

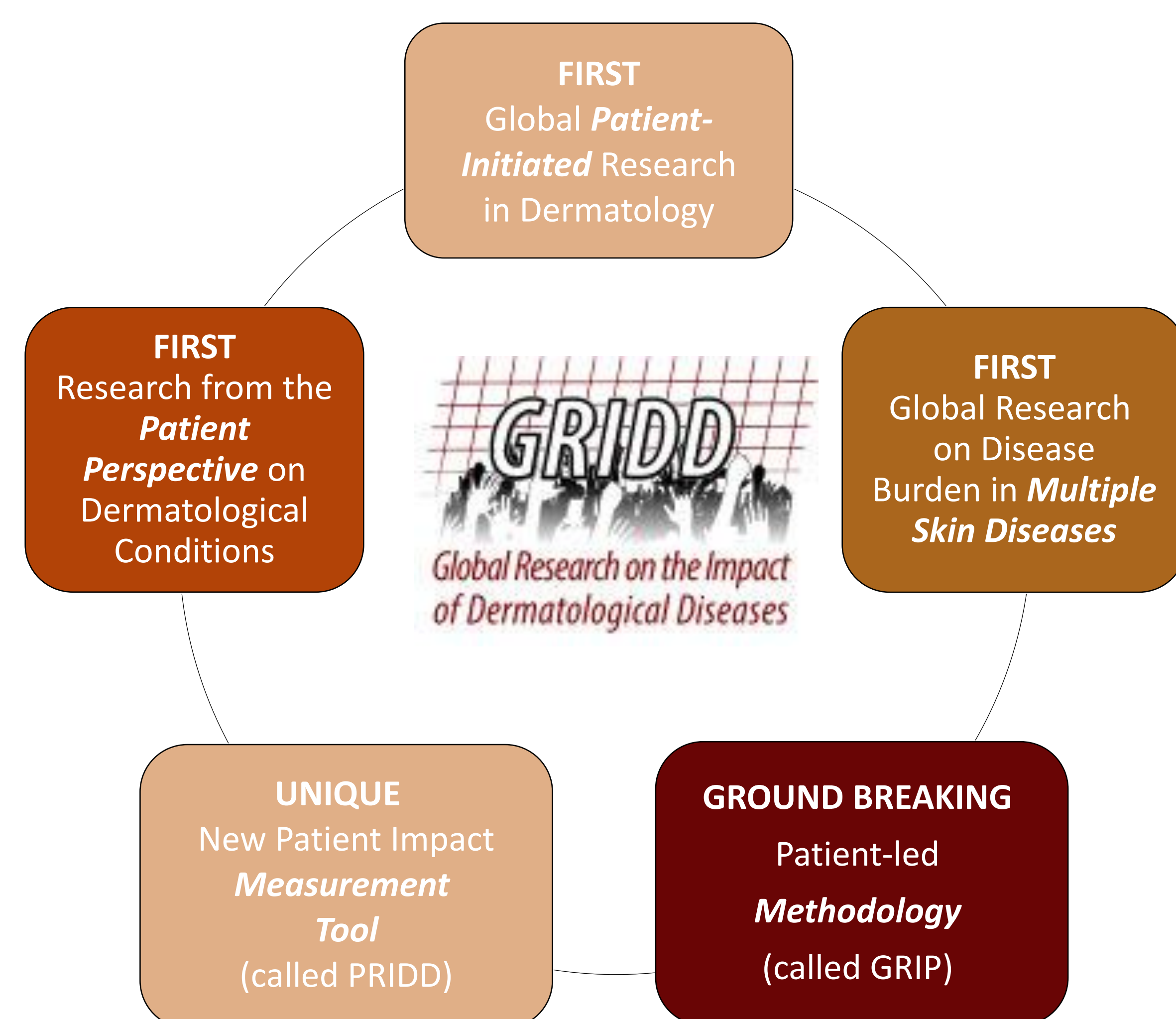
Development of the Patient-Reported Impact of Dermatological Disease (PRIDD) measure

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GRIDD

The Global Research on the Impact of Dermatological Diseases (GRIDD) is the first global patient-initiated and patient-led impact research study in dermatology. It aims to develop, using both qualitative and quantitative methods, a new comprehensive Patient-Reported Impact of Dermatological Diseases (PRIDD) measure.



INTRODUCTION

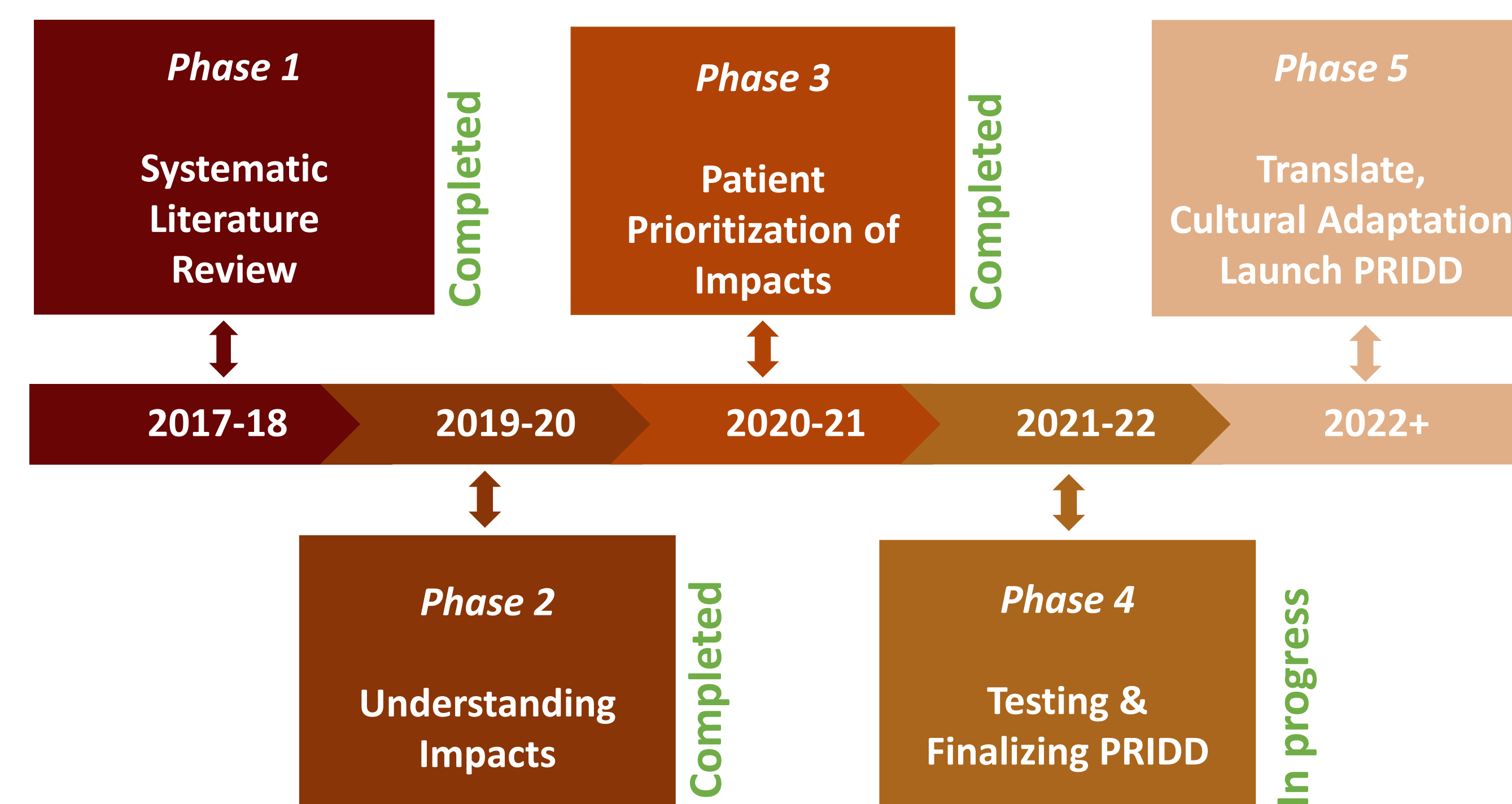
Existing patient-reported outcome measures (PROMs) and other metrics (e.g. Disability-adjusted life years [DALYs]) in dermatology arguably underestimate the breadth of impact of dermatological conditions on patients' lives. This impacts on treatment decision-making and resource allocation. To fully understand the impact of dermatological conditions, information must be obtained largely from those living with the conditions. The Global Research on the Impact of Dermatological Diseases (GRIDD) project, initiated and promoted by patients, is developing a new measure (Patient-Reported Impact of Dermatological Diseases - PRIDD) to better understand and measure true impact.

GRIDD is a project of:



METHODS

GRIDD was designed with the novel Global Research of Impact on Patients (GRIP) methodology:



- Phase 1 - Identification of existing dermatology-specific PROMs and development of a global network of patient organisations.
- Phase 2 - Concept elicitation study: interviews and focus groups with patients to gather impact data.
- Phase 3 - Delphi survey of patients (two rounds): testing if concepts identified in Phase 2 were valid and endorsed by a wider group of patients. Prioritized items for inclusion in PRIDD.
- Phase 4 - Cognitive interviews with patients to test PRIDD's comprehensibility, comprehensiveness, relevance, acceptability and feasibility.
- Phase 5 – Psychometric testing.

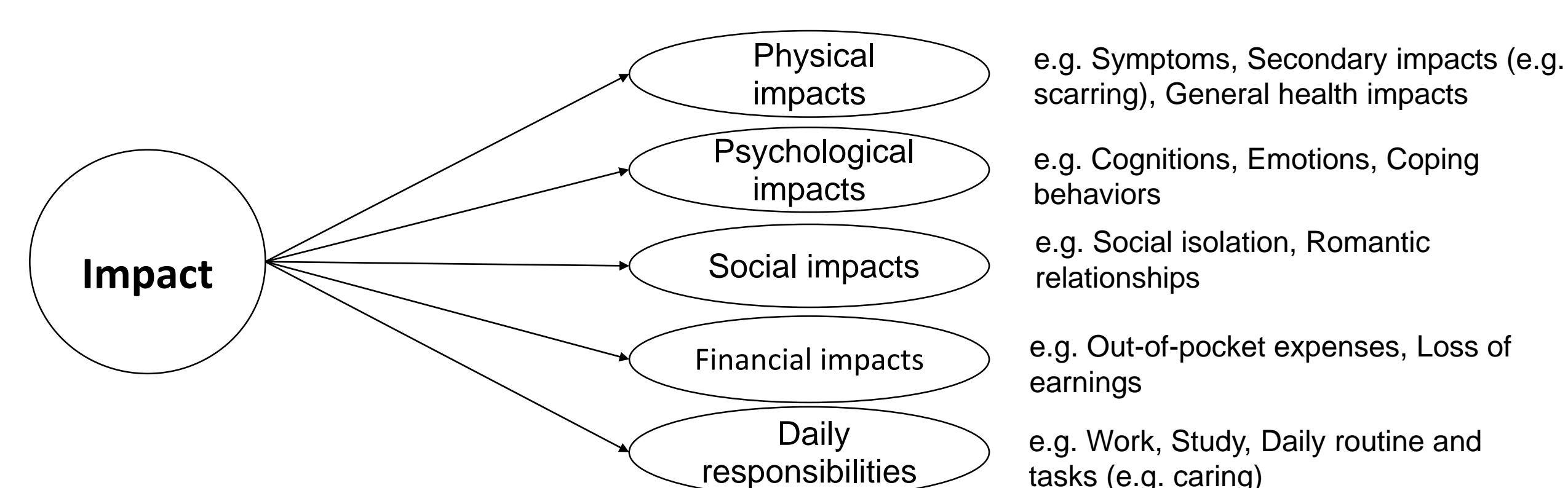
RESULTS PHASE 1

Our systematic review revealed there are no sufficient measures of patient impact in dermatology. None of the 36 PROMs identified met the gold standard COSMIN criteria. Each instrument was evaluated by its methodological quality and by its measurement properties.

RESULTS PHASE 2

The concept elicitation study involved 63 patients (68% female, across 29 dermatological conditions) from 29 countries.

Findings resulted in the first conceptual framework of the impact of dermatological conditions with five domains:

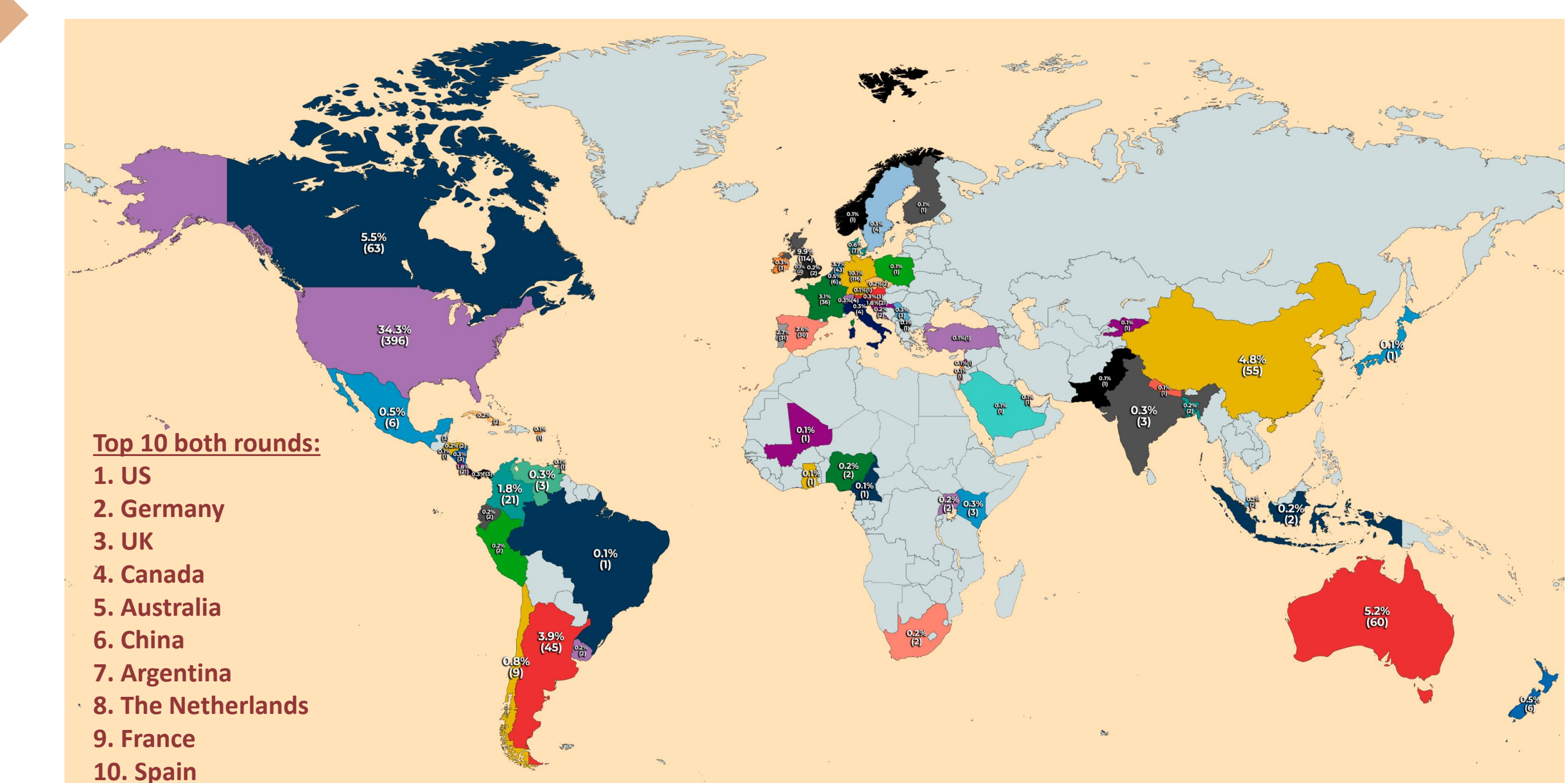


RESULTS PHASE 2 (CONTINUATION)

263 impact items were generated based on the conceptual framework. These items formed the basis of the Delphi study in the next phase.

RESULTS PHASE 3

Concept validity was tested in a Delphi study of 1,154 patients from 61 countries representing 90 dermatological conditions.



Patients prioritized which of the 263 potential impact items should be included in PRIDD. The results generated the first draft of PRIDD, consisting of 27 items across five domains, ready for pilot-testing in the next stage of development.

RESULTS PHASE 4

Cognitive interviews were conducted with 12 patients from 4 countries representing 6 dermatological conditions. Overall, patients found PRIDD to be comprehensible, comprehensive, relevant, acceptable and feasible. Patient feedback results in a 26-item version of PRIDD.

CONCLUSION

GRIDD adds new knowledge to existing information about the impact of living with skin conditions. We used both qualitative and quantitative methods in developing PRIDD.

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 patient-impact data. GRIDD supports local, regional and international attempts to better position the dermatology community (patients, patient organizations, healthcare professionals, researchers and 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.