

Patient Perspectives on Psoriatic Disease Burden: Results from the Global Psoriasis and Beyond Survey

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Abstract (357/400)

Background: Patients' understanding of the systemic nature of psoriatic disease (PsD) remains insufficiently explored.

Objectives: To assess patients' understanding of PsD, associated comorbidities, disease burden, and relationships with healthcare professionals (HCPs).

Methods: Psoriasis and Beyond was a cross-sectional, quantitative online survey conducted in patients with a self-reported, physician-given diagnosis of moderate to severe psoriasis (body surface area (BSA) >5% to <10%, affecting sensitive and/or prominent body parts or BSA ≥10%) at its worst, with/without psoriatic arthritis (PsA). Patients were recruited through online panels by the Institut de Publique Sondage d'Opinion Secteur (Ipsos SA) and patient advocacy groups.

Results: Overall, 4978 respondents with psoriasis completed the online survey from 20 countries across Australia, Asia, Europe, and the Americas; 30% of patients also reported having concomitant PsA. Overall, 69% of patients with psoriasis had heard that their disease was part of a systemic disease, and 60% had heard of the term "psoriatic disease". Despite this, recognition of common manifestations and comorbidities associated with PsD was low. Among psoriasis-only patients (n=3490), 38% screened positive using the Psoriasis Epidemiology Screening Tool (PEST), indicative of potential PsA. Overall, 48% of patients reported that their disease had a very large to extremely large effect on quality of life (QoL; Dermatology Life Quality Index (DLQI) score, 11–30); only 13% of patients reported no impact of the disease on QoL (DLQI, 0–1). Most patients had experienced stigma and discrimination (82%) and a negative impact on relationships (81%) in their lives. Overall, 59% of patients were not involved in deciding their treatment goals; 58% of all treated patients (n=4757) and 64% of treated patients with concomitant PsA (n=1409) were satisfied with their current treatment.

Conclusions: These results highlight that patients may not fully understand the systemic nature of their disease, were frequently uninvolved in deciding treatment goals, and were often not satisfied with their current treatment. Increasing patients' participation in their care can facilitate shared decision-making between patients and HCPs, which may result in better treatment adherence and patient outcomes. Furthermore, these data indicate that policies should be implemented to protect against stigma and discrimination, which are commonly experienced by patients with psoriasis.

Introduction

Plaque psoriasis is a chronic, systemic immune-mediated disease, characterized by erythematous scaly patches or plaques of the skin with extra-cutaneous areas involved, such as the nails, scalp, palms, soles and joints; psoriasis is associated with systemic comorbidities including cardiovascular disease (CVD) and metabolic syndrome [1-3]. Up to one-third of patients with psoriasis develop psoriatic arthritis (PsA), the most commonly recognized comorbidity of psoriasis [4]. Psoriatic disease (PsD) is the overarching term used to describe the many manifestations of psoriasis, PsA, and the associated comorbidities [5]. PsD has a substantial influence on patients' quality of life (QoL) and can result in social and occupational stigma and discrimination, disability, and functional decline [6-10].

Owing to the chronic nature of PsD, long-term treatment is often necessary. Evidence-based international treatment guidelines for PsD have been published and the main treatment goals are to achieve clinical remission and inhibit disease progression [11-19]. Further, treatment guidelines recognize PsD as a multi-system inflammatory disorder and emphasize a holistic approach to disease management focusing on comorbidities including mental health, psychosocial wellness and QoL [15]. However, despite recent advances in the management of psoriasis and PsD (e.g., with biologic agents), treatment gaps remain, which include under-treatment, timely access to specialists, access to biologic therapies, and early detection of comorbid diseases [20]. Further, diagnostic delays are commonly reported in PsD, particularly in the diagnosis of joint symptoms/PsA in patients with confirmed psoriasis [21, 4].

Recent guidelines for the management of psoriasis have emphasized the importance of a continuous dialog between healthcare professionals (HCPs) and patients, and reported that directly involving patients in their own care via shared decision-making is important in facilitating comprehensive care, empowering the patient and improving QoL [15]. Psoriasis and Beyond: The Global Psoriasis Disease Survey is a joint research initiative between the International Federation of Psoriasis Associations (IFPA) and Novartis, in collaboration with 16 patient advocacy groups (PAGs), a steering committee of patient advocates, and dermatology and rheumatology experts. This study aimed to assess patients' understanding of the systemic nature of psoriasis and PsA, the related manifestations and comorbidities and the impact of psoriasis and PsA on QoL. Here, we report the final results of the Psoriasis and Beyond study, which summarizes the perspectives of almost 5000 patients with PsD across 20 countries.

Methods

Study design

Psoriasis and Beyond was a cross-sectional, quantitative, online survey of patients with plaque psoriasis with or without concomitant PsA. The study included participants from 20 countries across Europe, Asia-Pacific, and the Americas (See **Table S1**). Data were collected between 12/11/2020 and 13/06/2021.

The online questionnaire was developed by the Institut de Publique Sondage d'Opinion Secteur (Ipsos SA) together with Novartis, IFPA and an external committee of patient advocates, and medical experts in the fields of psoriasis and PsA. Patients were recruited through online panels (either self-registered to the panel or recruited by the agency maintaining the panel) by Ipsos SA and PAGs. See **Supplementary Methods** for further information on the questionnaire employed.

Patients

Screening questions were used to determine the eligibility for each study respondent. To participate, patients (aged ≥ 18 years) had to have a self-reported, physician-given diagnosis of psoriasis or psoriasis with PsA before or at the time of data collection. Additionally, all patients had to have a self-assessed body surface area (BSA) of >5 to <10 (moderate to severe) affecting sensitive and/or prominent body parts (face, palms, hands, fingers, genitals, soles of feet or nails) or a BSA of ≥ 10 (severe), when a patient's psoriasis was at its worst. Exclusion criteria are noted in the **Supplementary Materials**. Following assessment of participant eligibility via a 5-minute online screener, a 25-minute internet-based survey was conducted without any follow-up.

Objectives

The primary objectives of this study were to assess patients' understanding of psoriasis and PsA as part of a systemic disease, and the humanistic and physical burden of living with these conditions.

Secondary objectives were to (1) assess patients' perceptions and attitudes related to their relationship with their HCP, (2) understand the patient journey through the healthcare system and (3) assess barriers to self-management and diagnosis, patient perceptions of biologic treatments, treatment expectations and satisfaction with care.

Data on self-reported diagnosis of psoriasis/PsA and comorbidities, and self-reported assessment of BSA (using a visual aid tool; see **Supplementary Materials**) and severity of psoriasis/PsA were also collected. Psoriasis severity was categorized using BSA scores (mild, BSA <5 ; moderate, BSA ≥ 5 to <10 ; severe, BSA ≥ 10).

88 See **Supplementary Methods** for primary and secondary endpoints, exclusion criteria and data analyses.

89 [Ethical considerations](#)

90 Informed digital consent was obtained from patients before study participation. This study was
91 reviewed and approved by the local Ethics Committees and Institutional Review Boards, according to the
92 local laws and regulations.

Results

Sample collection and demographics

In total, 4978 respondents were included in this study (81.0% (n=4034) recruited by Ipsos SA; 19.0% (n=944) recruited by PAGs). Sample collection by region and country is described in **supplementary Table 1**. Overall, 46.4% (n=2311), 28.0% (n=1394) and 25.6% (n=1273) of patients included were from Europe, Asia-Pacific and the Americas, respectively. Overall, 51.0% of patients were female (mean age, 44.0 years) and 49.0% were male (mean age, 42.5 years). Gender and age were relatively similar across regions (Europe, 47% female and mean age 45.0 years; Asia-Pacific, 57% female and mean age 40.0 years; Americas, 51% female and mean age 44.0 years).

Patients' understanding of psoriasis and PsA as part of a systemic disease

Overall (n=4978), 69% of all patients had heard that their disease was part of a systemic disease (shown in **Fig. 1a**), 60% had previously heard of the term "psoriatic disease" (shown in **Fig. 1b**) and of those with psoriasis only, 29% were aware that PsA was related to their psoriasis (shown in **Fig. 1c**). Further, less than one-third of the patients were aware of the relationship between psoriasis/PsA and common comorbidities including depression, anxiety, CVD and diabetes (shown in **Fig. 1d**). On average, all patients (n=4978) were aware of 2.5 manifestations and 2.8 comorbidities related to their psoriasis or PsA. Sources of awareness regarding manifestations and comorbidities (n=4616) are shown in **supplementary Fig. 1a**. Awareness of patient with psoriasis by region and country is further described in **supplementary Table 2**. In general, patient awareness was highest in Asia-Pacific countries, particularly India, South Korea and Taiwan.

Physical impact of PsD

Overall (n=4978), 82% of patients knew their BSA score, 4% did not remember and 14% answered that their HCP had never mentioned BSA. Of those patients who knew their BSA score, 63% reported a moderate (BSA: ≥ 5 to <10) and 37% reported a severe psoriasis (BSA: ≥ 10) when their psoriasis was at its worst. At the time of surveying, 60% of patients reported mild psoriasis (BSA <5), 24% reported moderate psoriasis while 16% had severe psoriasis. In total (n=4978), patients had an average of 5.4 body areas currently affected by their psoriasis; the most common areas affected were the legs (57%), scalp (56%), elbows (54%), arms (47%), knees (46%) and back (39%). Sensitive areas by current disease severity are presented in **Fig. 2a**. On average, patients had 2.0 affected sensitive areas, despite 60% currently having mild psoriasis; this percentage was higher in patients with a more severe psoriasis (shown in **Fig. 2b**).

Patients had already received a mean diagnosis of 2.5 comorbidities (mild, 2.4 comorbidities; moderate, comorbidities, 2.5 comorbidities; severe, 3.0 comorbidities), including anxiety (27%), obesity/overweight (26%), depression (25%), chronic gastrointestinal diseases (22%), and high cholesterol (22%) or CVD, including hypertension (20%). Presence of comorbidities based on the current psoriasis severity is shown in **supplementary Fig. 1b**.

Overall, 30% (1488/4978) of all patients reported also having been diagnosed with PsA (hereafter referred to as psoriasis-PsA). Of these patients, 14%, 47%, and 25% reported low, moderate and highly active PsA respectively, while 8% reported that their HCP had never told them about their PsA activity (shown in **Fig. 2c**). **Figure 2d** illustrates current psoriasis severity by the presence of PsA manifestations, demonstrating that even in patients with mild cutaneous disease, the presence of PsA symptoms is common.

Using the Psoriasis Epidemiology Screening Tool (PEST), which was developed to assist in identifying PsA at an early stage [22], patients who had not previously been diagnosed with PsA were screened for PsA signs and symptoms. Among those patients with psoriasis only (n=3490), 38% screened positive, indicative of a potential PsA presence. Positive PEST screening was higher in patients with moderate to severe psoriasis (mild, 36%; moderate, 43%; severe, 40%). Of the patients with only psoriasis, who were receiving biologics, 55% screened positive using PEST, suggestive of a potential presence and need for evaluation of PsA. Of interest, the proportion of PEST-positive patients with psoriasis only was highest in the Americas (49%) compared to Europe (34%) or the Asia-Pacific region (39%) (see **supplementary Table 2**).

Humanistic burden of psoriasis and PsA, and its impact on QoL

Previously reported Dermatology Life Quality Index (DLQI) ranges were used to evaluate the impact of psoriasis on QoL on the overall population (DLQI 0–1, no impact of the disease on QoL; 2–5, small impact; 6–10, moderate impact; 11–20, very large impact; 21–30, extremely large impact) [23]. Nearly half (48%) of all patients (n=4978) reported that their disease had a very large to extremely large impact on their QoL; only 13% of patients reported no impact of the disease on QoL (shown in **Fig. 3a**). The effect of the disease on QoL was greater in patients with moderate and severe psoriasis (shown in **Fig. 3b**). Further, the impact on QoL was substantially greater in patients with only psoriasis who had a positive PEST screening (n=1340); 64% had a very large to extremely large effect of their disease on QoL, with only 5% reporting no effect at all. Of all patients reporting an extremely large effect on QoL, 66%

also reported having clear skin. Further, 34% and 32% of patients with depression and anxiety also reported a very large to extremely large effect of their disease on QoL, respectively (shown in **supplementary Fig. 2**).

When asked about the effect of psoriasis on work experiences, 28% of all patients (n=4978) reported that their skin problems prevented them from working or studying within the previous week. Of those who had attended work (n=2686), 38% and 11% answered that their skin problems impacted their work either “*a little*” or “*a lot*”, respectively. In line with this, 14% of all patients’ (n=4978) careers were influenced by the presence of their disease, 12% had difficulty finding a job and 10% experienced discrimination at work due to their psoriasis and psoriasis-PsA. PEST-positive patients with psoriasis only (n=1340) were more impacted by their condition; 40% could not go to work due to their skin symptoms, and 48% and 16% of those who could attend work (60%) said that their skin problems impacted their work “*a little*” or “*a lot*”, respectively.

The impact of PsD on sexual life and relationships and their experiences of stigma and discrimination are shown in **Figure 4a–b**, respectively. One-fifth of the patients reported that they avoided having sex because of their condition (20%), and that they could not stand the thought of someone touching or seeing their skin (19%) (**shown in Fig. 4a**). Further, 35% of patients had been asked if they were contagious and 32% had been stared at in public due to their disease (**shown in Fig. 4b**). Coping mechanisms used by all patients (n=4978), and psoriasis-PsA patients (n=1488) are illustrated in **Fig. 4c–d**. On average, patients with psoriasis used 3.2 coping mechanisms to deal with their psoriasis (average of 3.7 in patients with psoriasis-PsA).

Patient knowledge, skill, and confidence for self-management were assessed using the Patient Activation Measure® 13 (PAM–13®) [24]. Overall (n=4978), 9% of patients were disengaged and overwhelmed (Level 1), 16% were becoming aware but still struggling (Level 2), 52% were taking action (Level 3), and 19% were maintaining behaviors and pushing further (Level 4).

Patient journey, patient-HCP relationship, and treatment perceptions

Of all patients (n=4978), the mean ages of first symptom onset and confirmed psoriasis diagnosis were 24.2 and 26.8 years, respectively. This relates to a delay in psoriasis diagnosis of 2.6 years. Further, in patients with psoriasis-PsA (n=1488), the mean ages of first symptom onset and confirmed PsA diagnosis were 30.8 and 32.8 years, respectively. This demonstrates a further delay in PsA diagnosis of 2.0 years. In all patients (n=4978), the most common current treatment for psoriasis was topical therapies (72%),

184 followed by biologics (42%) (shown in **Fig. 5a**); on average, patients had received 2.2 biologic treatments
185 for their psoriasis. In patients with psoriasis-PsA (n=1488), the most common current treatments were
186 biologics (55%), followed by non-steroidal anti-inflammatory drugs (NSAIDs; 46%) and disease-modifying
187 anti-rheumatic drugs (DMARDs; 44%; shown in **Fig. 5b**); on average, patients had received 2.8 biologic
188 treatments for their PsA. Only 36% and 46% of patients with psoriasis and psoriasis-PsA reported that
189 their condition improved with their current treatment, while 56% and 45% reported indifference,
190 respectively (shown in **Fig. 5c-d**). The effect of current psoriasis and PsA treatments by treatment type
191 are illustrated in **Fig. 5c-d**. Overall, 52% of patients achieved clear skin with their current treatment
192 regimen (shown in **Fig. 5e**) while 67% of patients believed that achieving clear skin was possible. The
193 highest proportion of clear skin was reported in patients with psoriasis currently receiving biologics
194 (67%; shown in **Fig. 5e**), followed by other systemic medications (57%) and phototherapy (52%), and in
195 patients with psoriasis-PsA currently receiving immunosuppressants (77%; shown in **Fig. 5f**) or biologics
196 (72%).

197 Only 58% of all treated patients (n=4757) and 64% of treated patients with psoriasis-PsA (n=1409) were
198 satisfied with their current treatment (shown in **Fig. 6a**). Key reasons for dissatisfaction were that the
199 treatment provided only partial or no relief of symptoms and did not improve the overall QoL (shown in
200 **Fig. 6b**). Treatment satisfaction was highest in those currently receiving biologics or other systemic
201 medications (73% and 67%, respectively; shown in **Fig. 6c**), for patients with psoriasis while similar levels
202 of satisfaction were recorded in patients with psoriasis-PsA receiving immunosuppressants (80%),
203 biologics (79%), and DMARDs (75%) (shown in **Fig. 6d**). Overall (n=4978), 29% of patients had previously
204 refused a biologic; the most frequent reasons for refusal were the possible side effects (46%), cost to the
205 patient (33%), possible long-term effects (30%) and frequency of treatment (30%).

206 Regarding treatment goals, 40% of patients reported that their HCP decided on the goals, 41% decided
207 on treatment goals along with their HCP and 19% reported having no discussion with the HCP on
208 treatment goals. Treatment goals were aligned between patients with psoriasis and psoriasis-PsA
209 (shown in **Fig. 7a**). Among all patients who had a discussion about treatment goals with their HCP
210 (n=4052), the most frequently reported aligned goals are shown in **Fig. 7b**. Further, personal treatment
211 goals (all patients) are shown in **Fig. 7c**. Overall (n=4978), 75% of patients always followed the advice of
212 their HCP, 65% felt that they could get in touch with their HCP if needed, and 65% felt listened to by
213 their HCP (shown in **supplementary Fig. 3**).

214 In total, 54% of patients experienced an impact of the coronavirus disease 2019 pandemic on their
215 treatment. Among those patients (n=2273), the most frequently reported impacts were the need for
216 telephone appointments (36%) or video call/online appointments (33%) instead of in-person
217 appointments, and issues with getting prescriptions (29%).

Discussion

Psoriasis and Beyond was a global study primarily designed to assess patients' understanding of the systemic nature of their PsD and the humanistic and physical burden of living with these conditions. Further, this study addresses ongoing problems associated with psoriasis despite therapeutic intervention. This study, conducted in 20 countries across four continents and including almost 5000 patients, highlighted the need for a greater understanding of the systemic nature of PsD and its associated manifestations and comorbidities. Further, it demonstrated the significant physical burden of PsD (as described by patients), the profound impact on QoL affecting patients' work experiences and personal relationships, and the related shame and stigma.

This study found that the majority of patients could not recognize the most common manifestations and/or comorbidities such as PsA, CVD and axial symptoms/disease. Although most patients had heard that psoriasis and PsA are part of a systemic disease, their understanding of the specific manifestations and comorbidities of PsA was lacking and as such, patients may require additional education. This is particularly important given the prevalence of these comorbidities within this patient population, with 30% and 18% already affected by PsA and CVD, respectively.

Psoriasis, especially nail psoriasis and extensive body surface involvement, is strongly associated with the development of PsA [25, 26]. Despite the observation that up to one-third of patients with psoriasis will develop PsA in their lifetime, PsA is underdiagnosed in patients with psoriasis, and a diagnostic delay of PsA of up to 5 years has been reported [27]. Early diagnosis of PsA is critical in minimizing non-reversible erosive joint damage [28]. Overall, 30% of the psoriasis population in this study had concomitant PsA; patients with PsA reported an average of a 2-year delay in their PsA diagnosis. Further, using PEST, 38% of patients with psoriasis only screened positive, indicating the presence of PsA. These results highlight the need for active screening for PsA by the psoriasis-treating HCP, since they represent the first line of care for PsD diagnosis and intervention. Guidelines for the management of PsD also indicate a role for the patient in identification of early signs of PsA; a proactive approach to patient education and routine screening by the psoriasis-treating HCP facilitates the earliest possible detection of PsA among patients with psoriasis [15].

The Psoriasis and Beyond study validate the need for evaluation of physical impact through different measures because although most patients had a BSA <5, a well-established clinical definition of mild disease, their description of current symptoms and body parts affected (especially sensitive areas) and DLQI scores suggests that the majority of patients were actually affected by more severe or poorly

controlled psoriasis. This finding is supported by the results of the Multinational Assessment of Psoriasis and Psoriatic Arthritis (MAPP) study, the first large-scale population-based survey focusing on the impact of PsD and patients' perceptions of and satisfaction with medical care [29]. The MAPP study uncovered many patient-reported unmet needs, including under-treatment of psoriasis, improved severity assessments, patient awareness and treatment options, key areas which are also highlighted in the current study. The MAPP study identified differences between self-perceived severities and validated clinical tools (e.g., 22% of patients with a BSA \leq 3% in the MAPP study rated their disease as "severe").

Despite 60% of patients in the present study currently experiencing mild psoriasis, only 13% reported no impact on QoL. Further, patients were commonly confronted with stigma and discrimination due to their skin condition. These findings are supported by the six key themes identified by Sumpton *et al.* in a recent systematic review describing the range and depth of patient perspectives and experiences in patients with psoriasis and PsA: (1) suffering uncontrollable and ongoing upheaval, (2) weighed down by mental load, (3) harboring shame and judgment, (4) demoralized by inadequacies and burden of therapy, (5) gaining control and (6) making confident treatment decisions [30]. The themes identified by Sumpton *et al.* (particularly gaining control and making confident treatment decisions) highlight the importance of the patients' role in the management of their own disease and the need for shared decision-making and a continuous dialog between patients and HCPs. Results from the PAM-13 screening demonstrated that only one fifth of patients were at Level 4 (representing the highest activation level at which patients are pro-active with their health). However, half of the patients were Level 3, indicating that they have begun taking action and viewed themselves as part of their own healthcare team. However, despite half of the patients taking action and despite the fact there are high levels of trust in the psoriasis treating HCP (the majority of patients followed their HCP's advice and felt that they could reach out to their HCP if needed), only 41% of patients were involved in goal setting with their HCP, and 19% reported never discussing treatment goals with their HCP at all. This is relevant since treatment goals may differ between HCPs and patients; consensus-driven treatment goals for psoriasis typically consider clear skin as the main treatment goal [31]; however our study showed that patients' personal goals were focused on the holistic impact of psoriasis, including the physical impact, the impact on the patient's everyday life and their QoL. Thus, it is crucial that HCPs understand and acknowledge patient goals' before initiating treatment.

The Observing Patient Involvement in Decision Making (OPTION) instrument previously determined that whatever the clinical context, only a few HCPs attempt to facilitate patient involvement and even fewer adjust care to patient preference [32]. Dermatologists reported that although they believed that patients' accessibility to dermatologists and information on treatment risks and benefits were the most important factors for decision-making, they also believed that the time that they had with patients and educational materials available were inadequate [33]. This was supported by an online survey of dermatologists and patients with psoriasis in which the key perceived barriers for shared decision-making were lack of continuity of care by the same HCP and lack of time [34]. A patient decision aid (PDA) may be a particularly valuable tool to facilitate shared decision-making. PDAs have been developed and piloted in patients with psoriasis [35-37] and those eligible for DMARDs [38]. These PDAs have demonstrated promise; were successful in increasing patient knowledge and reducing decisional conflict between patients and HCPs; and led to treatment decisions that were more in line with patient preferences [35, 36, 38, 37]. Further, PDAs may overcome the perceived barriers to shared decision-making, such as lack of time, since they may be taken home or provided in advance of consultations.

Clear skin was achieved by only 52% of patients in this study; this is in line with the Clear About Psoriasis [39] (2015/2016) study in which only 43% of patients achieved clear skin; of interest, 67% of patients believed that clear/almost clear skin was possible, compared to 44% in Clear About Psoriasis [39]. This suggests greater treatment expectations in this patient population. The highest levels of patient reported clear skin occurred in patients with psoriasis receiving biologic therapy, reflecting a high prevalence of treatment satisfaction in patients with psoriasis receiving biologics. This is in line with a systematic review which demonstrated that although patient satisfaction with currently available therapies was modest, patients treated with biologics reported the highest levels of treatment satisfaction compared to those treated with topicals, phototherapy or other oral therapies [40].

Limitations of this study include the use of self-reported data; diagnosis and any treatment-related aspects of the patient population were self-reported by the respondents. Survey answers were based on patients' perceptions and attitudes and therefore recall bias may be possible. Self-reported screening could reflect participant misconceptions of the screening processes, rather than the actual practice. Selection bias may be another limitation, as participants with eventful or burdensome experiences may have been more likely to participate. Further, patients with psoriasis or PsA who do not have access to the internet may be under-represented in this study. In addition, although the PEST tool has been widely validated, the authors are not aware of studies verifying similar test characteristics when applied in a

web-based format. Strengths of this study include the wide reach of the survey, large dataset, global population, and use of the visual aid tool provided in the survey for accurate self-assessment of disease severity.

Conclusion

The results of this study demonstrate that many patients do not yet fully understand that psoriasis and PsA are part of a systemic disease and therefore require further education. Further education should not only be facilitated via HCPs but also through PAGs and online platforms. Additionally, the impact and severity of the disease should always be assessed from different viewpoints, including the physical impact, the impact on the patient's everyday life and QoL, since physical impact alone is not a sufficient indicator of the burden of disease. Further, these assessments should also include the patient's perspective of impact, and not only what the HCP considers to be impactful. Given the complexity and impact of PsD, early diagnosis and increasing patient participation in their care (e.g., using PDAs) may facilitate shared decision-making between patients and HCPs, which along with providing a personalized and holistic treatment strategy, may result in better overall patient outcomes. Furthermore, these data indicate that policies should be implemented to protect against stigma and discrimination, which are commonly experienced by patients with psoriasis.

Statements

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(<http://www.ismpp.org/gpp3>).

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Statement of ethics

This study was reviewed by local ethics committees (EC) of the 20 countries included. Of the 20 countries, 13 did not need EC review or approval. In Norway, the Regional Committee for Medical and Health Research Ethics (REK) assessed the protocol and concluded that the study fell outside of the Health Research Act, cf. Section 2, and could therefore be carried out without the approval of REK (Application number, 246689). An institutional review board (IRB) in the US (Pearl IRB) considered this study to be exempt according to FDA 21 CFR 56.104 and 45CFR46.104(b)(2):(2). This exemption was applied to Canada and Chile. The study protocol was reviewed and approved by Bellbarry Human Research EC in Australia (Application number, 2021-02-196). The study protocol was reviewed and approved by the University of Tokyo Graduate School of Medicine EC (Serial number, 2020421NI). The study protocol was reviewed and approved by the Interuniversity Ethics Committee (A.I. Evdokimov Moscow State University of Medicine and Dentistry) in Russia (Protocol number, 13). Informed digital consent was obtained from patients before study participation. The procedure for obtaining electronic informed consent was outlined in the Psoriasis and Beyond study protocol, which was reviewed and approved according to local laws and regulations.

As per protocol:

Eligible patients may only be included in the study after providing IRB/EC-approved informed consent. Once a patient qualifies following the completion of the online qualification screener, the patient will be provided an electronic ICF, and will confirm consent by selecting “I have read, understood and accepted the points described in the informed consent document and I do freely give my consent to join this study as described to me in this document”.

Conflict of interest statement

April Armstrong serves as a research investigator and/or scientific advisor to AbbVie, BI, BMS, EPI, Incyte, Leo Pharma, UCB, Janssen, Eli-Lilly, Novartis, Ortho Dermatologics, Sun, Dermavant, Dermira, Sanofi, Regeneron, and Pfizer. **Barbra Bohannan**, **Sicily Mburu**, and **Silvia Fernandez Barrio** do not have any conflicts of interest. **Laura C Coates** has received grants/research support from AbbVie, Amgen, Celgene, Eli-Lilly, Janssen, Novartis, Pfizer and UCB; has worked as a paid consultant for AbbVie, Amgen, Boehringer Ingelheim, Bristol Myers Squibb, Celgene, Eli-Lilly, Gilead, Galapagos, Janssen, Moonlake, Novartis, Pfizer and UCB; and has been paid as a speaker for AbbVie, Amgen, Biogen, Celgene, Eli-Lilly, Galapagos, Gilead, GSK, Janssen, Medac, Novartis, Pfizer, and UCB. **Alexis Ogdie** has served as a consultant for AbbVie, Amgen, BMS, Celgene, CorEvitas, Gilead, GSK, Janssen, Eli-Lilly, Novartis, Pfizer,

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Author contributions

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All authors approved the final version to be published.

Data availability

The datasets generated and/or analyzed during the current study are not publicly available. Novartis is committed to sharing with qualified external researchers access to patient-level data and supporting clinical documents from eligible studies. These requests are reviewed and approved on the basis of scientific merit. All data provided are anonymized to respect the privacy of patients who have participated in the survey in line with applicable laws and regulations. The data may be requested from the corresponding author of the manuscript and further enquiries can be directed to the corresponding author.

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Figure Legends

Fig. 1. Patients' understanding of psoriasis and PsA as part of a systemic disease.

Pie charts demonstrating (a) proportion of patients (%) who had previously heard that their disease was a systemic disease or (b) had previously heard of the term 'psoriatic disease'. Bar charts showing proportion of patients (%) who were aware of (c) manifestations related to their disease and (d) comorbidities related to their disease (could be related to either psoriasis or PsA). *Questioned only to patients with psoriasis only. CVD, cardiovascular disease; GI, gastrointestinal; PsA, psoriatic arthritis.

Fig. 2. Current physical burden of psoriasis and PsA. (a) Bar graph showing the proportion of patients currently affected at sensitive areas by current disease severity. (b) Bar graph showing the proportion of patients with ≥ 1 , ≥ 2 , and ≥ 3 sensitive areas affected, overall and by current disease severity. (c) Pie chart illustrating the severity of disease in those patients with a diagnosis of PsA. (d) Bar chart showing current psoriasis severity (% mild, moderate, severe) by presence of PsA manifestations. Mild psoriasis: BSA < 5 ; moderate psoriasis: BSA ≥ 5 to < 10 ; severe psoriasis: BSA ≥ 10 . BSA, body surface area; PsA, psoriatic arthritis.

Fig. 3. Effect of psoriasis on patients' QoL. (a) Pie chart showing the effect on patients' QoL DLQI ranges (see Methods section). (b) Bar chart showing the impact on QoL based on current disease severity. Data are represented as proportion of patients (%). Mild psoriasis: BSA < 5 ; moderate psoriasis: BSA ≥ 5 to < 10 ; severe psoriasis: BSA > 10 . BSA, body surface area; DLQI, Dermatology Life Quality Index; QoL, quality of life.

Fig. 4. Effect of PsD on personal relationships and experiences of discrimination and coping mechanisms used. Bar charts showing the proportion of patients (%) reporting (a) an impact on sexual life and relationships and (b) experiences of discrimination and stigma. Results show the top ten most popular answers. Bar charts showing the proportion of patients with psoriasis (%) (c) and psoriasis-PsA (d) using specified coping mechanisms to deal with their disease. *Refusal to provide me a treatment at

beauty clinic/cosmetic studio, people refusing to serve me in shops, being asked to leave a form of public transport. PsA, psoriatic arthritis; PsD, psoriatic disease.

Fig. 5. Current treatments and effect of treatments for psoriasis and PsA. *Immunosuppressants (e.g. cyclosporine and azathioprine). Bar charts showing the proportion of patients (%) receiving specified treatments to treat psoriasis (a) and PsA (b). Bar charts showing the effect of the current treatments on psoriasis (c) and PsA (d) and the proportion of patients (%) achieving clear skin with the current psoriasis (e) and PsA (f) therapy. DMARD, disease-modifying anti-rheumatic drug; NSAID, non-steroidal anti-inflammatory drug; PsA, psoriatic arthritis; UV, ultraviolet.

Fig. 6. Treatment satisfaction overall and based on current treatments. Bar graph showing the proportion of patients with psoriasis and psoriasis-PsA satisfied with their current treatment (a). Frequency (%) of key reasons cited for dissatisfaction with current treatment regimen (b). Bar graphs showing patient satisfaction based on current treatments in patients with psoriasis (c) and psoriasis-PsA (d). DMARD, disease-modifying anti-rheumatic drug; NSAID, non-steroidal anti-inflammatory drug; PsA, psoriatic arthritis; UV, ultraviolet.

Fig. 7. Treatment goals. *These questions were only shown to patients with both psoriasis and PsA. (a) Pie charts showing the proportion of all patients, patients with psoriasis only, and patients with psoriasis-PsA who were involved in deciding treatment goals along with their HCP. Of all patients who had a discussion about treatment goals with their HCP (n=4052; navy and grey proportions in part a), treatment goals (top 10) aligned with HCPs are shown (b). Personal treatment goals (top 10) described by patients (c). Data are represented as proportion of patients (%). HCP, healthcare professional; PsA, psoriatic arthritis.