

Development of the Patient-Reported Impact of Dermatological Disease (PRIDD) measure: Delphi study

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GRIDD

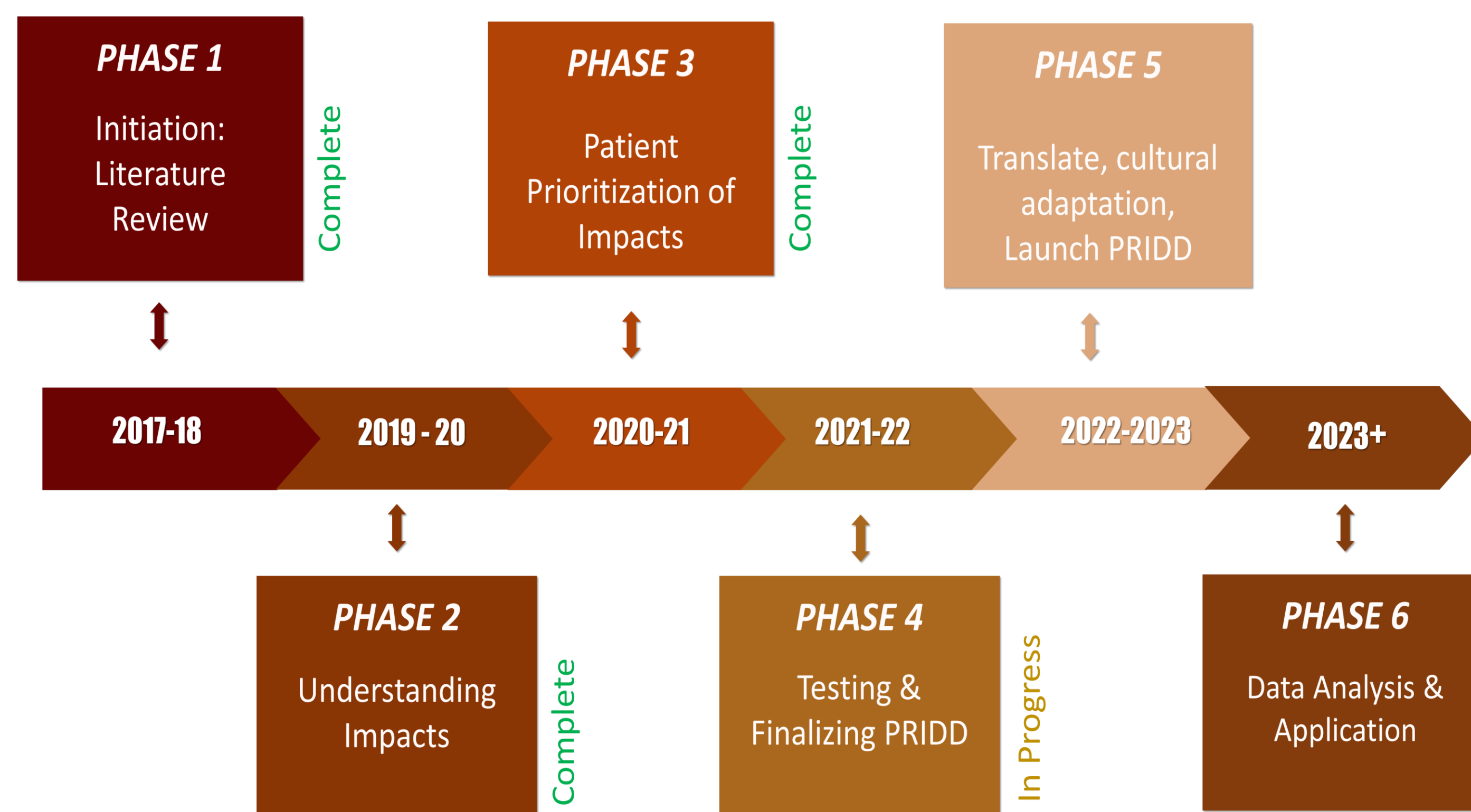
The Global Research on the Impact of Dermatological Diseases (GRIDD) project is developing a new Patient-Reported Impact of Dermatological Diseases (PRIDD) measure.



First global patient-initiated and patient-led impact research study in dermatology

Our systematic review revealed that none of the existing patient-reported outcome measures (PROMs) can comprehensively capture the full impact of living with a dermatological condition. Measurement instrument development is a multi-step process involving a content validity phase and psychometric testing phase. In the first step of the content validity phase, our qualitative concept elicitation study developed a conceptual framework of impact to form the basis of PRIDD. The next step and the aim of this study is to seek consensus from a wider pool of people with dermatological conditions on the validity of the concepts elicited and their prioritisation for inclusion in PRIDD.

METHODOLOGY: MULTIPHASE PROJECT



PHASE 3: DELPHI METHOD

A modified Delphi study, consisting of two rounds, starting with outcomes from the concept elicitation study in lieu of an idea generation round.

- Adults (≥ 18 years) living with a dermatological condition were recruited through the International Alliance of Dermatology Patient Organizations' membership network.
- The survey consisted of a demographics questionnaire and 263 items generated from the concept elicitation study.
- Six surveys: English, German, Spanish, French, Arabic and Chinese.

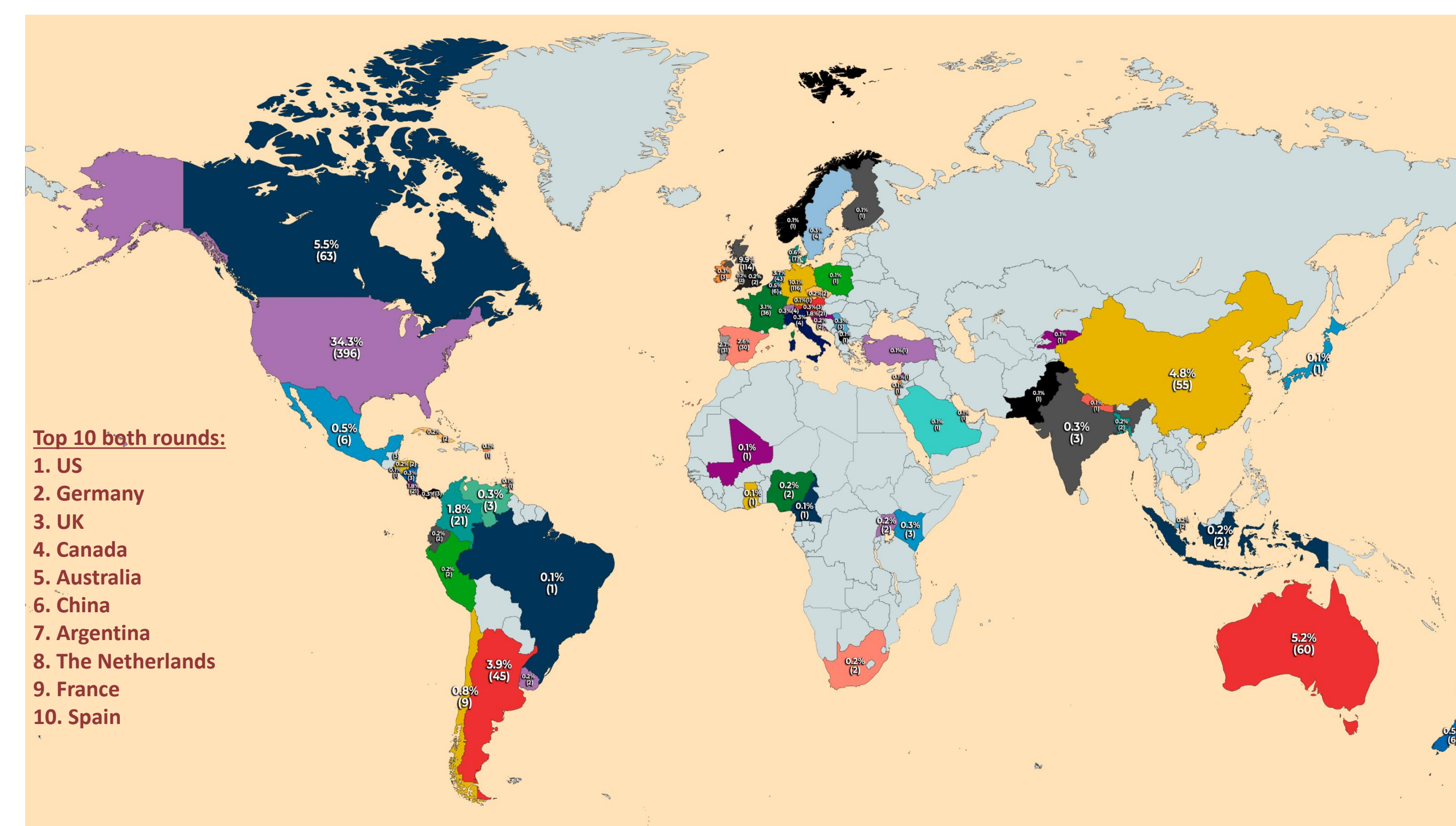
Quantitative data was collected using Likert-type ranking scales and analysed for descriptive statistics and against *a priori* consensus criteria.

Qualitative data was collected using free-text responses that provided participants with an opportunity to identify whether any important items were missing and a Framework analysis conducted.

RESULTS I

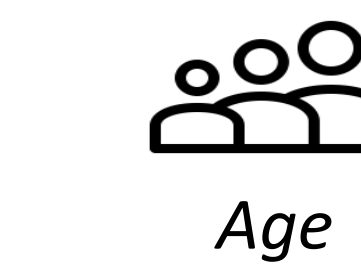
In total, 1978 people registered to the Delphi online platform. Of these, 1154 completed Round 1 and 493 Round 2 (42.72% response rate). 824 were excluded from Round 1 either because they did not meet the inclusion criteria ($n = 665$) or did not complete the minimum data required (age, gender, dermatological condition and at least one Delphi survey item; $n = 65$).

Completed Questionnaires by Country



RESULTS II

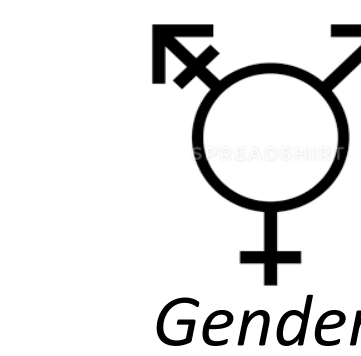
Participant characteristics of Delphi Rounds 1 and 2



Age

Round 1: M = 49.34 (SD = 15.61), range = 18-94

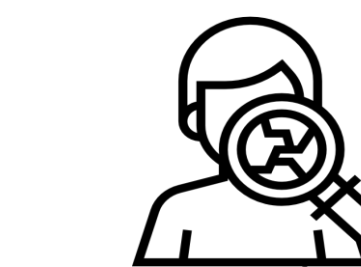
Round 2: M = 52.34 (SD = 14.91), range = 18-85



Gender

Round 1: Male = 332 (29.2%); Female = 802 (70.5%); Other = 3 (0.3%)

Round 2: Male = 160 (32.5%); Female = 325 (65.9%); Other = 1 (0.2%)



Dermatological conditions

In total, 90 dermatological conditions were represented. 158

participants had multiple dermatological conditions.

Quantitative data: Based on the consensus criteria, qualitative feedback and subgroup analyses, the items were either removed, edited or added on a case-by-case basis. From these findings, Round 2 survey was created consisting of five domains (physical, psychological, social, financial and daily responsibility impacts) with 76 items. Of the 76 items, 27 met the criteria to be prioritised for inclusion.

Qualitative data: Two overarching themes were discerned: 1) *General feedback* and 2) *Feedback on items and domains*. These themes contributed to both shortlisting items and edits to the survey instructions. Free-text responses supported the conceptual framework. No additional domains were identified, and the responses primarily served to confirm or clarify concepts, for example, physical discomfort emerged again as a common and significant impact.

DISCUSSION

This Delphi study represents the second of three steps in the content validity phase of PRIDD development. The data supported our conceptual framework as no new domains were elucidated and few items added. The large and diverse sample strengthen our confidence in the conceptual framework and Delphi findings. The results generated the first draft of PRIDD, consisting of 27 items across five domains, ready for pilot-testing in the next phase of development.

The GRIDD methodology can be a replicable model for pediatric dermatology as well as for other disease or conditions beyond dermatology. With additional research, the PRIDD measure could be developed to provide the true child/youth patient impact of living with a dermatological disease.

