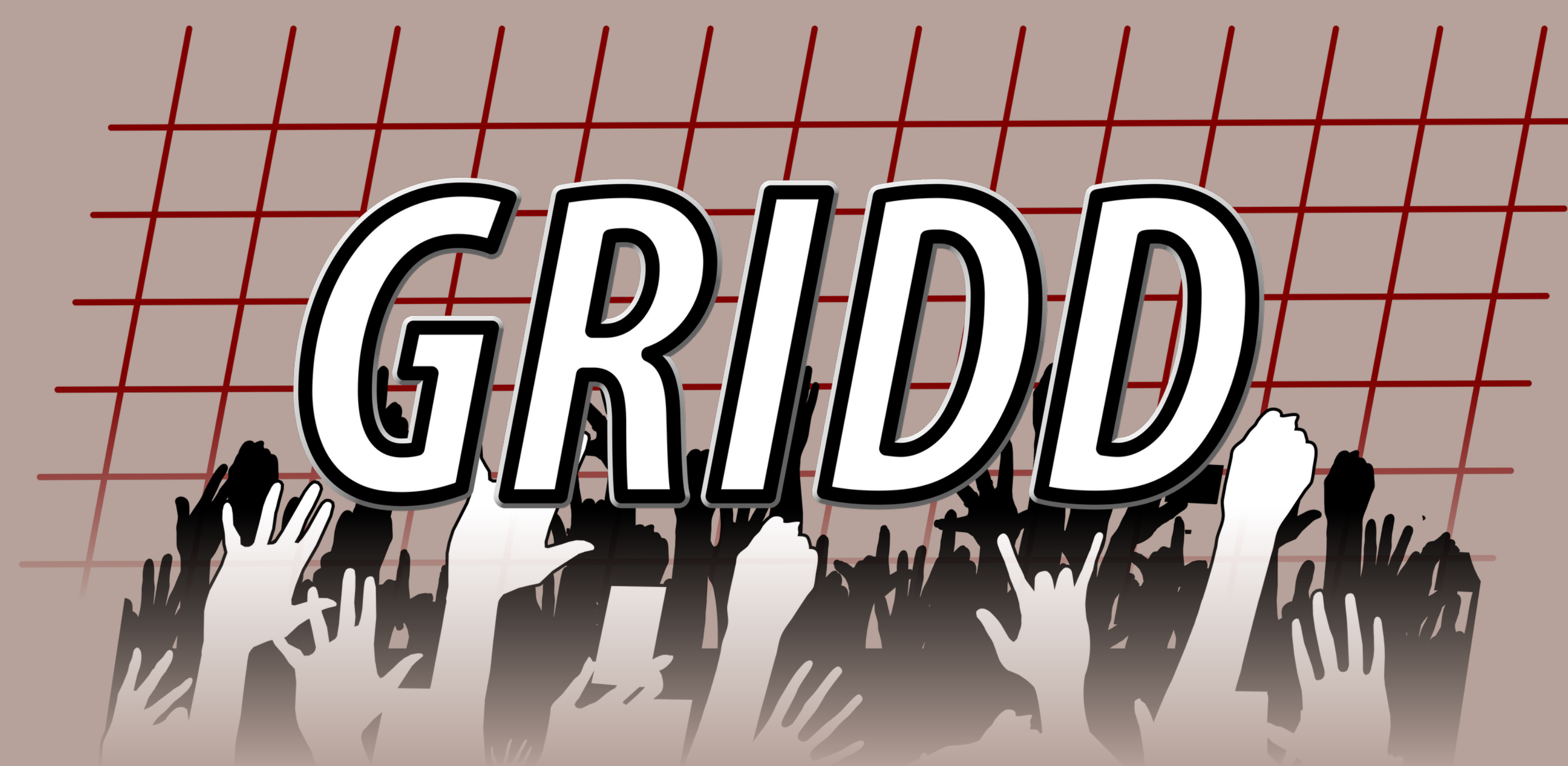




GRIDD is the first global, patient-driven research project on the impact of dermatological diseases.



Global Research on the Impact of Dermatological Diseases

Global Research on the Impact of Dermatological Diseases (GRIDD): *Improving Patient Engagement in Dermatology Research*

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INTRODUCTION

Existing patient-reported outcome measures (PROMs) and metrics (e.g. DALYs) in dermatology arguably underestimate the true impact of dermatological conditions on patients' lives. This impacts on treatment decision-making and resources allocation. To fully understand the impact of dermatological conditions, information must be obtained largely from patients. GRIDD will develop a new comprehensive patient-impact measure called PRIDD: Patient-Reported Impact of Dermatological Diseases. GRIDD is a project of the International Alliance of Dermatology Patient Organizations (IADPO, also known as GlobalSkin).

METHODS

GRIDD was designed using patient-facing methodology following a phased approach. GlobalSkin engages its full membership of over 170 patient organizations (in 54 countries representing over 63 diseases) in all Phases of GRIDD, both to participate in and *inform* the research. **Phase 1:** Systematic review of existing measures in dermatology and enhancement of a global network of patient organisations. **Phase 2:** Concept elicitation (focus groups and individual interviews with patients and patient organisations' leaders). **Phase 3:** Delphi survey to validate items generated in Phase 2. **Phase 4:** Cognitive interviews, psychometric testing and PRIDD launch. **Phase 5:** PRIDD data dissemination including: Research and Development; education; advocacy; fundraising; and support for patient organizations..



RESULTS

Phase 1 (2017-2018): Systematic review showed no gold standard measure of impact.

Phase 2 (2019-2020): Impact across life domains: physical, psychological [emotional, cognitive, behavioural], social, financial, daily activities and work/education. Key themes include pressure, cumulative impairment, lack of awareness, choice and control.

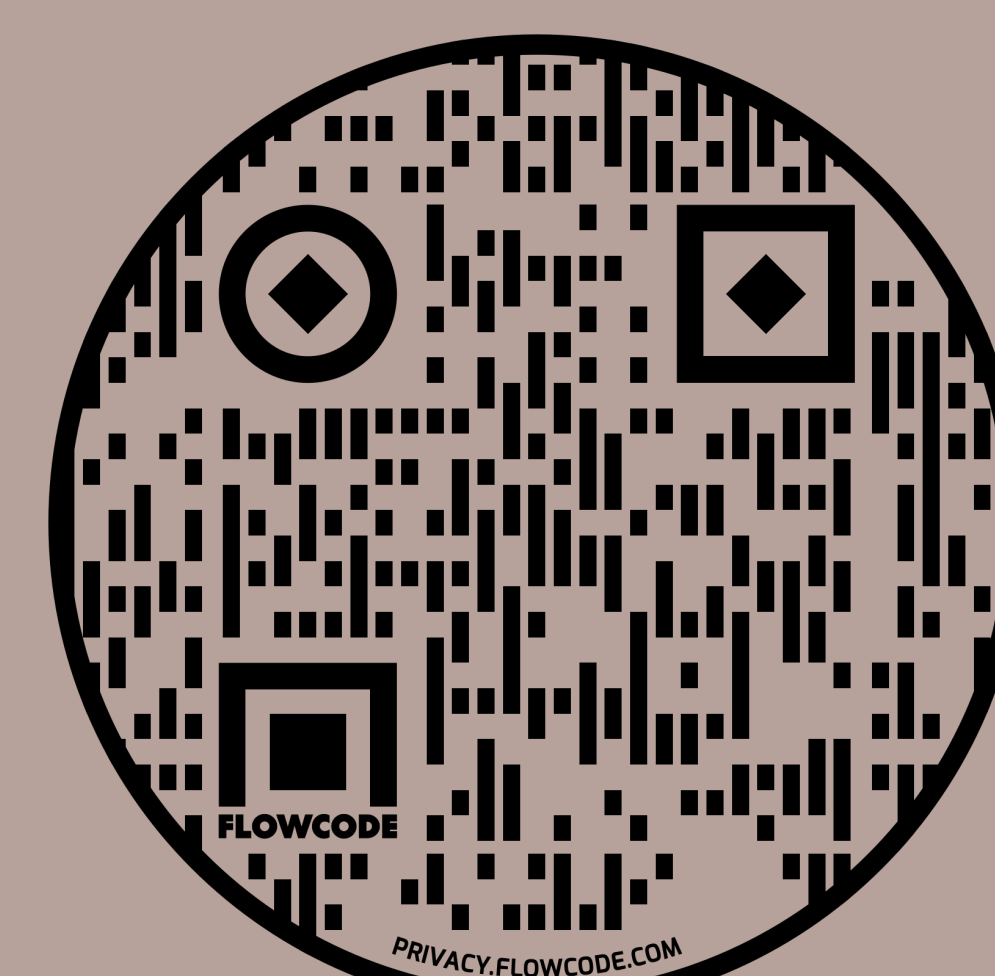
Phase 3 (2020-2021): Delphi surveys – *In progress*

DISCUSSION

GRIDD adds new knowledge to existing information about the impact of living with dermatological conditions. PRIDD, developed using both qualitative and quantitative methods, will produce much needed patient impact data. It will raise global awareness, locally, regionally and internationally, across conditions. This information will influence better decision-making and resource allocation for clinicians and policy makers and ultimately benefit patients.



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