

GRIDD Abstract - EADV Conference 2020

Introduction

Existing measures (e.g. PROMS) and metrics (e.g. DALYs) in dermatology arguably underestimate the true impact of skin conditions on patients' lives. This underestimation can influence treatment decision-making and negatively affect the full range of resources that dermatology may attract. To fully understand the impact of skin conditions, information must be obtained directly from patients. The first global, patient-driven impact research study in dermatology (Global Research on the Impact of Dermatological Diseases; GRIDD) was developed by patient organisations, clinicians and researchers to systematically gather this information. GRIDD aims to develop a new comprehensive impact measure and a rigorous global Patient-Reported Impact of Dermatological Diseases (PRIDD) database. The data will be used to enhance treatment decision-making and drive advocacy for better care, treatments, health care policies, resources and research.

Material and Methods

GRIDD was designed with a novel methodology consisting of five key phases. Patients are involved in each phase, both to participate in and *inform* the research. GRIDD is currently in phase 2. Phase 1 involved a systematic review of existing measures in dermatology and the development of a global network of patient organisations. In phase 2, interviews and group discussions were conducted with members of the patient organisations. Discussions used standard and creative methods of data collection including vignettes and visual data to identify key concepts for the measure. Phase 3 will employ a Delphi survey of patients, patient organisations, and dermatology specialists to determine whether the concepts identified in phase 2 are recognised and endorsed by a wider group. In phase 4, cognitive interviews with patients will confirm the content validity of the measure, and an online survey will be conducted to explore the measure's statistical structure. In phase 5, a larger online survey will be conducted to examine the psychometric properties of the final instrument. This last phase will also promote the measure and its open source data, provide training and support to patient organisations, and launch advocacy campaigns to address dermatology DALY rankings and wider perceptions of disease burden.

Results

The phase 1 systematic review revealed that there is no existing specific measure of impact in dermatology. Examination of 36 existing patient-reported measures identified poor psychometric properties and none could be recommended for immediate use based on their known measurement properties. A global network consisting of over 165 patient organisations in over 50 countries (located on all continents), with more than 60 disease areas has been established by the International Alliance of Dermatology Patient Organizations. The results of each phase are disseminated and discussed with patient organisation leaders, who in turn inform the design and conduct of the subsequent phases.

Discussion

GRIDD's novel patient-centric methodology will complement and enhance existing concepts of evaluating patient perspectives in dermatology and provide comprehensive and quantifiable patient impact data. It supports local, regional and international attempts to create awareness, better position dermatological diseases and their treatments and encourages decision-makers and stakeholders to include dermatological diseases in their planning and policy making.