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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 carry a physical, psychological and social burden for patients. The existing burden metrics in dermatology (e.g. patient-reported outcome measures [PROMs]) arguably underestimate the breadth of the impact of dermatological conditions on patients’ lives. The Global Research on the Impact of Dermatological Diseases (GRIDD) project is developing a new measure (Patient-Reported Impact of Dermatological Diseases - PRIDD) to better understand the true impact. GRIDD is the first global patient-initiated and -led impact research study in dermatology.

METHODS: This mixed methods study meets the gold-standard COSMIN (consensus-based standards for the selection of health measurement instruments) criteria. Adults (≥18-years) with a dermatological condition were recruited through the International Alliance of Dermatology Patient Organizations’ global membership network. First, a COSMIN systematic review evaluated existing dermatology-specific (used across conditions) PROMs. Next, the qualitative interview study developed a conceptual framework of impact. Subsequently, a Delphi study elicited consensus on items to prioritise for inclusion in PRIDD. Currently, a cognitive interview study is evaluating the content validity, acceptability and feasibility of PRIDD. The final stage will be psychometric testing.

RESULTS: The systematic review found that none of the 36 identified PROMs met the criteria to be recommended for use. The interview study (n = 63; 29 dermatological conditions; 29 countries) established impact as a multifaceted concept involving physical, psychological, social, financial and daily functioning. The Delphi study (n = 1154; 90 dermatological conditions; 61 countries) reduced an initial item pool of 263 impacts to produce the first draft of PRIDD (33 items across five domains).

CONCLUSION: PRIDD addresses shortcomings in existing PROMS and greatly enhances patient perspectives in dermatology by providing quantifiable patient-impact data. It supports local, regional and international attempts to better position the dermatology community (patients, patient organizations, health-care professionals, researchers, industry).