

Patient-Reported Outcome Measures in Atopic Dermatitis and Chronic Urticaria Are Underused in Clinical Practice



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What is already known about this topic? The significance of patient-reported outcome measures (PROMs) in managing atopic dermatitis and chronic urticaria is well recognized. However, from the limited data available, it is evident that their rates of use are low.

What does this article add to our knowledge? It highlights the considerable global underuse of PROMs, identifies barriers to their wider adoption, and underlines the strong demand for clinician training in their proper use.

How does this study impact current management guidelines? The findings advocate for a revision of current management guidelines to incorporate validated PROMs such as the Urticaria Activity Score 7, Urticaria Control Test, Chronic Urticaria Quality of Life Questionnaire for chronic urticaria, and the Patient-Oriented Scoring Atopic Dermatitis Index, Dermatology Life Quality Index, and numeric rating scale for atopic dermatitis, emphasizing the urgent need for educational initiatives to enhance clinician proficiency in these tools.

BACKGROUND: Patient-reported outcome measures (PROMs) are validated and standardized tools that complement physician evaluations and guide treatment decisions. They are crucial for monitoring atopic dermatitis (AD) and chronic urticaria (CU) in clinical practice, but there are unmet needs and knowledge gaps regarding their use in clinical practice.

OBJECTIVE: We investigated the global real-world use of AD and CU PROMs in allergology and dermatology clinics as well as their associated local and regional networks.

METHODS: Across 72 specialized allergy and dermatology centers and their local and regional networks, 2,534 physicians in 73 countries completed a 53-item questionnaire on the use of PROMs for AD and CU.

RESULTS: Of 2,534 physicians, 1,308 were aware of PROMs. Of these, 14% and 15% used PROMs for AD and CU, respectively. Half of physicians who use PROMs do so only rarely or sometimes. Use of AD and CU PROM is associated with being female, younger, and a dermatologist. The Patient-Oriented Scoring Atopic Dermatitis Index and Urticaria Activity Score were the most common PROMs for AD and CU, respectively. Monitoring disease control and activity are the main drivers of the use of PROMs. Time

constraints were the primary obstacle to using PROMs, followed by the impression that patients dislike PROMs. Users of AD and CU PROM would like training in selecting the proper PROM.

CONCLUSIONS: Although PROMs offer several benefits, their use in routine practice is suboptimal, and physicians perceive barriers to their use. It is essential to attain higher levels of PROM implementation in accordance with national and international standards. © 2024 The Authors. Published by Elsevier Inc. on behalf of the American Academy of Allergy, Asthma & Immunology. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>). (J Allergy Clin Immunol Pract 2024;12:1575-83)

Key words: Allergy; Atopic dermatitis; Chronic urticaria; Dermatology; Patient-reported outcome measures

INTRODUCTION

Atopic dermatitis (AD) and chronic urticaria (CU) are common and disabling chronic inflammatory skin diseases. They come with a significant burden on the life of patients, affect

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Abbreviations used

AD- Atopic dermatitis
AR- Allergic rhinitis
CIndU- Chronic inducible urticaria
CRUSE- Chronic Urticaria Self-Evaluation app
CSU- Chronic spontaneous urticaria
CU- Chronic urticaria
CU-Q2oL- Chronic Urticaria Quality of Life Questionnaire
DLQI- Dermatology Life Quality Index
NRS- Numeric rating scale
PROM- Patient-reported outcome measure
QoL- Quality of life
UAS- Urticaria Activity Score
UCT- Urticaria Control Test

mental health and sleep, impair the ability to perform daily tasks, and reduce performance at work and school.^{1,2}

Disease activity, impact, and control in AD and CU fluctuate, and both diseases are characterized by recurrent exacerbations. In AD, flare-ups are common and often unpredictable. In CU, physicians rarely see a representative picture of patients' disease owing to the transient nature and fluctuating occurrence of signs and symptoms. Furthermore, some biomarkers such as D-dimer³ for CU and thymus and activation-regulated chemokine for AD⁴ have been suggested to indicate disease activity. However, these biomarkers are impractical and costly to perform.^{5,6}

Thus, patient-reported outcome measures (PROMs) are necessary to determine the disease status of patients with AD and CU. They can aid in improving the quality of patients, and importantly, are guideline recommended.⁷⁻⁹ Patient-reported outcome measures are usually standardized and validated instruments completed by patients that critically educate and complement physician-based assessments and guide treatment decisions.⁵ Generally, CU PROMs are used to obtain information on disease activity (ie, symptom burden), disease impact (ie, impairment of quality of life [QoL]), and the control that

patients have over the disease. The use of PROMs was first proposed by the European Medicines Agency in 2005¹⁰ and the US Food and Drug Administration in 2006 to "report the status of a patient's condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else."¹¹ Validated PROMs are available for various disorders,¹² including allergic and dermatologic conditions such as AD⁵ and CU.^{13,14}

For AD, the Harmonising Outcome Measures for Eczema initiative recently provided guidance on the scope of PROMs recommended for use in clinical practice.⁸ The Patient-Oriented Eczema Measure and the Patient-Oriented Scoring Atopic Dermatitis Index are recommended for measuring signs and symptoms. Atopic dermatitis control should be assessed using the Recap of Atopic Eczema or the Atopic Dermatitis Control Tool, and three PROMs are recommended for assessing itch intensity: peak 24-hour numeric rating scale (NRS)-itch and 1-week NRS-itch instruments from the Patient-Reported Outcomes Measurement Information System Itch Questionnaire, measuring average and peak itch. As for QoL assessments, adults and children with AD should use the Dermatology Life Quality Index (DLQI) and the Children's Dermatology Life Quality Index or the Infants' Dermatitis Quality of Life Index, respectively.

The type and manifestation of CU are important for the correct selection of PROMs to assess CU activity, impact, and control. Chronic spontaneous urticaria (CSU), the most common type of CU, presents with wheals, angioedema, or both. In patients who have CSU with wheals with or without angioedema, the weekly Urticaria Activity Score (UAS7),¹⁵⁻¹⁸ Chronic Urticaria Quality of Life Questionnaire (CU-Q2oL),¹⁹⁻²² and Urticaria Control Test (UCT)²³⁻²⁷ are the PROMs of choice. In patients with CSU with predominant angioedema with or without wheals, the Angioedema Activity Score,^{28,29} Angioedema Quality of Life Questionnaire,³⁰⁻³² and Angioedema Control Test³³⁻³⁵ should be used.

In patients with chronic inducible urticaria (CIndU), the UCT and Angioedema Control Test should also be used, but the

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UAS7 and the Angioedema Activity Score as well as the CU-Q2oL and Angioedema Quality of Life Questionnaire are not suited for assessing disease activity or impact on patients with CIndU. Instead, CIndU-specific PROMs should be used, which include the Cold Urticaria Activity Score and the Cholinergic Urticaria Activity Score,^{36,37} to measure disease activity, and the Cholinergic Urticaria Quality of Life Questionnaire.³⁸

There are unmet needs and knowledge gaps in the use of these tools in clinical practice.³⁹ For example, physicians need training on the utility of these PROMs, including how to employ, evaluate, and interpret results.⁴⁰ Similarly, time necessary to complete these PROMs is a significant factor.⁴¹ The absence of integration of these tools within the health care systems itself has been firmly established as a problem.^{42,43} Although PROMs for AD and CU are commonly used in clinical trials, little is known about their use in routine clinical practice.⁵ To address these gaps, we explored the real-world use of PROMs in AD and CU care across allergy and dermatology centers worldwide, as well as their corresponding local and regional networks.

MATERIALS AND METHODS

Study participants and conduct

A 53-item questionnaire on the use of PROMs for AD and CU was developed and distributed to 72 medical centers across 73 countries that provide treatment for allergic diseases (see Table E1 in this article's Online Repository at www.jaci-inpractice.org). Of these centers, 45 were specialized centers of the Urticaria Centers of Reference and Excellence Network,⁴⁴ Atopic Dermatitis Centers of Reference and Excellence, and Angioedema Centers of Reference and Excellence Network,⁴⁵ whereas the remaining 28 centers were physicians affiliated with the Allergic Rhinitis and Its Impact on Asthma Network and Latin American centers. Because the survey was designed to explore the use of PROMs in AD and/or CU, only physicians affiliated with Allergic Rhinitis and Its Impact on Asthma who were allergists and pulmonologists and treated AD and/or CU during consultation were included in this study. The centers disseminated the survey to their physicians and those of local and regional networks, encompassing not only allergology and dermatology clinics but also various health care facilities and professionals; participants across these network centers and extended networks completed the survey.

Although this sampling strategy does not represent all medical doctors or specialists in specific geographic areas, it is an expert sampling that collected information from worldwide medical providers who treat mostly common allergic and related diseases such as urticaria, angioedema, allergic rhinitis (AR), allergic conjunctivitis, AD, rhinosinusitis, and asthma.

Questionnaire

The questionnaire was developed according to the guidelines of Passmore et al.⁴⁶ A steering committee for the PROMUSE project, which was composed of four experts and heads from four specialized allergy centers worldwide, reviewed the literature and developed the survey items, which integrated eight constructs to be assessed: demographics, knowledge about PROMs, frequency of use, PROM preferences, as well as satisfaction, physician training, attitudes, and barriers to using PROMs. This questionnaire consisted of 53 questions, which included multiple-choice questions, Likert and rating scales, and visual analog scales. For the AD and CU questions, we asked about PROMs described in Figure E1 (in this article's Online Repository at www.jaci-inpractice.org). A pilot study was

performed by the steering committee with colleagues and a sample of 20 physicians. After the survey was drafted, it was administered through formal invitation using e-mail.

Ethics review

This study complied with the World Medical Association Declaration of Helsinki on Ethics and was approved by the Institutional Review Board Comité de Ética e Investigación en Seres Humanos from Guayaquil, Ecuador (No. HCK-CEISH-21-002). We obtained informed consent from all participants before their voluntary participation in the survey. All participant data were de-identified and remained confidential.

Statistical analysis

Table I lists results of descriptive analyses of data from 1,308 physicians who were aware of PROMs. This table provides a summary of sample descriptive statistics, including the demographic characteristics (such as sex, age group, and type of consultation), PROM use, specialty status, and years of specialty for the total sample and broken down by providers who used PROMs for AD and CU. Table II lists the frequency of specific variables related to PROM use and presents the results separated by providers who employed AD PROMs ($n = 344$) and those who employed CU PROMs ($n = 376$). The variables analyzed include PROM use frequency, reason(s) for use, areas of training, barriers to PROM use, methods of access, and specific PROM use. Table III lists the percentage of PROM-aware physicians who reported using AD or CU PROMs in their clinical practice, across different variables of interest ($n = 1,308$). The variables of interest in the table include sex, age group, type of consultation, years the provider had been a specialist, and specialty status. For each variable of interest the proportion of physicians is included who reported using AD or CU PROMs out of the total number of physicians in each category. For example, the table shows that 20% of male physicians who were aware of PROMs reported using AD PROMs in their practice, out of the total number of male physicians who responded to the survey.

RESULTS

Physician demographics and distribution

Of 2,534 surveys, 1,308 were included in the main analysis according to the criterion of having knowledge about PROMs (Table I). Most participants were aged 30 to 49 years and worked in the public sector. About 80% were specialists (28% allergists, 18% pediatricians, 18% dermatologists, and 14% pulmonologists).

Only half of physicians know PROMs and only one of seven uses PROMs for AD and CU

Of the 2,534 physicians who participated in the survey, 1,308 knew what PROMs were (52%). Of those 1,308 physicians, 338 used PROMs in AD (26%) and 370 used them in CU (28%) (Table I). Of the physicians who used PROMs for AD or CU, only 48% (AD) and 52% (CU) used them often or always (Table II).

Atopic dermatitis and CU PROM use is linked to being female, young, and a dermatologist

Female physicians more often used PROMs for AD and CU than did male physicians (AD: 30% vs 20%, $P < .001$; and CU: 31% vs 25%, $P < .001$) (Table II). Rates of PROM users were highest in the youngest physicians, aged 20 to 29 years (AD: 28%; and CU: 30%) and in the oldest physicians aged 60 years

TABLE I. Characteristics of physicians who are aware of PROMs, divided by AD and CU use (n = 1,308)

Variables	Atopic dermatitis PROM use (26%)	Chronic urticaria PROM use (28%)	All
Sex (%)			
Male	32%	36%	41%
Female	68%	64%	59%
Age group, y			
20-29	12%	12%	11%
30-39	38%	36%	34%
40-49	23%	23%	24%
50-59	16%	19%	18%
≥60	11%	11%	13%
Type of consultation (%)			
Public practice	32%	41%	39%
Private practice	22%	18%	20%
Both public and private practice	46%	41%	41%
Do you use any PROMs? (%)			
No	0%	0%	49%
Yes	100%	100%	51%
Specialty status (%)			
Specialist	82%	84%	80%
Nonspecialist (GP)	18%	16%	20%
Dermatologist	36%	36%	18%
Non-dermatologist	64%	64%	82%
Allergist	36%	44%	28%
Non-allergist	64%	56%	72%
Pediatrician	19%	16%	18%
Non-pediatrician	81%	84%	89%
Family medicine specialist	6%	6%	9%
Non-family medicine specialist	94%	94%	91%
Pulmonologist	6%	5%	14%
Non-pulmonologist	94%	95%	86%
Ear, nose, and throat (otolaryngologist)	1%	1%	6%
Non-otolaryngologist	99%	99%	94%
Other	12%	11%	17%
Identified specialists and GPs	88%	89%	83%
Years provider has been a specialist (%)			
1-9	43%	40%	37%
10-19	28%	30%	28%
20-29	15%	16%	17%
≥30	14%	14%	18%

AD, Atopic dermatitis; CU, chronic urticaria; GP, general practitioner; PROM, patient-reported outcome measure.

The sample was composed only of respondents who knew what PROMs were. In specialty status, percentages can add up to more than 100% because respondents could select multiple answers. This table shows descriptives for the total sample broken down by their AD or CU PROM use. The specialist category encompasses a range of medical specialties represented in this study, including dermatologists, allergists, pediatricians, family medicine practitioners, pulmonologists, and ear, nose, and throat specialists. These categories are not mutually exclusive; respondents may identify with more than one specialty area. Each specialty and its corresponding "non-" category collectively represent 100% of the surveyed population. For each specialty listed (eg, dermatologist, allergist, pediatrician), the percentage indicates the proportion of respondents who are specialists within that specific field. Conversely, the "non-" category (eg, non-dermatologist, non-allergist, non-pediatrician) encompasses all individuals who do not specialize in that particular field, including both specialists in other areas and GPs. This categorization ensures a comprehensive overview, with each specialty and its "non-" counterpart together accounting for the entire respondent group, highlighting the distribution between specialized and broader medical practice roles within the surveyed population.

and greater (AD: 22%; and CU: 24%). Across medical specialties, dermatologists used PROMs the most (AD: 51%, and CU: 55%) followed by allergists (AD: 33%; and CU: 44%).

The most commonly used PROM for AD and CU was the Patient-Oriented Scoring Atopic Dermatitis Index and the UAS7, respectively

Physicians who used AD PROMs most often used the Patient-Oriented Scoring Atopic Dermatitis Index (61%), followed by the DLQI (48%) and the NRS (29%). They employed, on

average, three AD PROMs (SD, 2 PROMS). The most often used CU PROMs were the UAS7 (73%), the UCT (47%), and the CU-Q2oL (29%). On average, physicians used two CU PROMs (SD, 1 PROM). These rates were similar in male and female physicians and across age groups and specialties.

Monitoring of disease control was the most common reason for using PROMs for AD and CU

The most common reasons physicians used PROMs in AD and CU were to monitor disease control (94% AD; and 95%

TABLE II. AD and CU PROM users and their frequency of PROM use, reasons for using PROMs, PROM training needs, and choice of PROMs

Variables	AD (n = 344) %	CU (n = 376) %
Frequency of PROM use		
Always	13%	15%
Often	35%	37%
Sometimes	42%	40%
Rarely	10%	8%
Never	0%	0%
What do you use PROMs for?		
To monitor disease control	94%	96%
To monitor disease severity	92%	94%
To monitor performance and therapeutic approach	89%	89%
To facilitate decision-making	87%	90%
To improve efficiency of consultation	78%	80%
To facilitate communication with patients	71%	75%
For research	66%	67%
To facilitate communication across different health care sectors	57%	61%
Other	7%	11%
For which of the following would you like to receive further training/information?		
How to choose which PROMs to use	83%	80%
How to interpret PROM scores	75%	71%
The challenges of using PROMs	65%	63%
How to administer PROMs	62%	58%
How to calculate PROM scores	62%	58%
The benefits of using PROMS	58%	53%
What PROMS are	40%	36%
Other/further training areas	5%	6%
What are the main barriers to the use of PROMs?		
Time constraints	83%	80%
Lack of integration into clinical systems	58%	60%
Patients dislike questionnaires	57%	60%
Not available for certain groups	56%	52%
Mandated to complete	52%	55%
Sufficient understanding of the disease without PROMS	47%	46%
Not available in the native language of my patients	45%	41%
Uncertainty about reliability	39%	38%
Lack of confidence in interpreting	36%	34%
Too complicated to fill in	34%	34%
Too complicated to evaluate/score	33%	33%
Not suitable for obtaining the information I need	32%	28%
Feel uncomfortable	31%	31%
Perceived as additional cost	26%	24%
Constrain doctor–patient relationship	22%	19%
How patients access PROMs		
Paper	75%	79%
Online	70%	66%
Clinical systems	31%	31%
Other	5%	4%

(continued)

TABLE II. (Continued)

Variables	AD (n = 344) %	CU (n = 376) %
How patients complete the PROMs		
Paper	86%	88%
Electronically	47%	46%
AD		
Patient-Oriented Scoring Atopic Dermatitis Index	61%	
Dermatology Life Quality Index	48%	
Numeric rating scale	29%	
Patient-Oriented Eczema Measure	18%	
Atopic Dermatitis Control Tool	7%	
Other atopic dermatitis PROM	7%	
Recap of Atopic Eczema	4%	
CU PROMs used		
Urticaria Activity Score 7		73%
Urticaria Control Test		47%
Visual Analog Scale in Chronic Urticaria		30%
Chronic Urticaria Quality of Life Questionnaire		29%
11-Point Numeric Rating Scale		16%
Other chronic urticaria PROM		5%

AD, atopic dermatitis; CU, chronic urticaria; PROM, Patient-Reported Outcomes Measure.

These are the results of an analysis of specific variables related to PROM use by physicians who use AD CU PROMs. The table includes data from a survey of 720 providers, with 344 reporting the use of AD PROMs and 376 reporting the use of CU PROMs. The variables analyzed in the table include the frequency of PROM use, reasons for use, areas of training, barriers to PROM use, access methods, and specific PROMs used (questionnaires). The results are presented separately for providers who use AD PROMs and those who use CU PROMs. Percentages can add up to >100% because respondents could select multiple answers.

CU) and severity (92% AD; and 94% CU), followed by monitoring performance and therapeutic approach (89% for both AD and CU) and facilitating decision-making (87% and 90% in AD and CU, respectively). Other common reasons included to improve consultation efficacy (AD: 78%, and CU: 80%), to facilitate communication with patients (AD: 71%, and CU 74%), and research (66% in both AD and CU) (Table II).

Time constraints was the main barrier to PROM use, and choice of PROMs was the most common training need

For AD and CU, the main barriers to using PROMs were time constraints (83% and 80%, respectively), the perception that patients disliked PROMs (52% and 60%), and the lack of integration into clinical systems (58% and 60%, respectively) (Table II). When asked what topics physicians would like for training, how to choose which PROMs to use for AD and CU was most often reported (83% and 80%, respectively). Other common treatment needs were how to interpret PROM scores (75% and 71%, respectively) and how to administer PROMs (62% and 58%, respectively).

DISCUSSION

Our study shows that many physicians who treat patients with AD and CU are unaware of PROMs and that most, greater than 80%, do not use them. These results indicate that more

TABLE III. AD or CU PROM use (% variables of interest, n = 1,308)

Variables	AD PROM		CU PROM	
	users	P	users	P
Sex		.000		.017
Male	20%		25%	
Female	30%		31%	
Age group, y		.23		.478
20-29	28%		30%	
30-39	29%		29%	
40-49	25%		27%	
50-59	23%		30%	
≥60	22%		24%	
Type of consultation		.014		.522
Public practice	21%		30%	
Private practice	29%		26%	
Both public and private practice	29%		28%	
Years provider has been specialist		.072		.422
1-9	29%		30%	
10-19	26%		29%	
20-29	22%		27%	
≥30	22%		24%	
Specialty status				
Dermatologist	51%	.000	55%	.000
Allergist	33%	.001	44%	.000
Pediatrics	27%	.693	24%	.135
Specialist	27%	.250	30%	.035
Other	26%	.003	18%	.000
Family medicine	18%	.048	18%	.006
Pulmonologist	11%	.000	11%	.000
Ears, nose, throat	3%	.000	7%	.000
Total	14%		15%	

AD, atopic dermatitis; CU, chronic urticaria; PROM, patient-reported outcome measure.

The sample was composed only of respondents who knew what PROMs were. For each variable of interest, the table presents the proportion of physicians who reported using AD or CU PROMs out of the total number of physicians in each category. For example, the table shows that 20.2% of male physicians who were aware of PROMs reported using AD PROMs in their practice, out of the total number of male physicians who responded to the survey. *P* values are based on χ^2 tests. For specialties, *P* comes from comparing a specific specialist against not having it, for example dermatologist vs non-dermatologist.

physician information and education on AD and CU PROMs are urgently needed.

Published data regarding the use of PROMs by physicians in dermatology and allergy clinical practice are limited and may not be as widespread as in other disease states. A recent international study with 362 oncologists showed that one quarter were high-frequency PROM users who conducted PRO assessments on more than 80% of patients.⁴⁷ A 2019 survey of 449 US oncologists found that 92% reported using one or more PROMs in their practice.⁴⁸ In a 2020 survey of 262 orthopedic surgeons in Saudi Arabia, almost 70% did not use PROMs and only 5% used them regularly in daily clinical work.⁴⁹ In our study, less than 20% of physicians used PROMs for AD or CU, and of those, less than 20% always used them.

Our study identified and confirmed important barriers to PROM use, including time constraints, lack of integration into clinical systems, and the perception that patients dislike

questionnaires. These findings were partly similar to those of a previous study, which also identified other barriers such as a lack of physician resources and the additional workload when using PROMs.⁴⁰ Of note, the perception of physicians and patients regarding longitudinal assessments using PROMs appears to differ. Abernethy et al⁵⁰ examined patients' willingness to employ a longitudinal electronic tablet data collection system to assess symptoms and QoL; 88% of patients felt satisfied using PROMs and would suggest them to other patients, and 74% said the system helped them remember symptoms they needed to report.⁵⁰

Patients and physicians appear to also differ in their assessment of the impact of disease. Schatz⁵¹ conducted a prospective, cross-sectional, international survey among patients and physicians to identify symptom perception and the impact of AR on health-related QoL. Patients rated the disease as more severe than did physicians in all types of AR. A systematic review by Ta et al⁵² showed that objective tests that assess physiologic parameters and treatment effectiveness did not correlate with patients' appreciation of the disease. This disparity in perceptions may limit or even impair the use of PROMs.⁵⁰ Because clinicians systematically underestimate patients' symptoms and their impact, which often go unrecognized,⁴² the longitudinal use of PROMs may help to improve patients' QoL, enhance patient–physician communication, reduce emergency visits, and have a role in shared decision-making.⁴¹ Thus, Brunelli et al⁴³ proposed integrating health information technology to collect PROMs to ensure real-time clinical decision-making.⁴³

Valderas et al⁵³ proposed that using PROMs in daily clinical practice to facilitate patient–clinician communication about important issues could result in shared decision-making, accurate monitoring of disease progression and response to treatment, and the identification of vulnerable patients, while enabling the continuous assessment of quality of care. Moreover, the real-world use of PROMs may help capture high-quality data and provide evidence for health policy.^{54,55}

Our results show that physician information, training, and education on PROMs are needed, especially regarding the optimal selection of a PROM and the subsequent interpretation of the data it provides. For this, leadership and clinician engagement are important.⁵⁶ The Global European Allergy and Asthma Network and the Urticaria Centers of Reference and Excellence, Angioedema Centers of Reference and Excellence, and Atopic Dermatitis Centers of Reference and Excellence should promote the implementation of PROMs in routine clinical practice with a global perspective and through its educational programs.⁵⁷

Integrating PROMs into clinical care workflows presents challenges because it can be difficult to avoid overloading staff or requiring additional personnel. However, studies show that clinical systems that integrate PROM effectively monitored patients' symptoms and provided valuable feedback to physicians during follow-up appointments. For example, Cleeland et al demonstrated that using automated PROMs led to improved symptom management in postoperative patients.⁵⁸

Real-time digital tools used by patients before their visits could also counter time restraints. Examples include the success of the Mask-air app for rhinitis and asthma and the Chronic Urticaria Self-Evaluation (CRUSE) app for CSU.⁵⁹ The CRUSE app assists patients with CSU in tracking symptoms and treatment progress, enabling them to share valuable data with health care

providers during appointments. In addition, tools such as calculators available at the Sanofi Campus for Atopic Dermatitis incorporate PROMs and clinical reported outcomes.⁶⁰ This previsit data collection streamlines consultations, allowing physicians to review patient progress and make informed decisions quickly, ultimately improving patient care and saving time for both patients and providers.

Although this study significantly adds to available data on real-world PROM use in AD and CU, more research is needed, specifically, on the use of health information technology for collecting PROMs⁴³ (ie, CRUSE⁶¹). To understand the patient perspective better, further research is needed on patient knowledge, attitudes, perceptions, experiences, and satisfaction with the use of PROMs. This, together with medical education on the advantages of employing PROMs, may help to counteract the belief held by physicians that the use of PROMs is disliked by patients.

This study had some limitations. The results may not entirely reflect all allergic practice, especially in less specialized or research-oriented settings. The survey was conducted mainly with physicians from specialized centers that treat patients with allergic and dermatologic diseases, which probably employ PROMs more often than do primary care physicians or specialists who do not work at specialized centers. In addition, the limited representation of dermatologists in the study, who are the primary health care professionals responsible for treating moderate to severe AD and CU, may have resulted in overestimation or underestimation of the use of AD and CU PROMs. Our questionnaire was not validated. It also did not include questions about PROM use according to disease severity. Future questionnaires should include questions about the circumstances of PROM use.

Furthermore, our questionnaire did not differentiate between PROMs for CSU and CIndU. At the time of the questionnaire was designed, the distinction between these subtypes was not fully addressed owing to the limited availability and validation of specific PROM tools for CIndU. This represents a significant limitation of our study because it may have affected our ability to capture nuanced differences in PROM use between these urticaria subtypes. Recognizing this gap, future studies should aim to incorporate distinct measures for CSU and CIndU to understand the specific needs and outcomes of patients within these groups.

In addition, the geographic and cultural diversity of survey participants may not be representative, limiting the generalizability of our findings to other regions. The predominance of respondents from certain countries might not accurately mirror the diagnostic and treatment practices employed in diverse health care contexts across the globe. Recognizing this, future studies should strive for more varied international participation to ensure the broader applicability of results.

Although PROMs for allergic and dermatologic disease have been shown to improve treatment outcomes, management, and prognosis for patients when routinely applied in clinical settings, this study demonstrated that their use in AD and CU is still suboptimal owing to adoption barriers. To assess CU and AD, we advocate employing established and validated instruments, specifically the UAS7, UCT, and CU-Q2oL for CU, and the Patient-Oriented Scoring Atopic Dermatitis Index, DLQI, and NRS for AD. These tools are both extensively used and rigorously validated, ensuring their indispensability in achieving precise and dependable evaluations in clinical and research contexts.

Furthermore, the importance of training patients and carers in accurately completing PROMs cannot be overstated, because it significantly enhances the reliability of the data collected. Moreover, the integration of digital applications designed to assist with PROM collection in the clinical setting can streamline this process, making it more efficient and user-friendly. Achieving higher levels of implementation of these PROMs in routine clinical care for AD and CU is crucial for enhancing patient-centered outcomes and the overall quality of care.

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REFERENCES

- Langan SM, Irvine AD, Weidinger S. Atopic dermatitis. *Lancet* 2020;396:345-60.
- Gonçalo M, Giménez-Arnau A, Al-Ahmad M, Ben-Shoshan M, Bernstein JA, Ensina LF, et al. The global burden of chronic urticaria for the patient and society. *Br J Dermatol* 2021;184:226-36.
- Fok JS, Kolkhir P, Church MK, Maurer M. Predictors of treatment response in chronic spontaneous urticaria. *Allergy* 2021;76:2965-81.
- Himadri, George R, Mathew L, Shanmugam V, Mani T, Jeyaseelan L. The role of thymus and activation-regulated chemokine as a marker of severity of atopic dermatitis. *J Am Acad Dermatol* 2021;84:545-7.
- Barrett A, Hahn-Pedersen J, Kragh N, Evans E, Gnanasakthy A. Patient-reported outcome measures in atopic dermatitis and chronic hand eczema in adults. *Patient* 2019;12:445-59.
- Thijs J, Krastev T, Weidinger S, Buckens CF, de Bruin-Weller M, Bruijnzeel-Koomen C, et al. Biomarkers for atopic dermatitis: a systematic review and meta-analysis. *Curr Opin Allergy Clin Immunol* 2015;15:453-60.
- Zuberbier T, Abdul Latiff AH, Abuzakouk M, Aquilina S, Asero R, Baker D, et al. The international EAACI/GA²LEN/EuroGuiDerm/APAAACI guideline for the definition, classification, diagnosis, and management of urticaria. *Allergy* 2022;77:734-66.
- Leshem YA, Chalmers JR, Apfelbacher C, Furue M, Gerbens LAA, Prinsen CAC, et al. Measuring atopic eczema symptoms in clinical practice: The first consensus statement from the Harmonising Outcome Measures for Eczema in clinical practice initiative. *J Am Acad Dermatol* 2020;82:1181-6.
- Weller K, Siebenhaar F, Hawro T, Altrichter S, Schoepke N, Maurer M. Clinical measures of chronic urticaria. *Immunol Allergy Clin North Am* 2017;37:35-49.
- European Medicines Agency. Regulatory guidance for the use of health-related quality life (HRQL) measures in evaluation medicinal products - scientific guideline. Accessed February 1, 2023. <https://www.ema.europa.eu/en/regulatory-guidance-use-health-related-quality-life-hrql-measures-evaluation-medicinal-products>
- US Department of Health and Human Services FDA Center for Drug Evaluation and Research. US Department of Health and Human Services FDA Center for Biologics Evaluation and Research, US Department of Health and Human Services FDA Center for Devices and Radiological Health. Guidance for industry: patient-reported outcome measures: use in medical product development to support labeling claims: draft guidance. *Health Qual Life Outcomes* 2006;4:79.
- Krogsgaard MR, Brodersen J, Christensen KB, Siersma V, Kreiner S, Jensen J, et al. What is a PROM and why do we need it? *Scand J Med Sci Sports* 2021;31:967-71.
- Maurer M, Weller K, Bindslev-Jensen C, Giménez-Arnau A, Bousquet P, Bousquet J, et al. Unmet clinical needs in chronic spontaneous urticaria. A GA2LEN task force report 1. *Allergy* 2011;66:317-30.
- Maurer M, Ortonne J, Zuberbier T. Chronic urticaria: an internet survey of health behaviours, symptom patterns and treatment needs in European adult patients. *Br J Dermatol* 2009;160:633-41.

15. Hawro T, Ohanyan T, Schoepke N, Metz M, Peveling-Oberhag A, Staubach P, et al. The Urticaria Activity Score-Validity, Reliability, and Responsiveness. *J Allergy Clin Immunol Pract* 2018;6:1185-1190.e1.
16. Hawro T, Ohanyan T, Schoepke N, Metz M, Peveling-Oberhag A, Staubach P, et al. Comparison and interpretability of the available urticaria activity scores. *Allergy* 2018;73:251-5.
17. Hollis K, Proctor C, McBride D, Balp MM, McLeod L, Hunter S, et al. Comparison of Urticaria Activity Score Over 7 Days (UAS7) values obtained from once-daily and twice-daily versions: results from the ASSURE-CSU study. *Am J Clin Dermatol* 2018;19:267-74.
18. Mathias SD, Crosby RD, Zazzali JL, Maurer M, Saini SS. Evaluating the minimally important difference of the urticaria activity score and other measures of disease activity in patients with chronic idiopathic urticaria. *Ann Allergy Asthma Immunol* 2012;108:20-4.
19. Baiardini I, Fasola S, Maurer M, Weller K, Canonica GW, Braido F. Minimal important difference of the Chronic Urticaria Quality of Life Questionnaire (CU-Q2oL). *Allergy* 2019;74:2542-4.
20. Baiardini I, Pasquali M, Braido F, Fumagalli F, Guerra L, Compalati E, et al. A new tool to evaluate the impact of chronic urticaria on quality of life: chronic urticaria quality of life questionnaire (CU-Q2oL). *Allergy* 2005;60:1073-8.
21. Brzozza Z, Badura-Brzozza K, Mlynek A, Magerl M, Baiardini I, Canonica GW, et al. Adaptation and initial results of the Polish version of the GA(2)LEN chronic urticaria quality of life questionnaire (CU-Q(2)oL). *J Dermatol Sci* 2011;62:36-41.
22. Mlynek A, Magerl M, Hanna M, Lhachimi S, Baiardini I, Canonica GW, et al. The German version of the Chronic Urticaria Quality-of-Life Questionnaire: factor analysis, validation, and initial clinical findings. *Allergy* 2009;64:927-36.
23. Irani C, Hallit S, Weller K, Maurer M, Haber CE, Salameh P. Chronic urticaria in most patients is poorly controlled. *Saudi Med J* 2017;38:1230-6.
24. Kocatiürk E, Kızıltaç U, Can P, Öztaş Kara R, Erdem T, Kızıltaç K, et al. Validation of the Turkish version of the Urticaria Control Test: correlation with other tools and comparison between spontaneous and inducible chronic urticaria. *World Allergy Organ J* 2019;12:10009.
25. Kulthanan K, Chularojanamontri L, Tuchinda P, Rujitharanawong C, Maurer M, Weller K. Validity, reliability and interpretability of the Thai version of the urticaria control test (UCT). *Health Qual Life Outcomes* 2016;14:61.
26. Ohanyan T, Schoepke N, Bolukbasi B, Metz M, Hawro T, Zuberbier T, et al. Responsiveness and minimal important difference of the urticaria control test. *J Allergy Clin Immunol* 2017;140:1710-1713.e11.
27. Weller K, Groffik A, Church MK, Hawro T, Krause K, Metz M, et al. Development and validation of the Urticaria Control Test: a patient-reported outcome instrument for assessing urticaria control. *J Allergy Clin Immunol* 2014;133:1365-1372.e1-6.
28. Kulthanan K, Chularojanamontri L, Rujitharanawong C, Weerasubpong P, Weller K, Maurer M. Angioedema Activity Score (AAS): a valid and reliable tool to use in Asian patients. *BioMed Res Int* 2019;2019:9157895.
29. Weller K, Groffik A, Magerl M, Tohme N, Martus P, Krause K, et al. Development, validation, and initial results of the Angioedema Activity Score. *Allergy* 2013;68:1185-92.
30. Kulthanan K, Chularojanamontri L, Rujitharanawong C, Weerasubpong P, Maurer M, Weller K. Angioedema quality of life questionnaire (AE-QoL) - interpretability and sensitivity to change. *Health Qual Life Outcomes* 2019;17:160.
31. Weller K, Groffik A, Magerl M, Tohme N, Martus P, Krause K, et al. Development and construct validation of the angioedema quality of life questionnaire. *Allergy* 2012;67:1289-98.
32. Weller K, Magerl M, Peveling-Oberhag A, Martus P, Staubach P, Maurer M. The Angioedema Quality of Life Questionnaire (AE-QoL) - assessment of sensitivity to change and minimal clinically important difference. *Allergy* 2016;71:1203-9.
33. Zuberbier T, Abdul Latif AH, Abuzakouk M, Aquilina S, Asero R, Baker D, et al. The international EAACI/GA²LEN/EuroGuiDerm/APAAACI guideline for the definition, classification, diagnosis, and management of urticaria. *Allergy* 2022;77:734-66.
34. Mlynek A, Zalewska-Janowska A, Martus P, Staubach P, Zuberbier T, Maurer M. How to assess disease activity in patients with chronic urticaria? *Allergy* 2008;63:777-80.
35. Maurer M, Eyerich K, Eyerich S, Ferrer M, Gutermuth J, Hartmann K, et al. Urticaria: Collegium Internationale Allergologicum (CIA) Update 2020. *Int Arch Allergy Immunol* 2020;181:321-33.
36. Ahsan DM, Altrichter S, Gutsche A, Bernstein JA, Altunergil T, Brockstaedt M, et al. Development of the Cold Urticaria Activity Score. *Allergy* 2022;77:2509-19.
37. Koch K, Weller K, Werner A, Maurer M, Altrichter S. Antihistamine uposing reduces disease activity in patients with difficult-to-treat cholinergic urticaria. *J Allergy Clin Immunol* 2016;138:1483-1485.e9.
38. Ruft J, Asady A, Staubach P, Casale T, Sussmann G, Zuberbier T, et al. Development and validation of the Cholinergic Urticaria Quality-of-Life Questionnaire (CholU-QoL). *Clin Exp Allergy* 2018;48:433-44.
39. Moestrup K, Ghazanfar MN, Thomsen SF. Patient-reported outcomes (PRO s) in chronic urticaria. *Int J Dermatol* 2017;56:1342-8.
40. Brunelli C, Zito E, Alfieri S, Boreani C, Roli A, Caraceni A, et al. Knowledge, use and attitudes of healthcare professionals towards patient-reported outcome measures (PROMs) at a comprehensive cancer center. *BMC Cancer* 2022;22:161.
41. Kotronoulas G, Kearney N, Maguire R, Harrow A, Di Domenico D, Croy S, et al. What is the value of the routine use of patient-reported outcome measures toward improvement of patient outcomes, processes of care, and health service outcomes in cancer care? A systematic review of controlled trials. *J Clin Oncol* 2014;32:1480-501.
42. Basch E. Patient-reported outcomes—harnessing patients’ voices to improve clinical care. *N Engl J Med* 2017;376:105-8.
43. Brunelli C, Boreani C, Caraceni A, Roli A, Bellazzi M, Lombi L, et al. PATIENT VOICES, a project for the integration of the systematic assessment of patient reported outcomes and experiences within a comprehensive cancer center: a protocol for a mixed method feasibility study. *Health Qual Life Outcomes* 2020;18:252.
44. Maurer M, Metz M, Bindslev-Jensen C, Bousquet J, Canonica GW, Church MK, et al. Definition, aims, and implementation of GA(2) LEN Urticaria Centers of Reference and Excellence. *Allergy* 2016;71:1210-8.
45. Maurer M, Aberer W, Agondi R, Al-Ahmad M, Al-Nesf MA, Anstogui I, et al. Definition, aims, and implementation of GA²LEN/HAEi Angioedema Centers of Reference and Excellence. *Allergy* 2020;75:2115-23.
46. Passmore C, Dobbie AE, Parchman M, Tysinger J. Guidelines for constructing a survey. *Fam Med* 2002;34:281-6.
47. Cheung YT, Chan A, Charalambous A, Darling HS, Eng L, Grech L, et al. The use of patient-reported outcomes in routine cancer care: preliminary insights from a multinational scoping survey of oncology practitioners. *Support Care Cancer* 2022;30:1427-39.
48. Basch E, Deal AM, Kris MG, Scher HI, Hudis CA, Sabbatini P, et al. Symptom monitoring with patient-reported outcomes during routine cancer treatment: a randomized controlled trial. *J Clin Oncol* 2016;34:557-65.
49. Alshehri F, Alarabi A, Alharthi M, Alanazi T, Alohali A, Alsalem M. Use of patient-reported outcome measures (PROMs) by orthopedic surgeons in Saudi Arabia. *J Orthop Surg* 2020;15:598.
50. Abemethy AP, Herndon JE, Wheeler JL, Day JM, Hood L, Patwardhan M, et al. Feasibility and acceptability to patients of a longitudinal system for evaluating cancer-related symptoms and quality of life: pilot study of an e/Tablet data-collection system in academic oncology. *J Pain Symptom Manage* 2009;37:1027-38.
51. Schatz M. A survey of the burden of allergic rhinitis in the USA. *Allergy* 2007;62(suppl 85):9-16.
52. Ta NH, Gao J, Philpott C. A systematic review to examine the relationship between objective and patient-reported outcome measures in sinonasal disorders: recommendations for use in research and clinical practice. *Int Forum Allergy Rhinol* 2021;11:910-23.
53. Valderas JM, Alonso J, Guyatt GH. Measuring patient-reported outcomes: moving from clinical trials into clinical practice. *Med J Aust* 2008;189:93-4.
54. Calvert M, Thwaites R, Kyte D, Devlin N. Putting patient-reported outcomes on the ‘Big Data Road Map.’ *J R Soc Med* 2015;108:299-303.
55. Gilbody SM, House AO, Sheldon TA. Outcomes research in mental health: systematic review. *Br J Psychiatry* 2002;181:8-16.
56. Brower K, Schmitt-Boshnick M, Haener M, Wilks S, Soprovich A. The use of patient-reported outcome measures in primary care: applications, benefits and challenges. *J Patient Rep Outcomes* 2021;5(suppl 2):84.
57. Kolkhir P, Giménez-Armau AM, Kulthanan K, Peter J, Metz M, Maurer M. Urticaria. *Nat Rev Dis Prim* 2022;8:1-22.
58. Cleeland CS, Wang XS, Shi Q, et al. Automated symptom alerts reduce post-operative symptom severity after cancer surgery: a randomized controlled clinical trial. *J Clin Oncol* 2011;29:994-1000.
59. Sousa-Pinto B, Eklund P, Pfaar O, Klimek L, Zuberbier T, Czarlewski W, et al. Validity, reliability, and responsiveness of daily monitoring visual analog scales in MASK-air. *Clin Transl Allergy* 2021;11:e12062.
60. Sanofi Campus for Atopic Dermatitis. Accessed December 23, 2023. <https://www.campus.sanofi/qa/patient-support/Atopic-Dermatitis>
61. Kostenlose App für Patienten mit chronischer Urtikaria | CRUSE. Accessed December 23, 2023. <https://cruse-control.com/>

ONLINE REPOSITORY

TABLE E1. Centers and locations

Organization	Surveys	Country
Allergic Rhinitis and Its Impact on Asthma	127	France
The Americas	841	Ecuador
	120	Mexico
	53	Sociedad Latinoamericana de Alergia, Asma e Inmunología (SLAAI)
	33	Brazil
	20	Argentina
	3	Peru
Urticaria Centers of Reference and Excellence	257	Poland
	217	Russia
	143	Republic of Macedonia
	78	Romania
	68	Kuwait
	63	Qatar
	55	Spain
	53	Germany
	52	Georgia
	51	Iran
	41	India
	34	Slovenia
	31	Turkey
	21	China
	8	Lithuania
	7	Canada
	5	Germany
	3	London
	41	India
	34	Slovenia
31	Turkey	
21	China	
8	Lithuania	
7	Canada	
5	Germany	
3	London	