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Authors

Afifi, Ladan
Shankle, Lindsey
Armstrong, April W
et al.

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National Psoriasis Foundation Priorities for Patient-Centered Research: Proceedings from the 2016 Conference

Ladan Afifi, M.S.^{1,7}, Lindsey Shankle, M.P.H.^{2,7}, April W. Armstrong, M.D., M.P.H.^{3,7}, Marc Boas, A.S., A.K.C.E.S.C.L., P.M.P.⁷, Alisha Bridges⁷, Vivian Chiguil, Frank Doris⁷, Kristina Callis Duffin, M.D., M.S.⁴, Eric Fielding, M.B.A., P.M.P., C.P.L.P., Roy Fleischmann, M.D., M.A.C.R., Joel M. Gelfand, M.D., M.S.C.E.^{5,7}, Matthew Kiselica, Catherine Kiselica, Brian LaFoy, John J. Latella, Junko Takeshita, M.D., Ph.D., M.S.C.E.^{5,7}, Sarah Truman, M.P.A., C.P.P.⁷, Marilyn T. Wan, MB.Ch.B., M.P.H.^{5,7}, Vickie Wilkerson, Jashin J. Wu, M.D.^{6,7}, Michael P. Siegel, Ph.D.^{2,7}, and Wilson Liao, M.D.^{1,7}

¹University of California, San Francisco, San Francisco, California

²National Psoriasis Foundation, Portland, Oregon

³University of Southern California, Los Angeles, California

⁴University of Utah, Salt Lake City, Utah

⁵University of Pennsylvania, Philadelphia, Pennsylvania

⁶Kaiser Permanente Los Angeles Medical Center, Los Angeles, California

⁷Citizen Pscientist Governance Council, Portland, Oregon

Abstract

The National Psoriasis Foundation (NPF) is developing an agenda for patient-centered research to help patients and their caregivers make more informed health care decisions by engaging psoriasis patients in prioritizing comparative effectiveness research (CER) topics. The NPF has created a novel patient-centered research platform known as Citizen Pscientist (CP), allowing patients with psoriasis and psoriatic arthritis to register and contribute their health data. The CP Governance Council administered an online 23-question CER survey to the CP community and held a structured meeting on December 3, 2016, with patients and researchers to review CER survey results and discuss patient-centered research priorities. Of the 2,945 patients surveyed, 792 patients responded. Three CER topics were deemed to be of high priority for the research agenda: 1) Treat-to-target therapy for psoriasis, 2) Psoriatic arthritis screening questionnaires for early detection and treatment of psoriatic arthritis, and 3) Comparative effectiveness of home-based phototherapy for psoriasis.

Corresponding Author: Wilson Liao, M.D., Department of Dermatology, University of California, San Francisco, 2340 Sutter Street, Room N431, Box 0808, San Francisco, California 94115, Tel: 415.476.8364, Fax: 415.476.8837, wilson.liao@ucsf.edu.

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Keywords

psoriasis; psoriatic arthritis; comparative effectiveness research; patient-centered research; Citizen Pscientist; treat-to-target; screening questionnaire; home phototherapy

Introduction

Over the past two decades, the National Psoriasis Foundation (NPF) has been engaged in supporting a variety of research initiatives. A current priority for the NPF is developing an agenda for patient-centered research, which is research that is highly relevant to patients, and helps patients and their caregivers make informed health care decisions. Such research may be facilitated by patients who develop research ideas, design and participate in research, and perform research themselves. The patient perspective is vital to identifying research initiatives that matter to patients and may facilitate improved health care outcomes.

Along with patient-oriented research, the NPF aims to engage psoriasis patients in prioritizing comparative effectiveness research (CER) topics. The NPF has previously been engaged in CER through funding (RC1-AR058204) it received from the National Institutes of Health to participate in the Dermatology Comparative Effectiveness Research Network (DCERN).¹⁻¹⁰ CER aims to compare the effectiveness of treatment strategies or ways to deliver health care in a real-world setting, ultimately generating evidence that will inform health care decisions. Although randomized controlled trials (RCTs) are the gold standard for clinical trials, they are limited in their external validity as a result of strict inclusion criteria, short duration, and unrealistic settings for patient care,¹¹ and thus only measure idealized treatment *efficacy*. The alternative measure of *effectiveness* refers to performance in real-world conditions outside the ideal settings of an RCT,¹² making the evidence generated by CER more applicable to patients. Such research is the focus of a U.S. funding research agency called Patient Centered Outcomes Research Institute (PCORI).

Funded by a Pipeline to Proposal Award from PCORI, NPF has created a novel patient-centered research platform known as Citizen Pscientist (CP). This online platform (www.citizenpscientist.com) allows patients with psoriasis and psoriatic arthritis to register and complete a questionnaire contributing their health data, including demographics, psoriasis subtype, psoriasis severity, triggers, and response to treatments. The anonymized data are stored in a cloud database, and patients can explore the data by testing their own hypotheses and making discoveries. These findings can be graphed and posted in the discussion forum to generate ongoing dialogue among the CP patient community. CP can identify areas of patient research interest by examining popular and trending discussions among patients. Additionally, once validated, the data can serve as a rich database for psoriasis and psoriatic arthritis researchers. Overseeing the CP project is the CP Governance Council, composed of NPF research staff, patients with psoriasis and psoriatic arthritis, and researchers.

To better understand patient-centered research priorities and create a patient-centered research agenda, the CP Governance Council administered an online CER survey to patients

in the CP community and held a structured meeting with patients and researchers to discuss these topics in person.

Methods

CER Survey

Study Design—A 23-question survey was designed and administered by the CP Governance Council. The CER survey contained three distinct sections: 1) a section in which patients rated eight potential CER questions relevant to psoriatic disease, 2) a section with three open-ended questions asking about CER priorities and 3) a section containing 12 demographic questions (Table 1). The eight specific CER questions were generated by the CP Governance Council through collective brainstorming and subsequently refined through multiple conference calls involving patients, psoriasis researchers, and NPF staff. The eight CER questions were accompanied by explanatory text written in language designed to be clear to a lay audience. The requested demographic information was similar to prior demographic questions utilized in NPF research initiatives.

Setting and Study Participants—The survey was distributed to patients in the CP network using SurveyMonkey in a 4-week timeframe from October 24, 2016, to November 21, 2016. The CP network is composed of patients recruited through NPF's communication channels such as the NPF website, *Psoriasis Advance* magazine, social media pages, the Patient Navigation Center, and marketing materials distributed at NPF events. The CER survey was distributed to the CP network using the available contact information. The questions were randomized to prevent any bias and influence of order on responses.

Data Measurement and Statistical Analysis—CP patients were asked to prioritize the eight CER questions on a five-point Likert scale (from lowest to highest priority) according to what they deemed to be important from a patient perspective. Each response was recoded into numerical values on a five-point score, whereby CER questions given the highest priority by a respondent were given a score of 5 and those assigned the lowest priority were given 1 point. Total mean scores and mean scores based on age, gender, race, presence of psoriatic arthritis, psoriasis severity, and income were calculated for each CER question. Open-ended answers were categorized into groups based on broad themes, which included: treatment-related, side effects and safety, triggers, alternative treatments (diet/nutritional therapy), comorbidities, patient and physician education, delivery of care and communication, insurance and cost issues, disease etiology and progression, symptom related, pain-related, and individualized management.

Patient-Centered Research Meeting

On December 3, 2016, the NPF held a meeting with the Citizen Pscientist Governance Council and other stakeholders in Dallas, where patients and researchers reviewed CER survey results and jointly developed a roadmap for patient-centered research in psoriasis and psoriatic arthritis. A roster of meeting participants is shown in Table 2. The meeting structure involved a presentation of the CER survey results followed by a group discussion to identify CER priorities. Attendees were asked the following two questions:

1. If resources were unlimited, what CER questions would you most want to see addressed?
2. Do these priorities change if you considered resources that were limited? If so, how?

Results

CER Survey

Of the 2,945 patients in the CP network, 792 responded to the survey, resulting in a 27% response rate. This was considered favorable given the short amount of time the survey was open. Demographic and other characteristics of survey respondents are shown in Table 3. Respondents tended to be Caucasian, middle-aged, educated, females with a high prevalence of psoriatic arthritis, living in geographically diverse areas across the United States.

Numerical values for each CER question are summarized in Table 4. A CER question comparing outcomes in psoriatic arthritis patients using biologics vs. methotrexate was a popular topic among many groups, even in patients without psoriatic arthritis. The CER questions regarding a psoriatic arthritis screening questionnaire and treat-to-target management for psoriasis also scored highly among respondents. Younger patients without psoriatic arthritis and with more extensive psoriasis prioritized a CER question addressing differences in outcomes between home vs. office-based phototherapy for psoriasis as well as comparing effectiveness of the different scalp treatment formulations for psoriasis.

In regard to the free text section, 308, 372, and 363 respondents provided answers for open-ended questions 1, 2, and 3, respectively. Popular topics in the free text included comparative treatment effectiveness (e.g. comparing two biologics such as adalimumab vs. secukinumab, or comparing methotrexate vs. biologics), parameters of treatment (i.e., dose, duration, mode of administration, treat-to-target), comparative effectiveness of combination therapy, diet/alternative remedies, safety and side effect profiles (particularly of biologics, including adalimumab, etanercept, secukinumab, and others), risk/benefit ratios, cost/benefit ratios, personalized medicine, patient and physician education, physician and patient communication, and individualized management approaches.

Patient-Centered Research Meeting

Discussion of potential research priorities among meeting attendees led to high interest in the topics of the efficacy of methotrexate versus biologics in psoriatic arthritis, the treat-to-target approach, comparative effectiveness of home vs. office-based phototherapy, personalized medicine studies, benefit/risk ratio studies, and complementary medicine treatment approaches. Many of these priorities overlap with the primary themes identified by patients in the CER survey. Other CER priorities identified by the group include comparing the effectiveness of biologics with one another, determining the influence of patient support groups/assistance programs on patient outcomes, and research on patient outcomes when using prevention and screening protocols for psoriasis co-morbidities.

Discussion

Results from the CER survey highlighted important themes regarding screening and treatment for psoriatic arthritis and treat-to-target for psoriasis, as well as home phototherapy for psoriasis patients as a patient-centered therapy. The in-person discussion emphasized similar themes as well as personalized approaches to patient care. Integrating the results from the CER survey and group discussion as well as assessing the cost, feasibility, and resources available, three CER questions deemed to be of high priority on the research agenda were:

1) Are treatment outcomes different between psoriasis patients who are managed via a “treat-to-target” approach versus those who are not?

Conventional management for psoriasis and psoriatic arthritis involves starting a therapy and assessing for any kind of response, but without a certain target goal. Treating to a specific target level, also known as treat-to-target, is a disease-management approach that identifies a specific and well-defined treatment goal where frequent re-assessment occurs to evaluate whether treatment adjustment and/or escalation is required to achieve the predetermined goal. A treat-to-target approach has been utilized with improved outcomes for several diseases, such as blood glucose control in diabetes, blood pressure targets in hypertension, lipid levels for heart disease, and remission or minimal disease goals in rheumatoid arthritis.^{13,14} However, data on strict glucose control in diabetes have demonstrated increased mortality¹⁵ and consensus guidelines have determined insufficient support for lipid targets for cardiovascular disease,¹⁶ calling into question the use of treat-to-target for these diseases. The ongoing controversy over treat-to-target in these diseases further strengthens the need to study this management approach and determine whether the adoption of treat-to-target is feasible and effective for psoriatic disease. Disease-specific treat-to-target studies are particularly necessary, as outcomes and treatment targets are unique to each disease (i.e. quality of life in psoriasis vs. mortality in diabetes). Treat-to-target approaches in psoriatic arthritis have suggested a state of minimal disease activity (MDA) as a reasonable goal for psoriatic arthritis, where several observational and RCT studies validated its feasibility to achieve an MDA state and its efficacy as it was associated with less joint damage progression and improved quality of life function.¹⁷⁻²¹ Recently, the first-ever psoriasis treatment targets were published for use in the United States.²² Measuring the effectiveness of these new treatment targets on improving patient outcomes was identified as high priority.

2) Are outcomes different for psoriasis patients who receive a screening questionnaire for psoriatic arthritis compared to psoriasis patients who don't receive a screening questionnaire?

Early diagnosis for psoriatic arthritis allows for earlier treatment initiation, which has been shown to prevent joint damage and slow disease progression, ultimately improving patient outcomes.²³ Given the variable presentation of psoriatic arthritis, recognition of signs and symptoms suggestive of psoriatic arthritis remains challenging. As a result, various psoriatic arthritis screening questionnaires have been developed to aid in the screening for psoriatic arthritis and help determine when a referral to rheumatology is warranted. There are many

questionnaires available, including: Toronto Psoriatic Arthritis Screen II (ToPAS II), Psoriatic Arthritis Screening and Evaluation (PASE), Psoriasis Epidemiology Screening Tool (PEST), and Early Arthritis for Psoriatic Patients (EARP).^{24,25} Sensitivities and specificities of questionnaires are well documented,^{24,25} and studies comparing the effectiveness of questionnaire use to current standard of care at reducing delay in psoriatic arthritis diagnosis were identified as high priority.

3) For people with skin similar to mine, is treatment with home-based phototherapy as effective and safe as office-based phototherapy?

Home-based phototherapy for psoriasis was first reported in a 1979 Swedish study.²⁶ The initiation of home-based phototherapy addresses patient-centered issues such as desire for treatment with no risks of internal side effects, preference for treatments which can be used safely in pregnancy and lactation, need for convenience, time constraints, cost of travel, and loss of income,²⁷ which may be especially important for patients with extensive disease requiring frequent visits or specific age groups that have limited available free time or transportation barriers. Our prior work has indicated a strong preference for use of office-based phototherapy by dermatologists, whereas surveys of NPF psoriasis patients treated by dermatologists (N=1451) suggests a strong preference for phototherapy delivered in the home.^{9,28} Studies in the Netherlands have reported similar effectiveness, lower burden of treatment, improved adherence, no increase in acute adverse events and greater patient satisfaction with home-based phototherapy compared to office-based treatment.²⁹⁻³¹ The Netherlands study was small and was not representative of the diverse skin types seen in the U.S. population. Therefore, uncertainty of the effectiveness of home phototherapy by U.S. stakeholders (experts, physicians, payers, and patients) has led to very limited utilization of this modality in the U.S. despite its patient-centered nature. Given the interest in home-based phototherapy among survey respondents and meeting attendees, the existence of a U.S. data gap which has resulted in decisional uncertainty by a number of stakeholders, and potential impact for making a patient-centered and effective treatment option more widely and rapidly available by addressing decisional uncertainty through CER, a study comparing the effectiveness and tolerability of home-based phototherapy to outpatient-based phototherapy in a U.S. population was identified as a high priority.

Free Text Section

A variety of themes emerged from the free text portion of the survey that warrant further elaboration. A common theme entailed an interest in comparing treatments, particularly biologics. Patients expressed interest in comparing outcomes based on treatment parameters such as the starting dose, duration, administration type, step-up therapy, and use of combination therapy. Comparative effectiveness treatment research was not exclusive to pharmacotherapy, topicals, and phototherapy. Patients also reported interest in research regarding natural remedies, with the majority requesting more information on nutrition and dietary strategies to manage their disease. Patients shared in the free response section their interest in the role of diet, nutrition, herbal remedies, meditation, and exercise in treating their psoriasis and psoriatic arthritis, either as a monotherapy or in combination with other therapies. Additionally, patients expressed high interest in research on precision medicine, where research is used to identify the most effective treatment based on individual

characteristics such as age, gender, race, psoriasis type, severity of psoriasis, presence of comorbidities, genetics, and environmental influences.

In addition to determining the effectiveness of treatment, survey respondents emphasized the importance of understanding the adverse effects, particularly of biologics. Specifically, patients sought to understand the long-term effects of medication and ultimately have a better understanding of the benefit/risk ratio for each medication. Patients also want to understand if successful treatment of psoriasis will lower the risk of serious comorbidity such as cardiovascular disease and mortality. Not only is each patient unique in their disease and overall health profile, but patients also differ in their goals for treatment. Some patients are willing to undergo greater risks to achieve improved outcomes, while others may not find the risks to be worth the benefits.

When respondents were asked how physicians and the health care delivery organizations aid patients in making better decisions, a popular topic involved patient and physician education on treatments, side effects, the latest research, and new clinical trials. Respondents felt physicians should spend more time with patients discussing all the treatment options with the most up-to-date information on efficacy and side effects so they can be involved in the treatment choices and the direction of their care, and ultimately make informed decisions. Other themes included improved communication between patient and physicians and between physicians who manage the patient's care. For example, future research can address this issue by investigating whether differences in outcome are observed in patients who receive care for their psoriasis from a dermatologist, rheumatologist, and primary care physician (PCP) at different sites compared to patients who receive psoriasis care within an integrated clinic or in a setting where there is an established communication protocol between all treating physicians. Multidisciplinary clinics have demonstrated improved diagnostic accuracy and increased use of systemic medication, particularly biologics, in psoriasis and psoriatic arthritis patients after evaluation by a multidisciplinary team.³²

Because psoriasis confers an independent, increased risk for comorbidities including inflammatory arthritis, cardiovascular disease, and depression, coordinated care among specialists and PCPs is likely critical for successful long-term management of psoriasis and comorbidities. One way to increase patient-centered care for psoriasis patients is through telehealth. Specifically, communications technology can improve access and provide high quality care for psoriasis patients. Supported by PCORI, Armstrong et al. are evaluating whether an innovative telehealth model termed “collaborative connected health (CCH)” increases access to specialists and improves patient outcomes. Online models such as this offer multiple modalities for patients and PCPs to access dermatologists online directly and asynchronously to maximize effectiveness in a real-world setting.³³ Specifically, in such a model, patients can upload their clinical images and history and obtain evaluation and recommendations directly from the dermatologists. CCH also fosters patient engagement and team care through active sharing of management plans and multidirectional, informed communication among patients, PCPs, and dermatologists.

Respondents also identified the importance of individualized treatment strategies, in which treating physicians consider the patient's clinical picture and preferences when making a

management plan and do not necessarily follow standardized treatment algorithms. The cost of medication and insurance restrictions are additional concerns for patients with psoriasis and psoriatic arthritis. Patients report assistance with cost, insurance coverage, and information on cost/benefit ratios as other important areas where treating physicians and health care organizations can help enhance health care decisions.

Conclusion

The first NPF Patient-Centered Research meeting was a productive and insightful experience for all stakeholders. During the meeting, CER priorities were identified through the collaboration of researchers and patients as we outlined strategies to improve the platform in the future, including technology updates, better marketing, and improved patient outreach. Limitations to the survey include a risk of responder bias and answer/outcomes being dependent on the questions proposed. Nevertheless, the discussion and ideas developed have created a roadmap for research initiatives and will be used for future research proposals. Effective dialogue regarding strategies to enhance patient-centered research efforts also was discussed to increase participation, especially among diverse groups, and improve advocacy and awareness.

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Table 1**CER Survey**

Eight CER Questions	
1	For people with skin similar to mine, is treatment with home-based phototherapy as effective and safe as office-based phototherapy?
2	Are outcomes different among patients with psoriatic disease who have a peer mentor with similar background (i.e., someone of similar age, gender, race, etc.) compared to having a randomly assigned peer mentor (i.e., someone who does not necessarily have a similar background) or have no peer mentor?
3	Are treatment outcomes different between psoriasis patients who are managed via a “treat-to-target” approach versus those who are not?
4	Are outcomes different for psoriasis patients who receive a screening questionnaire for psoriatic arthritis compared to psoriasis patients who don't receive a screening questionnaire?
5	Is the treatment of scalp psoriasis using one formulation (e.g. medicated shampoo) more effective than using another formulation (e.g., foam, solution, suspension, etc.)?
6	Are treatment outcomes different between patients receiving help from NPF patient support programs compared to those not receiving such support?
7	Is patient adherence to biologic medications better when injections are given in a doctor's office or when injections are given at home via self or caregiver?
8	For psoriatic arthritis, are outcomes different when treating with an injectable biologic compared to treating with methotrexate?
Three Open-Ended Questions	
1	Would you be willing to provide your input on additional important questions for CER?
2	What information do you feel you need in order to make better decisions about your treatment for psoriasis that is not currently available?
3	How can your treating doctor and the care-delivery organizations they work in help you make better decisions about your psoriasis care?
Demographics Obtained	
	<ul style="list-style-type: none"> • Age • Gender • Race • Education • Income • Geographic location of residence • Prior diagnosis of psoriasis given by medical professional • Primary provider for psoriasis • Psoriasis severity • Prior diagnosis of psoriatic arthritis given by medical professional • Primary provider for psoriatic arthritis • Type of insurance

Table 2
Attendees of the NPF Patient-Centered Research Meeting

NPF Research Staff
Michael Siegel, Ph.D. Vice President of Research Programs, NPF
Lindsey Shankle, M.P.H. Patient-centered Research Manager, NPF
Expert Researchers and Clinicians
April Armstrong, M.D., M.P.H. University of Southern California
Kristina Callis Duffin, M.D., M.S. University of Utah
Joel Gelfand, M.D., M.S.C.E. University of Pennsylvania
Wilson Liao, M.D. University of California, San Francisco
Junko Takeshita M.D., Ph.D., M.S.C.E. University of Pennsylvania
Roy Fleischmann, M.D., M.A.C.R. University of Texas Southwestern Medical Center
Marilyn Wan, M.B.Ch.B., M.P.H University of Pennsylvania
Ladan Afifi, M.S. University of California, San Francisco
Patients
Marc Boas, A.S., A.K.E.S.C.I., P.M.P.
Alisha Bridges
Vivian Chiguil
Frank Doris
Eric Fielding, P.M.P., C.P.L.P.
Cat Kiselica
Matt Kiselica Member, NPF Board of Directors
Brian LaFoy
John J. Latella
Sarah Truman, M.P.A.
Vickie Wilkerson
Other Attendees
Cynthia Waisner, Ph.D. Facilitator

Table 3
CER Survey Baseline Characteristics of Respondents

Gender	Female: 430 (76%) Male: 139 (24%)	Prefer not to answer: N = 2 Blank: N = 221
Mean Age +/- SD	52.8 +/- 13.0	
Age	< 40: 100 (18%) 40-60: 305 (54%) > 60: 165 (29%)	Blank: N = 222
Racial Groups	White: 526 (94%) Non-White: 36 (6%) <ul style="list-style-type: none"> • American Indian or Alaska Native = 12 (1.5%) • Asian = 17 (2.1%) • Black or African American = 4 (0.5%) • Native Hawaiian or Pacific Islander = 3 (0.37%) 	Prefer not to answer: N = 5 Blank: N = 225
Hispanic, Latino or Spanish Origin	Yes: 35 (6%) No: 535 (94%)	Blank: N = 222
U.S. Geographic Distribution	South: 148 (27%) Northeast: 113 (20%) West: 109 (20%) Midwest: 99 (18%) Other: 83 (15%)	Prefer not to answer: N = 16 Blank: N = 224
Education Level	High school degree, some college, or associate's degree: 210 (38%) Bachelor's degree or greater: 347 (62%)	Prefer not to answer: N = 8 Blank: N = 239
Total household Income	< \$25,000: 64 (14%) \$25,000-49,999: 94 (21%) \$50,000-74,999: 72 (16%) \$75,000-99,000: 61 (13%) > \$100,000: 164 (36%)	Prefer not to answer: N = 103 Blank: N = 234
Psoriasis Severity	None/little: 66 (12%) Few patches (1-3 palms): 155 (28%) Scattered (3-10 palms): 219 (40%) Extensive (> 10 palms): 113 (20%)	Don't know: N = 3 Blank: N = 236
Diagnosed with Psoriatic Arthritis	Yes: 329 (60%) No: 219 (40%)	Not sure: N = 22 Blank: N = 222

Table 4
Mean Scores for CER Question Priority (5= Highest Priority, 1=Lowest Priority)

		Photo Home vs. Office (Q1)	Peer Mentor (Q2)	Treat -to-Target (Q3)	PsA Screen (Q4)	Scalp PsO (Q5)	Support Groups (Q6)	Inj. Bio. Home vs. Office (Q7)	Biologics vs. MTX (Q8)
	Total	3.04	3.49	3.30	3.24	3.17	2.90	3.81	
Gender	Females	3.06	3.54	3.38	3.31	3.23	2.91	3.85	
	Males	3.09	3.51	3.08	3.23	3.05	2.86	3.81	
Race	White	3.05	3.54	3.29	3.28	3.16	2.86	3.85	
	Non-White	3.11	3.72	3.5	3.52	3.55	3.14	3.65	
PsA Status	PsO	3.35	3.40	3.07	3.43	3.14	2.83	3.46	
	PsO + PsA	2.87	3.64	3.44	3.17	3.21	2.92	4.12	
PsO Severity	None/Little	2.81	3.71	3.58	3.28	3.14	2.75	4.01	
	Few	2.97	3.52	3.32	3.17	3.16	2.93	4.02	
	Scattered	3.15	3.51	3.26	3.45	3.20	2.85	3.70	
	Extensive	3.30	3.55	3.21	3.30	3.24	2.96	2.78	
Age	< 20	4.00	3.20	3.00	4.20	2.40	2.80	2.80	
	> 40	3.18	3.38	3.13	3.37	2.95	2.60	3.62	
	40-60	3.09	3.57	3.44	3.24	3.25	2.92	3.95	
	> 60	2.98	3.58	3.17	3.35	3.22	2.99	3.79	
Income	< 50,000	2.99	3.46	3.30	3.30	3.36	2.95	3.74	
	50,000-99,999	3.15	3.61	3.30	3.34	3.13	2.98	3.71	
	> 100,000	3.02	3.54	3.36	3.24	3.08	2.74	4.02	

PsA: psoriatic arthritis

PsO: psoriasis

Inj. Bio.: injectable biologic

MTX: methotrexate