

**Validated patient-reported outcome measurements for psoriasis may not reflect patients' current preferences**



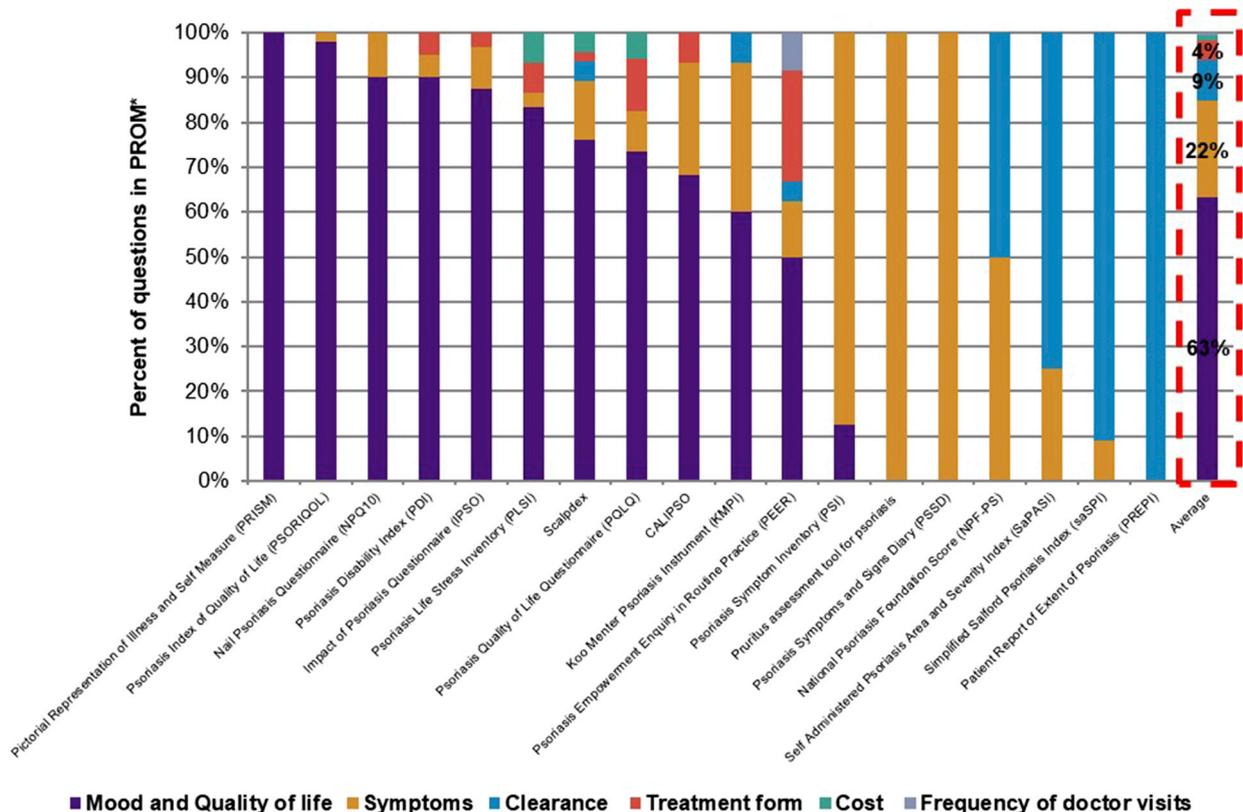
*To the Editor:* Health care reform initiatives have emphasized patient-reported outcome measurements (PROMs) to promote patient-centric services.<sup>1,2</sup> PROMs have been developed and validated for psoriasis<sup>3</sup> and may be tied to reimbursement going forward. However, it is debated whether existing instruments accurately reflect patients' priorities given a changing therapeutic landscape.<sup>3-6</sup> In this study, we characterized current validated psoriasis-specific PROMs (psPROMs) and compared them with patient-reported priorities from a psoriasis specialty clinic.

Validated psPROMs were identified through a structured PubMed search. Two investigators independently reviewed and categorized the questions in each psPROM into 6 focus areas: clearance, cost, mood and quality of life (MQOL), symptoms, frequency of doctor visits (FDV), and treatment form. Additionally, an 8-question survey regarding patients' perceptions of disease severity, therapy preferences, and treatment priorities and satisfaction was administered to English-speaking

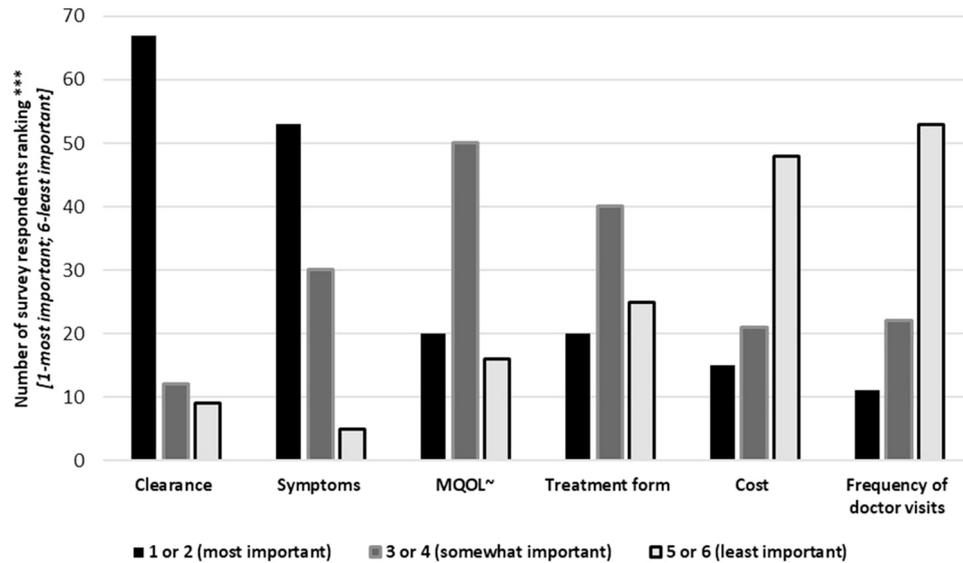
adult patients at a psoriasis clinic at New York University Langone Health from November 2017 to April 2018 (Supplemental Fig 1; available at <http://www.jaad.org>). Subjects' demographics and treatment histories were collected from medical records. Analyses included descriptive statistics and a  $\chi^2$  test for comparison among groups by using Excel software (Microsoft Corporation, Seattle, WA). The study was approved by the New York University School of Medicine's institutional review board.

A total of 18 unique psPROMs were identified (Fig 1) through a literature search. The questions overwhelmingly pertained to MQOL (63%) but also covered symptoms (22%), clearance rates (9%), treatment form (4%), cost (1%), and FDV (<1%).

A total of 88 eligible respondents completed the patient survey. Their average age was 53.5 years (standard deviation, 15.5 years) and 58% were male. Of the respondents, 64% received biologics and 34% received oral systemics as monotherapy or combination therapy. Clearance was selected as the most important treatment priority by 76% of respondents, reaching statistical significance (Fig 2). FDV and cost were ranked as least important by 62% and 57% of respondents, respectively.



**Fig 1.** Focus areas in the current validated psoriasis-specific patient-reported outcome measurements (PROMs).



**Fig 2.** Respondents' rankings of the focus areas in the psoriasis-specific patient-reported outcome measurements (psPROMs) by importance. Comparison across focus areas;  $\chi^2$   $P$  value < .00001. *MQOL*, Mood and quality of life.

Subgroup analysis demonstrated no significant difference in rankings of patient treatment priorities by age, sex, current treatment modality, or involvement of special sites. Respondents who rated their treatment satisfaction as less than 7 (with a rating of 1 indicating completely dissatisfied and 10 indicating completely satisfied) were significantly more likely to have a higher perceived body surface area involved ( $\chi^2$   $P$  value < .01).

On the basis of the results of this survey, patients appear to prioritize clearance in their psoriasis treatment. However, existing psPROMs largely focus on MQOL, with notably few questions pertaining to clearance. Thus, it is possible that available psPROMs do not accurately capture patients' treatment priorities in an era of increasingly effective biologic therapies. Interestingly, available psPROMs do not focus on cost, mirroring our survey's findings and possibly reflecting patients' insulation from drug prices through insurance and medication benefits. This study was performed at an academic psoriasis clinic, limiting the generalizability of its results, although this population may be more likely to have PROMs tied to reimbursement.<sup>1</sup>

Our study suggests that the existing psPROMs may need to be re-evaluated to match patient current priorities and to reflect an increasing focus on clearance before integration with reimbursement. Physician-reported outcomes, such as the Physician Global Assessment) and patient-reported global assessments, should be explored as outcome

measurements because they are easier to collect and are also correlated with clearance-related psPROMs.<sup>7</sup> Given the high prevalence of psoriasis, creating appropriate, relevant PROMs for this condition would be meaningful to patients and would have beneficial implications for clinical practice.

*Oluwatobi Ogbechie-Godec, MD, MBA,<sup>a</sup> Sarah Azarchi, BS,<sup>b</sup> Jasmine Lee, BS,<sup>b</sup> David E. Cohen, MD, MPH,<sup>a</sup> Andrea Neimann, MD,<sup>a</sup> and Arielle R. Nagler, MD<sup>a</sup>*

*From The Ronald O. Perelman Department of Dermatology<sup>a</sup> and New York University School of Medicine, New York University, New York, New York<sup>b</sup>*

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Reprint requests: Arielle Nagler, MD, 240 East 38th St, 12th Floor, New York, NY 10016.

E-mail: [Arielle.nagler@med.nyu.edu](mailto:Arielle.nagler@med.nyu.edu)

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## What do patients undergoing Mohs micrographic surgery want? Results of a patient values survey based on the Outpatient and Ambulatory Surgery Consumer Assessments of Healthcare Providers and Systems



*To the Editor:* The shift toward the evaluation of health care providers in terms of quality predates the Affordable Care Act and will continue irrespective of the act's political future.<sup>1</sup> Surveys of patient experience are a component of efforts to link provider payments with quality measures and value of care.<sup>2</sup> Relevant efforts to assess patient experience in Mohs micrographic surgery (MMS) have focused on examining specific operative and perioperative interventions associated with satisfaction,<sup>3</sup> as well as on patient characteristics predictive of satisfaction.<sup>4</sup> However, investigators have not asked what matters most to patients when undergoing MMS.

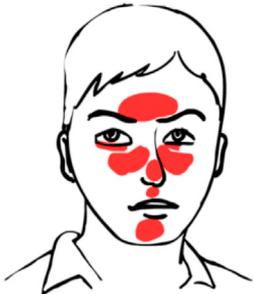
To answer this question, we utilized a validated national patient experience survey, the Outpatient and Ambulatory Surgery Consumer Assessments of Healthcare Providers and Systems (OAS-CAHPS).<sup>5</sup> The OAS-CAHPS survey asks patients to retrospectively evaluate aspects of care in a specific outpatient surgery experience. To instead determine which aspects of care patients value most, we converted 22 retrospective questions on the OAS-CAHPS that are directly relevant to MMS to statements and asked patients to rate the statements on a Likert scale from strongly agree to strongly disagree according to the importance of that statement in an MMS experience.

A total of 101 patients completed the survey (69 males, 31 females, and 1 for whom information on sex was missing) at their first postoperative visit following MMS. Of the 101 patients, 16 were younger than 55 years, 30 were between 55 and 64 years old, 44 were between 65 and 74 years old, and 10 were older than 75 years. Responses to most questions consisted of strongly agree, agree, or undecided as summarized in the Likert plot in Fig 1. To allow statistical comparison, questions were categorized into 4 groups by topic (communication, complications, facility, and courtesy). We determined the Cronbach  $\alpha$  to assess internal consistency within groups; the validity of the groupings was shown by correlation coefficients of 0.7 or higher. In the assigned categories, communication and courtesy had the lowest (most important) average scores, with medians of 1.38 (interquartile range [IQR] 1.13-1.75) and 1.4 (IQR 1.0-1.8), respectively. Statements regarding the occurrence of complications comprised the 3 statements with the fewest patients rating strongly agree in the survey; and median Likert scores of 1.8 demonstrated the least importance for the complications group (IQR 1.5-2.3). The median communication score was significantly lower than that of the categories complications ( $P < .01$ ) and facility ( $P = .01$ ). Table I shows demographic comparisons for the groups. Patients were also asked to rank the OAS-CAHPS statements in order of importance. These rankings confirmed the Likert analysis showing communication to be most important.

The importance of communication and bedside manner in patient satisfaction has been demonstrated across a number of medical specialties,<sup>6</sup> including MMS,<sup>4</sup> and our work confirms its primacy to patients when they are asked directly what they value. Our findings also suggest some tolerance for pain, bleeding, and nausea/vomiting that may result from the MMS procedure. This signals an understanding that removal of skin cancer by MMS will involve some

Study ID: \_\_\_\_\_

1. Which factors are **most important to you** in selecting a treatment for psoriasis?  
(please rank from **most important [1]** to least important [6])

<input type="checkbox"/> <b>Clearance</b> (how much of my body still has psoriasis rash) 	<input type="checkbox"/> <b>Cost</b> (how much do I pay for the treatment) 	<input type="checkbox"/> <b>Mood and Quality of Life</b> (how does the treatment affect my mood and typical life activities) 
<input type="checkbox"/> <b>Symptoms</b> (how much discomfort, like itching or pain, do I feel because of the psoriasis rash) 	<input type="checkbox"/> <b>Frequency of doctor visits</b> (how often do I have to go to a doctor's office or laboratory for treatment) 	<input type="checkbox"/> <b>Treatment form</b> (what type of treatment [creams, injectables, pills, phototherapy] and side effects do I have) 

2. Who drove your current treatment decision? (please circle one)

**I decided my treatment**

**My doctor(s) decided my treatment**

1	2	3	4	5	6	7	8	9	10
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Supplemental Fig 1. Psoriasis Patient Survey.

3. Why do you think **you and/or your doctor(s) decided** on your current treatment?  
(please rank from **most important [1]** to least important [6])

<input type="checkbox"/> <b>Clearance</b> (how much of my body still has psoriasis rash) 	<input type="checkbox"/> <b>Cost</b> (how much do I pay for the treatment) 	<input type="checkbox"/> <b>Mood and Quality of Life</b> (how does the treatment affect my mood and typical life activities) 
<input type="checkbox"/> <b>Symptoms</b> (how much discomfort, like itching or pain, do I feel because of the psoriasis rash) 	<input type="checkbox"/> <b>Frequency of doctor visits</b> (how often do I have to go to a doctor's office or laboratory for treatment) 	<input type="checkbox"/> <b>Treatment form</b> (what type of treatment [creams, injectables, pills, phototherapy] and side effects do I have)  

Supplemental Fig 1. Continued.

4. What is the **most frustrating** part about your current treatment? (please rank from **least frustrating [1]** to **most frustrating [6]**)

<input type="checkbox"/> <b>Clearance</b> ( <i>My skin is not clear</i> ) 	<input type="checkbox"/> <b>Cost</b> ( <i>My treatment costs too much</i> ) 	<input type="checkbox"/> <b>Mood and Quality of Life</b> ( <i>My mood and quality of life are not better</i> ) 
<input type="checkbox"/> <b>Symptoms</b> ( <i>I feel very uncomfortable because of my psoriasis rash</i> ) 	<input type="checkbox"/> <b>Frequency of doctor visits</b> ( <i>I still go often to the doctor's office or lab for treatment</i> ) 	<input type="checkbox"/> <b>Treatment form</b> ( <i>I do not like my treatment form [creams, injectables, pills, phototherapy] or side effects</i> )  

Supplemental Fig 1. Continued.

5. How satisfied are you with your current treatment?

**Completely  
Dissatisfied** ☹️

*(I am very unhappy  
with my treatment)*

**Completely  
Satisfied** 😊

*(I am very happy  
with my  
treatment)*

1	2	3	4	5	6	7	8	9	10
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6. Where are your current psoriasis lesions? *(check all that apply)*

- Scalp
- Face
- Trunk (chest, stomach, and back)
- Extremities (arms and legs)
- Hands
- Feet
- Nails
- Groin or genitals
- Other (please write): \_\_\_\_\_

7. What percent of your body do you think is covered with the psoriasis rash? *(please select one)*

- < 1%
- 1-5%
- 6-10%
- 11-20%
- 21-40%
- > 40%

8. Have you completed this survey before? *(please select one)*

- Yes
- No

**Supplemental Fig 1.** Continued.