

of Dermatological Diseases

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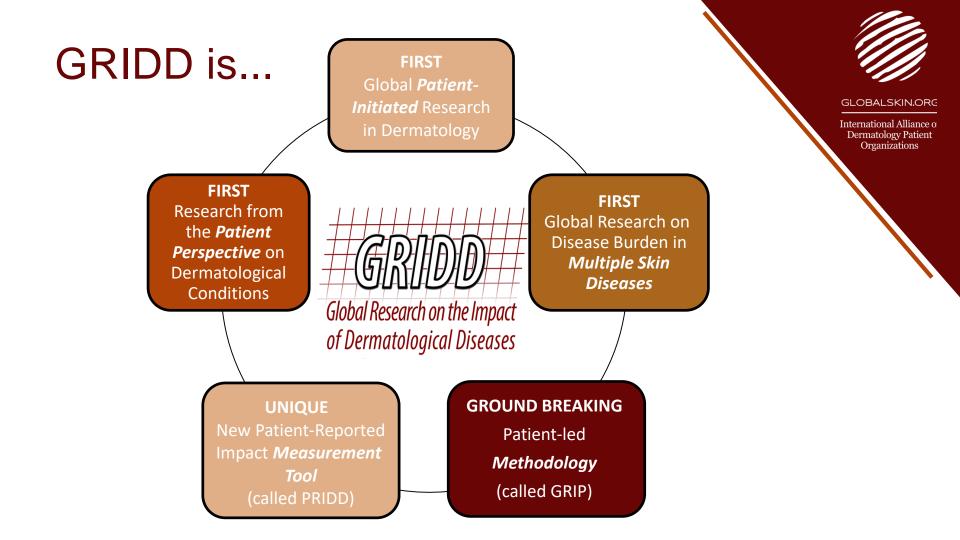
International Alliance of **Dermatology Patient** Organizations

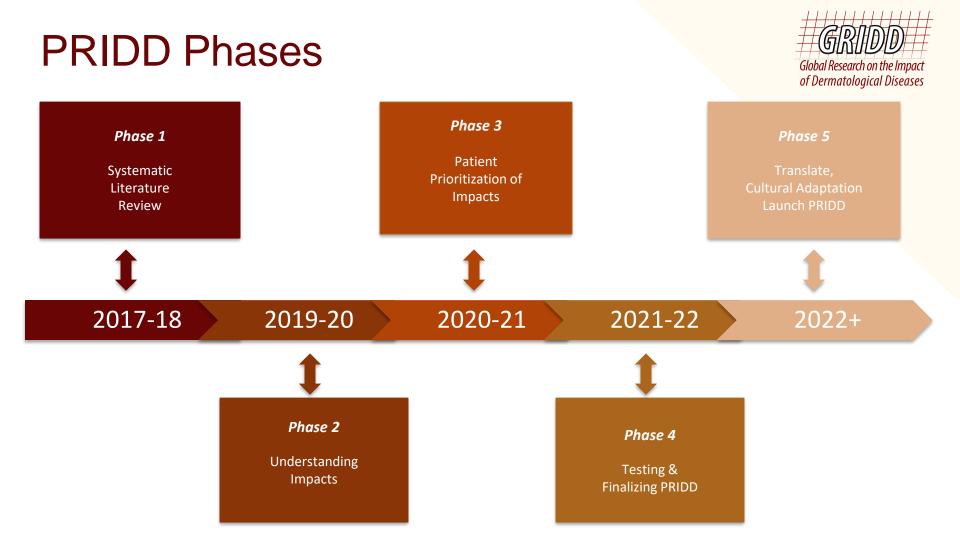
In partnership with:





University Medical Center Hamburg-Eppendorf





Results

Systematic literature review revealed no measures of patient impact in dermatology exists. None of the 36 PROMs met the gold standard for use based on rigorous COSMIN criteria, largely due to lack of patient input during development.

The **concept elicitation study** involved 63 people (68% female, across 29 dermatological conditions) from 29 countries. Findings show impact is a multifaceted concept - physical, psychological, social, and financial functioning – as well as burdensome daily responsibilities and challenging healthcare issues. These concepts formed the basis of PRIDD.

Concept validity was tested in a **Delphi study** of 1,154 participants from 61 countries and 90 dermatological conditions. Patients prioritised the 263 potential impact items for inclusion in PRIDD. The results generated the first draft of PRIDD, (33 items across five domains) – currently being pilot-tested.

conclusions

GRIDD's GRIP methodology and PRIDD – the new impact measure – addressed shortcomings in existing PROMS (e.g. Dermatology Life Quality Index) and global rankings (i.e. DALYs) and greatly enhanced patient perspectives in dermatology by providing quantifiable patientimpact data. It supports local, regional and international attempts to position the dermatology community (patients, better patient organizations, health-care professionals, researchers, industry) to be empowered with verifiable, patient-derived data and supportive advocacy tools and resources to collectively take action for a better future for patients.

Global Research on the Impact of Dermatological Diseases