimize the mental health impacts of the disease.

Metric 4:
Understanding the risk of comorbidities

Much of the evidence collected for this metric revealed that comorbid conditions are common in those living with psoriatic disease. All KOLs agreed that awareness of the risks of comorbidities in psoriatic disease has spread somewhat over the past 10 years. However, it is clear from the evidence that awareness is still poor, and that there are many systems who do not have consistent practices or guidelines in place to detect and treat comorbid conditions in people living with the disease, resulting in unnecessary burden for those who go untreated. Screening for comorbidities is vital; simple screening practices and referral processes are recommended to control for comorbidities.

Metric 5:
Recognition of psoriatic arthritis (PsA)

Only eight of the 31 survey respondents were made aware of the risk of developing psoriatic arthritis (PsA) by their providers. The KOLs and the collected evidence both indicated that little progress has been made to improve screening practices or time to diagnosis for PsA. Moreover, longer lifespans globally are leading to a higher risk for people with psoriasis to develop PsA. However, more widespread use of biologic systemic treatments has the potential to delay or even reduce the risk of developing PsA, according to both literature and KOL experience. There were also examples of good practice in multiple regions around the world, encouraging further improvements to screening and diagnosis.

Metric 6:
Delayed diagnosis, limited treatment options and access to care

This metric covered three major aspects of unmet need in the care of psoriatic disease, which are all interlinked. The delay between the time people present to healthcare with their symptoms and when they are given a diagnosis is considered far too long by all accounts. This delay can be impacted by structural issues (lack of available specialists, long wait times, etc.), lack of knowledge (e.g., misdiagnosis by providers), affordability of care, and other issues. All KOLs and many survey respondents agreed that access to treatment has improved in the last 10 years, particularly with the availability of biosimilars. But there are still parts of the world with limited access to treatments that are widely available elsewhere, or financial barriers to care. Access to specialist care is also a major issue, particularly in some less developed or rural systems. For settings where specialists have too many patients to manage, one KOL recommended the use of 'task-sharing', to free up time.

Metric 7:
Advocacy efforts of stakeholders

Psoriatic disease advocacy efforts have been steadily increasing and collectivizing over the past decade. The KOLs interviewed felt that public awareness had somewhat improved, which has in part been supported by pharmaceutical companies; pharma has a vested interest in spreading awareness of the disease, which in turn helps people living with the disease in a variety of ways. As of today, IFPA has member organizations in five of the six WHO regions (none so far in the Eastern Mediterranean Region), with most members concentrated in the Americas, Europe and the Western Pacific.

Measure A:
Evidence of QoL improvements

Evidence from around the world has shown the negative impact of psoriatic disease on peoples' quality of life, with survey data showing small improvements in the past decade. Studies recommend that timely management of symptoms is the key to reducing the impact, given that patients who receive adequate and early treatment report better quality of life. As access to treatment and care expands worldwide, quality of life can improve for those living with psoriatic disease.

> As access to treatment and care expands worldwide, quality of life can improve for those living with psoriatic disease.

Measure B:
Burden on people with psoriatic disease and their families

Psoriatic disease is burdensome for both those living with the disease and their loved ones. The collected evidence shows that this burden can take many forms, such as the inability to work, high costs for care, mental health issues and so on. Health systems are encouraged to reduce the economic burden by subsidizing care for patients, particularly for new systemics. Also, as above, well managed symptoms will reduce the burden on people living with the disease and their families.

Measure C:
Ability to rejoin society

Over two thirds of the survey respondents felt that it has become easier in the last decade for people with psoriatic disease to get a job or stay in the job they have. KOLs have reported that their patients anecdotally have felt more comfortable being in public with their disease, and that they have had an easier time going to work. However, a recent global survey has indicated that 35% of all people with the disease could not work or study the week prior to the survey as a result of their symptoms. People who do not have their disease adequately managed have a harder time regaining employment, so timely diagnosis and treatment are key.

Measure D:
Holistic approach to care

The multi-faceted nature of psoriatic disease poses a heavy socio-economic burden on society, affecting individuals physically and mentally. It is therefore important that patients are treated holistically. A paucity of data was found for this measure, but little was identified suggested that many patients are not managed holistically, which leads to poorly managed comorbidities and other issues.

Measure E:
Laws and regulations to promote care

System-wide efforts to promote access to and quality of psoriatic disease care are one way of improving patient outcomes across a population. There are some recent examples of laws and regulations passed in countries like the Philippines and Panama, which are promising. Continued advocacy efforts by stakeholders can encourage further systemic improvements.

Conclusions

A total of 138 out of 757 collected records were included in the review. In the 10 years since the WHA resolution, the average person living with the disease has likely experienced improvement in their access to treatments, specialized care, quality of life, and greater knowledge of the disease within stakeholders and the general public.

However, there are still major unmet needs in all metrics, in every region of the world. In particular, time to diagnosis, access to treatment and knowledge of the disease are paramount to improving outcomes for patients, both physically and emotionally. Each of these elements are interlinked, and require unified efforts by stakeholders to raise awareness, standardize provision practices, and improve both access and affordability for those with the disease. Timely, targeted and holistic management of peoples' symptoms is the key to reducing the burden on both individuals and the systems they live in.

Rationale & objectives

Psoriatic disease is a chronic disease that affects the skin (psoriasis), joints (psoriatic arthritis), and sometimes other organs of the body (1). Skin symptoms are typically characterized by scaly, red, and itchy plaques, while joint symptoms consist of joint pain, swelling, and stiffness. The exact cause of psoriatic disease is not yet fully understood, but it is believed to be a combination of genetic and environmental factors leading to a dysregulated immune response, resulting in signs and symptoms of chronic inflammation that manifest primarily in the skin and joints. Due to the systemic nature of psoriatic disease, affected individuals often also suffer from comorbidities, such as cardiovascular disease, metabolic syndrome, obesity, inflammatory bowel disease, and psychiatric illness (5-8).

The prevalence of psoriatic disease varies around the world, with recent estimates ranging from 0.14% in East Asia to 1.99% in Australasia, and greater prevalence in higher-income countries with older populations (2). However, while prevalence rate can vary by country, larger populations still include many affected individuals.

Those living with psoriatic disease often experience significant economic and quality-of-life (QoL) burden throughout their lifetimes. A 2017 systematic review of the QoL and economic burden across the Asia-Pacific region found that annual direct costs per person living with the disease ranged between $365 - $2289 (2022 USD) (9). The same study estimated high to very high impairment of QoL in Asian-Pacific countries, as measured by the Dermatology Life Quality Index (DLQI score 6-30). A 2022 study of people living with psoriasis in Sweden found that those with plaque psoriasis had total direct healthcare costs that were an average of 1.8 times higher than the general population, and that those with generalized pustular psoriasis were 3.3 times higher (10). People with moderate to severe plaque psoriasis in Brazil were estimated to pay $4034 USD (2019) on average for treatment (11). It has also been found that people living with psoriatic disease in the Asia-Pacific region suffer from challenges relating to social life, regular activities, lower productivity, anxiety, stress, and depression (12).

> “Those living with psoriatic disease often experience significant economic and quality-of-life (QoL) burden throughout their lifetimes.

A resolution to address the suffering of those with psoriatic disease

In 2014, efforts from the international patient community led to the adoption of a resolution on Psoriasis by the World Health Assembly (WHA 67.9), addressing the current major concerns and risk factors for people with psoriatic disease and encouraging further advocacy efforts by member states (3). The Resolution underscores that “too many people in the world suffer needlessly from psoriasis” and mandates the publication of a report on the public health impact of psoriasis. The following metrics were included in the 2014 WHA resolution:

1 Recognizing the urgent need to pursue multilateral efforts to promote and improve human health, providing access to treatment and health care education

2 Recognizing also that psoriasis (PsO) is a chronic, noncommunicable, painful, disfiguring, and disabling disease for which there is no cure

3 Recognizing further that in addition to the pain, itching and bleeding caused by psoriasis, many affected individuals around the world experience social and work-related stigma and discrimination

4 Underscoring that those with psoriasis are at an elevated risk for a number of co-morbid conditions, namely, cardiovascular diseases, diabetes, obesity, Crohn disease, heart attack, ulcerative colitis, metabolic syndrome, stroke, and liver disease

5 Also underscoring that up to 42% of those with psoriasis also develop psoriatic arthritis (PsA), which causes pain, stiffness and swelling at the joints and can lead to permanent disfigurement and disability

6 Underscoring that too many people in the world suffer needlessly from psoriasis due to incorrect or delayed diagnosis, inadequate treatment options and insufficient access to care

7 Recognizing the advocacy efforts of stakeholders, in particular through activities held every year on 29 October in many countries, to raise awareness regarding the disease of psoriasis, including awareness of the stigmatization suffered by those with psoriasis

The year 2024 marks the 10th anniversary of the WHA resolution on psoriasis. IFPA has therefore decided to produce a review of progress made across the globe since the resolution was published, based on the metrics contained within the resolution. The goal in conducting this review is not to attribute any progress made to the resolution itself, but rather to assess where efforts to improve care and awareness of psoriatic disease have been successful, and where there is still progress to be made.

In addition to the above metrics, IFPA is also interested in describing any evidence tied to the above metrics, which answer the following questions about the last 10 years:

Has quality of life (QoL) improved for people living with psoriasis?

Have there been any laws or regulations to promote psoriatic disease care since the resolution?

Has the burden on people living with psoriasis and their families lessened?

Are people living with psoriasis more easily able to regain employment?

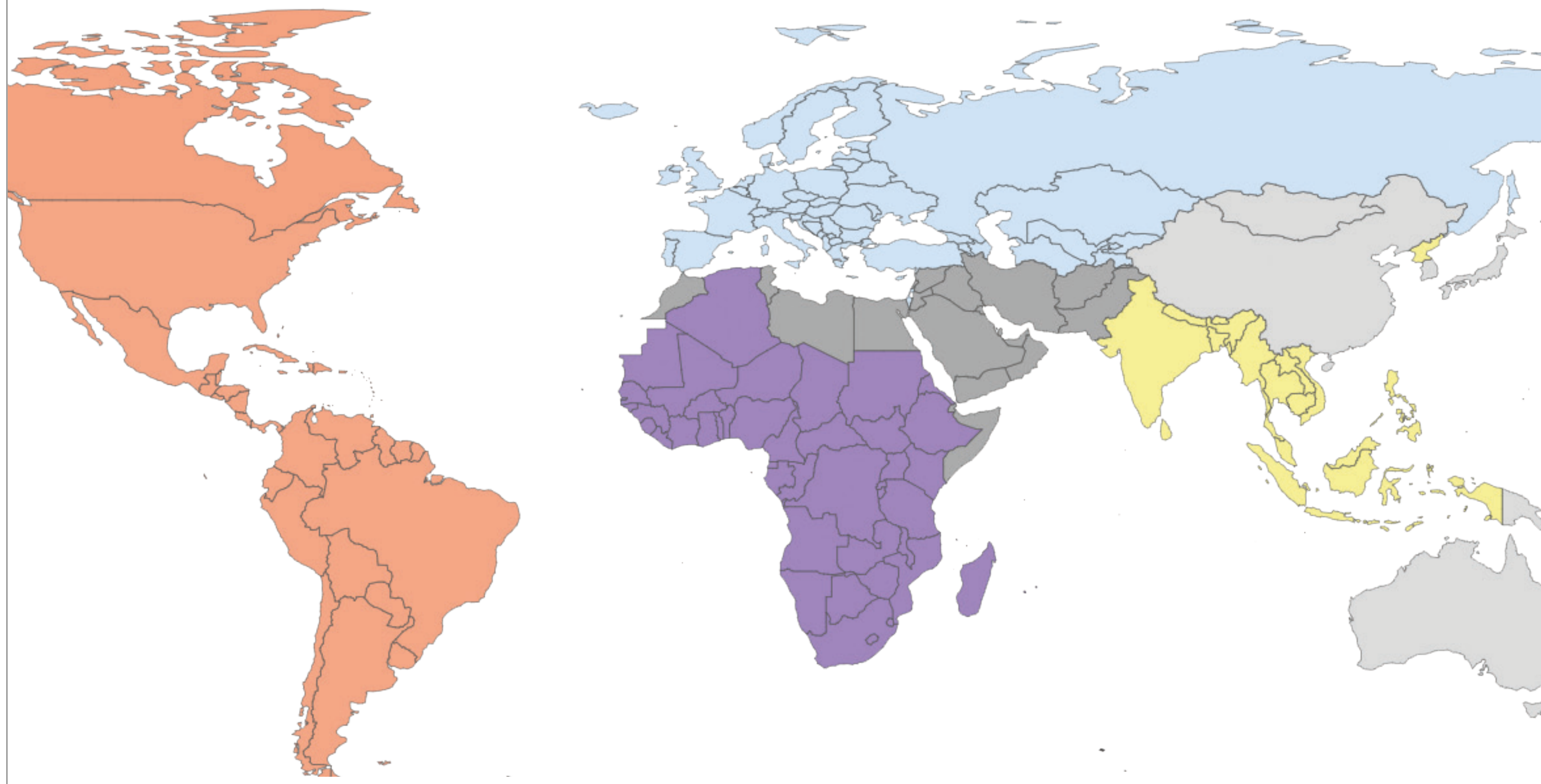
Is a holistic approach to care increasingly used in psoriatic disease?

Objectives

The objectives are to conduct a review of evidence assessing care and awareness progress for psoriatic disease across the globe in the last 10 years since the 2014 resolution, based on the metrics put forward in the resolution. This process included:

- Employing a combination of literature reviews, interviews, and surveys to collect data on the progress within each of these metrics, in countries around the world
- Summarizing the collected evidence in a report, which details the knowledge, care, policies, and awareness of psoriatic disease since the resolution, by region, where possible. The report would provide examples of good practices within each of the metrics, and highlight where progress still needs to be made

WHO global regions



USA, Argentina, Brazil

Ghana, South Africa, Kenya

Pakistan, Iran, Egypt

Germany, Turkey, UK

Indonesia, Bangladesh, Vietnam

China, Japan, Australia

To provide a more precise context for estimates of the progress made in each metric, the collected evidence has been grouped into global regions defined by the WHO for the purposes of reporting and analysis: Africa, the Americas, the Eastern Mediterranean, Europe, South-East Asia, and the Western Pacific.

To help with identifying evidence within each region, a set of sample countries were included in the search process, enabling the inclusion of country-specific records in addition to the region-specific records.

Methods

In order to assess progress since the WHA resolution, three tactics were employed for data collection: a targeted literature review, a series of interviews with key opinion leaders (KOLs) in the field, and a voluntary patient survey sent to all IFPA member organizations (13). The scope and approach for each tactic were pre-specified in a study protocol that was followed throughout the course of the work.

The literature review collected records from bibliographic databases, ad-hoc google searches and materials provided within IFPA, which met a set of eligibility criteria for inclusion. The collected records were screened in two steps, checking for relevancy to one or more of the chosen metrics, and then included for extraction. Relevant data for each indicator was then extracted into a grid for the data synthesis process.

In tandem with the literature review, a series of key opinion leader (KOL) interviews were conducted to provide the perspective of providers. A voluntary patient survey was also sent out to all IFPA member organizations, with the goal of interviewing one person living with the disease from each participating country.

The methods for each tactic are described in more detail below.

LITERATURE REVIEW

KOL INTERVIEWS

VOLUNTARY PATIENT SURVEY

Literature review

A targeted literature review identified academically published literature and grey literature (defined as information not formally published in scholarly journals, such as guidelines or reports) to identify relevant evidence. The eligibility criteria for inclusion were pre-specified in the protocol and based upon the resolution metrics. For more details about the eligibility criteria please see Appendix B, Table 2.

Records were collected from the following sources:

- A structured search of academic literature in PubMed
- Complementary Google searches to identify grey literature
- Additional material provided by IFPA

The PubMed search used a set of Medline search facets specified beforehand in the study protocol. The facets were based on the eligibility criteria. For details about the search facets, please see Appendix B, Table 3. To complement this search, Google searches were run, which utilized a set of syntax-driven, keyword searches based on the eligibility criteria, for each of the metrics, with teams for each region and the accompanying sample countries. For details about the ad hoc search terms, please see Appendix B, Table 4.

After the searches were conducted, all records were collected, and duplicates were removed before starting the review process. A single reviewer screened each record's title and abstract (or equivalent summary text) for relevance. Relevant records were retained, and their full text reviewed. Information relevant to the metrics was extracted from each article into a data grid to facilitate the data synthesis process. Multiple outcomes of interest were established in the protocol for each metric, to be used as measures of progress made. For details about the included outcomes, see appendix B, Table 5.

KOL interviews

To complement the literature review, a series of live interviews with international experts in the field of psoriatic disease care were conducted. The goal of these interviews was to better understand perceived progress since 2014 from the perspective of providers. The KOL interviews took about 1 hour to complete and were conducted in English. The collected data was added to the internal data grid for synthesis in the report. The questions used in the interview were established in the protocol phase, using the resolution metrics as a framework, and sent to the interviewees ahead of time.

The following international experts in psoriatic disease care were interviewed:

- Paolo Gisondi, MD - Dermatologist, University of Verona, Verona, Italy
- Alice B Gottlieb, MD, PhD Dermatology, Rheumatology - Icahn School of Medicine at Mt Sinai, New York, New York
- Christopher Griffiths, OBE, MD, FMedSci - Emeritus Professor of Dermatology, King's College London, London, United Kingdom

Voluntary patient surveys

In addition to the interviews, a voluntary patient survey was prepared and sent out to all IFPA member organizations, with a request for those organizations to interview a single person living with the disease. The survey was expected to take about 5 minutes to complete. The questions were written in straightforward English, with the perspective of the patient in mind, so that a team member from the IFPA member organization could conduct the interview in their local language and receive the numerical responses from the respondent. The collected data was added to the internal data grid for synthesis in the report. Data collected from these voluntary interviews was kept anonymous, with only the country of origin included as context for the response.

The questions used in the survey are provided in Appendix B, Table 6.

Data synthesis

Data collected through the aforementioned methods were collated and synthesized narratively, by metric and region. Available estimates and evidence pertaining to each of the outcomes were summarized, combining published sources with the opinions of people living with the disease in the respective regions, and supported by the opinions of the KOLs. As the context and circumstances vary significantly both within and between each of the regions, it was deemed best not to draw direct comparisons, instead presenting data side by side. Examples of good practice for furthering progress were highlighted where available. Furthermore, the report aimed to highlight the needs of people with psoriatic disease are still unmet.

This review constitutes a narrative synthesis of the collected data; no meta-analysis, pooled estimates, or other quantitative syntheses were performed.

Results

Summary statistics of the review

In total, 757 records were collected from PubMed and over 200 records from Ad Hoc searches. After the selection process, 138 records were included in the review. Most (62%) had been identified in the ad hoc searches. About 36% of the included records were observational studies, while 29% were reviews. Figure 1 presents a histogram of the number of studies by year of publication. There appears to be an increasing trend of publications assessing aspects related to the WHA resolution metrics in the published literature.

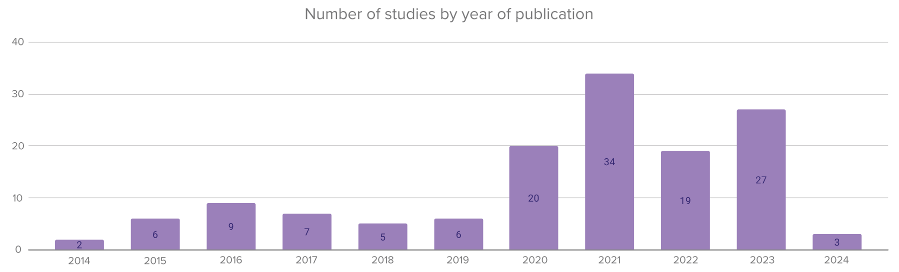


Figure 1

Of the included records, the majority (62%) contained evidence associated with the first metric (access to treatment and healthcare education), with 33% providing evidence associated with awareness of comorbidities in psoriatic disease. Some records contained evidence for multiple metrics. There was only one published record providing evidence associated with advocacy efforts. Figure 2 provides a breakdown of the number of records with evidence for each of the WHO regions. As expected, evidence for Europe and the Americas were the most abundant. There were also a few records with relevant information that did not have a particular setting.

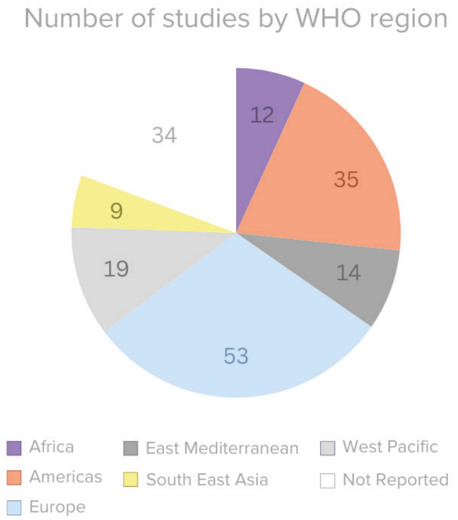


Figure 2

There were a number of associations, pharmaceutical companies, academic institutions, and other organizations who were responsible for sponsoring some of the research collected in this review. Certain organizations were responsible for sponsoring two or more collected records. Table 1 provides a breakdown of the organizations recognized for sponsorship, and the number of records they sponsored.

Sponsor	Studies
Novartis Pharma	12
Celgene Corporation	8
Pfizer	6
Abbvie	5
EULAR	4
Medical University of Bialystok, Poland.	4
NIHR	4
Boehringer Ingelheim	2
EuroGuiDerm Centre for Guideline Development The European Dermatology Forum	2
GRAPPA	2
National Natural Science Foundation of China	2
Projekt DEAL	2
UCB Pharma	2

Table 1

Patient survey responses

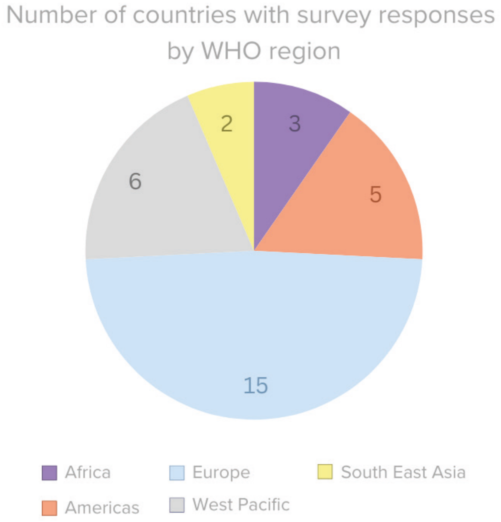


Figure 3

People living with psoriatic disease from 31 countries responded to the IFPA voluntary patient survey. Figure 3 breaks down the number of country responses by WHO region. Respondents from the following countries participated in the survey: Peru, Italy, Finland, Iceland, Georgia, Sweden, Estonia, Spain, Kenya, China, South Africa, Singapore, Japan, Philippines, Czech Rep., Ghana, Denmark, Colombia, Switzerland, Indonesia, Argentina, Netherlands, Germany, Puerto Rico, Greece, France, Bangladesh, Taiwan, Dominican Republic, Romania, Australia. None were available for the Eastern Mediterranean region.

Metric 1

Providing **access** to treatment and healthcare education

Overview

Access to treatment and healthcare education for both people with psoriatic disease and providers is integral to improving the outcomes of people with psoriatic disease. This metric had the most amount of evidence gathered from the identified literature, most of which described guidelines and real-world use of systemic and/or topical treatments. Throughout the collected literature, there were certain guidelines that were regularly referenced, both as examples of good practice and as inspiration for countries' individual guidelines, but also used as comparisons to real-world treatment practice: GRAPPA and EULAR guidelines for PsA (14, 15), and the AAD-NPF and EuroGuiDerm guidelines for PsO (16, 17). Each of these guidelines provides up to date information for providers, helping to improve the quality of care for people with psoriatic disease. From the patient side, we found limited published data on the quality of information provided to people with psoriatic disease by providers, with some reviews focusing on the quality of patient and provider education in specific regions.

While all of the KOLs agree that treatment and healthcare education has improved in the past ten years, they all felt that there are still major shortcomings in the knowledge of providers and people with psoriatic disease around the world. In many low-to-middle income countries, psoriatic disease is still not recognized, and people often do not get appropriate treatment because of a lack of diagnosis. Therefore, KOLs felt that it's important to improve the diagnostic capabilities in developing countries. People living with the disease are also not knowledgeable about their options, and therefore run the risk of being under-treated without their knowledge.

> “People living with the disease are also not knowledgeable about their options, and therefore run the risk of being under-treated without their knowledge.

The survey responses regarding treatment and healthcare education varied both within and between regions. Figure 4 below provides an overview of the responses to how helpful those people with psoriatic disease found the information they received from their provider at first diagnosis. The majority of answers lean towards a negative opinion of helpfulness. Furthermore, only nine of 31 respondents had received information about the risks of comorbidities, and only eight had received information about the risk of PsA; the majority of those informed of those respective risks were based in Europe.

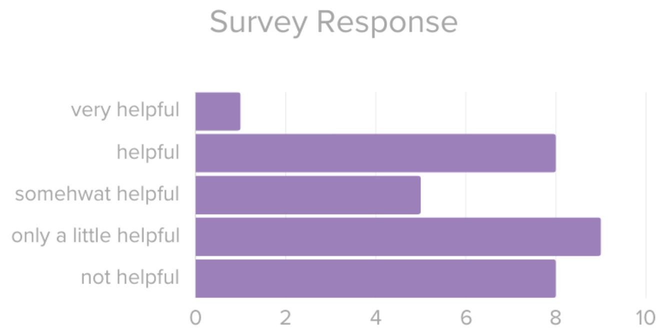


Figure 4

Regional perspectives

Africa

- There is limited attention paid to noncommunicable diseases by healthcare authorities in many of the countries in the African region. A 2021 study on PsA care in the African region described the difficulties in implementing international recommendations on the African continent, including the following: lack of trained personnel, lack of relevant data, the cost of advanced therapies, and validated questionnaires for screening (18).
- There is a lack of consensus regarding biologic use in clinical practice. Al Hammadi et al 2017 recommended the development of specific local guidelines for the treatment of both psoriasis and PsA to move towards understanding the distinct patient profiles in these regions (19).

- A 2021 study of skin disease management in an All-Africa Leprosy, Tuberculosis and Rehabilitation Training (ALERT) center in Ethiopia found that about 80% of psoriasis cases were managed by topical corticosteroids and only 14.5% were managed with methotrexate, suggesting a lack of options for systemic treatments or use in clinical practice (20).

- PsA is poorly understood in Africa and the Middle East due to a paucity of quality research, and under-recognized based on the available data. A 2019 study recommended establishing requirements for regional PsA guidelines to define the standard-of-care required. The study also discussed the possibility of introducing specialized clinics with multiple disciplines to aid early diagnosis and appropriate treatment management, encouraging patient and physician education of PsA, and increased cooperation between governments and private sectors to improve access to new therapies. Furthermore, the burden of PsA should be listed on the research agenda of African and Middle Eastern countries to provide much needed data that can be used in the future to obtain health funders' support for this chronic disease (21).

> “
>
> PsA is poorly understood in Africa and the Middle East due to a paucity of quality research, and under-recognized based on the available data.

- Recent South African guidelines on biologic treatment recommended that biologics be prescribed by rheumatologists experienced in the diagnosis and treatment of these diseases as well as the use of these therapies and knowledge of their possible adverse events (22).

The Americas

From the perspective of the US, one of the KOLs felt that the current complexities of the system make it critical to ensure that the right providers are given the right information about how to best support people living with psoriatic disease from within their role. For example, they felt that dermatologists and rheumatologists need to be more comfortable about diagnosing PsA and PsO, respectively, and then referring them as soon as possible. Primary care providers (PCPs) should act as a hub for referral depending on comorbid symptoms but shouldn't be responsible for diagnosis and treatment. The existence of advanced care practitioners and nurse practitioners provides an opportunity for speedier diagnosis and help with treatment.

They also felt that people living with psoriatic disease in the US are relatively uninformed of both the disease and treatment options, and thus don't know if and when doctors are under-treating them. On top of this, there is a risk for misinformation from social media.

- There is evidence of up to date, PsA guidelines from the American College of Rheumatology and the National Psoriasis Foundation in the US. The guidelines discuss comorbidities, treat-to-target, systemic therapy use and more (23).

- There is evidence of up to date, PsA guidelines in Colombia. The guidelines discuss comorbidities, treat-to-target, systemic therapy use and more (24).

- Research of real-world biologic use in the US suggested that the majority of people with PsA discontinued use of their first biologic treatment within the first 12 months of treatment (either switching to another biologic or discontinuing altogether). While the reasons for discontinuing index treatment were not studied here, the study highlights the importance of dialogue between the person with PsA and provider to find the treatment that best fits their needs (25).

- There is evidence of up to date, PsA guidelines in Brazil. The guidelines discuss comorbidities, treat-to-target, systemic therapy use and more (26).

> “
>
> The current complexities of the [health] system make it critical to ensure that the right providers are given the right information about how to best support people living with psoriatic disease from within their role.

Eastern Mediterranean

- In the Middle East, there is a lack of consensus regarding biologic use in clinical practice. Al Hammadi et al 2017 recommends the development of specific local guidelines for the treatment of both psoriasis and PsA to move towards understanding the distinct patient profiles in these regions (19).

- PsA is poorly understood in Africa and the Middle East due to a paucity of quality research, and under-recognized based on the available data. Bedaiwi et al 2019 recommended establishing requirements for regional PsA guidelines to define the standard-of-care required, introducing specialized clinics with multiple disciplines to aid early diagnosis and appropriate treatment management, encouraging patient and physician education of PsA, and increased cooperation between governments and private sectors to improve access to new therapies. Furthermore, the burden of PsA should be listed on the research agenda of African and Middle Eastern countries to provide much needed data that can be used in the future to obtain health funders' support for this chronic disease (21).

- There is evidence of up to date, PsA guidelines in Egypt. The guidelines discuss comorbidities, treat-to-target, systemic therapy use and more (27).

- A systematic review of PsO guidelines in Africa and the Middle East further detailed the unmet need for clinical guidelines on the management of PsO. Only one clinical guideline from 2014 on from Saudi Arabia included recommendations for the use of these biologics in people with plaque psoriasis, with no recommendations for older or pregnant persons (28).

Europe

From a European perspective, two KOLs felt that there were plenty of educational resources available for providers; congresses, webinars, and classes for providers on the international, national, and regional level can be found in most parts of Europe, with sponsorship and support from pharmaceutical companies. However, the situation today is much more complex, in terms of details to consider for both diagnosis, screening for comorbidities, and treating to target. There is also much more information for people living with the disease, but also a lot of misinformation online or on social media. Some current issues are that PCPs have limited information about biologics and therefore refer patients when they likely should be treated.

- A 2023 review of individual country guidelines for PsA in Europe found that only five of the 15 countries that were included had guidelines which were in line with the most recent EULAR and ASAS-EULAR guidelines for PsA (29). They also found that the criteria for treating patients with biologics and targeted synthetic disease-modifying antirheumatic drug (tsDMARDS) varied considerably by country.

> “There is also much more information for people living with the disease, but also a lot of misinformation online or on social media.

South-East Asia

No relevant data was identified for this region in this metric.

Western Pacific

- Up to date PsA guidelines are available in Taiwan. The guidelines discuss comorbidities, treat-to-target, systemic therapy use and more (30).

- An observational study of treatment practice involving the Western Japan Psoriasis Registry showed that systemic treatments were prescribed and taken regularly by patients, indicating good access to, and understanding of the benefits of systemic treatment in Japan. The registry itself shows that providers have a better understanding of patient needs in the region (31).

Examples of good practice

The International League of Associations for Rheumatology (ILAR) created an adapted set of guidelines for countries in Africa and the Americas. The recommendation have been derived principally by adapting the GRAPPA recommendations, additionally, EULAR recommendations where appropriate and supplemented by expert opinion and literature from these regions (32). This is an example of how the latest international recommendations for care can be adapted to fit the needs of people living with the disease in different settings.

Key areas of unmet need

It is clear from the evidence that up-to-date clinical guidelines are lacking in many countries around the world. Even in more developed regions, clinicians may still be using older guidelines, which lack the latest recommendations for treating both PsO and PsA. The sparse information about patient knowledge in different regions suggests a consistent issue with people being uninformed of both their disease and the treatment options that they have available to them. Materials should be provided to people living with the disease in order to support them with finding a managed care path that works best for them. However, in some low-to-middle income countries, access to both care and treatments must be secured in order to allow for people living with psoriatic disease to come into contact with providers that can help educate them.

In addition, all of the KOLs recognized the risks of misinformation spread through social media, particularly when it comes to treatment. They caution people living with psoriatic disease from listening to advice they get from the internet.

Metric 2

Understanding of the features of psoriatic disease

Overview

General understanding of the features of the disease have certainly improved over the last 10 years, according to all of the KOLs. This is in no small part due to awareness and education initiatives funded by pharmaceutical companies. PCPs are more aware than ever in countries with developed systems. However, while the features may be more broadly understood by providers, there is still a lack of knowledge about the disease in the general public. In addition, diseases affecting primarily the skin are often not considered a high priority in many places, particularly where infectious diseases are common. This is problematic, as psoriatic disease association with other diseases should make it more of a priority. Much of the collected literature for this section looks at the features of psoriatic disease from the perspective of burden and quality of life.

> “While the features may be more broadly understood by providers, there is still a lack of knowledge about the disease in the general public.

There were mixed feelings from those who responded about whether people’s understanding of psoriatic disease had improved in the past 10 years. Sixteen of the 31 respondents felt that the public’s awareness had improved while the rest felt otherwise.

Regional perspectives

Africa

- One study in conducted in a teaching hospital in Nigeria found that about 51.5% (34/66) of patients had severe psoriasis with a mean PASI score 33.2. The annual cost of treating mild, moderate, and severe psoriasis was N198,900.00, N261,633.00 and N323,708.00 respectively. This accounted for 1.77% of the national annual healthcare spending within the years under review, representing considerable burden associated with this chronic disease (33).

The Americas

No relevant data was identified for this region in this metric.

Eastern Mediterranean

- An Egyptian study found that psoriasis exerts a significant, negative effect on quality of life. Disease disability, severity and its acceptance are independent predictors of quality of life (34).

- A study conducted in Saudi Arabia collected data on self-reported psoriasis severity using three measures: the self-assessment Simplified Psoriasis Index (sa-SPI-s), measuring peoples’ quality of life using the dermatological life quality index (DLQI), and their feeling of stigmatization using the six-items stigmatization scale. The average self-assessment Simplified Psoriasis Index-severity was 10.08 (±10.41), which was associated with patients’ ages, disease duration, obesity, and itchiness. The majority of the patients had mild psoriasis (60.55%). The average DLQI and six-items stigmatization scale for psoriasis were 8.95 (±5.77) and 7.61 (±4.5), respectively, which correlated with the Simplified Psoriasis Index-severity. This study showed that psoriasis reduced the quality of life of those living with the disease and was also associated with social stigma (35).

Europe

- A 2020 study reviewing the complexity of German information booklets on PsO and PsA found that much of the online and paper educational materials for Germans require, on average, greater than a high school education level to understand. The results point to a need to tailor the information to a broader audience (36).

South-East Asia

- A global study conducted in Europe, America, and Asia in 2020 found that the disease disrupted the course of people's life, work, and family roles and could not be controlled. They feared deterioration of their clinical condition and felt that their concerns and distresses were trivialized by others. People with the disease felt burdened by treatment inadequacy, and immunosuppressive medications were regarded as toxic and causing long-term organ damage (37).
- Another study which was conducted in Europe, America and Asia reported a moderate impact on daily activities. Overall, 35% of all people living with psoriatic disease participating in the study could not work/study the week prior to the survey as a result of their skin problems. Overall, 14% reported that their work/career choice was influenced by their disease (38).of life of those living with the disease and was also associated with social stigma (35).
- A 2024 study in India surveyed people with psoriatic disease' understanding of PsO and PsA. About 90% understood that psoriatic disease was a systemic disease. Less than half of the people surveyed were aware of psoriatic disease manifestations and comorbidities (39).

Western Pacific

No relevant data was identified for this region in this metric.

Examples of good practice

KOLs had a number of recommendations related to fostering a better understanding of the disease in the general public and reducing the burden. PCPs should understand that obesity impacts PsO. In order to spread more general awareness, discussing visible skin diseases more in the news, or asking celebrities with the disease to share their experience can bring awareness of disease features. In high-income countries, psoriatic disease needs to be recognized as a noncommunicable disease that we already have treatments for. Moreover, dermatologists and PCPs should understand that there are comorbidities associated with psoriatic disease (cardiovascular disease, depression, etc.), and that it is important to treat individuals as early as possible to limit progression and burden. Early treatment as a way of mitigating disease progression and permanent damage has been studied previously in the literature (40, 41).

Key areas of unmet need

When left untreated or undertreated, psoriatic disease represents a considerable burden because of the chronic, incurable, and multi-faceted components of the disease. In order to recognize the importance of timely diagnosis and treatment, providers and people living with psoriatic disease need to be aware of the features of psoriatic disease.

- High cost of biologics treatment has created clinical unmet needs that disadvantage both people with psoriatic disease and healthcare professionals. These unmet needs include undertreatment, preventing access to treatment earlier in the disease course, which can in turn have a negative impact on the course of disease, the development of comorbidities, and the ability to sustain treatment responses (42).
- The clinical manifestations and chronic nature of psoriasis impaired people's quality of life and accompanied with social stigma due to skin manifestations. These effects need to be addressed for better care (35).

Metric 3

Social and work-related stigma

Overview

The Global Psoriatic Disease Survey, conducted in 2022 provided the perspective of people with psoriatic disease on a number of different topics. One of these topics was stigmatization; the survey found that most (84%) of people experienced some form of stigma and discrimination, which had a negative impact on work, mental health, and relationships. One-third of all respondents also felt ashamed of their skin (35%) or body (30%) (38).

According to KOLs, stigmatization had generally improved since the resolution, but it is still common regardless of region, and the progress is difficult to measure from the perspective of providers. In more high-income countries, providers may hear stories of people being more comfortable revealing their skin or being in public facilities such as pools. Similar accounts are heard of people with psoriatic disease being able to regain employment after treatment. However, stigmatization is still present, particularly in places where awareness of psoriatic disease is limited, and often correlating with limited access to care.

The overwhelming majority of survey respondents (30/31) felt that the general public had between ‘moderate’ and ‘very little’ understanding about psoriasis in their respective countries. In addition, the majority (17/31) of respondents felt that they experienced ‘occasional‘ negative reactions from people around them in e.g., public places or the workplace, while eight respondents felt they experienced negative reactions ‘frequently’ or ‘very often’.

> “Stigmatization is still present, particularly in places where awareness of psoriatic disease is limited, and often correlating with limited access to care.

Regional perspectives

Africa

One KOL mentioned that stigmatization was common for people living with psoriatic disease in Sub-Saharan Africa, where infectious skin conditions like leprosy can carry stigma. Also, in South Africa, HIV is associated with psoriasis. This can put a considerable mental health burden on people living with the disease and those conditions.

The Americas

One KOL recommends that special attention should be paid towards the stigmatization of underaged and young adults in the US, as they are more at risk for bullying, which can lead to negative mental health outcomes and even risk of suicide (43).

- A study conducted in the USA reported that there is a high prevalence of anticipated and perceived stigma reported by adults with psoriatic disease. The authors also suggested that objective measures of disease severity documented in routine clinical care do not reflect a person’s experience of stigma and that additional methods of accurately screening and monitoring stigmatization are needed to understand the impact of stigma on people with psoriatic disease (44).

Eastern Mediterranean

Saudi Arabia was mentioned among areas where stigmatization is common, according to one KOL

- A study in the United Arab Emirates reported that the majority of people showed feelings of stigmatization due to psoriasis. The dampening of positive attitudes and a feeling of being flawed were the most bothersome aspects of stigmatization. Involvement of the face appeared to be the only independent factor influencing the stigmatization level. In the Feelings of Stigmatization Questionnaire, itching was found to be a major factor responsible for feelings of stigmatization (45).
- The clinical manifestations and chronicity of psoriatic disease impaired quality of life and was accompanied with social stigma due to skin disfigurement, according to a recent study in Saudi Arabia. The average six-items stigmatization scale for psoriasis was 7.61 (±4.5) (35).

- A study of 200 people living with psoriatic disease from multiple Arabic countries detected stigmatization in most respondents including those who are satisfied with the management of their disease. People with more impaired quality of life experienced higher level of stigmatization and less satisfaction with life (46).

Europe

Eastern European countries were also specified by one KOL as an area where stigmatization is common.

- People with psoriasis participating in a study in Belarus showed moderate levels of illness acceptance and stigmatization, low level of satisfaction with life, and moderately deteriorated quality of life. Acceptance of illness was significantly modulated by gender: the level of illness acceptance was significantly higher among men than women (47).
- The majority (74%) of a group of people living with psoriatic disease in Germany surveyed in 2020 believe that people with psoriasis are disadvantaged. Similarly, a majority (69%) said that most people find psoriasis disgusting, do not want to touch people with psoriasis (59%) and think that people with psoriasis need to take better care of themselves (45%) (48).

> Acceptance of illness was significantly modulated by gender: the level of illness acceptance was significantly higher among men than women.

- Two additional studies on stigmatization were conducted in Belarus. One found that compared with women, men had higher stigmatization scores in the "Feeling of being flawed" domain ($p = 0.0362$), and those up to 30 years of age scored higher on the "Guilt and shame" domain than those older than 30 years. Also, persons with visible skin lesions were presented with higher stigmatization levels in the "Guilt and shame" domain than those without ($p = 0.0028$) (49).
- In a third Belarus study, higher stigmatization levels were found in men than in women. Significantly higher levels of stigmatization were observed in countryside dwellers ($p = 0.0311$) and unmarried persons ($p = 0.0321$). People with a longer history of the disease (≥15 years) scored significantly higher on the 6-item Stigmatization Scale ($p = 0.0217$) than those in whom psoriasis lasted less long (50).

- A Turkish study from 2022 found that internalized stigma level was high, their quality of life was low, and their quality of life decreased as the internalized stigma level increased. Furthermore, the internalized stigma level of the people who suffered more from psoriasis was higher, but their quality of life was lower than those who suffered less (51).

South-East Asia

India was also specified by one KOL as an area where stigmatization is common.

- From the literature, Chandrashekar et al 2024 found that 97% of people living with the disease reported experiencing stigma and discrimination by others (39).

Western Pacific

No relevant data was identified for this region in this metric.

Examples of good practice

All of the collected literature focused on quantifying the problem of stigmatization, and no clear examples of good practice were identified. However, that does not mean that awareness in the general public has not been improving, or that people living with psoriatic disease haven't been experiencing less stigmatization over time.

All three KOLs felt that it was important that providers spread awareness to people with psoriatic disease about avoiding online and social-media misinformation, and instead listen to the experts. In addition, they recognized the pressure that social media can put on one's appearance.

Key areas of unmet need

According to all sources, stigmatization is still a major issue for people living with psoriatic disease around the world, regardless of how advanced the healthcare system is. Stigmatization creates a substantial mental burden on people living with psoriatic disease, as detailed in the evidence above.

- Additional psychological assessment and multidisciplinary management should be done when people report a psychological burden due to feeling stigmatized (49).
- Stigmatization awareness should be promoted among physicians and people with psoriatic disease to improve psoriasis management (50).
- Health professionals must make significant contributions to preventing psoriasis from worsening, ensuring that the individual is being active and functional, decreasing the psychological effects of the disease, and increasing the quality of life (51).

One KOL recommends that further education should be provided about diseases affecting the skin and anti-bullying in school.

Metric 4

Understanding the risk of comorbidities

Overview

Only recently has the association between psoriatic disease and its various comorbidities been better documented. However, there is still a lack of awareness in both people with psoriatic disease and providers around the world, which results in further morbidity for those living with psoriatic disease.

All KOLs agreed that awareness of the risk of comorbidities has spread over the past 10 years, with one comparing the spread to a "slow burn". Even if providers are made aware, one KOL felt that there is a sizable risk that providers still won't act on it, in part due to lack of knowledge, time or resources. The KOLs had differing opinions on whether or not the screening process should be carried out by dermatologists and rheumatologists; one felt patients should be deferred to the PCPs for screening, who can then refer the patients for any detected comorbidities. One KOL felt that screening should be built into the specialist visit, and the screening process should be communicated to the patient, to increase their awareness, and one felt that in developing countries, comorbidities are less common, as they are associated but not causal.

> "There is still a lack of awareness in both people with psoriatic disease and providers around the world, which results in further morbidity for those living with psoriatic disease.

As mentioned previously, only nine of 31 survey respondents had received information about the risks of comorbidities from their providers.

Regional perspectives

Africa

- A review of psoriatic disease in the Middle East and Africa explained that almost all people with moderate-to-severe psoriasis will have at least one co-morbid condition. Apart from PsA, the most common co-morbidities in clinical practice are metabolic syndrome, obesity, and depression (19).

The Americas

- A number of comorbidities (e.g., cardiovascular disease, diabetes, fatty liver disease, osteoporosis) and non-joint related manifestations (i.e., inflammatory bowel disease and uveitis) are associated with PsA. The GRAPPA recommendations are the only set of recommendations to extensively discuss comorbidities related to PsA and the implications for management (52).

- The main comorbidities of a group of people with PsA in Brazil were osteoarthritis, lower back pain, shoulder injuries, oncological diseases, crystal arthropathies, and osteoporosis. (53)

- People living with PsA had a high comorbidity burden according to US claims data from an observational study. Compared with the non-PsA population, people living with PsA were associated with a higher incidence of cardiovascular comorbidities, autoimmune diseases, and other PsA-related comorbidities and a higher rate of all-cause and cardiovascular-related hospitalizations (54).

- A second study of comorbidities in Brazil found that a total of 51.9% (N = 54) of people living with psoriatic disease were diagnosed with metabolic syndrome , hypertension was found in 51.4% (N = 54) and obesity in 38.1% (N = 40) of the sample (55).

Eastern Mediterranean

- The prevalence of comorbidities (hypertension, diabetes mellitus, obesity, ischemic heart disease, chronic obstructive pulmonary disease, hepatitis C infection, and malignancy) was compared between people with PsA (60) and without PsA (140) in a 2021 Egyptian study. People with PsA had a significantly increased incidence of diabetes mellitus (p = 0.039), chronic obstructive pulmonary disease(p = 0.029), obesity (p = 0.04), and metabolic syndrome (p = 0.004) (56).

Europe

- A British register study in 2015 found that in total, 71% of all people living with psoriatic disease had comorbidities and 47% had more than one comorbidity. The most frequent comorbidities were obesity (42.1%), hypertension (25.7%), depression (22.1%) and psoriatic arthritis (17.1%) (57).

- In Germany, data in German employees from various branches, collected before the resolution, revealed that onychomycosis was the most frequent dermatological comorbidity with a prevalence of 7.8% among participants with psoriasis, followed by folliculitis (7.1%) and tinea pedis (5.9%). Among the inflammatory skin diseases, rosacea was most prevalent (3.4%). Hemangioma was the most prevalent skin change (43.7%), followed by solar lentigines (40.6%) and fibromas (29.9%) (58).

- Rech et al 2020 found that people with PsO and people with both PsO and PsA displayed a similar comorbid disease profile, with a high frequency of metabolic syndrome-associated conditions (obesity, essential arterial hypertension, disorders of lipoprotein metabolism and other lipidemias). Although unspecific arthritic symptoms (other joint disorders, other soft tissue disorders and somatoform disorders) were more frequent in people with both PsO and PsA, they were also present in people with psoriasis alone (59).

> “
> A British register study in 2015 found that in total, 71% of all people living with psoriatic disease had comorbidities and 47% had more than one comorbidity.

- People with psoriatic disease from Spain vs. other European countries reported a lower prevalence of depression (6% vs. 12%, P = 0.002) and hypertension (15% vs. 21%, P = 0.007), but the prevalence of diabetes was similar (10% vs. 9%, P = 0.775), as was heart disease (6% vs. 6%, P = 0.773) (60).

South-East Asia

- A recent Indian observational study found that dyslipidemia was the most prevalent comorbidity, followed by hypertension (HTN) (19.8%) and diabetes (16.6%). About 39% of people with psoriatic disease had a Body Mass Index (BMI) higher than 25 and 18% had obesity. Smoking, ischemic heart disease, hypothyroidism, osteoarthritis, depression, anxiety, and fractures were seen in <5% of the cohort. Increasing age, longer duration of psoriasis, a family history of cardiovascular disease or stroke, smoking, alcohol consumption, and higher waist circumference were associated with the presence of one or more comorbidities (61).

- Another recent study in India estimated that 52.2% of the Indians had hypertension, followed by dyslipidemia (44.1%), diabetes mellitus (34%), obesity (30%), ischemic heart disease (9.7%), cancer (2.4%), and tuberculosis (0.4%) (62).

> “
> A recent Indian observational study found that dyslipidemia was the most prevalent comorbidity, followed by hypertension (HTN) (19.8%) and diabetes (16.6%).

Western Pacific

- An earlier Japanese study estimated the prevalence of comorbidities in a Japanese cohort of people with psoriatic disease. They found that their estimates were also similar to those in the Western countries but were completely different from that in the national database; hyperlipidemia (43.9%), diabetes (15.1%), hyperuricemia (20.9%), hypertension (23.2%) and liver dysfunction (29.2%). Hyperlipidemia was numerically more prevalent in the PsA population than in the general population (63).

- Tsuruta et al’s 2021 registry study found that most common comorbidity was hypertension (35.0% in the total cohort, 37.7% in males, 28.1% in females), followed by diabetes (14.1% in the total cohort, 14.8% in males, 12.3% in females), hyperlipidemia (12.2% in the total cohort, 11.4% in males, 14.1% in females) and fatty liver (11.3% in the total cohort, 13.2% in males, 6.6% in females) (31).

- A recent survey revealed that approximately 56.3% of people with psoriatic disease in Japan had past history and comorbidities, such as hypertension (35.9%), dyslipidemia (20.7%), diabetes mellitus (19.2%), hyperuricemia (13.5%), cardiovascular disease (4.1%), and cerebrovascular disease (3.9%) (64).

Examples of good practice

There were a number of KOL recommendations related to recognizing the risk of comorbidities:

- ✓ Screening for mental health comorbidities is vital.
- ✓ Specialist providers are already stretched thin and should not be responsible for treating identified comorbidities, and in some cases, should not even be responsible for screening, instead feeling that patients should be referred to a PCP or relevant provider for screening and/or treatment of comorbidities.
- ✓ Rapid access clinics should be set up where possible, to see people early in disease course, and make comorbidity screening a part of the structure. These clinics could provide the potential to control the disease earlier and better (65).

Key areas of unmet need

The evidence is clear that comorbidities are common and worsen the burden of the disease for both the person living with it and the healthcare system trying to treat them. Awareness of comorbidities is still poor, and very few systems have simple screening processes to help catch comorbid conditions in people living with psoriatic disease, prolonging suffering.

- New screening tools for comorbidities should be developed to optimize the management of psoriatic disease especially in the Africa and the middle East region (19).
- A large-scale German study looked at employees between ages 16 and 70, with psoriasis, to assess the unmet need in treating comorbid skin diseases. They found that people with psoriasis needed concomitant treatment for onychomycosis (3.4%), tinea pedis (3.1%), and verruca plantaris (1.0%) in addition to their psoriasis treatment. Some individuals with psoriasis have an unmet treatment need for comorbid skin disease especially fungal diseases. Treatment of such diseases should be included in the treatment regimen of psoriasis and PsA (58).
- PsA is diagnosed too late or treated ineffectively in a significant number of people with skin manifestations of psoriatic disease. This suggests that there is an unmet need for rheumatological check-up soon after diagnosis of psoriasis (59).

Metric 5

Recognition of psoriatic arthritis (PsA)

Overview

This metric seeks to establish global recognition that PsA is a common and burdensome comorbidity for those with PsO. Most of the evidence collected in the literature review provided region-specific estimates of PsA prevalence.

In a 2019 meta-analysis of the prevalence of PsA in people with PsO, the pooled proportion (95% confidence interval [CI]) of PsA among people with psoriasis was 19.7% (95% CI,18.5%-20.9%). In children and adolescents (<18 years of age), the pooled prevalence was 3.3% (95% CI, 2.1%-4.9%) (66). Psoriasis burden is greatest in countries with high income and high sociodemographic index (67), which also correlates with geographic distance from the equator, and the quality of available data. A recent global survey also found that 31% of individuals with PsO reported concomitant PsA, and that 80% of individuals with both PsO and PsA had moderately or highly active PsA (38).

> “PsA is still regularly untreated in low-to-middle income countries and in high-income countries, and even when the symptoms are identified, it is commonly misdiagnosed.

On the subject of PsA, two of the KOLs felt that little progress had been made in improving screening practices or time to diagnosis for PsA. PsA is still regularly untreated in low-to-middle income countries and in high-income countries, and even when the symptoms are identified, it is commonly misdiagnosed.

A recent survey in the US found that 66% of those included had to wait more than 6 months between presenting to healthcare for symptoms and receiving an official diagnosis, and 32% had to wait for more than 5 years (52). In some high-income countries, diagnosis for PsA can take as long as 12 years from symptom onset, and by the time people receive treatment, permanent damage may have occurred for some. However, one of the KOLs was optimistic from the perspective of treatment; more widespread use of systemic therapies and earlier treatment of PsO can help to relieve symptoms, and in some cases, even prevent PsA (68, 69). Furthermore, a KOL reported that research is currently being done to identify a biomarker for detecting PsA, facilitating earlier intervention.

As mentioned previously, only eight of the 31 survey respondents received information about the risk of developing PsA.

Regional perspectives

Africa

- Bedaiwi et al 2019 found that the few available epidemiological studies of PsA in Africa are very inconsistent and sporadic in terms of available data and methods employed, highlighting the need for further research to better quantify the burden (21).

- A 2019 systematic review and meta-analysis tried to estimate the prevalence of PsA in people living with PsO in different regions of the world. The PsA prevalence was 15.5% (95% CI, 0.009%-51.5%) (66).

The Americas

- In the global Multinational Assessment of Psoriasis and Psoriatic Arthritis (MAPP) survey conducted right before the resolution, the household prevalence of psoriasis and/or PsA was found to be 6.5% and 4.0% in Canada and USA respectively, whereas population prevalence was found to be 3.3% and 2.2%, respectively. Globally, of the total 3426 respondents, 79% indicated a current diagnosis of psoriasis alone and 21% had PsA with or without psoriasis (70).

- A Brazilian study evaluated the treatment-seeking trends of 40,000 people in the general population between 2008 and 2021. The incidence of PsA-related visits has been increasing in recent years and an incidence of 8,982 new visits in 2020 had been observed, suggesting that more people are being diagnosed, and more people are getting treated (53).

- In a 2023 study in Colombia, 6,433 cases of psoriatic arthritis were reported between 2012 and 2018. The study estimated a prevalence in people over 18 years of 13.5 per 100,000 residents, was slightly more common in women (53%), and the 55–59-year age group. Additionally, 149,130 cases of psoriasis were identified, providing a prevalence estimate of psoriatic arthritis of 5.8% in people with psoriasis (24).

- In the population-based UPLIFT survey, a follow-up to the MAPP survey, estimated population prevalence of PsO and/or PsA in screened patients was found to be 6.65% and 7.37% in Canada and USA respectively, whereas estimated population prevalence of PsO alone in screened patients was found to be 4.06% and 3.74%, respectively (71).

- In a 2021 regional comparison of psoriasis prevalence by sex, high-income North America ranked highest for both females (2738 cases per 100,000) and males (2554 cases per 100,000) (67).

- In another US study, PsO prevalence among adults 20 years or older was 3.0% (95%CI,2.6%-3.4%). Based on the 2020 US census data, this outcome translates to an estimated 7.55 million US adults with psoriasis. Psoriasis prevalence was similar between women and men, with 3.2% (95%CI, 2.6%-3.8%) in women and 2.8% (95%CI, 2.4%-3.3%) in men. Psoriasis prevalence was highest in White individuals at 3.6% (95%CI, 2.9%-4.2%), followed by other racial/ethnic groups (non-Hispanic, including multiracial) at 3.1% (95%CI, 1.2%-5.1%), Asian individuals at 2.5% (95%CI, 1.6%-3.3%), Hispanic individuals (including Mexican American and other Hispanic individuals) at 1.9% (95%CI, 1.3%-2.5%), and Black individuals at 1.5% (95%CI, 1.0%-2.0%). Psoriasis prevalence was not different based on marital status, education, income, or medical insurance status. The prevalence of psoriasis among US adults has not changed significantly since 2003 (72).

- A 2019 systematic review and meta-analysis tried to estimate the prevalence of PsA in people with PsO in different regions of the world. The PsA prevalence was 21.5% (95% CI, 15.4%-28.2%) in South American with psoriasis and 19.5% (95% CI, 17.1%-22.1%) in North American with psoriasis (66).

> “
>
> Psoriasis prevalence was not different based on marital status, education, income, or medical insurance status.

Eastern Mediterranean

- In Egypt, a 2021 study found the prevalence of PsA in people with PsO to be 30%. Furthermore, psoriasis preceded the onset of PsA in 76.6% of included cases. Obesity, nail psoriasis, and intergluteal cleft site were associated with increased risk of PsA. However, classic plaque psoriasis and flexure site were associated with a decreased risk of PsA development (56).

Europe

- In Germany, data in German employees from various branches, collected before the resolution, revealed that psoriasis prevalence was 2.0% (men 2.2% and women 1.7%). Prevalence increased with higher age, except for the oldest age group where a slight decrease of prevalence was observed (58).

- In Norway, the 2017 point-prevalence of PsA was 0.46%. Among women, the prevalence of PsA was 0.50% and in men was 0.43% (73).

- The 2016 prevalence of PsA in Spain was 0.58% (95%CI: 0.38–0.87), indicating a relatively high prevalence in Europe (74).

- A 2023 study by Wang et al estimated and projected incidence trends for Germany. The overall conservatively estimated prevalence of PsA in Germany in 2019 was 0.31% (95% CI 0.28–0.36%). Women contribute a higher prevalence than men. In the assumed scenarios with increased incidence, the prevalence of PsA at 60 years of age could rise from 1% in 2019 to more than 3% in 2050 for both genders, with the increase particularly pronounced for women, reaching around 3.5%. However, in the assumed scenarios with decreasing incidence, the prevalence curve may flatten and begin a decreasing trend from 2035 to 2050 for both genders, achieving a prevalence of less than 1% in 2050 (75).

> “
>
> Prevalence increased with higher age, except for the oldest age group where a slight decrease of prevalence was observed.

- An earlier German study of prevalence found that the annual prevalence rate for PsA in 2014, 2015 and 2016 were 0.07% whereas for PsO it was 0.66, 0.63 and 0.61, respectively (76). When comparing this to the later study by Wang, the trend seems to be a reduction in the estimated prevalence of PsA in Germany.

- In the global MAPP survey, the household prevalence of psoriasis and/or PsA was found to be 3.5% in Germany, whereas population prevalence was found to be 1.7% (70).

- The prevalence of psoriasis including psoriatic arthritis ranged from 1.90% to 2.51%. For all case definitions, the prevalence increased with age, decreasing from the age of 70 with psoriasis and from the age of 65 with psoriatic arthritis. Males were more likely to be affected at an older age (p <0.0001), while in the under-20 age group, more girls were affected (p = 0.04) (77).
- In the population-based UPLIFT survey, estimated population prevalence of PsO and/or PsA in screened patients was found to be 7.07% in Germany, whereas estimated population prevalence of PsO in screened patients was found to be 4.32% (71).
- A 2019 systematic review and meta-analysis attempted to estimate the prevalence of PsA in people with PsO in different regions of the world. The PsA prevalence was 22.7% (95% CI, 20.6%-25.0%) in Europeans with psoriasis (66).

South-East Asia

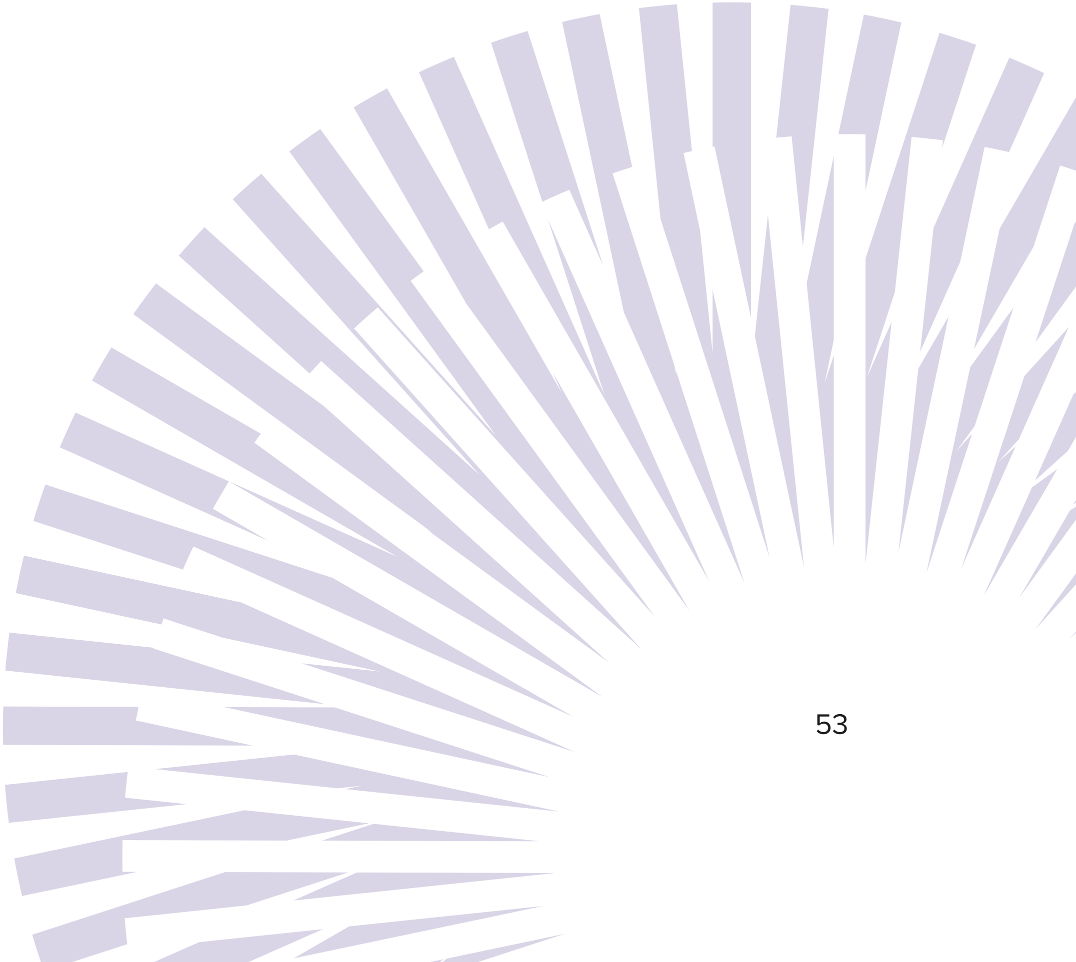
- In a 2024 study in India, among all the people with PsO without concomitant PsA, 81% screened positive for PsA using the validated Psoriasis Epidemiology Screening Tool, which indicates an underdiagnosis of PsA (39).
- A 2014 study of 1149 Indian individuals with psoriasis found that 100 (8.7%) people had PsA, of which 83% were newly diagnosed. This points to an increasing trend in the recognition and diagnosis of PsA (78).
- A 2019 systematic review and meta-analysis attempted to estimate the prevalence of PsA in people living with PsO in different regions of the world. The PsA prevalence was 14.0% (95% CI, 95% CI, 11.7%-16.3%) in Asians with psoriasis (66).

> “
>
> In a 2024 study in India, among all the people with PsO without concomitant PsA, 81% screened positive for PsA using the validated Psoriasis Epidemiology Screening Tool.

Western Pacific

- Tanaka et al conducted an observational study with a total of 3021 people with psoriatic disease, who were enrolled from a group of patients in 2016. In total, 431 people were diagnosed by rheumatologists, based on clinical findings, with a mean prevalence of 14.3% (ranged 8.8 to 20.4%). It is different from that shown in the Japanese national database (1.9%), but it is similar to that of PsA in Caucasians, 6.42% (63).
- The prevalence of psoriatic arthritis in the Western Japan Psoriasis Registry was 27.2% (31).

- The prevalence of clinically diagnosed psoriasis and PsA has increased steadily over 12 years, and the results suggest that psoriasis and PsA affect 0.86% and 0.08% of the general population in Taiwan, respectively. In contrast, the incidence of psoriasis and PsA remained stable. Age-specific incidence rates remained constant within the various age groups throughout the follow-up period. At the same time, the prevalence increased more steadily in the older age groups than in younger age groups, suggesting an increasing population living longer with psoriasis and PsA. Nevertheless, the risk of all-cause mortality was higher for people with both psoriasis and PsA than in the general population (79).
- From 2002 to 2016, the incidence of psoriasis significantly decreased from 43.33 to 23.14 per 100,000 persons. The incidence of psoriatic arthritis significantly increased from 3.57 to 5.22 per 100,000 persons. In the age–period–cohort analysis, the net age effect on the incidence of psoriasis and psoriatic arthritis increased with advancing age (6-fold and 7.7-fold difference, respectively). These trends suggests that elderly individuals are associated with an increased risk for developing new-onset psoriasis and psoriatic arthritis (80).



Examples of good practice

According to one KOL, early treatment with biologics in people with moderate to severe plaque psoriasis may have the potential to delay or reduce the risk of developing PsA (81). Another KOL recommended the use of easy screening tests, which have the potential to be delegated to other staff members to save time.

- A recent study explained that in Taiwan, it is recommended that treatment targets should aim for clinical remission or minimal disease activity, and patient-concerned outcomes should be taken into consideration. Nonsteroidal anti-inflammatory drugs can be used to relieve pain, with the lowest effective dose to minimize the risk of side effects (30).

- In Norway, the combined prevalence of PsA, Axial Spondyloarthritis, and rheumatoid arthritis was over 1.5%. Reflecting the good overall access to highly effective but costly biologic treatments, more than a fourth of these individuals used biologic agents, which corresponds to over 0.4% of Norwegian adult population (73).

- In an Egyptian study, people with psoriasis were screened for PsA using the Psoriasis Epidemiology Screening Tool and the Early Arthritis for Psoriatic Patients tool. They were then further categorized using CASPAR criteria, a set of criteria aiding doctors in the diagnosis of PsA. All of these factors aid in effectively identifying targets for treatment (56).

Key areas of unmet need

With the global population living longer lives on average, the incidence rates of PsA may vary between countries, but prevalence appears to be increasing, according to different estimates around the world. However, there are still issues with physicians taking the time to look for PsA, and being able to recognize it, particularly in the low-to-middle income countries, according to KOL opinion.

- A 2021 review sought to assess the unmet needs for PsA provision around the world. There were three key areas of unmet need reported: early diagnosis, medication choice and comorbidity management. For those areas, biomarker development, targeted screening practices, structured lifestyle interventions and integration of mental health services were important, among others (82).

- Available treatment guidelines i.e., EULAR, GRAPPA and the ACR/NPF have limitations and new methods for guideline development for complex, heterogeneous diseases are needed. There is no one best guideline recommended for all clinicians. Therefore, guidelines should be tailored to the circumstances of the local population of people with psoriatic disease (52).

- In India there is a lack of awareness of the manifestations and comorbidities associated with psoriatic disease and poor quality of life. It thus, highlights the need for patient education, shared treatment decision-making, and a multidimensional approach to psoriatic disease management in India (39).

- In Africa and in the Middle East there is an urgent need to establish regional PsA guidelines to define the standard-of-care required and setting up of clinics with multiple disciplines for early diagnosis and treatment management of PsA. Since there is a paucity of data in this region the need is to list the burden of PsA on the research agenda to provide much needed information about the disease (21).
- The MAPP survey suggests that there is a high rate of undertreatment of both psoriasis and PsA and a mismatch between patient and physician assessment severity. The survey further highlights the importance of screening and assessment of people with psoriasis for symptoms of PsA, the need to establish patient-specific treatment goals—which ensure optimal treatment regimens and realistic expectations with regard to the effectiveness and tolerability of available treatments—and the ongoing need for safe and effective therapies for patients with psoriasis and PsA (70). This survey highlighted the even greater unmet need at the start of this 10-year period. The findings are also corroborated by the UPLIFT study mentioned below.
- According to UPLIFT survey there is an unmet need for better management of psoriatic disease and several areas in which patient and dermatologist perceptions are not aligned (71).

Metric 6

Delayed diagnosis, limited treatment options and access to care

Overview

This metric involves three major issues in the provision of psoriatic disease care. As such, much of the collected literature provided evidence related to these topics.

In a study conducted in 17 countries to evaluate the impact of clinical specialty setting on the time to diagnosis and treatment of individuals with PsA (LOOP study), the median time from diagnosis to treatment was significantly shorter in the rheumatology setting, and individuals in the dermatology setting had higher disease activity. This data shows the importance of improved collaboration between rheumatologists and dermatologists. An important finding of this study was that irrespective of clinical setting or geographical region, people experienced a delay before being diagnosed with PsA, with a median time from onset of musculoskeletal symptoms to diagnosis of up to approximately 6 months. (83). The findings of this study are indicative of a ubiquitous issue for people with psoriatic disease all over the world: delay in diagnosis.

> “
> Delays to diagnosis are often associated with a scarcity of qualified personnel, whether that is long waiting times or wide geographic distances to reach available providers.

Based on KOL opinion there are still major issues with individuals not receiving a diagnosis and thus going untreated. The time to diagnosis is still hugely variable, and often takes years. Delays to diagnosis are often associated with a scarcity of qualified personnel, whether that is long waiting times or wide geographic distances to reach available providers.

When it comes to misdiagnosis, one KOL felt that the root of this issue is often the knowledge of the PCP that the symptomatic person is presenting to. As discussed previously, in some low-income countries, there is a higher chance for misdiagnosis as the symptoms might be associated with other diseases.

All of the KOLs agreed that access to treatment has improved in the past 10 years, particularly when it comes to biologic treatments. The widespread availability of more affordable biosimilars provides an opportunity to reduce the economic burden for individuals and health systems, while also allowing for better disease control earlier in the disease. However, the KOLs explained that the majority of the world still has limited access to systemic treatments, even in places like the UK and US. This is in part due to limitations such as: geographic location, underdeveloped healthcare systems, privatized provision, lack of subsidization, limited resources, and others.

> “
> As discussed previously, in some low-income countries, there is a higher chance for misdiagnosis as the symptoms might be associated with other diseases.

One KOL with experience in less developed healthcare systems recognized that the majority of people with psoriasis are never going to see a dermatologist. That problem is even worse with people needing specialist care from rheumatologists.

Across all the WHO regions with survey responses, people felt that they experienced issues with diagnosis, treatment options and access to care. Almost half (14/31) of respondents had received their PsO diagnosis within 1 month, while for 8 out of 31 respondents, it had taken more than a year (mostly in European countries). Almost one third of individuals surveyed had experienced problems with misdiagnosis for their symptoms, spread across all five of the WHO regions with survey responses.

Almost half of those surveyed (14/31) felt that they had moderate access to the treatments they needed, though 7 of 31 respondents felt that they had ‘easy access to care and six said ‘very easy’. The vast majority (27/31) felt that access to treatments had improved in the past 10 years. Figure 5 presents the survey results for the opinions on the difficulty accessing dermatologists and rheumatologists. Opinions on access are similar for both specialists, and most fall somewhere between ‘difficult’ and ‘easy’. In this case, most survey respondents (26/31) also felt that access to specialists had improved.

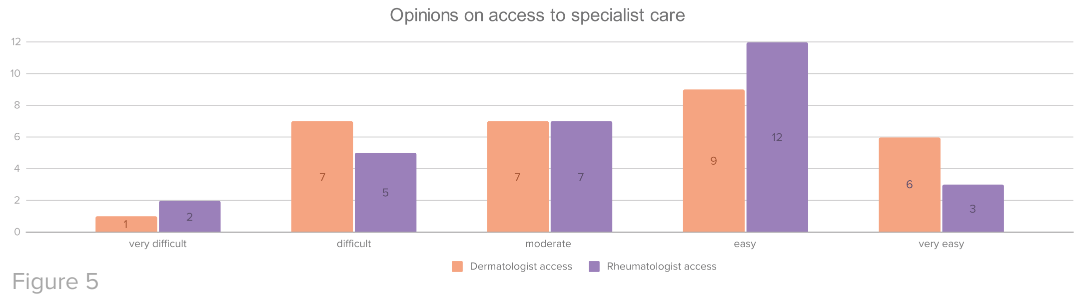


Figure 5

Regional perspectives

Africa

A multi-national survey of dermatologists and rheumatologists in the Asia–Pacific region and the Middle East reported that individuals waited an average of 0.9 years for a confirmed diagnosis of PsA, and longer for appropriate treatment (n = 364) (21).

PsA is poorly understood and under-recognized in Africa and the Middle East due to a paucity of quality research. The lack of consistency when applying treatment guidelines for PsA management in Africa and the Middle East likely means that different practices are being implemented within individual countries, and between physicians within the same hospitals.

- In sub-Saharan Africa, a shortage of qualified health professionals is a contributory factor to the lack of rheumatology services which can lead to delayed diagnosis of PsA.

- Multiple obstacles faced by rheumatologists practicing in Africa and the Middle East include lack of disease awareness among both people with psoriatic disease and healthcare professionals, drug accessibility, inadequate health funding, and a lack of rheumatologists.
- Delays in the referral of people with PsA to rheumatologists in Africa can be because primary care practitioners and dermatologists do not recognize the symptoms of PsA in time due to a lack of training in identifying the disease.
- While all medications licensed for the treatment of PsA are available in some African and Middle Eastern countries, their prohibitive cost limits their use in resource-poor countries.

- A review in Africa found limited access to specialized units/specialists, delay in diagnosis, limited attention by healthcare authorities to non-communicable diseases, and the difficulties in implementing international recommendations on the African continent were discussed. A relative lack of data from the African continent, the cost of specialized medication in resource-poor countries, and comorbidities of psoriatic arthritis were also discussed (18).

> “
> While all medications licensed for the treatment of PsA are available in some African and Middle Eastern countries, their prohibitive cost limits their use in resource-poor countries.

- Wide variation in the structure and development of healthcare systems in different countries means that each system faces a different set of challenges. One KOL referred to a recent survey conducted in South Africa, where many people with psoriatic disease explained that they received no form of care whatsoever.

The Americas

In the US, a KOL reported that despite widespread availability of almost all systemic treatments in the market, people with psoriatic disease may still have trouble accessing the right treatment for them for economic reasons. Many people on Medicare still have to pay coinsurance for biologics, which some might not be able to afford.

- Rheumatologists, general practitioners, and dermatologists diagnosed two thirds of patients with PsA. Musculoskeletal symptoms were common preceding a PsA diagnosis. Greater awareness of patterns of health events may alert healthcare providers to suspect a diagnosis of PsA (84).

- Early diagnosis of both PsO and PsA is pertinent in effective treatment and management of the disease, as a substantial delay was reported by individuals between symptom onset and the confirmed diagnosis of PsO/PsA. Patient education with a focus on monitoring joints for early detection of PsA may enable early access to treatments. These results demonstrated that less than half of people with PsA were treated by a rheumatologist. This may lead to disease mismanagement, with patients treated by non-specialists (38).
- In a population-based study, more than half of people with PsA were diagnosed at least two years after symptom onset. Younger age at PsA symptom onset, obesity, and enthesitis were associated with a delay in diagnosis of longer than 2 years (85).

Eastern Mediterranean

No relevant data was identified for this region in this metric.

Europe

- A 2023 study of guidelines in Europe found that the eligibility criteria for biologic /targeted synthetic disease-modifying antirheumatic drug (ts-DMARD) treatment varied by country, limiting access (29).

- A study conducted in UK described the time interval between the onset of psoriasis and PsA in the UK primary care setting and compared it with a large, well-classified secondary care cohort. In the study the majority of people (82.3 and 61.3%, respectively) had psoriasis before their PsA diagnosis or within the same calendar year (10.5 and 23.8%), with only a minority receiving their PsA diagnosis first (7.1 and 14.8%) (86).

- A study conducted in Spain concluded that the delay in diagnosis far outweighs other European results- around 4 years from the onset of symptoms. The study outlined two problems: issues with delayed diagnoses which widely exceed that estimated in another European estimates (the Danish DANBIO register), and is positioned around that reported by the American MAPP survey. Second, the idea that in emergency departments there is a large medical group whom patients who are finally diagnosed with PsA have previously consulted and from whom very few referrals are made (87).

> “
> A study conducted in Spain concluded that the delay in diagnosis far outweighs other European results- around 4 years from the onset of symptoms.

- A study conducted in Germany suggested that there is an unmet need for rheumatological check-up in people with psoriasis soon after diagnosis; however, only a small percentage of individuals with or without concomitant PsA consulted a rheumatologist. The mean time to PsA diagnosis of only 1.5 years demonstrated that the development of PsA can occur early after a diagnosis of psoriasis. Given that development of PsA drastically impairs the ability to work and quality of life, these data reinforce the need to include rheumatologists early on for clinical decision-making for people with psoriasis (59).

- In a subgroup analysis of MAPP survey in Spanish population it was observed that psoriatic arthritis may be underdiagnosed among individuals with a diagnosis of ‘psoriasis only’, as 34% of respondents reported joint pain or soreness, and sausage digits or heel pain and/or swelling were reported to have occurred upon specific questioning by 29% and 24% of individuals, respectively (60).

- Risk factors associated with diagnostic delay for both PsA and rheumatoid arthritis disease in an Italian study were: living in a small city, receiving the diagnosis from a non-rheumatologist, and having previous misdiagnoses. In comparison, PsA showed greater diagnostic delay than rheumatoid arthritis (88).

> “
> Risk factors associated with diagnostic delay for both PsA and rheumatoid arthritis disease in an Italian study were: living in a small city, receiving the diagnosis from a non-rheumatologist, and having previous misdiagnoses.

- Approximately one-third of people living with PsA still experience diagnostic delays exceeding 2 years. Several factors, including education level, arthritis symptoms preceding skin manifestations, first visit symptoms, particularly low back pain, age of symptom onset, and psoriasis subtype were identified as significant factors associated with delayed diagnosis (89).

- A 2017 study of MAPP survey participants in Spain found that the vast majority of surveyed individuals (84%) were not receiving systemic therapy whatsoever, suggesting these people are undertreated (60).

- A 2016 study of MAPP survey participants in Italy similarly found that the vast majority of surveyed individuals were not receiving systemic therapy whatsoever, and that even 48% of people with severe disease were not receiving any medication, suggesting these individuals are undertreated (90).

South-East Asia

- Sub-analysis of the Global Psoriasis and Beyond Survey in Indian population found that the diagnosis of PsO and PsA from the first onset of symptoms was delayed by 1.6 years and 1.2 years, respectively. Consequently, this resulted in a significant impact on treatment decisions, highlighting the gap in patient education, delays in screening, and diagnosis by the HCPs. (39)

One KOL explained that some of their dermatologist colleagues in India did not have access to any biologics whatsoever, which was related to issues with market access for the treatments themselves.

Western Pacific

- Subgroup analysis of LOOP study in Japanese population observed that PsA diagnosis from onset of symptoms was delayed in Japan in the rheumatology/orthopedic setting (median time: 23 months) compared with that in the dermatology setting (median time: 5 months). There were two main reasons associated with the delays: the preference of patients to visit rheumatologists only at an advanced stage, and the Japanese government health insurance system only reimbursing medical expenses for the management of joint pain by osteopaths or physiotherapists (i.e., not rheumatologists) (91).

- Four major challenges in diagnosis of PsA were “Difficulties in identification of atypical or hidden psoriasis”, “Absence of diagnostic biomarkers”, “No active self-report of history or family history of psoriasis” and “Various musculoskeletal manifestations” (92).

Examples of good practice

One KOL recommended the use of a process called “task sharing” or “task shifting” to recognize and manage psoriasis and other common conditions manifesting on the skin. This is where specific tasks are delegated to less specialized healthcare workers, such as screening, patient monitoring and adherence to treatment. Previous literature has shown that outcomes for patients are either similar or improved when tasks are delegated appropriately, while significantly reducing the workload of specialized personnel and reducing costs of care (93). Another KOL recommended that providers consider biologics as a first line treatment in cases where it would be feasible.

- Patients recruited from a site with an established relationship between rheumatologists and dermatologists experienced a numerically shorter time to diagnosis and time to treatment than those from a site with a newly formed relationship. Diagnosis and management of PsA were much improved due to closer collaboration between rheumatologists and dermatologists (83).

- About three quarters of Chinese rheumatologists know about the elements in PsA diagnosis and have good practice habits in diagnosing PsA (92).

Key areas of unmet need

These three pillars of psoriatic disease care all have region and country-specific issues making it difficult for people to receive the care they need in a timely manner. Diagnostic delay is rampant for different reasons everywhere in the world. Access to treatment can be limited by a multitude of systemic issues and access to specialist care is a difficulty that is faced in all countries.

- The delay in diagnosis and high disease burden in people with PsA support the need for improved management of this disease (83).
- A subgroup analysis of Japanese individuals from the LOOP study showed differences in treatment approach and patient characteristics between rheumatology/orthopedic and dermatology setting. These results lend further support to a tighter collaboration between rheumatologists/orthopedists and dermatologists to optimize and individualize the management of PsA. Furthermore, an integrated dermo-rheumatologic approach could potentially aid in early diagnosis and timely management, thereby lowering disease activity and burden in people with PsA (91).
- Some of the unmet needs in PsA include diagnostic challenges, delay in diagnosis, prognostication systems and varying medicine approaches and precision medicine strategies for established and emerging therapies (82).
- There is a need for increasing awareness of the systemic aspect of psoriatic disease and need for patient educational programs, since psoriatic disease impacts people's physical and mental health (38).

Metric 7

Advocacy efforts of stakeholders

Overview

Psoriatic disease advocacy efforts have been steadily increasing and collectivising in order to improve outreach and messaging on behalf of people living with psoriatic disease. One study evaluated the digital impact of Psoriasis Action Month and World Psoriasis Day by studying trends in relevant Twitter (X) posts and studying the global reach of these awareness initiatives to steer future policy development. A total of 3384 and 1925 tweets were identified in 2022 related to Psoriasis Action Month and World Psoriasis Day, respectively.

Tweets related to Psoriasis Action Month and World Psoriasis Day comprised 7.99% and 31.18%, respectively, of the total tweets posted about psoriasis in 2022. More users tweeted about World Psoriasis Day than Psoriasis Action Month between 2019 and 2021. A network analysis revealed relatively high collaboration between the top users. Google Trends analysis demonstrated that the majority of web searches were from the American, European, Russian, South Asian, and Australian regions with limited involvement from African and Central Asian countries” (94).

The KOLs interviewed expressed that public awareness had improved over the past 10 years, in large part due to the efforts of pharmaceutical companies. Pharma has a vested interest in spreading awareness of the disease, which in turn helps people living with the disease in a variety of ways (e.g., reducing stigmatization, improving knowledge of both people with psoriatic disease and providers, advocating for access to treatment, etc.).

> “
> Psoriatic disease advocacy efforts have been steadily increasing and collectivising in order to improve outreach and messaging on behalf of people living with psoriatic disease.

As mentioned in Metric 3, almost all survey respondents (30/31) felt that the general public had between ‘moderate’ and ‘very little’ understanding about psoriasis in their respective countries.

IFPA has collected available information on the founding dates of their members, as well as the dates that those members joined the federation. Figure 6 presents the cumulative instances of available founding and joining dates for IFPA members, respectively.

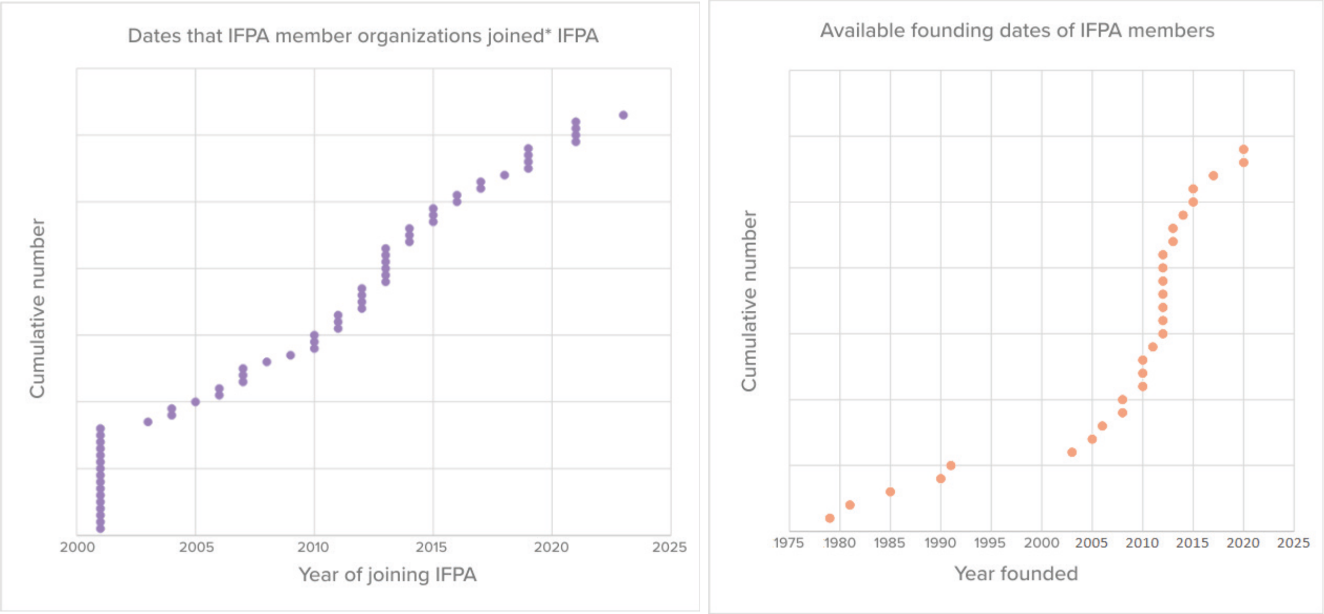


Figure 6

** Please note that no specific dates were available for members who joined before 2002, meaning that those marked as having joined in 2001 count as having joined ‘before 2002’.*

About 45% of the organizations with available data were founded between 2010 and 2013, indicating a surge in patient advocacy just before the 2014 WHA resolution was adopted. In terms of membership, 16 of the IFPA member organizations joined before 2002. After this, there were two minor waves of membership: one in 2013 and one in 2020. This data provides a bit of insight about the global interest in patient advocacy, and hopefully encourages additional members to join, promoting a united effort to further improve access to and quality of care for people living with psoriatic disease.

Regional perspectives

Africa

- The psoriasis organizations in Africa that have joined IPFA include the international organization known as Psoriasis Africa, as well as country-specific organizations in: Ghana, Kenya, and South Africa.

The Americas

In the US, one KOL described that one of the largest contributors to awareness of the disease is direct-to-consumer advertising, which is not as common in European regions.

Some of the countries and territories with IFPA member organizations in the region of the Americas include the following: Argentina, Brazil, Canada, Colombia, Dominican Republic, El Salvador, Mexico, Panama, Peru, Puerto Rico, USA, and Uruguay.

Eastern Mediterranean

Currently, there are no IFPA member organizations located in the Eastern Mediterranean region.

Europe

The European region includes the highest concentration of IFPA member organizations. Countries in the Europe that have psoriasis organizations and are part of IFPA include the following: Austria, Belgium, Bulgaria, Croatia, Denmark, Estonia, Finland, France, Georgia, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Montenegro, Netherlands, Norway, Portugal, Romania, Russia, Serbia, Slovakia Slovenia, Spain, Sweden, Switzerland, and Turkey.

South-East Asia

There are two countries in South-East Asia with IFPA member organizations: Bangladesh and Indonesia.

Western Pacific

The territories in the Western Pacific Region with IFPA member organizations include the following: Australia, China, Hong Kong, Japan, Malaysia, Philippines, Singapore, South Korea, Taiwan, and Vietnam. There is also a regional organization named Psorasia.

Examples of good practice

There are many countries around the world with organizations that have membership in IFPA, which helps to provide a collective front for patient advocacy in those countries.

Key areas of unmet need

There are still many countries and areas around the world without patient advocacy organizations. Even in areas where organizations exist, some people are not aware of the support they can get from patient organizations. Social media and traditional media campaigns to raise awareness of advocacy efforts and encourage membership require time, coordination, and funding.

Additional measure A

Evidence of QoL improvements

Overview

Due to the chronic and comorbid nature of psoriatic disease, the disease has varying and lasting impacts on the people living with it. There were a number of collected records that assessed impact on quality of life in addition to other factors of daily living.

- A global study conducted in Europe, America and Asia found that the disease disrupted the course of life, work, and family roles and could not be controlled. They feared deterioration of their clinical condition and felt that their concerns and distresses were trivialized by others. People felt burdened by treatment inadequacy, and immunosuppressive medications were regarded as toxic and causing long-term organ damage (37).

- Another study which was conducted in Europe, America and Asia reported a moderate impact of people's health on daily activities. Overall, 35% of all people with psoriatic disease could not work/study the week prior to the survey as a result of their skin symptoms. Overall, 14% reported that their work/career choice was influenced by their disease (38).

> “Almost all of the respondents to the patient survey felt that their quality of life has improved since receiving treatment for their PsO and/or PsA.

Almost all of the respondents to the patient survey (29/31) felt that their quality of life has improved since receiving treatment for their PsO and/or PsA.

Regional perspectives

Africa

No relevant data was identified for this region in this metric.

The Americas

No relevant data was identified for this region in this metric.

Eastern Mediterranean

- An Egyptian study found that psoriasis exerts significant, negative effect on quality of life. Disease disability, severity and its acceptance are independent predictors of quality of life (34).

- A 2022 study in Saudi Arabia found that the average DLQI and six-items stigmatization scale for people with psoriasis were 8.95 (±5.77) and 7.61 (±4.5), respectively, that were correlated with the Simplified Psoriasis Index-severity (35).

Europe

- An observational study conducted in Spain concluded that achieving lower absolute Psoriasis Area and Severity Index (PASI) values may correlate not only with better health-related quality of life but also with better work productivity and treatment satisfaction (95).

- A 2015 study of real-world treatment practices in Germany found that people were far more satisfied with systemic and biologic treatment than with topical and phototherapy (96).

- In a study conducted in the UK and Republic of Ireland, people with psoriatic disease registered with British Association of Dermatologists Biologic Interventions Register were analyzed. Patients receiving biologic therapies had more severe psoriasis and more severe impairment of quality of life compared to patients on conventional systemic therapies. However, a higher proportion of patients in the biologic cohort reported more than one comorbidity, including obesity, hypertension, depression and PsA, compared with the comparator group at enrolment (57).

- The real-world data in Turkish PsA patients receiving anti-TNF treatment showed improvement in Work Productivity and Activity Impairment , Quality of Life , and disease activity over 9 months of treatment (97).

South-East Asia

- An Egyptian study found that psoriasis exerts significant, negative effect on quality of life. Disease disability, severity and its acceptance are independent predictors of quality of life (34).

- A 2022 study in Saudi Arabia found that the average DLQI and six-items stigmatization scale for people with psoriasis were 8.95 (±5.77) and 7.61 (±4.5), respectively, that were correlated with the Simplified Psoriasis Index-severity (35).

- In a study conducted in India the majority of people enrolled indicated that their skin problems had a “very-large” (31%; DLQI score: 11–20) to “extreme-large” (58%; DLQI score: 21–30) impact on their quality of life over the past week. On a scale of 1–10, on average, they stated the impact of PsO/PsA on their emotional well-being as 8.1; 72% reported their condition impacting their overall emotional well-being considerably, and only 5% reported their condition did not influence their overall emotional well-being at all or only very little. The high disease burden and the associated complexity of both PsO and PsA have a negative impact on the quality-of-life of affected people leading to social stigma and discrimination. The primary goal of PsA treatment are to maintain regular joint function and improve quality of life (39).

Western Pacific

No relevant data was identified for this region in this metric.

Has quality of life improved for people with psoriatic disease?

Quality of life seems to improve for people who are able to manage their disease in a timely manner. However, as discussed above, there are still many around the world who are not yet able to manage their disease, and if it is not done in a timely manner, permanent damage can leave lasting effects on peoples’ quality of life.

Burden on people with psoriatic disease and their families

Overview

Psoriatic disease poses a sizable burden on both the person living with the disease and their loved ones. There were a few studies that reported on this topic.

- A global study conducted in Europe, America and Asia in 2020 found that the disease disrupted the course of life, work, and family roles and could not be controlled. They feared deterioration of their clinical condition and felt that their concerns and distresses were trivialized by others. People felt burdened by treatment inadequacy, and immunosuppressive medications were regarded as toxic and causing long-term organ damage (37).
- Another study which was conducted in Europe, America and Asia reported a moderate impact on daily activities. Overall, 35% of all people with the disease participating in the study could not work/study the week prior to the survey as a result of their disease. Overall, 14% reported that their work/career choice was influenced by their disease (38).
- Armstrong 2022 reported that for global survey responders who reported how their psoriatic disease has impacted their daily activities, the main coping mechanisms for people with psoriatic disease were talking with family and friends, engaging with social media and exercise/sport, and finding comfort in food (38).

> “A global study conducted in Europe, America and Asia in 2020 found that the disease disrupted the course of life, work, and family roles and could not be controlled.

Regional perspectives

Africa

No relevant data was identified for this region in this metric.

The Americas

- An observational study which analyzed the large US claim database and compared direct costs of treatment switchers (people who switched from their original prescribed biologics to a newer therapy), non-switchers (those who remained on their original biologics), and discontinuers (those who discontinued their biologic therapy) among people with PsA who newly initiated a biologic concluded that people with PsA who switch or discontinue biologics have higher medical costs and healthcare utilization than those continuing the same biologic. The findings further highlighted that discontinuing or switching biologic therapies is associated with higher costs in people with PsA which may inform treatment and/or formulary decision-making (98).

> “A 2022 study of people living with psoriasis in Sweden found that those with plaque psoriasis had total direct healthcare costs that were an average of 1.8 times higher than the general population, and that those with generalized pustular psoriasis were 3.3 times higher.

Eastern Mediterranean

- No relevant data was identified for this region in this metric.

Europe

- A 2022 study of people living with psoriasis in Sweden found that those with plaque psoriasis had total direct healthcare costs that were an average of 1.8 times higher than the general population, and that those with generalized pustular psoriasis were 3.3 times higher (10).
- An observational study conducted in Spain concluded that achieving lower absolute Psoriasis Area and Severity Index (PASI) values may correlate not only with better health-related quality of life but also with better work productivity and treatment satisfaction (95).

- A study which reviewed the cost of psoriasis and psoriatic arthritis in 5 European countries, and analyzed the economic burden of the disease in, Germany, Spain, France, Italy, and the United Kingdom showed that costs increase with the treatment and management of more severe disease and the use of biologics (99).

- A review concluded that the treatment of moderate-to-severe psoriasis with biologic agents poses a significant economic burden to healthcare systems. Despite increasing recognition of the potential of biologic therapies to reduce both direct and indirect healthcare costs in the long term, economic considerations focus solely on drug acquisition costs (42).

South-East Asia

No relevant data was identified for this region in this metric.

Western Pacific

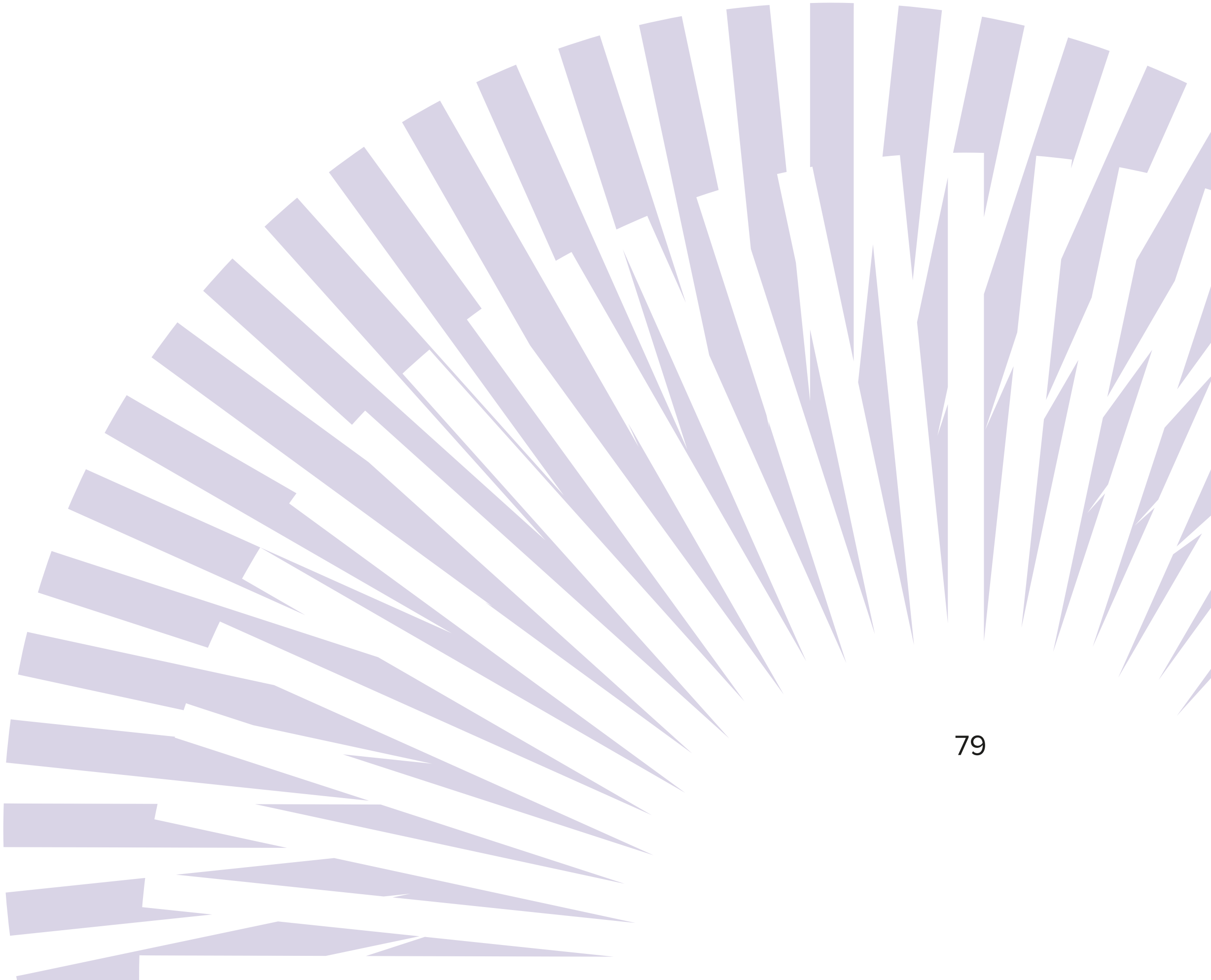
- An observational study conducted in China reported direct medical cost for people with psoriatic disease on non-biologic therapy was 7,249 CNY, accounting for 70.0% of the total cost, while people on biologics incurred 15,176 CNY, making up 94.3% of the total cost. The non-biologic group had higher costs related to hospitalization, self-purchase of drugs, and indirect costs than the biologic treatment group. Additionally, DLQI scores were higher in the non-biologic group (100).

- An observational study conducted in China reported direct medical cost for people treated with non-biologic drugs was 7,249 CNY, accounting for 70.0% of the total cost, while people treated with biologic drugs incurred 15,176 CNY, making up 94.3% of the total cost. The non-biologic group had higher costs related to hospitalization, self-purchase of drugs, and indirect costs than the biologic treatment group. Additionally, DLQI scores were higher in the non-biologic group (100).

> “Despite increasing recognition of the potential of biologic therapies to reduce both direct and indirect healthcare costs in the long term, economic considerations focus solely on drug acquisition costs.

Has the burden on people with the disease and their families lessened?

As more and more people receive adequate care for their disease, the burden on them and their loved ones decreases. However, as discussed in all the metrics above, there is still major unmet need for people living with psoriatic disease, and thus significant burden remains. As the lifespan of the average person grows, the opportunity for further psoriatic disease burden increases.



Additional measure C

Ability to rejoin society

Overview

PsA greatly impacts capacity to work. Its impact on work, which includes absenteeism, presenteeism and increased indirect cost (increased economic burden) is deleterious.

- In the Global survey conducted by Armstrong et al 2022, 35% of all people with the disease could not work/study the week prior to the survey as a result of their skin problems. Overall, 14% reported that their work/career choice was influenced by their disease (38).

> “Over two thirds of people responding to the survey made for this report felt that it has become easier over time in the past 10 years for people with PsO and/or PsA to get a new job or stay in the job they have.

- People with active PsA have a substantially reduced capacity to work and participate in leisure activities. Substantial improvements across various Work Productivity and Activity Impairment domains were noted after 24 weeks of treatment, especially in presenteeism, total work productivity, and activity impairment (101).

Over two thirds of people responding to the survey made for this report (21/30) felt that it has become easier over time in the past 10 years for people with PsO and/or PsA to get a new job or stay in the job they have.

Regional perspectives

Africa

No relevant data was identified for this region in this metric.

The Americas

No relevant data was identified for this region in this metric.

Eastern Mediterranean

No relevant data was identified for this region in this metric.

Europe

- Results from a large UK multicenter study showed that reduced effectiveness at work was associated with measures of disease activity, whereas unemployment, considered the endpoint of work disability, was associated with employer factors, age and disease duration (102).

South-East Asia

- In an Indian study, disease impact on work-related experiences measured using Work Productivity and Activity Impairment questionnaire, 74% of the enrolled patients could not go to work at all due to skin problems in the past week. Overall, 25% reported discrimination at work, and 33% had difficulty finding a job. In addition, 33% said that their choice of work and/or career was influenced by their condition. However, there is reportedly a robust patient–health care professional relationship. Most of the people (>80%) trusted their health care professional to treat skin and joint problems, and nearly two-thirds (62%) of patients actively questioned health care professionals about their disease condition. There is a clear need to enhance and support patient–health care professional communication for shared decision-making, timely screening, and diagnosis with a multidimensional approach for the management of psoriatic disease in India (39).

Western Pacific

No relevant data was identified for this region in this metric.

Are people with psoriatic disease more easily able to regain employment?

According to survey data and some of the included literature, the opportunities for people living with psoriatic disease to rejoin society are improving, but for people who don't have their disease adequately managed, morbidity can make it difficult to regain employment.

Additional measure D

Holistic approach to care

Overview

Psoriatic disease is a complex disease with a heavy socio-economic burden. It affects individuals both physically and mentally. As such a complete and holistic approach is needed for their treatment. There were a few studies that discussed holistic approaches to care:

- A Delphi panel study was conducted to identify current evidence and gain advanced insights into Generalized pustular psoriasis (GPP). The study concluded that treatments with rapid action are essential and should be provided at centers with dermatologists experienced in treating and managing people with GPP. Individuals should be carefully monitored by a dermatologist throughout a flare, and the following clinical assessments are useful for monitoring disease severity. Greater knowledge is needed regarding the triggers of GPP, associated comorbidities and differential diagnoses, and future studies should focus on generating much-needed evidence in these areas (103).

- Difficulties faced by people with PsA and physicians in Latin America included the high incidence of opportunistic infections, followed by nonadherence to therapy, discordance between people with psoriatic disease and physicians regarding remission rates, low drug persistence, limited access to disease-modifying antirheumatic drugs, issues related to the storage of biologic drugs, elevated cost of biologic drugs, limited access to medical care, diagnostic delay, and the individual- and country-level impact of socioeconomic factors on work- and health-related outcomes (104).

> “
>
> Psoriatic disease is a complex disease with a heavy socio-economic burden. It affects individuals both physically and mentally. As such a complete and holistic approach is needed for their treatment.

Is a holistic approach to care increasingly used in psoriatic disease?

Over time, holistic care tailored to the individual, with realistic treatment targets is being promoted more and more in the literature. However, the persistence of untreated comorbidities described above, and difficulties with delay to diagnosis and access to treatment suggest that in general, care is not being managed holistically for the average individual with psoriatic disease.

There are examples around the world where people are innovating ways to treat psoriasis along with its comorbidities, using common pathologic pathways (105), and considering a person with psoriatic disease’s daily habits (106) to help reduce the impact of the disease and its comorbidities simultaneously. The main hindrances are the time and resources required to manage that care. This means that integrated, time-saving solutions that facilitate a holistic approach to care should be prioritized in established systems.

Additional measure E

Laws and regulations to promote care

Overview

One of the most far-reaching but difficult ways to promote psoriatic disease care is through the passing of laws and regulations in a given system. This can involve increasing funding for disease care, research or treatment, or appointing a particular institution to attempt to improve systemic issues with access. A few examples of recent laws passed in select countries were identified.

Regional perspectives

Africa

No relevant data was identified for this region in this metric.

Eastern Mediterranean

No relevant data was identified for this region in this metric.

The Americas

- In Panama, the Public Health Department had little knowledge of psoriasis and the disease was not even in their disease chart. Also, their basic medication chart does not include any biologics developed for psoriasis. For years, Panama Psoriasis Foundation tried to raise awareness about the disease and insisted that it was necessary to have a law for psoriasis. Ultimately on August 30th, 2022, Law 322 on Psoriasis and Psoriatic Arthritis was passed. This law aims to establish a general framework to prevent Psoriasis, early detection of the disease and raise awareness about the disease (107).

> “In Panama, the Public Health Department had little knowledge of psoriasis and the disease was not even in their disease chart. Ultimately on August 30th, 2022, Law 322 on Psoriasis and Psoriatic Arthritis was passed.

Europe

- In Sweden, over 200,000 people live with psoriasis. Although new and effective treatment is available, many with the disease still remained undertreated. In 2019, the National Board of Health and Welfare issued National guidelines for care in psoriasis: Support for governance and management. The guidelines emphasized giving the right interventions for psoriasis to the right patient groups. The goals were to improve resource use in the care of this population and reduce the large regional differences in psoriatic care (108).

South-East Asia

- In Philippines, most people with psoriatic disease did not seek medical help to treat the disease due to high medicine and treatment cost, and risk aggravations. In 2019, a meeting of Coalition for Psoriatic Disease was held to discuss the ideal care for people living with the disease. After months of advocacy, eventually, in July 2021 National Psoriasis Care Act was passed by Philippines' Committee on Health. The bill aims to ensure an integrated and comprehensive approach to health development which includes the strengthening of integrative, multidisciplinary, patient and family-centered policies, programs, systems, interventions, and services at all levels of the existing health care delivery system for people with Psoriasis (109).

Western Pacific

No relevant data was identified for this region in this metric.

Have there been any laws or regulations to promote psoriatic disease care since the resolution?

Yes! And hopefully with continued advocacy efforts, further laws and regulations can be passed to promote access to and quality of care for people living with psoriatic disease.

Conclusions

This review aimed to collect recent data from around the world on how far the quality of and access to psoriatic disease care has come in the past ten years. The available evidence for each metric shows that in general, some progress has been made, but that there are still large areas of unmet need.

Therapeutic options for psoriasis and psoriatic arthritis have advanced considerably in the past 10 years. There have also been some improvements in treatment and healthcare education, especially in high-income countries. Many of the latest treatment recommendations, such as GRAPPA, EULAR and ILAR, have been updated with the latest evidence to empower providers, but these recommendations have not been employed locally in some countries. In many low-to-middle income countries, there is still a lack of treatment guidance and recommendations leading to mistaken or delayed diagnoses. There is a need for improving diagnostic capacities in such countries.

> “Therapeutic options for psoriasis and psoriatic arthritis have advanced considerably in the past 10 years. There have also been some improvements in treatment and healthcare education, especially in high-income countries.

General understanding of the disease has improved in the past 10 years, due to increased awareness and efforts to educate stakeholders. However, there are still issues with lack of awareness regarding comorbidities in psoriatic disease, both in people with the disease and providers. The introduction of biosimilars have allowed for a more cost-effective, systemic management of the disease, which in turn has reduced the socio-economic burden of psoriatic disease. That being said, the burden is still substantial, and if left unchecked, will rise with an aging global population. In the past 10 years, general awareness of psoriatic disease has increased, both in provider and patient circles. Because of this, a holistic approach to care is increasingly being promoted, though holistic care is nowhere near a standard practice as of yet.

Most people living with psoriatic disease still experience stigmatization irrespective of the region. This in turn affects the mental health and quality of life of those with the disease and their loved ones. To prevent continued stigmatization, greater social awareness of the disease should be encouraged in the general population. Providers should continue to promote psychological counselling for people facing stigmatization.

There are many clinical guidelines that still lack recommendations for screening and managing comorbidities related to psoriatic disease. There is a need to develop new and time-effective screening methods for comorbidities, especially in the developing countries, where qualified personnel may be lacking. PsA is still regularly untreated or misdiagnosed in different parts of the world, regardless of the system’s level of development. Available treatment guidelines have limitations and newer guidelines should address the complex, heterogeneous nature of psoriatic disease. This is especially pertinent as people around the world are living longer, and those with psoriatic disease will therefore have a higher risk for developing this comorbidity.

> “PsA is still regularly untreated or misdiagnosed in different parts of the world, regardless of the system’s level of development.

Based on evidence from both records and interviews, delay in the time to diagnosis is still a serious issue, as well as access to treatment and access to specialist care. Apart from the aforementioned recommendations for guidelines and education, settings with established relationships between rheumatologists and dermatologists experienced a numerically shorter time to diagnosis, and this should be promoted where possible. States should be encouraged to facilitate the affordability of care for people living with the disease. Advocacy efforts to improve access to treatment can be bolstered by pharmaceutical companies and other stakeholders. Task-shifting is another recommended method to improve the availability of specialists and the care of those with psoriatic disease.

Public awareness about the disease has improved over the last 10 years. Also, due to the efforts of various advocacy groups, many countries have included psoriasis and PsA in their health charts and in their budgets. However, the general public is still considered to be largely ignorant of the disease, which means that people with psoriatic disease still risk being stigmatized or impacted economically because their symptoms are inadequately managed.

> “The general public is still considered to be largely ignorant of the disease, which means that people with psoriatic disease still risk being stigmatized

Better quality of life was seen in individuals who received a timely diagnosis and an early start to their treatments. People on systemic therapies reportedly also had better QoL. When it comes to gender, the quality of life for women with the disease was, on average, worse than their male counterparts. Psoriatic disease greatly impacts capacity to work. In the past 10 years it has reportedly become a bit easier for people living with psoriatic disease to stay in their job or get a new job, but there is still unmet need, resulting in emotional and economic burden for individuals with the disease and their families.

Limitations

This study was not a systematic review, and therefore did not have the scope to conduct a comprehensive overview of all literature pertaining to these diverse topics. The voluntary patient survey only collected the perspective of a single person in each of the participating countries. Therefore, their responses might not be indicative of the average person living with the disease in that system. As this was a narrative review, no statistical comparisons could be made between estimates of e.g., the prevalence of PsA either over time or between regions. However, despite these limitations, the evidence gathered provides enough information to draw some conclusions about the state of progress for psoriatic disease care over the past decade.

Appendix A:

References

1. IFPA. Our Cause 2023 [Available from: https://ifpa-pso.com/about-ifpa/our-cause.
2. Parisi R, Iskandar IYK, Kontopantelis E, Augustin M, Griffiths CEM, Ashcroft DM. National, regional, and worldwide epidemiology of psoriasis: systematic analysis and modelling study. Bmj. 2020;369:m1590.
3. Organization WH. 67th World Health Assembly - Agenda item 13.5: Psoriasis. WHO; 2014.
4. World Health Organization. Global report on psoriasis. WHO; 2016.
5. Geale K, Henriksson M, Jokinen J, Schmitt-Egenolf M. Association of Skin Psoriasis and Somatic Comorbidity With the Development of Psychiatric Illness in a Nationwide Swedish Study. JAMA Dermatol. 2020;156(7):795-804.
6. Menter MA, Armstrong AW, Gordon KB, Wu JJ. Common and Not-So-Common Comorbidities of Psoriasis. Semin Cutan Med Surg. 2018;37(2s):S48-s51.
7. Perez-Chada LM, Merola JF. Comorbidities associated with psoriatic arthritis: Review and update. Clin Immunol. 2020;214:108397.
8. Takeshita J, Grewal S, Langan SM, Mehta NN, Ogdie A, Van Voorhees AS, et al. Psoriasis and comorbid diseases: Epidemiology. J Am Acad Dermatol. 2017;76(3):377-90.
9. Chen C, Ni Q. A Systematic Literature Review On Quality Of Life And Economic Burden Of Psoriasis In The Asia-Pacific Region. Value in Health. 2017;20(9):A552-A3.
10. Löfvendahl S, Norlin JM, Schmitt-Egenolf M. Economic Burden of Generalized Pustular Psoriasis in Sweden: A Population-Based Register Study. Psoriasis (Auckl). 2022;12:89-98.
11. Lopes N, Dias LLS, Azulay-Abulafia L, Oyafuso LKM, Suarez MV, Fabricio L, et al. Humanistic and Economic Impact of Moderate to Severe Plaque Psoriasis in Brazil. Adv Ther. 2019;36(10):2849-65.
12. Schenkel B, Leartsakulpanitch J, Yue N. PSY1 burdens of psoriasis in the Asia pacific region: a literature review. Value in Health. 2012;15(7):A677-A8.
13. IFPA. IFPA: Members Sweden: IFPA; 2024 [Available from: https://ifpa-pso.com/about-ifpa/members.
14. Coates LC, Soriano ER, Corp N, Bertheussen H, Callis Duffin K, Campanholo CB, et al. Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA): updated treatment recommendations for psoriatic arthritis 2021. Nat Rev Rheumatol. 2022;18(8):465-79.
15. Kerschbaumer A, Smolen JS, Dougados M, de Wit M, Primdahl J, McInnes I, et al. Pharmacological treatment of psoriatic arthritis: a systematic literature research for the 2019 update of the EULAR recommendations for the management of psoriatic arthritis. Ann Rheum Dis. 2020;79(6):778-86.
16. 16. Elmets CA, Korman NJ, Prater EF, Wong EB, Rupani RN, Kivelevitch D, et al. Joint AAD-NPF Guidelines of care for the management and treatment of psoriasis with topical therapy and alternative medicine modalities for psoriasis severity measures. J Am Acad Dermatol. 2021;84(2):432-70.
17. Nast A, Smith C, Spuls PI, Avila Valle G, Bata-Csörgö Z, Boonen H, et al. EuroGuiDerm Guideline on the systemic treatment of Psoriasis vulgaris - Part 2: specific clinical and comorbid situations. J Eur Acad Dermatol Venereol. 2021;35(2):281-317.
18. Maharaj AB, Adebajo A. Psoriatic arthritis in Africa. Clin Rheumatol. 2021;40(9):3411-8.
19. Al Hammadi A, Al-Sheikh A, Ammoury A, Ghosn S, Gisondi P, Hamadah I, et al. Experience and challenges for biologic use in the treatment of moderate-to-severe psoriasis in Africa and the Middle East region. J Dermatolog Treat. 2017;28(2):129-35.
20. Kumsa SM, Tadesse TA, Woldu MA. Management practice, quality of life and associated factors in psoriasis patients attending a dermatological center in Ethiopia. PLoS One. 2021;16(11):e0260243.
21. Bedaiwi M, Al-Homood IA, El-Garf A, Uthman I, Sunna N, Nassier R, et al. Disease burden and treatment challenges of psoriatic arthritis in Africa and the Middle East. Rheumatol Int. 2019;39(8):1321-9.
22. SARAA. The South African Rheumatism and Arthritis Association (SARAA) recommendations for The use of biologic disease modifying anti-rheumatic drugs Africa: The South African Rheumatism and Arthritis Association (SARAA); 2019 [Available from: http://www.saraa.co.za/.
23. Singh JA, Guyatt G, Ogdie A, Gladman DD, Deal C, Deodhar A, et al. Special Article: 2018 American College of Rheumatology/National Psoriasis Foundation Guideline for the Treatment of Psoriatic Arthritis. Arthritis Care Res (Hoboken). 2019;71(1):2-29.
24. Fernández-Ávila DG, González AMA, Arteaga CE, Arroyave DJ, Correa CIC, Chiquito S, et al. Clinical practice guideline for the treatment of psoriatic arthritis in Colombia. Revista Colombiana de Reumatología. 2023;30:S55-S64.
25. Walsh JA, Adejoro O, Chastek B, Palmer JB, Hur P. Treatment Patterns Among Patients with Psoriatic Arthritis Treated with a Biologic in the United States: Descriptive Analyses from an Administrative Claims Database. J Manag Care Spec Pharm. 2018;24(7):623-31.
26. Carneiro S, Palominos PE, Anti SMA, Assad RL, Gonçalves RSG, Chiereghin A, et al. Brazilian Society of Rheumatology 2020 guidelines for psoriatic arthritis. Adv Rheumatol. 2021;61(1):69.
27. El Miedany Y, El Gaafary M, GadAllah N, Mansour M, Fathy N, Hassan W, et al. Psoriatic arthritis treatment to the target: a consensus, evidence-based clinical practice recommendations for the management of psoriatic arthritis and its concomitant clinical manifestations. Egyptian Rheumatology and Rehabilitation. 2022;49(1):32.
28. Steinhoff M, Ammoury AF, Ahmed HM, Gamal MFS, El Sayed MH. The Unmet Need for Clinical Guidelines on the Management of Patients with Plaque Psoriasis in Africa and the Middle East. Psoriasis (Auckl). 2020;10:23-8.
29. Michelsen B, Østergaard M, Nissen MJ, Ciurea A, Möller B, Ørnbjerg LM, et al. Differences and similarities between the EULAR/ASAS-EULAR and national recommendations for treatment of patients with psoriatic arthritis and axial spondyloarthritis across Europe. Lancet Reg Health Eur. 2023;33:100706.

30. Tsai TF, Hsieh TY, Chi CC, Chou CT, Hsieh LF, Chen HH, et al. Recommendations for psoriatic arthritis management: A joint position paper of the Taiwan Rheumatology Association and the Taiwanese Association for Psoriasis and Skin Immunology. J Formos Med Assoc. 2021;120(3):926-38.
31. Tsuruta N, Imafuku S. Establishment of the Western Japan Psoriasis Registry and first cross-sectional analysis of registered patients. J Dermatol. 2021;48(11):1709-18.
32. Elmamoun M, Eraso M, Anderson M, Maharaj A, Coates L, Chandran V, et al. International league of associations for rheumatology recommendations for the management of psoriatic arthritis in resource-poor settings. Clin Rheumatol. 2020;39(6):1839-50.
33. Ukonu BA, Ibekwe PU. Clinical and economic burden of psoriasis: a retrospective study of the cost implications among cohorts in Abuja, Nigeria. International Journal of Research. 2020;6(4):443.
34. Aladl S, El-Gilany A-H, Ghanem B, Fayed H. Quality of life of psoriatic patients and their acceptance of the disease. Iranian Journal of Dermatology. 2020;23(3):91-7.
35. Bayomy HE, Albedaiwi Y, Alabdulatif SKA, Almutairi FSF, Aloufi FAS, Alruwaili RHA, et al. Psoriasis in Northern Saudi Arabia: Clinical features and implications for quality of life. J Public Health Res. 2022;11(4):22799036221123961.
36. Wiesner M, Zowalla R, Pobiruchin M. The difficulty of German information booklets on psoriasis and psoriatic arthritis: automated readability and vocabulary analysis. JMIR Dermatology. 2020;3(1):e16095.
37. Sumpton D, Kelly A, Tunnicliffe DJ, Craig JC, Hassett G, Chessman D, et al. Patients' Perspectives and Experience of Psoriasis and Psoriatic Arthritis: A Systematic Review and Thematic Synthesis of Qualitative Studies. Arthritis Care Res (Hoboken). 2020;72(5):711-22.
38. Armstrong A, Bohannan B, Mburu S, Alarcon I, Kasparek T, Toumi J, et al. Impact of Psoriatic Disease on Quality of Life: Interim Results of a Global Survey. Dermatol Ther (Heidelb). 2022;12(4):1055-64.
39. Chandrashekar BS, Nayak CS, Kar BR, Salloju V. Patient Perspectives of the Impact of Psoriatic Disease on Quality-of-Life in India: Sub-analysis from the Global Psoriasis and Beyond Survey. Indian Dermatol Online J. 2024;15(2):233-41.
40. Felix PAO, Sampaio AL, Silva BL, Viana ALP. Early intervention in psoriasis: Where do we go from here? Front Med (Lausanne). 2022;9:1027347.
41. Kerdel F, Don F. The Importance of Early Treatment in Psoriasis and Management of Disease Progression. J Drugs Dermatol. 2018;17(7):737-42.
42. Girolomoni G, Savage L, Gisondi P, Svensson Å, Mahé E, Augustin M, et al. Increasing Access to Effective Systemic Treatments in Patients with Moderate-to-Severe Psoriasis: Narrative Review. Dermatol Ther (Heidelb). 2023;13(10):2171-85.
43. Kelly KA, Balogh EA, Kaplan SG, Feldman SR. Skin Disease in Children: Effects on Quality of Life, Stigmatization, Bullying, and Suicide Risk in Pediatric Acne, Atopic Dermatitis, and Psoriasis Patients. Children (Basel). 2021;8(11).
44. Wan MT, Pearl RL, Chiesa Fuxench ZC, Takeshita J, Gelfand JM. Anticipated and Perceived Stigma Among Patients With Psoriasis. J Psoriasis Psoriatic Arthritis. 2020;5(3):93

45. Dimitrov D, Matusiak Ł, Szepietowski JC. Stigmatization in Arabic psoriatic patients in the United Arab Emirates - a cross sectional study. Postepy Dermatol Alergol. 2019;36(4):425-30.
46. Soliman MM. Feeling of stigmatization and satisfaction with life among Arabic psoriatic patients. Saudi Pharm J. 2020;28(12):1868-73.
47. Kowalewska B, Cybulski M, Jankowiak B, Krajewska-Kułak E. Acceptance of Illness, Satisfaction with Life, Sense of Stigmatization, and Quality of Life among People with Psoriasis: A Cross-Sectional Study. Dermatol Ther (Heidelb). 2020;10(3):413-30.
48. Sommer R, Topp J, Mrowietz U, Zander N, Augustin M. Perception and determinants of stigmatization of people with psoriasis in the German population. J Eur Acad Dermatol Venereol. 2020;34(12):2846-55.
49. Jankowiak B, Kowalewska B, Krajewska-Kułak E, Khvorik DF. Stigmatization and Quality of Life in Patients with Psoriasis. Dermatol Ther (Heidelb). 2020;10(2):285-96.
50. Jankowiak B, Kowalewska B, Krajewska-Kułak E, Kowalczuk K, Khvorik DF. The Sense of Stigmatization in Patients with Plaque Psoriasis. Dermatology. 2021;237(4):611-7.
51. Demirkiran BC, Kiyak E. Evaluation of Internalized Stigma and Quality of Life of Patients with Psoriasis. Makara Journal of Health Research. 2022;26(3):6.
52. Ogdie A, Nowell WB, Applegate E, Gavigan K, Venkatachalam S, de la Cruz M, et al. Patient perspectives on the pathway to psoriatic arthritis diagnosis: results from a web-based survey of patients in the United States. BMC Rheumatol. 2020;4:2.
53. Rossetto CN, Palominos PE, Machado NP, Dos Santos Paiva E, Azevedo VF. Epidemiological analysis of patients with psoriatic arthritis in follow-up at the brazilian Unified Health System. Adv Rheumatol. 2023;63(1):47.
54. Kaine J, Song X, Kim G, Hur P, Palmer JB. Higher Incidence Rates of Comorbidities in Patients with Psoriatic Arthritis Compared with the General Population Using U.S. Administrative Claims Data. J Manag Care Spec Pharm. 2019;25(1):122-32.
55. Cipriani L, Campos A, Simioni J, Nisihara R, Skare T. Anxiety and Depression in Psoriatic Arthritis: A Cross Sectional Study in Brazilian Patients. J Rheum Dis Treat. 2021;7:091.
56. El-Garf A, Teleb DA, Said ER, Eissa M. Psoriatic arthritis among Egyptian patients with psoriasis attending the dermatology clinic: prevalence, comorbidities, and clinical predictors. Reumatologia. 2021;59(6):394-401.
57. Iskandar IYK, Ashcroft DM, Warren RB, Yiu ZZN, McElhone K, Lunt M, et al. Demographics and disease characteristics of patients with psoriasis enrolled in the British Association of Dermatologists Biologic Interventions Register. British Journal of Dermatology. 2015;173(2):510-8.
58. Zander N, Schäfer I, Radtke M, Jacobi A, Heigel H, Augustin M. Dermatological comorbidity in psoriasis: results from a large-scale cohort of employees. Arch Dermatol Res. 2017;309(5):349-56.
59. Rech J, Sticherling M, Stoessel D, Biermann MHC, Häberle BM, Reinhardt M. Psoriatic arthritis epidemiology, comorbid disease profiles and risk factors: results from a claims database analysis. Rheumatol Adv Pract. 2020;4(2):rkaa033.

60. Puig L, van de Kerkhof PCM, Reich K, Bachelez H, Barker J, Girolomoni G, et al. A European subset analysis from the population-based Multinational Assessment of Psoriasis and Psoriatic Arthritis shows country-specific features: results from psoriasis patients in Spain. J Eur Acad Dermatol Venereol. 2017;31(7):1176-82.
61. Chanakya K, Shobha V, Chandrashekara S, Kumar S, Haridas V, Rao V, et al. Comorbidity burden in psoriatic arthritis and its impact on disease measures. Indian Journal of Rheumatology. 2023;18(3):185-91.
62. Sulaiman W, Tan LK, Mat H, Tohar N, Muhaimin Fathi A, Kosenin NMA, et al. Clinical characteristics and comorbidities in psoriatic arthritis: Experience from a single rheumatology centre in Malaysia. The Egyptian Rheumatologist. 2023;45(4):309-13.
63. Tanaka Y. Psoriatic arthritis in Japan: difference in clinical features and approach to precision medicine. Clin Exp Rheumatol. 2016;34(4 Suppl 98):49-52.
64. Kamiya K, Ohtsuki M. Epidemiological survey of patients with psoriatic arthritis in the Japanese Society for Psoriasis Research from 2017 to 2020. J Dermatol. 2023;50(1):12-25.
65. Reid C, Welsh C, Martin-Smith H, Dharmaprasad S, Warren RB, Cordingley L, et al. A rapid access clinic for psoriasis: first experiences. Br J Dermatol. 2022;187(3):426-8.
66. Alinaghi F, Calov M, Kristensen LE, Gladman DD, Coates LC, Jullien D, et al. Prevalence of psoriatic arthritis in patients with psoriasis: A systematic review and meta-analysis of observational and clinical studies. J Am Acad Dermatol. 2019;80(1):251-65.e19.
67. Mehrmal S, Uppal P, Nedley N, Giesey RL, Delost GR. The global, regional, and national burden of psoriasis in 195 countries and territories, 1990 to 2017: A systematic analysis from the Global Burden of Disease Study 2017. J Am Acad Dermatol. 2021;84(1):46-52.
68. Gisondi P, Bellinato F, Maurelli M, Geat D, Zabotti A, McGonagle D, et al. Reducing the Risk of Developing Psoriatic Arthritis in Patients with Psoriasis. Psoriasis (Auckl). 2022;12:213-20.
69. Loredo M, Braña I, Queiro R. Does pharmacological intervention prevent or delay the onset of psoriatic arthritis among psoriasis patients? : Taylor & Francis; 2023. p. 1159-62.
70. Lebwohl MG, Bachelez H, Barker J, Girolomoni G, Kavanaugh A, Langley RG, et al. Patient perspectives in the management of psoriasis: results from the population-based Multinational Assessment of Psoriasis and Psoriatic Arthritis Survey. J Am Acad Dermatol. 2014;70(5):871-81.e1-30.
71. Lebwohl M, Langley RG, Paul C, Puíg L, Reich K, van de Kerkhof P, et al. Evolution of Patient Perceptions of Psoriatic Disease: Results from the Understanding Psoriatic Disease Leveraging Insights for Treatment (UPLIFT) Survey. Dermatol Ther (Heidelb). 2022;12(1):61-78.
72. Armstrong AW, Mehta MD, Schupp CW, Gondo GC, Bell SJ, Griffiths CEM. Psoriasis Prevalence in Adults in the United States. JAMA Dermatol. 2021;157(8):940-6.
73. Kerola AM, Rollefstad S, Kazemi A, Wibetoe G, Sexton J, Mars N, et al. Psoriatic arthritis, axial spondyloarthritis and rheumatoid arthritis in Norway: nationwide prevalence and use of biologic agents. Scand J Rheumatol. 2023;52(1):42-50.
74. Romero Pérez A, Queiro R, Seoane-Mato D, Graell E, Chamizo E, Chaves Chaparro L, et al. Higher prevalence of psoriatic arthritis in the adult population in Spain? A population-based cross-sectional study. PLoS One. 2020;15(6):e0234556.

75. Wang J, Tulka S, Knippschild S, Schneider M, Distler JHW, Baraliakos X, et al. A population-based projection of psoriatic arthritis in Germany until 2050: analysis of national statutory health insurance data of 65 million German population. Rheumatol Int. 2023;43(11):2037-47.
76. Grellmann C, Dombrowsky W, Fabricius V, Suruki R, Sheahan A, Joeres L. Epidemiology and Treatment of Patients with Rheumatoid Arthritis, Psoriatic Arthritis and Psoriasis in Germany: A Real-World Evidence Study. Adv Ther. 2021;38(1):366-85.
77. Hagenström K, Müller K, Garbe C, Augustin M. Prevalence of psoriasis and psoriatic arthritis in Germany - analysis of claims data. J Dtsch Dermatol Ges. 2024;22(1):45-54.
78. Kumar R, Sharma A, Dogra S. Prevalence and clinical patterns of psoriatic arthritis in Indian patients with psoriasis. Indian J Dermatol Venereol Leprol. 2014;80(1):15-23.
79. Iskandar IYK, Chen TC, Chen LC, Lee MS, Yang YY, Wang TC, et al. Incidence, Prevalence, and Mortality of People with Psoriasis and Psoriatic Arthritis in Taiwan: A Nationwide Cohort Study. Acta Derm Venereol. 2022;102:adv00807.
80. Chen YT, Wu CY, Li YL, Chen LY, Chiou HY. Time Trends in Psoriasis and Psoriatic Arthritis Incidence from 2002 to 2016 in Taiwan: An Age-Period-Cohort Analysis. J Clin Med. 2022;11(13).
81. Gisondi P, Bellinato F, Targher G, Idolazzi L, Girolomoni G. Biological disease-modifying antirheumatic drugs may mitigate the risk of psoriatic arthritis in patients with chronic plaque psoriasis. Ann Rheum Dis. 2022;81(1):68-73.
82. Kuan BCK, Jadon DR. Unmet needs in psoriatic arthritis. Best Pract Res Clin Rheumatol. 2021;35(2):101693.
83. Boehncke WH, Horváth R, Dalkiliç E, Lima SAL, Okada M, Hojnik M, et al. Association between clinical specialty setting and disease management in patients with psoriatic arthritis: results from LOOP, a cross-sectional, multi-country, observational study. J Eur Acad Dermatol Venereol. 2020;34(9):2035-43.
84. Ogdie A, Rozycki M, Arndt T, Shi C, Kim N, Hur P. Longitudinal analysis of the patient pathways to diagnosis of psoriatic arthritis. Arthritis Res Ther. 2021;23(1):252.
85. Karmacharya P, Wright K, Achenbach SJ, Bekele D, Crowson CS, Ogdie A, et al. Diagnostic Delay in Psoriatic Arthritis: A Population-based Study. J Rheumatol. 2021;48(9):1410-6.
86. Tillett W, Charlton R, Nightingale A, Snowball J, Green A, Smith C, et al. Interval between onset of psoriasis and psoriatic arthritis comparing the UK Clinical Practice Research Datalink with a hospital-based cohort. Rheumatology (Oxford). 2017;56(12):2109-13.
87. Guillen Astete CA, Gaite Gonzalez I, Zurita Prada PA, Urrego Laurin C. Delay and diagnostic pathway of patients with psoriatic arthritis in Spain. Reumatología Clínica (English Edition). 2021;17(9):525-9.
88. Iacovantuono M, Ferrigno S, Conigliaro P, Triggianese P, D'Antonio A, Spinelli FR, et al. Evaluation of diagnostic and therapeutic delay in patients with rheumatoid arthritis and psoriatic arthritis. Reumatismo. 2024;76(1).
89. Kılıç G, Kılıç E, Tekeoğlu İ, Sargın B, Cengiz G, Balta NC, et al. Diagnostic delay in psoriatic arthritis: insights from a nationwide multicenter study. Rheumatol Int. 2023.

90. Gisondi P, Girolomoni G. Patients' perspectives in the management of psoriasis: the Italian results of the Multinational Assessment of Psoriasis and Psoriatic Arthritis (MAPP) survey. J Dermatolog Treat. 2017;28(5):390-3.
91. Okada M, Kurimoto S, Ganz F, Boehncke WH. LOOP, a cross-sectional, observational study investigating the clinical specialty setting as a determinant of disease management in psoriatic arthritis: Subgroup analysis results from Japan. PLoS One. 2021;16(1):e0245954.
92. Chen M, Zhang H, Chen Z, Dai SM. Perceptions of Rheumatologists on Diagnosis of Psoriatic Arthritis in China. Front Immunol. 2021;12:733708.
93. Martínez-González NA, Tandjung R, Djalali S, Rosemann T. The impact of physician–nurse task shifting in primary care on the course of disease: a systematic review. Human Resources for Health. 2015;13(1):55.
94. Malhotra K, Aggarwal P, Malhotra S, Goyal K. Evaluating the Global Digital Impact of Psoriasis Action Month and World Psoriasis Day: Serial Cross-Sectional Study. JMIR Dermatol. 2023;6:e49399.
95. Daudén E, Vidal D, Romero A, Bordel MT, Rivera R, Márquez J, et al. Psoriasis Severity, Health-Related Quality of Life, Work Productivity, and Activity Impairments Among Patients With Moderate to Severe Psoriasis Receiving Systemic Treatment: Real-World Data From Clinical Practice in Spain. Actas Dermosifiliogr. 2024;115(1):T1-t9.
96. Schaarschmidt ML, Kromer C, Herr R, Schmieder A, Goerdt S, Peitsch WK. Treatment satisfaction of patients with psoriasis. Acta Derm Venereol. 2015;95(5):572-8.
97. Karadag O, Dalkilic E, Ayan G, Kucuksahin O, Kasifoglu T, Yilmaz N, et al. Real-world data on change in work productivity, activity impairment, and quality of life in patients with psoriatic arthritis under anti-TNF therapy: a postmarketing, noninterventional, observational study. Clin Rheumatol. 2022;41(1):85-94.
98. Hur P, Kim N, Dai D, Piao OW, Zheng JZ, Yi E. Healthcare Cost and Utilization Associated with Biologic Treatment Patterns Among Patients with Psoriatic Arthritis: Analyses from a Large US Claims Database. Drugs Real World Outcomes. 2021;8(1):29-38.
99. Burgos-Pol R, Martínez-Sesmero JM, Ventura-Cerdá JM, Elías I, Caloto MT, Casado M. The Cost of Psoriasis and Psoriatic Arthritis in 5 European Countries: A Systematic Review. Actas Dermosifiliogr. 2016;107(7):577-90.
100. Min S, Wang D, Xia J, Lin X, Jiang G. The economic burden and quality of life of patients with psoriasis treated with biologics in China. J Dermatolog Treat. 2023;34(1):2247106.
101. Gossec L, Humphries B, Rutherford M, Taieb V, Willems D, Tillett W. Improvement in work productivity among psoriatic arthritis patients treated with biologic or targeted synthetic drugs: a systematic literature review and meta-analysis. Arthritis Res Ther. 2024;26(1):50.
102. Tillett W, Shaddick G, Askari A, Cooper A, Creamer P, Clunie G, et al. Factors influencing work disability in psoriatic arthritis: first results from a large UK multicentre study. Rheumatology. 2014;54(1):157-62.
103. Puig L, Choon SE, Gottlieb AB, Marrakchi S, Prinz JC, Romiti R, et al. Generalized pustular psoriasis: A global Delphi consensus on clinical course, diagnosis, treatment goals and disease management. J Eur Acad Dermatol Venereol. 2023;37(4):737-52.
104. Ribeiro AL, Dullius L, Sartori NS, Azeredo-da-Silva A, Kohem CL, Coates L, et al. Challenges in the Management of Psoriatic Arthritis in Latin America: A Systematic Review. Clin Ther. 2023;45(9):860-7.
105. Camela E, Potestio L, Fabbrocini G, Pallotta S, Megna M. The holistic approach to psoriasis patients with comorbidities: the role of investigational drugs. Expert Opin Investig Drugs. 2023;32(6):537-52.
106. Lubrano E, Scriffignano S, de Vlam K, Ronga M, Perrotta FM, Lories R. Triple jump for the optimal management of psoriatic arthritis: diet, sleep and exercise - a review. RMD Open. 2023;9(3).
107. IFPA. Law 322 passes in Panama Sweden: IFPA; 2023 [Available from: https://ifpa-pso.com/resources-tools/law-322-passes-in-panama.
108. Socialstyrelsen. Nationella riktlinjer för vård vid psoriasis Sweden2022 [Available from: https://www.socialstyrelsen.se/kunskapsstod-och-regler/regler-och-riktlinjer/nationella-riktlinjer/riktlinjer-och-utvarderingar/psoriasis/.
109. Psoriasisbill.org. AN ACT INSTITUTIONALIZING A NATIONAL PSORIASIS CARE PROGRAM AND APPROPRIATING FUNDS THEREFOR Philippines2021 [Available from: https://psoriasisbill.org.ph/about/house-resolution-no-9821.

Appendix B:

Methodological details

This section contains additional details about the methods used in this study.

Table 2. Eligibility criteria for study inclusion of records

Category	Inclusion criteria	Exclusion criteria
Population	People with Psoriatic Disease	People without psoriasis or psoriatic arthritis
Outcomes	• Availability of biologic and/or systemic treatments in the region / country • Clinical guidelines or treatment guidelines available • Patient surveys about stigma and discrimination • Publications assessing the risk of comorbidity • Publications assessing rate of screening for comorbidity • Prevalence of psoriatic arthritis in psoriasis patients by country / region • Rate of misdiagnosis • Time from presentation to healthcare to diagnosis • Pharmaceutical sales of systemic therapies • Assessments of access to psoriatic disease care • Funding to psoriasis patient groups • Countries with organizations participation in world psoriasis day Additional outcome measures** • Evidence of QoL improvement for patients • Evidence of a reduction of burden on patients and families • Evidence that patients are more easily able to regain employment / contribute to society • Evidence of holistic management approach to psoriatic disease care • Organizations mentioned to have an impact on progress in the above categories • Evidence of laws passed since the resolution • Evidence of guidelines improved since the resolution	Outcomes other than those in the inclusion criteria
Study design	• Published literature: books and documents, classical article, evaluation study, government publication, guideline, news, observational study, patient education handout, periodical index, practice guideline, review, systematic review, validation • Grey literature: reports, guidelines, campaign literature, official • Web pages: patient / advocacy organization sites	Interventional studies
Language	English	Other languages
Regions and countries	• Africa: Ghana, South Africa, Kenya • Americas: USA, Argentina, Brazil • Eastern Mediterranean: Pakistan, Iran, Egypt • Europe: Germany, Turkey, UK • South-East Asia: Indonesia, Bangladesh, Vietnam • Western Pacific: China, Japan, Australia	
Time limit	Since 24th of May, 2014	
Text limit	Available in full text	

Abbreviations:, PCP = primary care practitioner, DLQI = Dermatology Life Quality Index

* The primary search language will be English. Any records in other languages that are deemed as clearly relevant will be reviewed using Google Translate, and relevant content from that record will be collected in its translated form.

*** The additional outcome measures are included for the purposes of record selection and extraction, but since expanding the search to include these additional outcomes would expand the scope of the review beyond what was feasible, the search did not include terms for these additional outcomes. Instead, any records and evidence relevant to these outcomes were captured from the body of literature collected for the metric outcomes.*

Table 3: PubMed search facets

Search facet	Search terms	Hits (05/03/24)
Population	"psoriasis"[MeSH Terms] OR "psoriasis"[All Fields] OR "arthritis, psoriatic"[MeSH Terms] OR "psoriatic arthritis"[All Fields] OR "psoriatic"[All Fields]	68,858
Outcomes	"guidelines as topic"[MeSH Terms] OR "clinical guidelines"[TIAB] OR "treatment guidelines"[TIAB] OR "national guidelines"[TIAB] OR "national recommendations"[TIAB] OR (("biological products"[MeSH Terms] OR "biologic*"[Title/Abstract] OR "systemic*"[Title/Abstract] OR "therapeutics"[MeSH Terms]) AND ("access*"[TIAB] OR “sales”[TIAB] OR "commerce"[MeSH Terms] OR “Market access”[TIAB])) OR "patient survey*"[Title/Abstract] OR "discriminat*"[Title/Abstract] OR "social stigma"[MeSH Terms] OR "stigma"[Title/Abstract] OR "stigmas"[Title/Abstract] OR (("comorbidity"[MeSH Terms] OR "comorbidity"[Title/Abstract] OR "comorbidities"[Title/Abstract] OR "arthritis, psoriatic"[MeSH Terms] OR "psoriatic arthritis"[Title/Abstract]) AND ("risk"[Title/Abstract] OR "risks"[Title/Abstract] OR "rate"[Title/Abstract] OR "rates"[Title/Abstract] OR "probabilit*"[Title/Abstract] OR "epidemiology"[MeSH Subheading] OR "frequency"[Title/Abstract] OR "frequencies"[Title/Abstract] OR "prevalence"[Title/Abstract] OR "prevalence"[MeSH Terms] OR "probability"[MeSH Terms] OR "probability"[Title/Abstract] OR "likelihood"[Title/Abstract] OR "assess*"[Title/Abstract] OR "check*"[Title/Abstract] OR "diagnosis"[MeSH Subheading] OR "screen*"[Title/Abstract] OR "testing"[Title/Abstract] OR "test"[Title/Abstract]))	1,347,674

	OR "diagnostic errors"[MeSH Terms] OR "diagnostic error"[Title/Abstract] OR "misdiagnoses"[Title/Abstract] OR "misdiagnosis"[Title/Abstract] OR "misdiagnose"[Title/Abstract] OR "misdiagnosed"[Title/Abstract] OR "misdiagnosing"[Title/Abstract] OR "time to diagnosis"[TIAB] OR "diagnostic time"[TIAB] OR "TTD"[TIAB] OR "diagnostic delay"[TIAB] OR "health services accessibility"[MeSH Terms] OR "health services accessibility"[Title/Abstract] OR "access to care"[TIAB] OR "access to healthcare"[TIAB] OR ("access"[TIAB] AND "care"[TIAB]) OR ("access"[TIAB] AND "healthcare"[TIAB]) OR (("economics"[MeSH Subheading] OR "economics"[Title/Abstract] OR "funding"[Title/Abstract] OR "financial management"[MeSH Terms] OR "financial management"[Title/Abstract] OR "organization and administration"[MeSH Subheading]) AND ("patient organization*"[TIAB] OR "patient advocacy group*"[TIAB] OR "NGO"[TIAB] OR "patient association*"[TIAB])) OR "world psoriasis day"[Title/Abstract]	
Regions and countries	"africa"[MeSH Terms] OR "africa"[All Fields] OR "african"[All Fields] OR "ghana"[MeSH Terms] OR "ghana"[All Fields] OR "ghanian"[All Fields] OR "South Africa"[All Fields] OR "South African"[All Fields] OR "south africa"[MeSH Terms] OR "kenya"[MeSH Terms] OR "kenya"[All Fields] OR "kenyan"[All Fields] OR "americas"[MeSH Terms] OR "americas"[All Fields] OR "South America"[All Fields] OR "South American"[All Fields] OR "North America"[All Fields] OR "North American"[All Fields] OR "united states"[MeSH Terms] OR "USA"[All Fields] OR "United States"[All Fields] OR "american"[All Fields] OR "argentina"[MeSH Terms] OR "argentina"[All Fields] OR "argentines"[All Fields] OR "brazil"[MeSH Terms] OR "brazil"[All Fields] OR "brazilian"[All Fields] OR "Eastern Mediterranean"[All Fields] OR "middle east"[All Fields] OR "Middle Eastern"[All Fields] OR "pakistan"[MeSH Terms] OR "pakistan"[All Fields] OR "pakistani"[All Fields] OR "iran"[MeSH Terms] OR "iran"[All Fields] OR "iranian"[All Fields] OR "egypt"[MeSH Terms] OR "egypt"[All Fields] OR "egyptian"[All Fields] OR"europe"[MeSH Terms] OR "europe"[All Fields] OR "european"[All Fields] OR "European Union"[All Fields] OR "european union"[MeSH Terms] OR "germany"[MeSH Terms] OR "germany"[All Fields] "german"[All Fields] OR "turkey"[MeSH Terms] OR "turkey"[All Fields] OR "Turkish"[All Fields] OR "united kingdom"[MeSH Terms] OR "UK"[All Fields] OR "United Kingdom"[All Fields] OR "british"[All Fields] OR "England"[All Fields] OR "South-East Asia"[All Fields] OR "South-East Asian"[All Fields] OR "indonesia"[MeSH Terms] OR "indonesia"[All Fields] OR "indonesian"[All Fields] OR "bangladesh"[MeSH Terms] OR "bangladesh"[All Fields] OR "bengali"[All Fields] OR "bangladeshi"[All Fields] OR "vietnam"[MeSH Terms] OR "vietnam"[All Fields] OR "vietnamese"[All Fields] OR "western pacific"[All Fields] OR “east asia”[TIAB] OR "china"[MeSH Terms] OR "china"[All Fields] OR "chinese"[All Fields] OR "japan"[MeSH Terms] OR "japan"[All Fields] OR "japanese"[All Fields] OR "australia"[MeSH Terms] OR "australia"[All Fields] OR "australian"[All Fields]	8,719,231
All	1 AND 2 AND 3	672
Filters	Filters: Full text, Books and Documents, Classical Article, Evaluation Study, Government Publication, Guideline, Meta-Analysis, News, Observational Study, Patient Education Handout, Periodical Index, Practice Guideline, Review, Systematic Review, Validation Study, English, from 2014/5 - 3000/12/12	3,322

Table 4: Ad-hoc Google search terms for, by category (run for each region)

Metric search terms (one of each set, run for each region/sample country)	Search time
[REGION OR SAMPLE COUNTRIES] AND (psoriasis OR psoriatic arthritis) AND (access OR availability OR sales) AND (biologics OR biologic therapies OR systemics OR systemic therapies)	2 hours per region (average, 15 minutes per search string, per region)
[REGION OR SAMPLE COUNTRIES] AND (psoriasis OR psoriatic arthritis) AND (clinical guidelines OR treatment guidelines OR national guidelines OR national recommendations)	
[REGION OR SAMPLE COUNTRIES] AND (psoriasis OR psoriatic arthritis) AND (survey OR quality of life) AND (discrimination OR stigma)	
[REGION OR SAMPLE COUNTRIES] AND (psoriasis OR psoriatic arthritis) AND (comorbidity OR comorbidities) AND (prevalence OR risk OR rate OR probability OR frequency OR assessment OR screen OR screening OR check OR test OR testing)	
[REGION OR SAMPLE COUNTRIES] AND (psoriasis OR psoriatic arthritis) AND (misdiagnosis OR diagnostic errors OR misdiagnosed OR diagnostic delay OR time to diagnosis OR TTD OR diagnostic time)	
[REGION OR SAMPLE COUNTRIES] AND (psoriasis OR psoriatic arthritis) AND (access to healthcare OR health services accessibility OR access to care)	
[REGION OR SAMPLE COUNTRIES] AND (psoriasis OR psoriatic arthritis) AND (patient organization OR advocacy group OR NGO OR patient association) AND (funding OR management OR administration)	
[REGION OR SAMPLE COUNTRIES] AND (psoriasis OR psoriatic arthritis) AND (world psoriasis day)	

Table 5: Outcomes of interest to assess progress in each metric

Metric 1: Improvements to healthcare education and access to treatment of psoriatic disease

- Evidence of systemic and biologic treatments being prescribed/ reimbursed in the region / sample country
- Availability of up-to-date guidelines in the region / sample countries
- Assessment of clinical guidelines in the region / sample countries

Metric 2: Recognition of the chronicity and burdensome symptoms of psoriatic disease

- Assessment of clinical guidelines in the region / sample country

Metric 3: Improvements to social and work-related stigma and discrimination

- Assessment of patient survey-based evidence of stigma and discrimination

Metric 4: Greater understanding of the elevated risk of comorbidities from psoriatic disease

- Assessment of clinical guidelines in the region / sample country
- Density of publications assessing the risk of comorbidities or describing screening for comorbidities in the region / sample countries
- Estimates of the prevalence of comorbidities in psoriasis, by country / region

Metric 5: Greater understanding of the prevalence of PsA in PsO patients

- Assessment of clinical guidelines in the region / sample country
- Assessment of clinical guidelines in the region / sample country
- Density of publications assessing the risk of PsA or describing screening for PsA in the region / sample countries
- Studies on the prevalence of psoriatic arthritis in psoriasis patients by country / region, compared to the average estimate of PsO patients affected with PsA
- Estimates of the prevalence of comorbidities in psoriasis, by country / region

Metric 6: Reductions in diagnostic delay, treatment limitations and care limitations

- Density of publications assessing the rate of misdiagnosis
- Estimates of the rate of misdiagnosis
- Estimates for time from presentation to healthcare till diagnosis
- Estimates of systemic / biologic therapy sales in the region / sample country
- Assessments from studies looking at access to psoriatic disease care

Metric 7: Greater advocacy by stakeholders

- Estimates of funding for psoriasis patient groups
- Participation in World Psoriasis Day

Additional measures

- Measure A: evidence of QoL improvement for patients since 2014
- Measure B: evidence of a reduction of burden on patients and families since 2014
- Measure C: evidence that patients are more easily able to regain employment / contribute to society over the past 10 years
- Measure D: evidence of holistic management approach to psoriatic disease care in the healthcare system
- Measure E: evidence of laws passed since the resolution

Table 6: Voluntary patient survey questions

Voluntary patient survey questions

1. How long did it take for you to receive a psoriasis diagnosis, since you first talked to a doctor about your symptoms?
   a. less than a month
   b. 2 – between 1 and 3 months
   c. 3 – between 3 and 6 months
   d. 4 – between 6 and 12 months
   e. 5 – more one year

2. Before you received your psoriasis or psoriatic arthritis diagnosis, did you have any problems with doctors giving you the wrong diagnosis for your symptoms?
   a. 1 – yes
   b. 2 – no

3. When you were first diagnosed, how helpful was the information you received from your doctor or nurse?
   a. 1 – not helpful
   b. 2 – only a little helpful
   c. 3 – somewhat helpful
   d. 4 – helpful
   e. 5 – very helpful

4. Did the doctor who diagnosed you inform you that it is common for people with psoriasis to develop psoriatic arthritis?
   a. 1 – no
   b. 2 – yes

5. Did the doctor who diagnosed you inform you that having psoriasis can increase your risk for other diseases such as heart disease, diabetes, or liver disease?
   a. 1 – no
   b. 2 – yes

6. How easy is it for you to access the psoriasis and/or psoriatic arthritis treatment you currently need?
   a. 1 – very difficult
   b. 2 –difficult
   c. 3 – moderate
   d. 4 –easy
   e. 5 – very easy

7. Do you feel that access to treatment has improved in the last 10 years?
   a. 1 – no
   b. 2 – yes

8. (If applicable) How difficult was it for you to meet with a dermatologist?
   a. 1 – very difficult
   b. 2 –difficult
   c. 3 – moderate
   d. 4 –easy
   e. 5 – very easy

9. (If applicable) How difficult was it for you to meet with a rheumatologist?
   a. 1 – very difficult
   b. 2 –difficult
   c. 3 – moderate
   d. 4 –easy
   e. 5 – very easy

10. Do you feel that specialist care has become more accessible in the last 10 years?
    a. 1 – no
    b. 2 – yes

11. How much do you think the average person without psoriasis or psoriatic arthritis in your country knows about psoriasis?
    a. very little
    b. little
    c. moderate
    d. much
    e. very much

12. How often have you experienced negative reactions to your symptoms from people around you, for example at work or in public places?
    a. 1 – never
    b. 2 – rarely
    c. 3 – occasionally
    d. 4 – frequently
    e. 5 – very often

13. Do you feel that people’s understanding of psoriasis has improved in the last 10 years?
    a. 1 – no
    b. 2 – yes

14. Since you started receiving treatment for psoriasis / psoriatic arthritis, do you feel that your quality of life has improved?
    a. 1 – no
    b. 2 – yes

15. In the past 10 years do you feel that it has become easier over time for people with psoriasis or psoriatic arthritis to get a new job or stay in the job they have?
    a. 1 – no
    b. 2 – yes

IFPA
GLOBAL LEADER IN FIGHTING
PSORIATIC DISEASE