

GLOBAL SKIN HEALTH

GLOBAL RESEARCH ON IMPACT OF DERMATOLOGICAL DISEASES (GRIDD): A PATIENT-DRIVEN WORLDWIDE PROGRAM

N Suthakharan (1) - R Pattinson (2) - C Bundy (2) - C Janus (3) - J Austin (3) - M Augustin (1)

University Medical Center Hamburg-eppendorf (uke), Institute For Health Services Research In Dermatology And Nursing (ivdp), Hamburg, Germany (1) - Cardiff University, College Of Biomedical And Life Sciences, School Of Healthcare Sciences, Cardiff, United Kingdom (2) - International Alliance Of Dermatology Patient Organization (iadpo), International Alliance Of Dermatology Patient Organization (iadpo), Ottawa, Canada (3)

Introduction: The Global Research on the Impact of Dermatological Diseases (GRIDD) project is the first global patient-initiated and patient-led impact research study in dermatology. By including the patient perspective stringently into the burden metrics, this will be the first program to systematically challenge Global Burden of Disease concept, which markedly underestimates burden of skin diseases in patients.

Objective: GRIDD aims to develop, with patient organizations, a global instrument to measure the impact of living with skin diseases globally. Further, it will capture patient experiences including the extent of disease impact and burden for patients and their families.

Material and Methods: Phase 1 systematically reviews published patient-reported outcomes (PRO) measures of the life impact of skin diseases and conducts a patient-centred item identification exercise. Phase 2 focuses on instrument development: develop the wording for items (i.e. impact categories) and appropriate item scaling. Phase 3 included the acquisition of real world data to test the validity and acceptability of the measure. Phase 4 and 5 focus on the dissemination and launch of the new measure and an implementation strategy to increase uptake of the measure.

Results: The research teams from the Universities of Hamburg and Cardiff started with phases 1 and 2. The systematic literature review has identified 59 generic, 23 dermatology-specific, and 149 disease-specific PROs used in dermatology research and practise. The measurement properties of the dermatology- and disease-specific measures will be identified and analysed to ground the development of the new measure. In the meantime, patient groups in more than 40 countries are preparing the first item collection.

Conclusion: This novel patient-centric methodology will complement existing concepts of











A new ERA for global Dermatology 10 - 15 JUNE 2019 MILAN, ITALY

evaluating patient perspective in dermatology. GRIDD will provide an extended patient view for better decision making at global and country level and, better positioning of skin diseases.





