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-esteem, sense of pride, self-worth, and body satisfaction, and increased feeling of uselessness. 3,4
• 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 solicited 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), hopelessness/worries about skin (3), social functioning (social media activities, impact on real-life plans), efforts to hide AV (1), and activities of daily living (picked/judged, 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. 5,6
• 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.

REFERENCES