Development of the Patient-Reported Impact of Dermatological Diseases (PRIDD) measure

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OBJECTIVES: Dermatological conditions are the fourth most common health condition worldwide and have a physical, psychological, and social burden for patients. The full impact of dermatological conditions on patients is underestimated because current dermatology-specific (used across conditions) patient-reported outcome measures (PROMs) do not comprehensively capture the wider impact of the condition on the patient's life. The Global Research on the Impact of Dermatological Diseases (GRIDD) team is developing the new Patient-Reported Impact of Dermatological Diseases (PRIDD) measure, a PROM of the impact of dermatological conditions on the patient's life. GRIDD is the first global patient-initiated and -led impact research study in dermatology.

METHODS:

A mixed-methods study, consisting of five sequential phases, was designed to meet the COSMIN criteria. Adults (≥ 18 years) worldwide living with a dermatological condition were recruited through the International Alliance of Dermatology Patient Organizations' membership network. 1) A COSMIN systematic review evaluated the quality and suitability of existing dermatology-specific PROMs to comprehensively measure impact. 2) The qualitative interview study formed the basis of a conceptual framework of impact, which guided PRIDD's item generation. 3) A Delphi study elicited consensus from patients on which items to prioritise for inclusion in PRIDD. 4) A cognitive interview study evaluated the content validity, acceptability, and feasibility of PRIDD. 5) We are currently completing the psychometric testing of PRIDD using Item Response Theory techniques.

RESULTS:

1718 people with 84 dermatological conditions from 74 countries across six continents participated. None of the 36 PROMs evaluated in the systematic review was recommended for use as the 'gold standard', primarily due to insufficient patient input. The conceptual framework depicted impact as a multifaceted construct involving physical, psychological, social, financial, and daily functioning. The Delphi study reduced an initial item pool of 263 impacts to produce a 27-item version of PRIDD. The cognitive interviews produced a 26-item version of PRIDD with evidence of content validity, feasibility, and acceptability from patients.

CONCLUSION:

This series of studies represents best practice in new measurement development. PRIDD's was developed in close collaboration with patients and met the gold-standard COSMIN criteria, providing strong evidence of content validity. PRIDD addresses shortcomings in existing PROMS and greatly enhances patient perspectives in dermatology by providing quantifiable, patient-impact data that reflects what patients think should be measured. It supports local, regional, and international attempts to better position the dermatology community (patients, patient organisations, healthcare professionals, researchers, industry). The final phase, psychometric testing, is ongoing.