

SUPPLEMENTARY MATERIALS

Understanding Social Drivers of Health Among US Adults with Psoriasis from Different Races and Ethnicities

Short title: Social Health Drivers in Psoriasis Across US Racial and Ethnic Groups

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Victoria Barbosa,¹ Tina Bhutani-Jacques,² Valerie D Callender,^{3,4} Elizabeth D Bacci,⁵ Evangeline Pierce,⁶ Beth Mitchell,⁶ Julia R. Correll,⁵ Nicole Huang⁷

¹University of Chicago Medicine, Section of Dermatology, Chicago, Illinois, USA

²Synergy Dermatology, San Francisco, California, USA

³Howard University College of Medicine, Washington, District of Columbia, USA

⁴Callender Dermatology & Cosmetic Center, Glenn Dale, Maryland, USA

⁵PPD Evidera Patient-Centered Research, Thermo Fisher Scientific, Waltham, Massachusetts, USA

⁶Eli Lilly and Company, Indianapolis, Indiana, USA

⁷National Psoriasis Foundation, Portland, Oregon, USA

Corresponding author:

Beth Mitchell

Eli Lilly and Company, Indianapolis, USA

E-mail: mitchell_beth_d@lilly.com

Online Resource Table 1: Patient-reported outcome measures and other assessments

Survey Item	Description, Scoring, and Interpretation
Fitzpatrick Skin Scale²⁰	- Used to determine an individual's skin's response to ultraviolet light; recall period: current - Single-item measure comprising 6 skin types (I through VI). Decreasing numbers associated with increased burning, lighter skin tone, and an increased risk of skin cancer - Participants were shown a description of 6 skin types and asked to choose the 1 that most closely matches their own.
Monk Skin Tone Scale²¹	- Visual presentation of 10 skin tones; designed to be inclusive and representative of darker skin tones. No associated scoring; recall period: current - In the survey, participants were shown an image of each skin tone and were able to choose the 1 that most closely matches their own.
EQ-5D-5L²²	- Non-disease-specific instrument for describing and evaluating health-related quality of life; recall period: today - Includes 5 domains: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression, each with 5 levels: no problems, slight problems, moderate problems, severe problems, and extreme problems
EQ Visual Analogue Scale (VAS)²²	- Non-disease-specific instrument for describing and valuing health-related quality of life; recall period: today - Vertical VAS, endpoints labelled 'The best health you can imagine' (100) and 'The worst health you can imagine' (0)
The Dermatology Life Quality Index (DLQI)²³	- Patient-administered, 10-item, validated, quality of life questionnaire that covers 6 domains including symptoms and feelings, daily activities, leisure, work and school, personal relationships, and treatment; recall period: 1 week - DLQI scores range from 0 to 30; higher scores indicate worse quality of life
Patient Global Impression of Severity (PGI-S)²⁴	- To assess patient's impression of their disease severity; 1 item; recall period: 1 month 5-point scale with a higher value indicating more severe disease (0=no symptoms, 2=very mild, 3=mild, 4=moderate, 5=severe)
Quality of Life in Neurological Disorders (Neuro-QoL) Stigma Short Form²⁵	8-item, self-reported, quality of life questionnaire with response options: never, rarely, sometimes, often, and always; recall period: lately - Each item is scored from 1 to 5; total scoring ranges from 8 to 40; higher scores indicate increased stigma
Patient-Reported Outcomes Measurement Information System – Managing Social Interactions Short Form (PROMIS)²⁶	8-item self-reported questionnaire on managing social interactions with response options: I am not at all confident, I am a little confident, I am somewhat confident, I am quite confident, I am very confident; recall period: current - Each item scored 1 to 5; total score ranges from 8 to 40; higher scores indicate higher confidence
Protocol for Responding to & Assessing Patients' Assets, Risks and Experiences (PRAPARE)²⁷	- Social risk assessment/screening tool designed to assess social drivers of health; 17 core questions; recall period: current - The core question domains are personal characteristics, family and home, money and resources, and social and emotional health. All response options are assigned a value of 0 or 1, with individual question scores totaling 0 to 7. Total scores range from 0 to 22, with 0 indicating the participant reported no social driver of health risks and 22 indicating the participant reported all measured risks
All of Us Research Program²⁸	6 questions from the All of Us research program healthcare access and utilization survey were included - The questions have verbal response options for frequency and level of importance. Each item is reported individually

Online Resource Table 2: EQ-5D-5L index scores and visual analogue scale scores

Item	Overall (N=285)	Race						Ethnicity	
		White (N=194)	Black or African American (N=55)	Asian (N=10)	American Indian and Alaska Native (N=5)	Native Hawaiian and Other Pacific Islander (N=3)	Two or More Races (N=18)	Not Hispanic nor Latino (N=227)	Hispanic or Latino (N=58)
EQ-5D-5L Index Score ^a									
Mean (SD) ^b	0.71 (0.27)	0.72 (0.27)	0.63 (0.23)	0.84 (0.14)	0.42 (0.34)	0.86 (0.15)	0.78 (0.26)	0.71 (0.28)	0.67 (0.18)
Range (Min - Max)	-0.45 - 1.00	-0.45 - 1.00	-0.31 - 1.00	0.59 - 1.00	-0.16 - 0.72	0.71 - 1.00	0.16 - 1.00	-0.45 - 1.00	-0.06 - 0.94
95% CI (Lower - Upper)	0.67 - 0.74	0.68 - 0.76	0.56 - 0.69	0.74 - 0.94	-.00 - 0.84	0.50 - 1.22	0.65 - 0.90	0.68 – 0.75	0.63 - 0.72
EQ-5D-5L Health VAS (0-100 with 100=best health imaginable)									
EQ-5D-5L Health VAS Responses (n, %)									
0 - 10	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
11 - 20	2 (0.7)	1 (0.5)	0 (0)	0 (0)	1 (20.0)	0 (0)	0 (0)	2 (0.9)	0 (0)
21 - 30	9 (3.2)	7 (3.6)	0 (0)	1 (10.0)	0 (0)	0 (0)	1 (5.6)	9 (4.0)	0 (0)
31 - 40	12 (4.2)	7 (3.6)	2 (3.6)	2 (20.0)	0 (0)	0 (0)	1 (5.6)	11 (4.8)	1 (1.7)
41 - 50	20 (7.0)	14 (7.2)	3 (5.5)	1 (10.0)	2 (40.0)	0 (0)	0 (0)	17 (7.5)	3 (5.2)
51 - 60	36 (12.6)	25 (12.9)	9 (16.4)	1 (10.0)	0 (0)	1 (33.3)	0 (0)	26 (11.5)	10 (17.2)
61 - 70	64 (22.5)	51 (26.3)	11 (20.0)	0 (0)	0 (0)	0 (0)	2 (11.1)	50 (22.0)	14 (24.1)
71 - 80	83 (29.1)	55 (28.4)	19 (34.5)	1 (10.0)	2 (40.0)	0 (0)	6 (33.3)	64 (28.2)	19 (32.8)
81 - 90	44 (15.4)	25 (12.9)	7 (12.7)	4 (40.0)	0 (0)	1 (33.3)	7 (38.9)	34 (15.0)	10 (17.2)
91 - 100	13 (4.6)	9 (4.6)	2 (3.6)	0 (0)	0 (0)	1 (33.3)	1 (5.6)	12 (5.3)	1 (1.7)
Missing	2 (0.7)	0 (0)	2 (3.6)	0 (0)	0 (0)	0 (0)	0 (0)	2 (0.9)	0 (0)
Mean (SD) ^b	67.8 (17.4)	68.0 (16.1)	67.1 (18.8)	61.7 (25.1)	54.0 (26.6)	78.3 (22.1)	73.7 (17.1)	67.3 (18.5)	70.0 (11.5)
Range (Min - Max)	0 – 100	12 - 100	0 - 100	23 - 89	15 - 80	53 - 94	24 - 91	0 - 100	40 - 93
95% CI (Lower - Upper)	65.8 - 69.9	65.7 - 70.3	62.1 - 72.2	43.8 - 79.7	20.9 - 87.1	23.3 - 133.3	65.2 - 82.2	64.9 - 69.7	66.9 - 72.9

CI, confidence interval; max, maximum; min, minimum; SD, standard deviation; VAS, Visual Analogue Scale

^aThe EQ-5D-5L Index Score is calculated using the country-specific value set for the United States.

^bHigher scores for the index score and the VAS indicate greater utility and quality of life.

Online Resource Table 3: EQ-5D-5L descriptive statistics of the 5 categorical items

Item	Overall (N=285)	Race						Ethnicity	
		White (N=194)	Black or African American (N=55)	Asian (N=10)	American Indian and Alaska Native (N=5)	Native Hawaiian and Other Pacific Islander (N=3)	Two or More Races (N=18)	Not Hispanic nor Latino (N=227)	Hispanic or Latino (N=58)
EQ-5D-5L, Current health: Mobility (n, %)									
No problems walking	152 (53.3)	114 (58.8)	14 (25.5)	7 (70.0)	2 (40.0)	3 (100.0)	12 (66.7)	131 (57.7)	21 (36.2)
Slight problems walking	94 (33.0)	53 (27.3)	35 (63.6)	3 (30.0)	0 (0)	0 (0)	3 (16.7)	61 (26.9)	33 (56.9)
Moderate problems walking	34 (11.9)	24 (12.4)	5 (9.1)	0 (0)	2 (40.0)	0 (0)	3 (16.7)	30 (13.2)	4 (6.9)
Severe problems walking	5 (1.8)	3 (1.5)	1 (1.8)	0 (0)	1 (20.0)	0 (0)	0 (0)	5 (2.2)	0 (0)
Unable to walk	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
EQ-5D-5L, Current health: Self-Care (n, %)									
No problems washing/dressing	204 (71.6)	159 (82.0)	18 (32.7)	8 (80.0)	0 (0)	3 (100.0)	16 (88.9)	179 (78.9)	25 (43.1)
Slight problems washing/dressing	66 (23.2)	28 (14.4)	33 (60.0)	1 (10.0)	3 (60.0)	0 (0)	1 (5.6)	34 (15.0)	32 (55.2)
Moderate problems washing/dressing	11 (3.9)	4 (2.1)	3 (5.5)	1 (10.0)	2 (40.0)	0 (0)	1 (5.6)	11 (4.8)	0 (0)
Severe problems washing/dressing	2 (0.7)	2 (1.0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (0.4)	1 (1.7)
Unable to wash/dress	2 (0.7)	1 (0.5)	1 (1.8)	0 (0)	0 (0)	0 (0)	0 (0)	2 (0.9)	0 (0)
EQ-5D-5L, Current health: Usual Activities (n, %)									
No problems doing usual activities	147 (51.6)	111 (57.2)	13 (23.6)	9 (90.0)	1 (20.0)	2 (66.7)	11 (61.1)	128 (56.4)	19 (32.8)
Slight problems doing usual activities	96 (33.7)	52 (26.8)	36 (65.5)	1 (10.0)	2 (40.0)	1 (33.3)	4 (22.2)	61 (26.9)	35 (60.3)

Item	Overall (N=285)	Race						Ethnicity	
		White (N=194)	Black or African American (N=55)	Asian (N=10)	American Indian and Alaska Native (N=5)	Native Hawaiian and Other Pacific Islander (N=3)	Two or More Races (N=18)	Not Hispanic nor Latino (N=227)	Hispanic or Latino (N=58)
Moderate problems doing usual activities	30 (10.5)	23 (11.9)	3 (5.5)	0 (0)	2 (40.0)	0 (0)	2 (11.1)	27 (11.9)	3 (5.2)
Severe problems doing usual activities	8 (2.8)	5 (2.6)	2 (3.6)	0 (0)	0 (0)	0 (0)	1 (5.6)	7 (3.1)	1 (1.7)
Unable to do usual activities	4 (1.4)	3 (1.5)	1 (1.8)	0 (0)	0 (0)	0 (0)	0 (0)	4 (1.8)	0 (0)
EQ-5D-5L, Current health: Pain/Discomfort (n, %)									
No pain/discomfort	62 (21.8)	43 (22.2)	4 (7.3)	5 (50.0)	1 (20.0)	2 (66.7)	7 (38.9)	53 (23.3)	9 (15.5)
Slight pain/discomfort	122 (42.8)	72 (37.1)	39 (70.9)	3 (30.0)	2 (40.0)	0 (0)	6 (33.3)	86 (37.9)	36 (62.1)
Moderate pain/discomfort	70 (24.6)	58 (29.9)	5 (9.1)	2 (20.0)	1 (20.0)	1 (33.3)	3 (16.7)	59 (26.0)	11 (19.0)
Severe pain/discomfort	20 (7.0)	15 (7.7)	4 (7.3)	0 (0)	0 (0)	0 (0)	1 (5.6)	18 (7.9)	2 (3.4)
Extreme pain/discomfort	11 (3.9)	6 (3.1)	3 (5.5)	0 (0)	1 (20.0)	0 (0)	1 (5.6)	11 (4.8)	0 (0)
EQ-5D-5L, Current health: Anxiety/Depression (n, %)									
Not anxious/depressed	76 (26.7)	63 (32.5)	4 (7.3)	1 (10.0)	0 (0)	1 (33.3)	7 (38.9)	71 (31.3)	5 (8.6)
Slightly anxious/depressed	108 (37.9)	55 (28.4)	39 (70.9)	7 (70.0)	0 (0)	0 (0)	7 (38.9)	75 (33.0)	33 (56.9)
Moderately anxious/depressed	70 (24.6)	51 (26.3)	9 (16.4)	2 (20.0)	3 (60.0)	2 (66.7)	3 (16.7)	56 (24.7)	14 (24.1)
Severely anxious/depressed	19 (6.7)	13 (6.7)	3 (5.5)	0 (0)	2 (40.0)	0 (0)	1 (5.6)	14 (6.2)	5 (8.6)
Extremely anxious/depressed	12 (4.2)	12 (6.2)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	11 (4.8)	1 (1.7)

Online Resource Table 4: Descriptive statistics for individual DLQI questions and DLQI scores

Item	Overall (N=285)	Race						Ethnicity	
		White (N=194)	Black or African American (N=55)	Asian (N=10)	American Indian and Alaska Native (N=5)	Native Hawaiian and Other Pacific Islander (N=3)	Two or More Races (N=18)	Not Hispanic nor Latino (N=227)	Hispanic or Latino (N=58)
Itchy, sore, painful or stinging skin (n, %)									
Very much	51 (17.9)	32 (16.5)	11 (20.0)	2 (20.0)	1 (20.0)	1 (33.3)	4 (22.2)	36 (15.9)	15 (25.9)
A lot	103 (36.1)	63 (32.5)	30 (54.5)	3 (30.0)	2 (40.0)	1 (33.3)	4 (22.2)	77 (33.9)	26 (44.8)
A little	112 (39.3)	86 (44.3)	10 (18.2)	4 (40.0)	2 (40.0)	0 (0)	10 (55.6)	96 (42.3)	16 (27.6)
Not at all	18 (6.3)	13 (6.7)	3 (5.5)	1 (10.0)	0 (0)	1 (33.3)	0 (0)	17 (7.5)	1 (1.7)
Missing	1 (0.4)	0 (0)	1 (1.8)	0 (0)	0 (0)	0 (0)	0 (0)	1 (0.4)	0 (0)
Embarrassed or self-conscious because of skin (n, %)									
Very much	70 (24.6)	40 (20.6)	22 (40.0)	1 (10.0)	1 (20.0)	1 (33.3)	5 (27.8)	48 (21.1)	22 (37.9)
A lot	82 (28.8)	52 (26.8)	21 (38.2)	3 (30.0)	4 (80.0)	0 (0)	2 (11.1)	56 (24.7)	26 (44.8)
A little	95 (33.3)	73 (37.6)	9 (16.4)	3 (30.0)	0 (0)	1 (33.3)	9 (50.0)	87 (38.3)	8 (13.8)
Not at all	35 (12.3)	27 (13.9)	2 (3.6)	3 (30.0)	0 (0)	1 (33.3)	2 (11.1)	33 (14.5)	2 (3.4)
Missing	3 (1.1)	2 (1.0)	1 (1.8)	0 (0)	0 (0)	0 (0)	0 (0)	3 (1.3)	0 (0)
Skin interfered with shopping, looking after home/garden (n, %)									
Very much	13 (4.6)	7 (3.6)	3 (5.5)	0 (0)	1 (20.0)	0 (0)	2 (11.1)	10 (4.4)	3 (5.2)
A lot	46 (16.1)	14 (7.2)	26 (47.3)	2 (20.0)	1 (20.0)	0 (0)	3 (16.7)	19 (8.4)	27 (46.6)
A little	79 (27.7)	63 (32.5)	9 (16.4)	3 (30.0)	1 (20.0)	0 (0)	3 (16.7)	65 (28.6)	14 (24.1)
Not at all	113 (39.6)	86 (44.3)	12 (21.8)	4 (40.0)	1 (20.0)	2 (66.7)	8 (44.4)	104 (45.8)	9 (15.5)
Not relevant	33 (11.6)	24 (12.4)	4 (7.3)	1 (10.0)	1 (20.0)	1 (33.3)	2 (11.1)	28 (12.3)	5 (8.6)
Missing	1 (0.4)	0 (0)	1 (1.8)	0 (0)	0 (0)	0 (0)	0 (0)	1 (0.4)	0 (0)
Skin influenced clothes you wear (n, %)									
Very much	44 (15.4)	21 (10.8)	17 (30.9)	3 (30.0)	0 (0)	0 (0)	3 (16.7)	27 (11.9)	17 (29.3)
A lot	64 (22.5)	46 (23.7)	10 (18.2)	2 (20.0)	1 (20.0)	0 (0)	5 (27.8)	48 (21.1)	16 (27.6)
A little	85 (29.8)	60 (30.9)	20 (36.4)	1 (10.0)	2 (40.0)	0 (0)	2 (11.1)	71 (31.3)	14 (24.1)

Item	Overall (N=285)	Race						Ethnicity	
		White (N=194)	Black or African American (N=55)	Asian (N=10)	American Indian and Alaska Native (N=5)	Native Hawaiian and Other Pacific Islander (N=3)	Two or More Races (N=18)	Not Hispanic nor Latino (N=227)	Hispanic or Latino (N=58)
Not at all	73 (25.6)	54 (27.8)	7 (12.7)	2 (20.0)	2 (40.0)	1 (33.3)	7 (38.9)	64 (28.2)	9 (15.5)
Not relevant	17 (6.0)	13 (6.7)	0 (0)	1 (10.0)	0 (0)	2 (66.7)	1 (5.6)	15 (6.6)	2 (3.4)
Missing	2 (0.7)	0 (0)	1 (1.8)	1 (10.0)	0 (0)	0 (0)	0 (0)	2 (0.9)	0 (0)
Skin affected social or leisure activity (n, %)									
Very much	25 (8.8)	12 (6.2)	7 (12.7)	2 (20.0)	1 (20.0)	0 (0)	3 (16.7)	15 (6.6)	10 (17.2)
A lot	51 (17.9)	24 (12.4)	24 (43.6)	1 (10.0)	0 (0)	0 (0)	2 (11.1)	24 (10.6)	27 (46.6)
A little	98 (34.4)	73 (37.6)	15 (27.3)	2 (20.0)	3 (60.0)	0 (0)	5 (27.8)	84 (37.0)	14 (24.1)
Not at all	89 (31.2)	70 (36.1)	6 (10.9)	3 (30.0)	1 (20.0)	2 (66.7)	7 (38.9)	82 (36.1)	7 (12.1)
Not relevant	19 (6.7)	14 (7.2)	2 (3.6)	1 (10.0)	0 (0)	1 (33.3)	1 (5.6)	19 (8.4)	0 (0)
Missing	3 (1.1)	1 (0.5)	1 (1.8)	1 (10.0)	0 (0)	0 (0)	0 (0)	3 (1.3)	0 (0)
Skin made it difficult to do any sport (n, %)									
Very much	24 (8.4)	12 (6.2)	8 (14.5)	1 (10.0)	1 (20.0)	0 (0)	2 (11.1)	14 (6.2)	10 (17.2)
A lot	40 (14.0)	17 (8.8)	22 (40.0)	0 (0)	0 (0)	0 (0)	1 (5.6)	16 (7.0)	24 (41.4)
A little	67 (23.5)	49 (25.3)	10 (18.2)	2 (20.0)	1 (20.0)	0 (0)	5 (27.8)	58 (25.6)	9 (15.5)
Not at all	93 (32.6)	66 (34.0)	11 (20.0)	3 (30.0)	2 (40.0)	3 (100.0)	8 (44.4)	83 (36.6)	10 (17.2)
Not relevant	58 (20.4)	49 (25.3)	3 (5.5)	3 (30.0)	1 (20.0)	0 (0)	2 (11.1)	53 (23.3)	5 (8.6)
Missing	3 (1.1)	1 (0.5)	1 (1.8)	1 (10.0)	0 (0)	0 (0)	0 (0)	3 (1.3)	0 (0)
Skin prevented you from working or studying (n, %)									
Yes	56 (19.6)	35 (18.0)	17 (30.9)	1 (10.0)	0 (0)	0 (0)	3 (16.7)	31 (13.7)	25 (43.1)
No	195 (68.4)	135 (69.6)	33 (60.0)	6 (60.0)	5 (100.0)	3 (100.0)	13 (72.2)	165 (72.7)	30 (51.7)
Not relevant	33 (11.6)	24 (12.4)	4 (7.3)	3 (30.0)	0 (0)	0 (0)	2 (11.1)	30 (13.2)	3 (5.2)
Missing	1 (0.4)	0 (0)	1 (1.8)	0 (0)	0 (0)	0 (0)	0 (0)	1 (0.4)	0 (0)
Skin has been a problem at work or studying (n, %)	n=195	n=135	n=33	n=6	n=5	n=3	n=13	n=165	n=30

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A lot	3 (1.5)	2 (1.5)	0 (0)	0 (0)	1 (20.0)	0 (0)	0 (0)	2 (1.2)	1 (3.3)
A little	85 (43.6)	56 (41.5)	19 (57.6)	2 (33.3)	2 (40.0)	1 (33.3)	5 (38.5)	66 (40.0)	19 (63.3)
Not at all	105 (53.8)	75 (55.6)	14 (42.4)	4 (66.7)	2 (40.0)	2 (66.7)	8 (61.5)	95 (57.6)	10 (33.3)
Missing	2 (1.0)	2 (1.5)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	2 (1.2)	0 (0)
Skin created problems with partner, close friends or relatives (n, %)									
Very much	12 (4.2)	6 (3.1)	4 (7.3)	0 (0)	0 (0)	0 (0)	2 (11.1)	7 (3.1)	5 (8.6)
A lot	42 (14.7)	17 (8.8)	24 (43.6)	0 (0)	1 (20.0)	0 (0)	0 (0)	13 (5.7)	29 (50.0)
A little	82 (28.8)	59 (30.4)	6 (10.9)	4 (40.0)	2 (40.0)	2 (66.7)	9 (50.0)	70 (30.8)	12 (20.7)
Not at all	124 (43.5)	92 (47.4)	18 (32.7)	4 (40.0)	2 (40.0)	1 (33.3)	7 (38.9)	113 (49.8)	11 (19.0)
Not relevant	23 (8.1)	19 (9.8)	2 (3.6)	2 (20.0)	0 (0)	0 (0)	0 (0)	22 (9.7)	1 (1.7)
Missing	2 (0.7)	1 (0.5)	1 (1.8)	0 (0)	0 (0)	0 (0)	0 (0)	2 (0.9)	0 (0)
Skin caused sexual difficulties (n, %)									
Very much	28 (9.8)	9 (4.6)	17 (30.9)	1 (10.0)	0 (0)	0 (0)	1 (5.6)	9 (4.0)	19 (32.8)
A lot	38 (13.3)	27 (13.9)	6 (10.9)	1 (10.0)	1 (20.0)	0 (0)	3 (16.7)	27 (11.9)	11 (19.0)
A little	62 (21.8)	44 (22.7)	10 (18.2)	2 (20.0)	2 (40.0)	1 (33.3)	3 (16.7)	48 (21.1)	14 (24.1)
Not at all	114 (40.0)	80 (41.2)	17 (30.9)	3 (30.0)	2 (40.0)	2 (66.7)	10 (55.6)	103 (45.4)	11 (19.0)
Not relevant	40 (14.0)	33 (17.0)	4 (7.3)	2 (20.0)	0 (0)	0 (0)	1 (5.6)	37 (16.3)	3 (5.2)
Missing	3 (1.1)	1 (0.5)	1 (1.8)	1 (10.0)	0 (0)	0 (0)	0 (0)	3 (1.3)	0 (0)
Problem caused by skin treatment (n, %)									
Very much	17 (6.0)	9 (4.6)	6 (10.9)	0 (0)	0 (0)	0 (0)	2 (11.1)	11 (4.8)	6 (10.3)
A lot	60 (21.1)	31 (16.0)	25 (45.5)	3 (30.0)	0 (0)	0 (0)	1 (5.6)	31 (13.7)	29 (50.0)
A little	98 (34.4)	78 (40.2)	9 (16.4)	2 (20.0)	2 (40.0)	0 (0)	7 (38.9)	85 (37.4)	13 (22.4)
Not at all	88 (30.9)	60 (30.9)	12 (21.8)	2 (20.0)	3 (60.0)	3 (100.0)	8 (44.4)	80 (35.2)	8 (13.8)
Not relevant	18 (6.3)	14 (7.2)	2 (3.6)	2 (20.0)	0 (0)	0 (0)	0 (0)	16 (7.0)	2 (3.4)
Missing	4 (1.4)	2 (1.0)	1 (1.8)	1 (10.0)	0 (0)	0 (0)	0 (0)	4 (1.8)	0 (0)

Item	Overall (N=285)	Race						Ethnicity	
		White (N=194)	Black or African American (N=55)	Asian (N=10)	American Indian and Alaska Native (N=5)	Native Hawaiian and Other Pacific Islander (N=3)	Two or More Races (N=18)	Not Hispanic nor Latino (N=227)	Hispanic or Latino (N=58)
DLQI Score									
DLQI Responses (n, %)									
No effect at all on patient's life (0-1)	22 (7.7)	16 (8.2)	3 (5.5)	1 (10.0)	0 (0)	1 (33.3)	1 (5.6)	22 (9.7)	0 (0)
Small effect on patient's life (2-5)	69 (24.2)	55 (28.4)	4 (7.3)	3 (30.0)	1 (20.0)	0 (0)	6 (33.3)	61 (26.9)	8 (13.8)
Moderate effect on patient's life (6-10)	77 (27.0)	51 (26.3)	16 (29.1)	3 (30.0)	2 (40.0)	2 (66.7)	3 (16.7)	71 (31.3)	6 (10.3)
Very large effect on patient's life (11-20)	81 (28.4)	61 (31.4)	9 (16.4)	3 (30.0)	1 (20.0)	0 (0)	7 (38.9)	60 (26.4)	21 (36.2)
Extremely large effect on patient's life (21-30)	36 (12.6)	11 (5.7)	23 (41.8)	0 (0)	1 (20.0)	0 (0)	1 (5.6)	13 (5.7)	23 (39.7)
Mean (SD)	10.3 (7.2)	9.1 (6.4)	15.1 (8.2)	8.8 (6.6)	10.8 (6.8)	4.3 (3.8)	10.1 (7.9)	8.7 (6.2)	16.6 (7.4)
Median	9.0	8.0	19.0	7.0	9.0	6.0	8.5	7.0	19.0
Range (min - max)	0 - 30	0 - 30	0 - 27	0 - 20	5 - 22	0 - 7	1 - 30	0 - 30	2 - 30
IQR (Q1- Q3)	5.0 - 14.0	4.0 - 13.0	8.0 - 23.0	5.0 - 12.0	6.0 - 12.0	0.0 - 7.0	3.0 - 15.0	4.0 - 12.0	11.0 - 23.0

DLQI, Dermatology Life Quality Index; IQR, interquartile range; max, maximum; min, minimum; Q, quartile

Online Resource Table 5: Descriptive statistics for Neuro-QoL Stigma Short Form and Neuro-QoL scores

Item	Overall (N=285)	Race						Ethnicity	
		White (N=194)	Black or African American (N=55)	Asian (N=10)	American Indian and Alaska Native (N=5)	Native Hawaiian and Other Pacific Islander (N=3)	Two or More Races (N=18)	Not Hispanic nor Latino (N=227)	Hispanic or Latino (N=58)
Because of my illness, some people avoided me (n, %)									
Never	119 (41.8)	88 (45.4)	14 (25.5)	3 (30.0)	2 (40.0)	3 (100.0)	9 (50.0)	104 (45.8)	15 (25.9)
Rarely	60 (21.1)	45 (23.2)	8 (14.5)	3 (30.0)	1 (20.0)	0 (0)	3 (16.7)	55 (24.2)	5 (8.6)
Sometimes	92 (32.3)	54 (27.8)	31 (56.4)	3 (30.0)	1 (20.0)	0 (0)	3 (16.7)	57 (25.1)	35 (60.3)
Often	11 (3.9)	7 (3.6)	1 (1.8)	0 (0)	1 (20.0)	0 (0)	2 (11.1)	9 (4.0)	2 (3.4)
Always	2 (0.7)	0 (0)	0 (0)	1 (10.0)	0 (0)	0 (0)	1 (5.6)	1 (0.4)	1 (1.7)
Missing	1 (0.4)	0 (0)	1 (1.8)	0 (0)	0 (0)	0 (0)	0 (0)	1 (0.4)	0 (0)
Because of my illness, I felt left out of things (n, %)									
Never	113 (39.6)	86 (44.3)	11 (20.0)	4 (40.0)	1 (20.0)	3 (100.0)	8 (44.4)	99 (43.6)	14 (24.1)
Rarely	46 (16.1)	29 (14.9)	8 (14.5)	3 (30.0)	1 (20.0)	0 (0)	5 (27.8)	42 (18.5)	4 (6.9)
Sometimes	101 (35.4)	63 (32.5)	31 (56.4)	1 (10.0)	2 (40.0)	0 (0)	4 (22.2)	65 (28.6)	36 (62.1)
Often	19 (6.7)	14 (7.2)	2 (3.6)	2 (20.0)	1 (20.0)	0 (0)	0 (0)	16 (7.0)	3 (5.2)
Always	4 (1.4)	2 (1.0)	1 (1.8)	0 (0)	0 (0)	0 (0)	1 (5.6)	3 (1.3)	1 (1.7)
Missing	2 (0.7)	0 (0)	2 (3.6)	0 (0)	0 (0)	0 (0)	0 (0)	2 (0.9)	0 (0)
Because of my illness, people avoided looking at me (n, %)									
Never	108 (37.9)	81 (41.8)	12 (21.8)	5 (50.0)	2 (40.0)	2 (66.7)	6 (33.3)	94 (41.4)	14 (24.1)
Rarely	59 (20.7)	44 (22.7)	7 (12.7)	1 (10.0)	0 (0)	1 (33.3)	6 (33.3)	54 (23.8)	5 (8.6)
Sometimes	94 (33.0)	55 (28.4)	31 (56.4)	2 (20.0)	2 (40.0)	0 (0)	4 (22.2)	60 (26.4)	34 (58.6)
Often	18 (6.3)	12 (6.2)	3 (5.5)	2 (20.0)	1 (20.0)	0 (0)	0 (0)	15 (6.6)	3 (5.2)
Always	3 (1.1)	1 (0.5)	0 (0)	0 (0)	0 (0)	0 (0)	2 (11.1)	1 (0.4)	2 (3.4)
Missing	3 (1.1)	1 (0.5)	2 (3.6)	0 (0)	0 (0)	0 (0)	0 (0)	3 (1.3)	0 (0)
I felt embarrassed about my illness (n, %)									
Never	45 (15.8)	33 (17.0)	5 (9.1)	4 (40.0)	1 (20.0)	1 (33.3)	1 (5.6)	42 (18.5)	3 (5.2)

Item	Overall (N=285)	Race						Ethnicity	
		White (N=194)	Black or African American (N=55)	Asian (N=10)	American Indian and Alaska Native (N=5)	Native Hawaiian and Other Pacific Islander (N=3)	Two or More Races (N=18)	Not Hispanic nor Latino (N=227)	Hispanic or Latino (N=58)
Rarely	41 (14.4)	29 (14.9)	5 (9.1)	1 (10.0)	0 (0)	1 (33.3)	5 (27.8)	36 (15.9)	5 (8.6)
Sometimes	117 (41.1)	70 (36.1)	34 (61.8)	4 (40.0)	2 (40.0)	0 (0)	7 (38.9)	79 (34.8)	38 (65.5)
Often	57 (20.0)	45 (23.2)	6 (10.9)	1 (10.0)	1 (20.0)	0 (0)	4 (22.2)	48 (21.1)	9 (15.5)
Always	23 (8.1)	16 (8.2)	4 (7.3)	0 (0)	1 (20.0)	1 (33.3)	1 (5.6)	20 (8.8)	3 (5.2)
Missing	2 (0.7)	1 (0.5)	1 (1.8)	0 (0)	0 (0)	0 (0)	0 (0)	2 (0.9)	0 (0)
Because of my illness, some people seemed uncomfortable with me (n, %)									
Never	97 (34.0)	73 (37.6)	9 (16.4)	5 (50.0)	1 (20.0)	2 (66.7)	7 (38.9)	85 (37.4)	12 (20.7)
Rarely	58 (20.4)	42 (21.6)	9 (16.4)	1 (10.0)	0 (0)	1 (33.3)	5 (27.8)	53 (23.3)	5 (8.6)
Sometimes	99 (34.7)	56 (28.9)	33 (60.0)	4 (40.0)	3 (60.0)	0 (0)	3 (16.7)	64 (28.2)	35 (60.3)
Often	22 (7.7)	18 (9.3)	2 (3.6)	0 (0)	1 (20.0)	0 (0)	1 (5.6)	18 (7.9)	4 (6.9)
Always	6 (2.1)	4 (2.1)	0 (0)	0 (0)	0 (0)	0 (0)	2 (11.1)	4 (1.8)	2 (3.4)
Missing	3 (1.1)	1 (0.5)	2 (3.6)	0 (0)	0 (0)	0 (0)	0 (0)	3 (1.3)	0 (0)
I felt embarrassed because of my physical limitations (n, %)									
Never	92 (32.3)	67 (34.5)	13 (23.6)	4 (40.0)	1 (20.0)	2 (66.7)	5 (27.8)	84 (37.0)	8 (13.8)
Rarely	40 (14.0)	32 (16.5)	3 (5.5)	1 (10.0)	0 (0)	0 (0)	4 (22.2)	35 (15.4)	5 (8.6)
Sometimes	107 (37.5)	60 (30.9)	36 (65.5)	4 (40.0)	2 (40.0)	0 (0)	5 (27.8)	69 (30.4)	38 (65.5)
Often	29 (10.2)	23 (11.9)	1 (1.8)	1 (10.0)	1 (20.0)	1 (33.3)	2 (11.1)	25 (11.0)	4 (6.9)
Always	14 (4.9)	10 (5.2)	1 (1.8)	0 (0)	1 (20.0)	0 (0)	2 (11.1)	12 (5.3)	2 (3.4)
Missing	3 (1.1)	2 (1.0)	1 (1.8)	0 (0)	0 (0)	0 (0)	0 (0)	2 (0.9)	1 (1.7)
Because of my illness, people were unkind to me (n, %)									
Never	136 (47.7)	100 (51.5)	18 (32.7)	5 (50.0)	2 (40.0)	2 (66.7)	9 (50.0)	122 (53.7)	14 (24.1)
Rarely	45 (15.8)	32 (16.5)	4 (7.3)	4 (40.0)	1 (20.0)	1 (33.3)	3 (16.7)	39 (17.2)	6 (10.3)
Sometimes	81 (28.4)	45 (23.2)	31 (56.4)	0 (0)	0 (0)	0 (0)	5 (27.8)	48 (21.1)	33 (56.9)
Often	14 (4.9)	13 (6.7)	1 (1.8)	0 (0)	0 (0)	0 (0)	0 (0)	10 (4.4)	4 (6.9)
Always	4 (1.4)	2 (1.0)	0 (0)	0 (0)	1 (20.0)	0 (0)	1 (5.6)	3 (1.3)	1 (1.7)

Item	Overall (N=285)	Race						Ethnicity	
		White (N=194)	Black or African American (N=55)	Asian (N=10)	American Indian and Alaska Native (N=5)	Native Hawaiian and Other Pacific Islander (N=3)	Two or More Races (N=18)	Not Hispanic nor Latino (N=227)	Hispanic or Latino (N=58)
Missing	5 (1.8)	2 (1.0)	1 (1.8)	1 (10.0)	1 (20.0)	0 (0)	0 (0)	5 (2.2)	0 (0)
Some people acted as though it was my fault I have this illness (n, %)									
Never	139 (48.8)	101 (52.1)	20 (36.4)	6 (60.0)	1 (20.0)	2 (66.7)	9 (50.0)	125 (55.1)	14 (24.1)
Rarely	33 (11.6)	25 (12.9)	2 (3.6)	2 (20.0)	1 (20.0)	1 (33.3)	2 (11.1)	28 (12.3)	5 (8.6)
Sometimes	84 (29.5)	49 (25.3)	30 (54.5)	0 (0)	2 (40.0)	0 (0)	3 (16.7)	52 (22.9)	32 (55.2)
Often	22 (7.7)	16 (8.2)	1 (1.8)	2 (20.0)	0 (0)	0 (0)	3 (16.7)	16 (7.0)	6 (10.3)
Always	4 (1.4)	1 (0.5)	1 (1.8)	0 (0)	1 (20.0)	0 (0)	1 (5.6)	3 (1.3)	1 (1.7)
Missing	3 (1.1)	2 (1.0)	1 (1.8)	0 (0)	0 (0)	0 (0)	0 (0)	3 (1.3)	0 (0)
Neuro-QoL Stigma Short Form Score^a									
Mean (SD)	17.6 (7.4)	17.1 (7.4)	19.8 (6.3)	15.9 (6.4)	21.0 (9.9)	12.0 (4.0)	18.1 (8.7)	16.7 (7.2)	21.1 (6.9)
Median	16.0	16.0	24.0	15.0	19.0	12.0	16.5	15.0	24.0
Range (min - max)	6 - 40	6 - 36	6 - 28	8 - 28	11 - 36	8 - 16	8 - 40	6 - 36	8 - 40
IQR (Q1- Q3)	11.0 - 24.0	10.0 - 24.0	15.0 - 24.0	12.0 - 20.0	14.0 - 25.0	8.0 - 16.0	11.0 - 25.0	10.0 - 24.0	14.0 - 24.0
Missing	1 (0.4)	0 (0)	1 (1.8)	0 (0)	0 (0)	0 (0)	0 (0)	1 (0.4)	0 (0)
Neuro-QoL Stigma Short Form T Score^b									
Mean (SD)	54.4 (7.9)	53.8 (8.1)	56.7 (6.5)	52.9 (7.6)	58.3 (8.6)	47.8 (7.4)	55.6 (9.5)	53.5 (7.9)	57.9 (7.2)
Median	55.3	54.5	60.7	54.4	58.2	51.6	54.6	54.3	60.7
Range (min - max)	39 - 82	39 - 72	39 - 64	39 - 64	49 - 71	39 - 53	39 - 82	39 - 72	39 - 82
IQR (Q1- Q3)	48.9 - 60.7	48.1 - 60.7	54.0 - 60.7	46.6 - 57.9	52.6 - 61.5	39.2 - 52.5	48.9 - 61.5	46.3 - 60.7	53.4 - 60.7
Missing	1 (0.4)	0 (0)	1 (1.8)	0 (0)	0 (0)	0 (0)	0 (0)	1 (0.4)	0 (0)

IQR, interquartile range; max, maximum; min, minimum; Neuro-QoL, Quality of Life in Neurological Disorders; Q, quartile; SD, standard deviation

^aEach item is scored from 1 to 5 and total scoring ranges from 8 to 40, with higher scores indicating increased stigma.

^bT-score metric is scored by Health Measures in which 50 is the mean of a relevant reference population and 10 is the standard deviation (SD) of that population. High scores mean more of the concept being measured.

Online Resource Table 6: Descriptive statistics for PROMIS self-efficacy for managing chronic conditions - managing social interactions and PROMIS scores

Item	Overall (N=285)	Race						Ethnicity	
		White (N=194)	Black or African American (N=55)	Asian (N=10)	American Indian and Alaska Native (N=5)	Native Hawaiian and Other Pacific Islander (N=3)	Two or More Races (N=18)	Not Hispanic nor Latino (N=227)	Hispanic or Latino (N=58)
I can talk about my health problems with someone (n, %)									
I am not at all confident	9 (3.2)	6 (3.1)	2 (3.6)	0 (0)	0 (0)	0 (0)	1 (5.6)	5 (2.2)	4 (6.9)
I am a little confident	33 (11.6)	18 (9.3)	6 (10.9)	1 (10.0)	2 (40.0)	2 (66.7)	4 (22.2)	22 (9.7)	11 (19.0)
I am somewhat confident	70 (24.6)	40 (20.6)	25 (45.5)	3 (30.0)	0 (0)	0 (0)	2 (11.1)	45 (19.8)	25 (43.1)
I am quite confident	93 (32.6)	73 (37.6)	11 (20.0)	2 (20.0)	1 (20.0)	0 (0)	6 (33.3)	85 (37.4)	8 (13.8)
I am very confident	79 (27.7)	57 (29.4)	11 (20.0)	3 (30.0)	2 (40.0)	1 (33.3)	5 (27.8)	69 (30.4)	10 (17.2)
Missing	1 (0.4)	0 (0)	0 (0)	1 (10.0)	0 (0)	0 (0)	0 (0)	1 (0.4)	0 (0)
If I need help, I can find someone to take me to the doctor's office (n, %)									
I am not at all confident	7 (2.5)	5 (2.6)	1 (1.8)	0 (0)	0 (0)	1 (33.3)	0 (0)	6 (2.6)	1 (1.7)
I am a little confident	28 (9.8)	17 (8.8)	8 (14.5)	0 (0)	1 (20.0)	0 (0)	2 (11.1)	20 (8.8)	8 (13.8)
I am somewhat confident	76 (26.7)	39 (20.1)	26 (47.3)	4 (40.0)	1 (20.0)	0 (0)	6 (33.3)	45 (19.8)	31 (53.4)
I am quite confident	72 (25.3)	54 (27.8)	8 (14.5)	3 (30.0)	2 (40.0)	0 (0)	5 (27.8)	62 (27.3)	10 (17.2)
I am very confident	102 (35.8)	79 (40.7)	12 (21.8)	3 (30.0)	1 (20.0)	2 (66.7)	5 (27.8)	94 (41.4)	8 (13.8)
I can get emotional support when I need it (n, %)									
I am not at all confident	21 (7.4)	16 (8.2)	1 (1.8)	0 (0)	1 (20.0)	1 (33.3)	2 (11.1)	17 (7.5)	4 (6.9)
I am a little confident	35 (12.3)	19 (9.8)	12 (21.8)	0 (0)	2 (40.0)	0 (0)	2 (11.1)	25 (11.0)	10 (17.2)
I am somewhat confident	86 (30.2)	48 (24.7)	28 (50.9)	6 (60.0)	0 (0)	0 (0)	4 (22.2)	57 (25.1)	29 (50.0)
I am quite confident	74 (26.0)	58 (29.9)	6 (10.9)	2 (20.0)	2 (40.0)	2 (66.7)	4 (22.2)	68 (30.0)	6 (10.3)
I am very confident	69 (24.2)	53 (27.3)	8 (14.5)	2 (20.0)	0 (0)	0 (0)	6 (33.3)	60 (26.4)	9 (15.5)

Item	Overall (N=285)	Race						Ethnicity	
		White (N=194)	Black or African American (N=55)	Asian (N=10)	American Indian and Alaska Native (N=5)	Native Hawaiian and Other Pacific Islander (N=3)	Two or More Races (N=18)	Not Hispanic nor Latino (N=227)	Hispanic or Latino (N=58)
I can ask for help when I don't understand something (n, %)									
I am not at all confident	5 (1.8)	3 (1.5)	0 (0)	0 (0)	0 (0)	1 (33.3)	1 (5.6)	2 (0.9)	3 (5.2)
I am a little confident	26 (9.1)	16 (8.2)	7 (12.7)	0 (0)	1 (20.0)	0 (0)	2 (11.1)	16 (7.0)	10 (17.2)
I am somewhat confident	83 (29.1)	46 (23.7)	26 (47.3)	3 (30.0)	1 (20.0)	1 (33.3)	6 (33.3)	56 (24.7)	27 (46.6)
I am quite confident	84 (29.5)	63 (32.5)	10 (18.2)	5 (50.0)	2 (40.0)	0 (0)	4 (22.2)	77 (33.9)	7 (12.1)
I am very confident	86 (30.2)	65 (33.5)	12 (21.8)	2 (20.0)	1 (20.0)	1 (33.3)	5 (27.8)	75 (33.0)	11 (19.0)
Missing	1 (0.4)	1 (0.5)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (0.4)	0 (0)
I have someone who helps me understand medical information (n, %)									
I am not at all confident	16 (5.6)	13 (6.7)	1 (1.8)	0 (0)	0 (0)	1 (33.3)	1 (5.6)	12 (5.3)	4 (6.9)
I am a little confident	37 (13.0)	21 (10.8)	9 (16.4)	1 (10.0)	1 (20.0)	1 (33.3)	4 (22.2)	29 (12.8)	8 (13.8)
I am somewhat confident	81 (28.4)	47 (24.2)	30 (54.5)	2 (20.0)	0 (0)	0 (0)	2 (11.1)	51 (22.5)	30 (51.7)
I am quite confident	73 (25.6)	53 (27.3)	7 (12.7)	5 (50.0)	1 (20.0)	0 (0)	7 (38.9)	66 (29.1)	7 (12.1)
I am very confident	78 (27.4)	60 (30.9)	8 (14.5)	2 (20.0)	3 (60.0)	1 (33.3)	4 (22.2)	69 (30.4)	9 (15.5)
If I need help, I have someone to help me manage my daily activities (n, %)									
I am not at all confident	29 (10.2)	22 (11.3)	4 (7.3)	0 (0)	0 (0)	1 (33.3)	2 (11.1)	24 (10.6)	5 (8.6)
I am a little confident	46 (16.1)	29 (14.9)	14 (25.5)	0 (0)	1 (20.0)	0 (0)	2 (11.1)	38 (16.7)	8 (13.8)
I am somewhat confident	82 (28.8)	43 (22.2)	27 (49.1)	3 (30.0)	2 (40.0)	1 (33.3)	6 (33.3)	56 (24.7)	26 (44.8)
I am quite confident	63 (22.1)	51 (26.3)	5 (9.1)	4 (40.0)	2 (40.0)	0 (0)	1 (5.6)	55 (24.2)	8 (13.8)
I am very confident	65 (22.8)	49 (25.3)	5 (9.1)	3 (30.0)	0 (0)	1 (33.3)	7 (38.9)	54 (23.8)	11 (19.0)
I have someone to help me plan and make decisions related to my illness (n, %)									
I am not at all confident	28 (9.8)	23 (11.9)	3 (5.5)	1 (10.0)	0 (0)	0 (0)	1 (5.6)	22 (9.7)	6 (10.3)
I am a little confident	36 (12.6)	26 (13.4)	9 (16.4)	0 (0)	1 (20.0)	0 (0)	0 (0)	27 (11.9)	9 (15.5)
I am somewhat confident	81 (28.4)	41 (21.1)	30 (54.5)	3 (30.0)	0 (0)	1 (33.3)	6 (33.3)	55 (24.2)	26 (44.8)
I am quite confident	67 (23.5)	47 (24.2)	8 (14.5)	3 (30.0)	3 (60.0)	1 (33.3)	5 (27.8)	59 (26.0)	8 (13.8)
I am very confident	70 (24.6)	54 (27.8)	5 (9.1)	3 (30.0)	1 (20.0)	1 (33.3)	6 (33.3)	61 (26.9)	9 (15.5)

Item	Overall (N=285)	Race						Ethnicity	
		White (N=194)	Black or African American (N=55)	Asian (N=10)	American Indian and Alaska Native (N=5)	Native Hawaiian and Other Pacific Islander (N=3)	Two or More Races (N=18)	Not Hispanic nor Latino (N=227)	Hispanic or Latino (N=58)
Missing	3 (1.1)	3 (1.5)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	3 (1.3)	0 (0)
I can communicate well with my doctors and nurses (n, %)									
I am not at all confident	4 (1.4)	3 (1.5)	0 (0)	0 (0)	0 (0)	0 (0)	1 (5.6)	2 (0.9)	2 (3.4)
I am a little confident	22 (7.7)	11 (5.7)	8 (14.5)	0 (0)	1 (20.0)	0 (0)	2 (11.1)	13 (5.7)	9 (15.5)
I am somewhat confident	70 (24.6)	36 (18.6)	25 (45.5)	3 (30.0)	2 (40.0)	0 (0)	4 (22.2)	45 (19.8)	25 (43.1)
I am quite confident	84 (29.5)	71 (36.6)	7 (12.7)	2 (20.0)	0 (0)	1 (33.3)	3 (16.7)	76 (33.5)	8 (13.8)
I am very confident	102 (35.8)	72 (37.1)	15 (27.3)	4 (40.0)	2 (40.0)	2 (66.7)	7 (38.9)	89 (39.2)	13 (22.4)
Missing	3 (1.1)	1 (0.5)	0 (0)	1 (10.0)	0 (0)	0 (0)	1 (5.6)	2 (0.9)	1 (1.7)
PROMIS Self-Efficacy for Managing Chronic Conditions, Score^a									
Mean (SD)	28.9 (7.2)	29.6 (7.3)	26.1 (6.3)	30.0 (5.6)	28.2 (7.7)	27.0 (10.6)	28.8 (7.7)	29.7 (6.9)	25.5 (6.9)
Median	29.0	30.0	24.0	30.0	31.0	31.0	28.0	30.0	24.0
Range (min - max)	8 - 40	8 - 40	14 - 40	24 - 40	15 - 34	15 - 35	15 - 40	11 - 40	8 - 40
IQR (Q1- Q3)	24.0 - 35.0	26.0 - 36.0	24.0 - 31.0	25.0 - 33.0	28.0 - 33.0	15.0 - 35.0	22.0 - 36.0	25.0 - 36.0	24.0 - 29.0
PROMIS Self-Efficacy for Managing Chronic Conditions, T Score^b									
Mean (SD)	42.1 (7.8)	43.0 (8.1)	39.2 (5.9)	43.3 (6.9)	40.6 (5.9)	40.0 (9.2)	42.2 (8.2)	42.9 (7.6)	39.0 (7.5)
Median	40.7	41.2	36.6	42.0	42.1	43.1	41.2	41.7	36.6
Range (min - max)	20 - 60	20 - 60	28 - 60	37 - 60	31 - 46	30 - 47	31 - 60	28 - 60	20 - 60
IQR (Q1- Q3)	36.6 - 46.2	38.1 - 47.1	36.6 - 42.7	38.3 - 43.0	39.2 - 45.3	29.7 - 47.3	35.6 - 47.7	38.0 - 47.1	36.6 - 40.7

IQR, interquartile range; max, maximum; min, minimum; PROMIS, Patient-Reported Outcomes Measurement Information System, Q, quartile; SD, standard deviation

^aEach item is scored from 1 to 5 and total scoring ranges from 8 to 40, with higher scores indicating higher levels of confidence.

^bT-score metric is scored by Health Measures in which 50 is the mean of a relevant reference population and 10 is the standard deviation (SD) of that population. High scores mean more of the concept being measured.

Online Resource Table 7: Descriptive statistics for healthcare access responses overall and by race/ethnicity

Item		Race						Ethnicity	
	Overall (N=285)	White (N=194)	Black or African American (N=55)	American Indian and Alaska Native (N=5)	Asian (N=10)	Native Hawaiian and Other Pacific Islander (N=3)	Two or More Races (N=18)	Not Hispanic nor Latino (N=227)	Hispanic or Latino (N=58)
Which of the following influenced you to see a healthcare provider for your Psoriasis? (n, %) ^a									
Friend	40 (14.0%)	30 (15.5%)	5 (9.1%)	0 (0%)	2 (20.0%)	1 (33.3%)	2 (11.1%)	30 (13.2%)	10 (17.2%)
Website	42 (14.7%)	27 (13.9%)	13 (23.6%)	0 (0%)	0 (0%)	0 (0%)	2 (11.1%)	28 (12.3%)	14 (24.1%)
Other provider	43 (15.1%)	28 (14.4%)	12 (21.8%)	1 (20.0%)	1 (10.0%)	0 (0%)	1 (5.6%)	31 (13.7%)	12 (20.7%)
Hairdresser/barber	28 (9.8%)	15 (7.7%)	10 (18.2%)	2 (40.0%)	0 (0%)	0 (0%)	1 (5.6%)	16 (7.0%)	12 (20.7%)
Social media (online groups) ^a	53 (18.6%)	27 (13.9%)	24 (43.6%)	0 (0%)	1 (10.0%)	0 (0%)	1 (5.6%)	29 (12.8%)	24 (41.4%)
Twitter	48 (90.6%)	25 (92.6%)	23 (95.8%)	-	0 (0%)	-	0 (0%)	25 (86.2%)	23 (95.8%)
Instagram	0 (0%)	0 (0%)	0 (0%)	-	0 (0%)	-	0 (0%)	0 (0%)	0 (0%)
Facebook	51 (96.2%)	26 (96.3%)	24 (100.0%)	-	0 (0%)	-	1 (100.0%)	27 (93.1%)	24 (100.0%)
TikTok	52 (98.1%)	27 (100.0%)	23 (95.8%)	-	1 (100.0%)	-	1 (100.0%)	28 (96.6%)	24 (100.0%)
Reddit	2 (3.8%)	2 (7.4%)	0 (0%)	-	0 (0%)	-	0 (0%)	2 (6.9%)	0 (0%)
Snapchat	0 (0%)	0 (0%)	0 (0%)	-	0 (0%)	-	0 (0%)	0 (0%)	0 (0%)
Other	0 (0%)	0 (0%)	0 (0%)	-	0 (0%)	-	0 (0%)	0 (0%)	0 (0%)
Church or religious group	20 (7.0%)	7 (3.6%)	13 (23.6%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	6 (2.6%)	14 (24.1%)
Commercial or ad	26 (9.1%)	14 (7.2%)	12 (21.8%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	14 (6.2%)	12 (20.7%)
Radio	17 (6.0%)	9 (4.6%)	7 (12.7%)	1 (20.0%)	0 (0%)	0 (0%)	0 (0%)	9 (4.0%)	8 (13.8%)
Podcast	19 (6.7%)	10 (5.2%)	9 (16.4%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	9 (4.0%)	10 (17.2%)
Community center	29 (10.2%)	13 (6.7%)	16 (29.1%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	14 (6.2%)	15 (25.9%)
Family member	103 36.1%)	71 (36.6%)	21 (38.2%)	1 (20.0%)	3 (30.0%)	2 (66.7%)	5 (27.8%)	83 (36.6%)	20 (34.5%)
Co-worker	16 (5.6%)	6 (3.1%)	9 (16.4%)	0 (0%)	1 (10.0%)	0 (0%)	0 (0%)	7 (3.1%)	9 (15.5%)
Significant other	50 (17.5%)	32 (16.5%)	10 (18.2%)	0 (0%)	3 (30.0%)	0 (0%)	5 (27.8%)	35 (15.4%)	15 (25.9%)
Previous experience or knowledge	58 (20.4%)	39 (20.1%)	15 (27.3%)	0 (0%)	2 (20.0%)	0 (0%)	2 (11.1%)	48 (21.1%)	10 (17.2%)

Item		Race						Ethnicity	
	Overall (N=285)	White (N=194)	Black or African American (N=55)	American Indian and Alaska Native (N=5)	Asian (N=10)	Native Hawaiian and Other Pacific Islander (N=3)	Two or More Races (N=18)	Not Hispanic nor Latino (N=227)	Hispanic or Latino (N=58)
Non-profit organization	17 (6.0%)	6 (3.1%)	11 (20.0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	6 (2.6%)	11 (19.0%)
Other	21 (7.4%)	16 (8.2%)	1 (1.8%)	0 (0%)	1 (10.0%)	1 (33.3%)	2 (11.1%)	20 (8.8%)	1 (1.7%)
None of the above	53 (18.6%)	38 (19.6%)	6 (10.9%)	1 (20.0%)	4 (40.0%)	0 (0%)	4 (22.2%)	46 (20.3%)	7 (12.1%)
Missing	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)

^aResponses are not mutually exclusive.

De novo survey questions

Instructions for Completing the Questionnaires

Thank you for agreeing to take part in this survey. The objective of this study is to learn more about participants' disease knowledge and perception of illness, healthcare access and utilization, impact on quality of life, and social impact. All information that you provide will be kept strictly confidential.

On the following screens, you will be asked to complete a series of questions (estimated time to complete: approximately 20 to 30 minutes).

After you answer all questions on each screen, click **Continue** at the bottom of each page to save your responses and move to the next set of questions.

While completing the questions, you may choose not to answer a question(s). Just click **Continue** to move to the next question. You will not be able to go back and change your answer on a question once you click continue.

You may notice that some of the questions you are going to answer sound similar to one another, but they are each a little different. Please answer each question to the best of your ability.

EQ5DQ3. Under each heading, please check the 1 box that best describes your health TODAY.

a. **Mobility**

- 1 I have no problems walking
- 2 I have slight problems walking
- 3 I have moderate problems walking
- 4 I have severe problems walking
- 5 I am unable to walk

b. **Self-Care**

- 1 I have no problems washing or dressing myself
- 2 I have slight problems washing or dressing myself
- 3 I have moderate problems washing or dressing myself
- 4 I have severe problems washing or dressing myself
- 5 I am unable to wash or dress myself

c. **Usual Activities (e.g., work, study, housework, family or leisure activities)**

- 1 I have no problems doing my usual activities
- 2 I have slight problems doing my usual activities

3 I have moderate problems doing my usual activities

4 I have severe problems doing my usual activities

5 I am unable to do my usual activities

d. **Pain/Discomfort**

1 I have no pain or discomfort

2 I have slight pain or discomfort

3 I have moderate pain or discomfort

4 I have severe pain or discomfort

5 I have extreme pain or discomfort

e. **Anxiety/Depression**

1 I am not anxious or depressed

2 I am slightly anxious or depressed

3 I am moderately anxious or depressed

4 I am severely anxious or depressed

5 I am extremely anxious or depressed

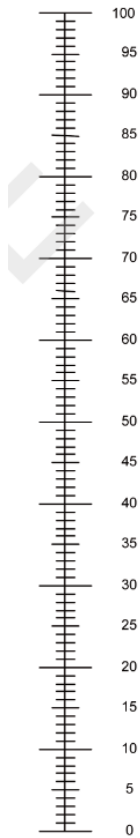
EQ5DQ4. We would like to know how good or bad your health is **TODAY**.

Please format so rating scale below is to the right of the bullet points just below here

- This scale is numbered from **0** to **100**.
- **100** means the best health you can imagine.
- **0** means the worst health you can imagine.
- Please indicate on the scale how your health is TODAY.

YOUR HEALTH TODAY= _____

The best health
you can imagine



The worst health
you can imagine

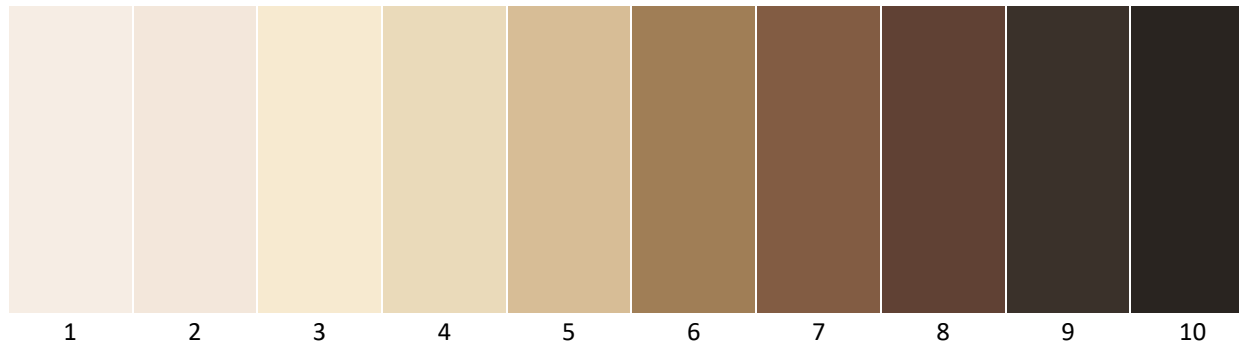
The next questions are about your skin and your <skin condition>.

Q5. How does your healthy skin respond to being in the sun?

- 1 Always burns, does not tan
- 2 Burns easily, tans with difficulty
- 3 Sometimes burns, tans gradually
- 4 Rarely burns, tans easily
- 5 Very rarely burns, tans very easily

6 Never burns, tans very easily

MonkQ8. What is your skin color? Please choose the color image that most closely matches your skin.



Q12. Where do you currently look for support to help you manage your <skin condition>? Please check all that apply.

- a I do not seek support
- b Family member(s)
- c Friends
- d <skin condition> organizations
- e In-person patient support groups
- f Virtual patient support groups
- g Community-based organization, such as church or school
- h Online community
- i Online search
- j Primary care provider
- k Dermatologist (a doctor who treats skin problems)
- l Naturopathic doctor
- m Allergist
- n Immunologist
- o Mental health professional

p Other healthcare specialist

The next questions are about your access to healthcare.

Q15. Which of the following influenced you to see a healthcare provider for your <skin condition>? Please check all that apply.

a Friend

b Website

c Other provider

d Hairdresser/barber

e Social media (online groups). Which ones?

1 Twitter

2 Instagram

3 Facebook

4 Tik Tok

5 Reddit

6 Snapchat

7 Other

f Church or religious group

g Commercial or ad

h Radio

i Podcast

j Community center

k Family member

l Co-Worker

m Significant other

n Previous experience or knowledge

p Non-profit organization

q Other

r None of the above – cannot select any of the above options

Q16. What type of healthcare provider or medical specialist do you primarily see for medications to treat your <skin condition>?

1 I do not see any healthcare providers to treat my <skin condition>

2 My primary healthcare provider (internist or general practitioner)

3 Dermatologist

4 Naturopathic doctor

5 Allergist

6 Immunologist

7 Nurse practitioner or physician assistant

8 Other medical specialist

7 Only when in crisis

Q21. How much do you trust that your [insert provider name] is able to effectively treat your [condition]?

1 Very much

2 Quite a bit

3 Somewhat

4 A little bit

5 Not at all

Q22. How often are you treated with respect by your doctors or healthcare providers?

1 Always

2 Most of the time

3 Some of the time

4 None of the time

5 Don't know

Q23. How often do your doctors or healthcare providers ask for your opinions or beliefs about your medical care or treatment? For example, what kind of tests, procedures, or medications you prefer.

- 1 Always
- 2 Most of the time
- 3 Some of the time
- 4 None of the time
- 5 Don't know

Q24. How often do your doctors or healthcare providers tell or give you information about your health and healthcare that was **easy to understand**?

- 1 Always
- 2 Most of the time
- 3 Some of the time
- 4 None of the time
- 5 Don't know

The following questions are about your experiences with doctors and other healthcare providers in the past year. Some people think it is helpful if their providers are from the same background that they are –such as race or religion or native language –because they think their doctors will better understand what they’re experiencing or going through.

Q25. How important is it to you that your doctors or healthcare providers understand or are similar to you in any of these ways?

- 1 Very important
- 2 Somewhat important
- 3 Slightly important
- 4 Not important at all
- 5 Don't know

Q26b. How often have you either delayed or not gone to see doctors or healthcare providers because they were different from you in any of these ways?

- 1 Always
- 2 Most of the time
- 3 Some of the time

4 None of the time

5 Don't know

Q28. When you have a flare-up of symptoms of <skin condition>, which of the following steps do you usually take? Please select all that apply.

1 Email/text/message provider

2 Use an over-the-counter product or medication

3 Use a non-medical intervention or home remedy

4 Use a prescription medication I already have

5 Call my healthcare provider for advice

6 Make an appointment to see my healthcare provider

7 Go to an urgent care or walk-in clinic

8 Go to the emergency room

9 Conduct an online search

10 Make a dietary or lifestyle change

11 Make an appointment to see my mental healthcare provider

12 Do nothing **cannot be selected if any others are selected**

Q29. From the time you contact your [insert provider from question above]'s office to schedule an appointment, how long does it typically take to get an appointment for your <skin condition>?

1 Days

2 A week or more, but less than a month

3 1 month

4 2 months

5 3 months

6 4 months to 6 months

7 Longer than 6 months

Q33. How long does it take you to travel to your [insert provider from question above] office?

1 Less than 15 minutes

2 15 to 30 minutes

3 30 to 60 minutes

4 1 to 2 hours

5 More than 2 hours

PRAPAREQ34. Has lack of transportation kept you from medical appointments, meetings, work, or getting things needed for daily living? Check all that apply.

1 Yes, it has kept me from medical appointments

2 Yes, it has kept me from non-medical meetings, appointment, work, or from getting things that I need

3 No

The next set of questions are about you and your general health. Please consider your overall health when answering these questions, not just your <skin condition>.

The next set of questions are about your **CURRENT** level of confidence in different situations.

CURRENT level of confidence...

PROMISQ38.	I am not at all confident	I am a little confident	I am somewhat confident	I am quite confident	I am very confident
a. I can talk about my health problems with someone	1	2	3	4	5
b. If I need help, I can find someone to take me to the doctor's office	1	2	3	4	5
c. I can get emotional support when I need it	1	2	3	4	5
d. I can ask for help when I don't understand something	1	2	3	4	5
e. I have someone who helps me understand medical information	1	2	3	4	5

f. If I need help, I have someone to help me manage my daily activities	1	2	3	4	5
g. I have someone to help me plan and make decisions related to my illness	1	2	3	4	5
h. I can communicate well with my doctors and nurses	1	2	3	4	5

The next questions are about the impact of your <condition>.

PRAPAREQ39. What is your current work situation?

1 Unemployed → Skip to Q41

2 Part-time or temporary work → Go to Q40

3 Full-time work → Skip to Q42

4 Otherwise, unemployed but not seeking work (ex: student, retired, disabled, unpaid primary care giver) → Skip to Q41

Q43. Please select if your <skin condition> has affected any of the following areas of your life. Please check all that apply.

- a <skin condition> has not affected any of my educational activities, relationships, family plans, or leisure activities → If selected, no other responses allowed
- b Pursue higher education (inc. delay in education, changed area of study, increased length of time to complete studies, etc.)
- c Do things that interest you (inc. personal hobbies, travel, join a special interest group, be active in a religious organization, etc.)
- d Marry or become involved in a long-term relationship
- e Have children
- f Perform parenting duties

DLQIQ44. Over the last week, how **itchy**, **sore**, **painful** or **stinging** has your skin been?

1 Very much

2 A lot

3 A little

4 Not at all

DLQIQ45. Over the last week, how **embarrassed** or **self-conscious** have you been because of your skin?

1 Very much

2 A lot

3 A little

4 Not at all

DLQIQ46. Over the last week, how much has your skin interfered with you going **shopping** or looking after your **home** or **garden**?

1 Very much

2 A lot

3 A little

4 Not at all

5 Not relevant

DLQIQ47. Over the last week, how much has your skin influenced the **clothes** you wear?

1 Very much

2 A lot

3 A little

4 Not at all

5 Not relevant

DLQIQ48. Over the last week, how much has your skin affected any **social** or **leisure** activities?

1 Very much

2 A lot

3 A little

4 Not at all

5 Not relevant

DLQIQ49. Over the last week, how much has your skin made it difficult for you to do any **sport**?

1 Very much

2 A lot

3 A little

4 Not at all

5 Not relevant

DLQIQ50. Over the last week, has your skin prevented you from **working** or **studying**?

1 Yes → Go to Q51

2 No → Go to Q50a

3 Not relevant

DLQIQ50a. Over the last week, how much has your skin been a problem at **work** or **studying**?

1 A lot

2 A little

3 Not at all

DLQIQ51. Over the last week, how much has your skin created problems with your **partner** or any of your **close friends** or **relatives**?

1 Very much

2 A lot

3 A little

4 Not at all

5 Not relevant

DLQIQ52. Over the last week, how much has your skin caused any **sexual difficulties**?

1 Very much

2 A lot

3 A little

4 Not at all

5 Not relevant

DLQIQ53. Over the last week, how much of a problem has the treatment for your skin been, for example by making your home messy, or by taking up time?

1 Very much

2 A lot

3 A little

4 Not at all

5 Not relevant

The next set of questions are about your <skin condition>.

Lately...

NeuroQOLQ54.					
	Never	Rarely	Sometimes	Often	Always
a. Because of my illness, some people avoided me	1	2	3	4	5
b. Because of my illness, I felt left out of things	1	2	3	4	5
c. Because of my illness, people avoided looking at me	1	2	3	4	5
d. I felt embarrassed about my illness	1	2	3	4	5
e. Because of my illness, some people seemed uncomfortable with me	1	2	3	4	5
f. I felt embarrassed because of my physical limitations	1	2	3	4	5
g. Because of my illness, people were unkind to me	1	2	3	4	5

h. Some people acted as though it was my fault I have this illness	1	2	3	4	5
--	---	---	---	---	---

The next questions are about your insurance and possible medications for your <skin condition>.

PRAPAREQ55. What is your main healthcare insurance?

- 1 None/uninsured → Go to Q56
- 2 Medicaid → Skip to Q57
- 3 CHIP Medicaid → Skip to Q57
- 4 Medicare → Skip to Q57
- 5 Military insurance (e.g., Veterans Affairs (VA), Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA), TRICARE)
- 6 Other public insurance (not CHIP) → Skip to Q57
- 7 Other Public Insurance (CHIP) → Skip to Q57
- 8 Private Insurance (e.g., employer-provided, United, Blue Cross Blue Shield, etc.) → Skip to Q57

Q57. In the past 6 months, which of the following healthcare services for treatment of your <skin condition> did you need to pay for partially out-of-pocket? Please check all that apply.

- 1 Outpatient visits with my primary care provider
- 2 Outpatient visits with a specialist doctor
- 3 Outpatient visits with a mental healthcare provider
- 4 Hospital stays
- 5 Emergency room visit
- 6 Medications
- 7 Other treatments (e.g., acupuncture, chiropractic, etc.)
- 8 I haven't received any healthcare services in the past 6 months.
- 9 None of the above → cannot be selected if any others are selected; Skip to Q58

Q57a. Do out-of-pocket costs ever stop you from making or going to an appointment for your <skin condition>?

1 Yes

2 No

Q58. Do you receive any financial assistance with paying for your treatment through a patient assistance program? Patient assistance programs aim to provide solutions for patients and may provide financial assistance to help patients access medications.

1 Yes

2 No

Q60b. What medication are you currently taking for your Psoriasis?

1 Over-the-counter creams/lotions

2 Phototherapy

3 Prescription creams/lotions

4 Prescription pills

5 Prescription injections

6 None of the above

Q61. How satisfied are you with your current treatment regimen for [condition]?

1 Very satisfied

2 Satisfied

3 Dissatisfied

4 Very dissatisfied

You are almost done with the survey.

The last questions are to learn a little more about you.

Q63. What is your sex (assigned at birth)?

1 Male

2 Female

Q64. How do you describe yourself?

1 Male

2 Female

3 Transgender

4 Do not identify as male, female, or transgender

Q65. What is your marital status?

1 Married

2 Widowed

3 Divorced

4 Separated

5 Single, Never Married

PRAPAREQ66. What is the highest level of school that you have finished?

1 Less than high school degree

2 High school diploma or GED

3 More than high school

PRAPAREQ75. In the past year, have you or any household members been unable to get any of the following when it was really needed?

	Yes	No
a. Food	1	2
b. Utilities	1	2
c. Medicine or any healthcare (medical, dental, mental health, vision)	1	2
d. Phone	1	2
e. Clothing	1	2
f. Child care	1	2
g. Other. Please describe _____	1	2

Q76. Do you have access to the internet every day?

1 Yes

2 No

Q77. How do you access the internet? Select all that apply.

a Personal smart phone

b Other person's smart phone

c Smart phone from workplace

d Computer or tablet at home

e Computer or tablet at workplace

f Computer or tablet in public place (e.g., public library)

Q78. Do you have a smartphone?

1 Yes

2 No → End survey

Q78a. What type of data plan do you have on your smartphone?

1 Limited data

2 Unlimited data