Background: Evaluation of patient-reported outcomes including health-related quality of life (HRQoL) and perceived benefits from treatment has become a fundamental component of medical decisions. Standardised evaluation of treatment benefits in rosacea based on patient preferences still is lacking.

Objective: Development and validation of an instrument for recording patient-defined benefits in rosacea therapy based on the Patient Benefit Index (PBI) methodology.

Methods: In an open survey of n = 50 patients, potential benefits of therapy from the patient’s perspective were examined. The generated item pool was combined with pre-existing PBI items for other skin conditions and reviewed by an expert panel of dermatologists, psychologists and patients. Items were condensed to n = 25 and converted into a Likert-scaled questionnaire. The validity and feasibility of the resulting Patient Benefit Index for rosacea (PBI-RO) were tested in individuals with rosacea recruited from the German rosacea patient organisation.

Results: N = 446 patients with rosacea completed the PBI-RO. The internal consistencies measured by Cronbach’s alpha were high (Patient Needs Questionnaire [PNQ] 0.94). Mean PBI-RO was 1.9 ± 1.2 (scale from 0 = no benefit to 4 = maximum benefit), 23.5 % of the patients experienced a PBI-RO < 1 (no clinically relevant benefit). The PBI-RO correlated with HRQoL, health state, current extent of rosacea lesions and treatment satisfaction. The highest correlation was found between PBI-RO and satisfaction with previous treatment (r = -0.59, p < 0.001); correlation with the extent of rosacea lesions was low (r = 0.16, p < 0.001).

Conclusion: The PBI-RO shows satisfying internal consistency and construct validity. It offers the option of a patient-weighted evaluation of the therapeutic benefit of rosacea.
therapy and may add to more stringent goal-orientation in therapy.