

AN EXPERT PANEL QUESTIONNAIRE FOR ASSESSING PATIENT-REPORTED AND CAREGIVER-REPORTED OUTCOMES IN ACNE VULGARIS

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BACKGROUND

- Acne Vulgaris, hereinafter referred to as acne, affects up to 50 million Americans and is the most common skin condition in the United States (US).¹
- Patients with acne report more effects on their functioning, emotions, and symptoms, related to their skin condition, than do patients with isolated benign skin lesions or those in the normative sample.²
- Acne has been shown to negatively affect patient functioning, emotions, and overall QoL. Acne has considerable psychosocial impact on patients causing significant negative effects on self-image, leading to feelings of isolation and loneliness, and a significantly lower self-attitude, sense of pride, self-worth, and body satisfaction, and increased feeling of uselessness.³⁻⁵
- Current existing patient-reported outcome (PRO) instruments does not adequately assess acne impact on patients.

OBJECTIVE

- To create an expert panel questionnaire (EPQ) comprising of Acne-specific PROs measures and caregiver-reported measures for use in research studies to fully capture adult and pediatric patient experience and disease impact.

METHODS

- A 10-person consensus panel of 8 dermatologists with expertise in the treatment of acne, including pediatric and skin of color focused expertise, one dermatologist/clinical psychologist, and one dermatologist/psychiatrist was virtually convened using a three-step modified Delphi method to establish consensus on EPQ items that relate to how acne impacts the patient's emotional functioning, social functioning, activities of daily living.
- In the first round, targeted literature reviews were used to identify over 50 PRO items for EPQ by a subgroup of panelists and narrowed EPQ to 11 items to complement validated ASIS questionnaire and was identified as an optimal tool to use in community-based real world research involving acne patients.
- In second round, 11 EPQ items were distributed to panel for discussion and solicit comments individually and as a group.
- In third round, refined EPQ items were distributed for feedback and approval.

RESULTS

- Panel discussed 11 PROs encompassing emotional functioning (angry/mad/sad (1), hopelessness/worries about skin (3)), social functioning (social media activities (1), impact on real-life plans (1), efforts to hide AV (1)), and activities of daily living (picked/judged (1), ability to reach future goals (1), parent understanding of AV concerns (1), sleep impact (1)).
 - These recommendations were aligned with literature depicting the issues impacting acne patients.^{6,7}
- Panel suggested wording changes to specific PRO measures (Table 1).
- Panel also discussed select questions to parents/caregivers regarding their perspectives of the pediatric patients' AK and its impact (Table 1; items 12-17).
- Following refinement of EPQ items, panel unanimously (100%) achieved consensus in approving each of the EPQ items.

CONCLUSIONS

The newly developed EPQ represents a critical contribution to literature to elicit patient-centric, acne-specific symptoms, impact, and outcomes from acne patients and their caregivers and help improve Acne patient management and health outcomes.

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RESULTS

Table 1. Expert Panel Deliberations on EPQ

DOMAIN	CONCEPT	QUESTION	EDITS FROM ROUND 2	FINALIZED EPQ
Emotional Functioning	Angry	1	Changed from "how often did you feel" to "how often has your acne made you feel"	Over the last 7 days, how often has your acne made you feel angry (mad/sad)? (1-5; never – all of the time)
		2	Changed from "the future of your acne" to "how long will your acne will last and how bad it will get"	How worried are you about how long your acne will last and how bad it will get? (1-5; not at all – extremely)
	Hopelessness about Skin	3	No change.	How often do you think about your acne? (1-5; never – all of the time)
		4	New question added.	Over the past 7 days, how worried have you been about your acne? (1-5; not at all – extremely)
Social Functioning	Social Media	5	Changed from "are you likely to alter or manipulate" to "do you change, edit, or filter"	How often do you change, edit, or filter your social media photo or selfie because of your acne? (1-5; never – all of the time)
	Interpersonal relationships	6	Added more examples of "real-life" plans.	How often does acne impact your "real-life" plans (IRL) (like dating or social engagements, playing sports, swimming, hanging out)? (1-5; never – all of the time)
		7	Changed from "to conceal your acne (e.g., makeup, concealer, camouflage)" to "hide your acne (like mess with, squeeze/pop, or use makeup, concealer, hairstyle, clothes to cover up)?"	How often are you doing something to hide your acne (like mess with, squeeze/pop, or use makeup, concealer, hairstyle, clothes to cover up)? (1-5; never – all of the time)
Activities of Daily Living	School/Work	8	Clarified definition of "judged". "picked on".	How often do you feel picked on or judged because of your acne? (1-5; never – all of the time)
		9	Changed from "Are you concerned about your ability to accomplish your future goals and reach your potential due to your acne?"	How concerned are you that your acne will affect your ability to reach your future goals (in school and work) and be the best you can be? (1-5; not at all – extremely)
	Parent Interaction	10	No change.	Do you feel your parents understand your acne-related concerns? (1-5; never – all of the time)
	Sleep	11	Added "worrying about, or discomfort (itching/hurting) from your acne".	Over the last 7 days, how often has worrying about, or discomfort (itching/hurting) from your acne affected your sleep? (1-5; never – all of the time)
Perspectives of parents/caregivers	Perspectives, Concerns	12	Changed from "have you been more or less worried" to "how worried have you been".	Over the past 7 days, how worried have you been about your child's acne? (1-5; not at all – extremely)
		13	No change.	Overall, how is your child's acne right now? [NOTE: Ask these questions of both the child and the parent to look for asynchrony] – covered in ASIS for patient. 5-point adjectival scale (1-5; severe - clear)
		14	No change.	How concerned are you about your child using antibiotics for acne? (1-5; not at all – extremely) (Ask at baseline and Week 12)
		15	New question added.	How concerned are you about antibiotic resistance (1-5; not at all – extremely) (Ask at baseline and Week 12)
		16	Changed from "are you concerned about" to "how concerned are you about".	How concerned are you about your child's ability to accomplish future goals and reach full potential due to acne? (1-5; not at all – extremely) (CONSISTENTLY USE 5 POINTS)
17	New question added.	Do you feel that you understand your child's acne-related concerns? (1-5; never – all of the time)		

REFERENCES

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