

Initial query of the GREAT database yielded 164 studies, 40 of which met inclusion criteria (Table 1). Included studies were geographically diverse, located in Europe (57.5%), North America (25%), Asia (5%), Africa (2.5%), and transcontinentally (10%), and encompassed adult (42.5%), pediatric (37.5%), and combined (20%) populations. A total of 34 unique instruments were identified from the 40 included studies, with the following 3 instruments found in 1 or more studies: Patient Global Assessment (n = 3), Patient's Self-assessment (n = 2), and Patient's Assessment of Global Response (n = 4). The PtGA was reported as a secondary outcome in 100% of studies. Just more than half (52.5%) of PtGAs were static (Table 2).

The scale used for patient responses varied greatly between studies. Many used a point-based format in which numerical values correlated with response options, ranging from 4 (37.5%) to 9 points (2.5%). Others were based on a 100-mm visual analog scale (10%). A distinguishing feature between PtGAs was a clear/no disease option, with 32.5% including a clear option, 47.5% without a clear option, and 20% without sufficient data (Table 2).

This systematic review revealed significant heterogeneity of PtGA instruments used in AD studies. Key defining features between PtGAs were the inclusion of clear option and whether the instrument was static or dynamic. Levels of severity and recall periods also varied. Further work is needed in developing, standardizing, and validating a PtGA for AD for use in clinical practice.

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Willingness to Participate in Atopic Dermatitis Studies and Clinical Trials

To the Editor:

There remain unmet therapeutic needs for atopic dermatitis (AD) that warrant further research and development of novel therapies.¹ We performed a prospective online questionnaire-based study to determine AD patients' willingness and barriers to participate in research and clinical trials. Members of nonprofit support groups for AD (National Eczema Association and National Eczema Society) were invited to respond to the survey. All patients provided electronic informed consent. The completion rate for the survey was 95.1% among those who began the survey; partial responses were excluded. Data were deidentified and confidential and posed minimal risk to participants. The study was approved by the institutional review board at Northwestern University.

Overall, 313 adults (18–39 years: 65.0%; 79.3% female) and 157 parents of children (<5 years: 40.9%; 37.7% female) with AD completed the survey. Thirty-one adults (10.2%) and 14 children (9.4%) were offered to participate in AD research, of which 21 (72.4%) and 9 (69.2%) agreed to participate, respectively.

In adults, the top 3 factors that respondents reported strongly influenced their participation in research were as follows: other patients with eczema may benefit (71.9%), contributing to the advancement of knowledge in the field (71.9%), and feeling study's objectives were important (61.9%) (Table 1). In parents of children, the top factors that strongly influenced their child's participation in research were feeling study's objectives were important (77.7%), contributing to the advancement of knowledge in the field (66.6%), other patients with eczema may benefit (44.4%), and fully understanding the study (44.4%). Other less influential reasons included minimal risk to self or child, given sufficient time to make a decision, felt comfortable with the person presenting the study, may discontinue participation at any point, and participation in the study will ensure the best medical care. No respondents reported feeling pressured to participate as an influencing factor.

In this study, approximately 10% of respondents were invited to participate in research, of which 70% agreed to participate. A

J.I.S. served as a consultant and/or advisory board member for Abbvie, Asana, Dermira, Eli Lilly, Galderma, GlaxoSmithKline, Glenmark, Kiniksa, Leo, Menlo, Pfizer, Regeneron-Sanofi, Realm, and Dermavant that granted honoraria; served as a speaker for Regeneron-Sanofi and received research grants from GlaxoSmithKline and Galderma. J.I.S. is supported by the Dermatology Foundation. K.R.P. has no funding or conflicts of interest to declare.

J.I.S. had full access to all the data in the study and take responsibility for the integrity of the data and accuracy of the data analysis, did the study concept and design, did the acquisition of the data, and obtained funding. P.K.R. and J.I.S. drafted the article, did the critical revision of the article for important intellectual content, and did the statistical analysis.

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TABLE 1. Willingness to Participate in AD Research and Clinical Trials

Survey Question	n (%)	
	Adults (n = 313)	Children (n = 157)
Have you ever been offered to participate in research for your or your child's eczema?		
No	282 (88.8%)	143 (91.6%)
Yes	31 (10.2%)	14 (9.4%)
Did you agree to or for your child to participate in any research?		
No	10 (27.6%)	5 (30.8%)
Yes	21 (72.4%)	9 (69.2%)
Other patients with eczema may benefit		
Strongly influenced	15 (71.4)	4 (44.4)
Somewhat influenced	1 (4.8)	2 (22.2)
Did not influence	1 (4.8)	1 (11.1)
Not applicable	4 (19.0)	2 (22.3)
Contribute to advancement of knowledge in the field		
Strongly influenced	15 (71.4)	6 (66.6)
Somewhat influenced	1 (4.8)	1 (11.1)
Did not influence	1 (4.8)	0 (0.0)
Not applicable	4 (19.0)	2 (22.3)
Minimal risk to self or child		
Strongly influenced	7 (33.3)	2 (22.2)
Somewhat influenced	7 (33.3)	3 (33.4)
Did not influence	2 (9.5)	2 (22.2)
Not applicable	5 (23.9)	2 (22.2)
Felt pressured to participate		
Strongly influenced	0 (0.0)	0 (0.0)
Somewhat influenced	2 (9.5)	0 (0.0)
Did not influence	15 (71.4)	7 (77.7)
Not applicable	4 (19.1)	2 (22.3)
Fully understood the study		
Strongly influenced	7 (33.3)	4 (44.4)
Somewhat influenced	6 (28.7)	3 (33.3)
Did not influence	4 (19.0)	0 (0.0)
Not applicable	4 (19.0)	2 (22.3)
Felt study's objectives were important		
Strongly influenced	13 (61.9)	7 (77.7)
Somewhat influenced	2 (9.5)	0 (0.0)
Did not influence	2 (9.5)	0 (0.0)
Not applicable	4 (19.1)	2 (22.3)
Given sufficient time to make a decision		
Strongly influenced	6 (28.7)	3 (33.3)
Somewhat influenced	7 (33.3)	4 (44.4)
Did not influence	4 (19.0)	0 (0.0)
Not applicable	4 (19.0)	2 (22.3)
Felt comfortable with the person presenting the study		
Strongly influenced	7 (33.3)	1 (11.1)
Somewhat influenced	6 (28.7)	5 (55.6)
Did not influence	4 (19.0)	0 (0.0)
Not applicable	4 (19.0)	3 (33.3)
May discontinue participation at any point		
Strongly influenced	7 (33.3)	0 (0.0)
Somewhat influenced	5 (23.8)	3 (33.3)
Did not influence	5 (23.8)	3 (33.3)
Not applicable	4 (19.1)	3 (33.3)

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TABLE 1. (Continued)

Survey Question	n (%)	
	Adults (n = 313)	Children (n = 157)
Participation in the study will ensure the best medical care for me		
Strongly influenced	7 (33.3)	3 (33.3)
Somewhat influenced	4 (19.0)	0 (0.0)
Did not influence	6 (28.7)	3 (33.3)
Not applicable	4 (19.0)	3 (33.3)

survey of 1621 patients with 9 chronic disorders found that the most important considerations in trial participation were improving the health of themselves and others.² Other common reasons for nonparticipation were eligibility criteria, inconvenience of travel, and concerns about adverse effects.² A study of 165 Taiwanese adults evaluated the relationship between patients' trust in research and willingness to participate in studies.³ One half (49.9%) agreed or strongly agreed that they completely trusted doctors conducting research. However, 54.8% disagreed that doctors conduct medical research only for patients' interest; 54.9% disagreed that it is safe to be in a medical research study.³ In contrast, our study found that patients with AD were less influenced by trust and more influenced by a desire to help other patients and the field. To our knowledge, no studies examined willingness to participate in trials for other dermatologic disorders.

Many patients with AD are willing to participate in research, although barriers to participation remain. These barriers can be mitigated by promoting the benefits of participation and importance of study objectives, improving informed consent, maximizing benefits, and minimizing risk to participants. These strategies may improve recruitment in AD research.

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