



University Medical Center
Hamburg-Eppendorf

PRESS RELEASE

GlobalSkin Launches Groundbreaking GRIDD Study

Novel patient-led research initiative will measure the true impact of skin diseases globally

Ottawa, July 10, 2023 – The International Alliance of Dermatology Patient Organizations (GlobalSkin), in partnership with Cardiff University (UK), and University Medical Centre Hamburg-Eppendorf (Germany), recently launched the Global Research on the Impact of Dermatological Diseases (GRIDD) Study. This patient-led research partnership generates comprehensive global data on the impact of conditions of the skin, hair, nail, and mucosa on people's lives.

The GRIDD Study leverages a newly developed tool, the Patient-Reported Impact of Dermatological Diseases (PRIDD) measure, designed over a four-year period with input from nearly 2500 patients with skin diseases from around the world, to capture and quantify lived experience. This comes at a time when key agencies in public health, such as the US Food and Drug Administration and European Medicines Agency, have placed a high priority on the generation and use of Patient Experience Data (PED or PXD).

A total of 10,000 adults living with skin diseases are anticipated to take part in the GRIDD Study. The survey takes 10-20 minutes to complete and is accessible in the following 17 languages: Arabic, Bengali, Chinese (simplified), English, French, Dutch, Danish, German, Hindi, Italian, Japanese, Portuguese, Russian, Serbian, Spanish, Swahili, and Vietnamese.

GRIDD data will support local, national, and international advocacy work calling for greater research investment as well as more accessible care and treatment, to ultimately improve the lives of dermatology patients. For the first time, patients from around the world and all dermatological disease types will contribute to a dataset that measures the true impact of living with their diseases. The GRIDD Study will empower the dermatology community, including patients, patient organizations, health care professionals, researchers, and industry with verifiable, patient-derived data.

The GRIDD study is open until September 28, 2023. Eligible individuals may participate by visiting <https://globalskin.org/GRIDDStudy>.

Quotes

"This is a landmark moment for us at GlobalSkin, and indeed for the entire dermatology community. The launch of the GRIDD Study, following seven years of extensive research and the tireless support of our patient organization community, marks a significant step forward in our mission to enhance understanding of skin conditions and patients' unmet needs. I'm deeply grateful to our worldwide network of patient organizations and partners, whose commitment and support have been instrumental in this vital project. We are enthusiastic about the potential of the GRIDD Study and look forward to leveraging its insights to help create a better future for people living the stigma, mental health impacts and often-debilitating symptoms of skin conditions worldwide." *Jennifer Austin, GlobalSkin Chief Executive Officer*

"The GRIDD Study is an opportunity for people with skin conditions to share their unfiltered views of the day-to-day challenges they face. These individuals are disease experience experts and vital contributors in helping us gather data validating the need for improved care, better treatment options, and more affordable medicines. By getting involved in the GRIDD Study, patients can play a key role in reshaping global perceptions around dermatological diseases, stimulating research, right-sizing health care systems spending, and moulding future policies for improved patient outcomes." *Marc Yale, GlobalSkin Board President*

"This patient organisation and academic partnership has changed the way I approach research and practice. The rigor of the research plus the invaluable insights and participation from patients and patient organisation leaders has resulted in a new measure of the highest quality which we hope will become the gold standard at capturing the full impact of living with skin conditions. I am indebted to GlobalSkin for initiating and supporting this collaboration. The GRIDD Study is a shining example of how people living with the condition can be at the centre of important research initiatives and make their voices heard." *Christine Bundy PhD, AFBPS, CPsychol, Professor of Behavioural Medicine, Cardiff University - Co-lead Researcher GRIDD project*

"The GRIDD project is a milestone in collaborative research between scientists, dermatologists and patients. It is the first global research program initiated and organized by a patient organization in dermatology. Also, for the first time in history, a worldwide survey measuring the burden of skin diseases is conducted. This is particularly important because the negative impact of skin diseases is often greatly underestimated. With this unique project, we expect robust scientific data to achieve a powerful collective voice for greater and equitable access to care for people with skin diseases worldwide. In this sense, the project is a prime example of successful research in the spirit of People Centered Health Care as promoted by WHO." *Prof. Dr. Matthias Augustin, MD, PhD, Professor of Dermatology and Chair of Health Economics, University Medical Center of Hamburg - Co-lead Researcher GRIDD project*

Contact Information

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Background

About GlobalSkin

GlobalSkin is a not-for-profit organization dedicated to improving the lives of dermatology patients through awareness, advocacy, research, and collaboration with patient organizations, healthcare professionals, and industry partners. Established in 2015, the organization has a diverse membership-base comprising over 230 patient organizations that span 65 countries and 54 disease areas. GlobalSkin empowers patients by providing resources and support, while advocating for advancements in dermatology, access to care, and policy changes. Through conferences, publications, and research initiatives, GlobalSkin facilitates knowledge exchange and promotes patient-centric health care at local, national, regional, and global levels.

When GlobalSkin was formed in 2015, founding patient organizations from around the world identified significant gaps in their ability to advocate for their patients due to a lack of verifiable patient experience data. This is largely because existing Patient-reported outcome measures (PROMs) are rarely theory-informed and do not comprehensively capture the full impact of dermatological diseases on patients' lives - including stigma, mental health, and barriers to inclusion - and therefore underestimate patient burden.

About Global Research on the Impact of Dermatological Diseases (GRIDD)

Dermatological conditions are highly prevalent worldwide and significantly impact upon quality of life. Most published dermatology-specific (used across conditions) Patient-reported outcome measures (PROMs) cannot be recommended for use according to [the Consensus-based Standards for the Selection of Health Measurement Instruments \(COSMIN\)](#) criteria. They do not fully capture the substantial physical, psychological, and social impact dermatological conditions can have on patients' lives. This is largely because of insufficient patient involvement during PROM development and a reliance on classical psychometric methods. We developed the Patient-Reported Impact of Dermatological Diseases (PRIDD) measure in close partnership with patients. PRIDD meets the gold-standard COSMIN criteria, the only dermatology-specific measure to do so.

PRIDD is a valid and reliable tool that can help clinicians provide better care, and stakeholders to understand the global burden of skin diseases. PRIDD will greatly enhance patient perspectives by providing quantifiable patient impact data for better decision-making at the individual, national and global levels, with higher prioritisation of dermatological conditions.

Published medical journal articles on GRIDD:

- [Evidence of the content validity, acceptability, and feasibility of a new Patient-Reported Impact of Dermatological Diseases measure](#) - *Frontiers in Medicine*, May 2023
- [Development of a Conceptual Framework for a Patient-Reported Impact of Dermatological Diseases \(PRIDD\) Measure: A Qualitative Concept Elicitation Study](#) - *ActaDV*, November 2022
- [Patient-Reported Outcome Measures in Dermatology: A Systematic Review](#) - *Acta Dermato-Venereologica* - July 2021