#### Patient prioritisation of items for the new Patient-Reported Impact of Dermatological Diseases (PRIDD) measure: Rare disease data from a global Delphi study

**Background:** TheGlobal Research on the Impact of Dermatological Diseases (GRIDD) is a patient-led research project. The GRIDD team is developing the new Patient-Reported Impact of Dermatological Diseases (PRIDD) measure, a patient-reported outcome measure of the impact of dermatological conditions on the patient’s life. We developed a list of 263 potential impact items through a global qualitative interview study with 68 patients (25 with rare diseases). We next sought consensus from patients on which of these items to prioritise for inclusion in PRIDD.

**Methods:** We conducted a modified Delphi study, consisting of two rounds. Adults (≥ 18 years) worldwide living with a dermatological condition were recruited through the International Alliance of Dermatology Patient Organizations’ global membership network. The survey consisted of a demographics questionnaire and the 263 potential impact items and was translated from English into German, Spanish, French, Arabic and Chinese. Quantitative data were collected using Likert-type ranking scales and analysed against *a priori* consensus criteria. Qualitative data were collected using free-text responses and a Framework analysis was conducted.

**Results:** 1154 people representing 90 dermatological conditions across 65 countries participated. Of these, 377 (33%) had a rare disease. Items were either removed, edited, or added according to the consensus thresholds and qualitative feedback. The results generated the first draft of PRIDD, consisting of 27 items across five domains.

**Conclusions and implications:** This Delphi: 1) informed the item reduction process and resulted in the first draft of PRIDD. 2) identified what people with dermatological conditions from around the world, and subgroups (e.g. rare diseases), consider to be the most important issues impacting their lives. 3) Prepared PRIDD for pilot testing with patients and is currently undergoing psychometric testing.