Appendix S1

Supplementary Methods

Study Design

Data were collected between February–October 2020. This was a market research survey conducted by Adelphi Real World, independently of Novartis, using a combination of physician-reported survey data, physician-completed medical record data abstraction, and patient/carer-reported survey data.

Inclusion and Exclusion Criteria

To be included in this survey, physicians had to consult with ≥10 paediatric PsO patients in a typical month. There were no exclusion criteria for physicians. To be included in the study, patients had to be 4–17 years old with a diagnosis of PsO, visiting a participating dermatologist, paediatrician, or GP/PCP, and receiving treatment for PsO. Patients could have been receiving multiple treatment classes together (e.g., topical and conventional systemic therapy, or conventional systemic and biologic therapy).

Data sources and questionnaires employed

The Patient self-completion questionnaires (PSC)/ carer self-completion questionnaires (CSC) were completed via pen and paper in the physician's office immediately after consultation and returned to the physician in a sealed envelope. The PSC/CSC consisted of nine sections (sections A–I) with each covering the following topics: (A) about you/your child, (B) your/your child's psoriasis (PsO), (C) severity and symptoms of your/your child's PsO, (D) Children's Dermatology Life Quality Index (CDLQI), (E) FDLQI (only filled out by carers of PsO patients <12 years), (F) treatment aspirations, (G) treatment satisfaction, (H) feelings about your/your child's PsO, (I) general questions about your/your child's PsO. The PSC/CSC were linked to the Physician Record Form (PRF) at data processing.

Study outcomes

Specific outcomes reported included:

- Health-related QoL; (CDLQI) and family QoL (FDLQI) scores
- Itching and pain severity due to PsO in the past 24 hours (0–10 numerical scale, where 10 represents the worst imaginable itch)
- Frequency of itching due to PsO in the past week (Likert scale: never, once in a while, sometimes, usually, all of the time)

- Impact of itching and PsO on school/study/work, sleep, physical activity, and social activity in the past week (Likert scale: not at all, a little, quite a bit, a lot, or a huge amount)
- Correlation of itch with CDLQI
- Level of satisfaction with treatment as reported by physician, patients, and carers, and reasons (pre-specified in the respective questionnaires) for dissatisfaction
- Treatment goals as reported by physicians, patients, and carers (pre-specified in the respective questionnaires)
- Size of alignment/concordance with physicians, patients, and carers regarding satisfaction with treatment using Cohen's Kappa. Cohen's Kappa scale is between 0–1, where 1 indicates complete agreement, and 0 indicates that any agreement is due to random chance (scale: 0–0.2 a slight alignment, 0.2–0.4 a fair alignment, 0.4–0.6 a moderate alignment, 0.6–0.8 a substantial alignment and 0.8–1 an almost perfect alignment)[1]

Data analysis

In addition to subgroup analyses by physician-judged disease severity, data were also filtered as follows:

- To adequately assess clinical unmet needs in the overall patient population, allowing sufficient time to respond to treatments, data were filtered to exclude paediatric patients with a treatment time <4 weeks for topical therapy and/or <12 weeks for conventional systemic and/or biologic therapy
- Based on geographical location (US vs EU5)
- Based on biologic treatment (currently receiving/not receiving a biologic; including biosimilars)

Spearman's correlation was calculated, and count plots were generated to measure and illustrate the association between itch severity and CDLQI. Regression-adjusted means were derived for CDLQI and regressions were adjusted for itch severity. The weighted Cohen's Kappa statistic was calculated as a measure of agreement to compare survey responses as stated by physicians, patients and carers. The data were analysed as observed.

Regulatory and ethics considerations

The survey was performed in compliance with the European Pharmaceutical Market Research Association (EphMRA) and in full accordance with the US Health Insurance Portability and Accountability Act (HIPAA) 1996. Ethical approval was granted by the Western Copernicus Group Institutional Review Board (WCG-IRB).

Appendix S2

Supplementary Results

Impact on quality of life

F-DLQI

PsO affected the QoL of family members, as measured by the FDLQI (overall, 4.9±5.3); this effect was more pronounced in patients with moderate or severe disease (**Fig. S3A**).

Data presented by US vs EU5

On average, the effect of PsO on patients' QoL was greater in patients from the EU5 (overall, 5.1±5.1, as reported by patients [PSC]; 6.3±5.4, as reported by carers [CSC]) compared with the US (overall, 3.8±5.0, as reported by patients [PSC]; 3.8±4.5, as reported by carers [CSC]) (**Fig. S4A–B**). When looking at individual CDLQI item means between the EU5 and US, numerically, the greatest differences were observed for items 3 (effect on friendships), 5 (effect on socialising/hobbies), 6 (effect on sports/swimming), and 8 (experiencing teasing/bullying) (S**Table I**). The effect of disease on the QoL of patients' families, as measured by FDLQI, was also greater in the EU5 compared with the US (**Fig. S3B–C**).

Overall, additional QoL outcomes were similarly reported by patients and carers of patients and between the EU5 and US (**Fig. S4C–H**). Of note, carers of paediatric patients (CSC) with a severe disease in the US reported low impact on QoL across all endpoints (**Fig. S4B, D, F, H**), however, this is likely due to the small sample size of this group (n=3).

Treatment dissatisfaction was relatively similar between the overall EU5 and US populations (S**Fig. 1A–H**).

Alignment between physician, patients, and carers of patients

Analysis of Cohen's Kappa was used to assess the level of alignment/concordance (between physicians and patients in addition to physicians and carers) on disease severity, treatment satisfaction, and treatment goals (**SFig. 2**). Generally, the alignment between physicians and either patients or carers were similar (i.e., similar alignment in adolescents and younger children). The greatest alignment was observed between physicians and patients with regards to satisfaction with current treatment (Cohen's Kappa, 0.48; 79.7% agreement, n=650 pairs). Physicians were only fairly aligned with patients or carers regarding treatment goals and current severity (**SFig. 2**).

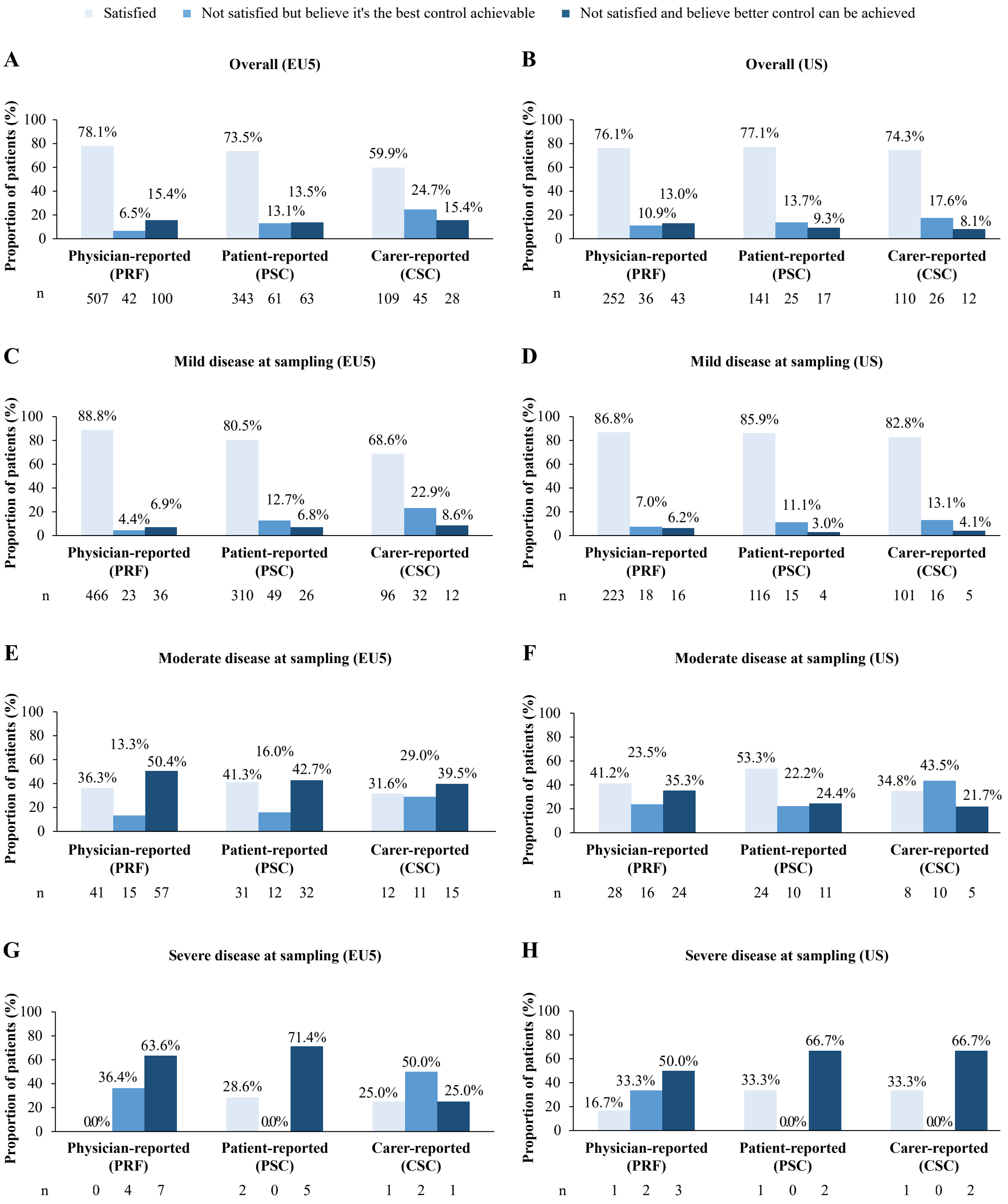
STable I. Mean patient- and carer-reported individual CDLQI items in the EU5 and US

	EU5		US	
CLDQI item, mean±SD	**Patient-reported (PSC) N=475**	**Carer-reported (CSC) N=191**	**Patient-reported (PSC) N=186**	**Carer-reported (CSC) N=156**
(1) Over the last week, how itchy, scratchy, sore or painful has your skin been?	0.83±0.72	0.97±0.75	0.82±0.75	0.90±0.71
(2) Over the last week, how embarrassed or self-conscious, upset or sad have you been because of your skin?	0.68±0.75	0.82±0.79	0.54±0.78	0.49±0.70
(3) Over the last week, how much has your skin affected your friendships?	0.41±0.66	0.52±0.69	0.19±0.51	0.17±0.48
(4) Over the last week, how much have you changed or worn different or special clothes/shoes because of your skin?	0.57±0.80	0.70±0.77	0.42±0.81	0.30±0.68
(5) Over the last week, how much has your skin trouble affected going out, playing or doing hobbies?	0.53±0.74	0.68±0.77	0.32±0.65	0.27±0.60
(6) Over the last week, how much have you avoided swimming or other sports because of your skin?	0.60±0.81	0.69±0.90	0.34±0.74	0.33±0.68
(7) Over the last week, how much did your skin problem affect your schoolwork or interfered with your enjoyment of the holiday?	0.05±0.26	0.05±0.25	0.09±0.43	0.02±0.18
(8) Over the last week, how much trouble have you had because of your skin with other people calling you names, teasing, bullying, asking questions, or avoiding you?	0.34±0.58	0.45±0.65	0.14±0.47	0.24±0.57
(9) Over the last week, how much has your sleep been affected by your skin problem?	0.51±0.69	0.70±0.75	0.42±0.66	0.49±0.62
(10) Over the last week, how much of a problem has the treatment for your skin been?	0.53±0.68	0.74±0.73	0.53±0.71	0.54±0.68

CDLQI, Children's Dermatology Life Quality Index; CSC, carer self-completion questionnaire; EU5, 5 key European countries; PSC, patient self-completion questionnaire; US, United States.

SFig. 1. Physician-reported and patient- and carer-reported satisfaction with current treatment, overall and by physician-judged severity at the time of sampling in the EU5 and US

Bar graphs demonstrating treatment satisfaction by disease severity **(A, C, E, F)** in the EU5 and **(B, D, F, H)** US separately. Physician-reported data are derived from PRFs and patient and carer data are derived from PSC/CSC. Only physician data in which there were matched patient-level data (PSC or CSC) are reported. CSC, carer self-completion questionnaire; EU5, 5 key European countries; n, total number of patients with available data; PRF, patient record form; PSC, patient self-completion questionnaire; US, United States.



SFig. 2. Level of alignment between physicians, patients and carers regarding disease severity, treatment satisfaction and treatment goals

Only physician data in which there were matched patient-level data (PSC or CSC) are reported. CSC, carer self-completion questionnaire; n, number of pairs (physician and carer or physician; PSC, patient self-completion questionnaire.