Seeing the Skin in a New Light:

Changing How the World Measures and Understands Dermatological Diseases

March 2025

International Alliance of Dermatology Patient Organizations

GLOBALSKIN.ORG

University Medical Center Hamburg-Eppendorf

Cardiff University

Prifysgol Caerdydd

Disclosures: Funding Partners

GRIDD
Global Research on the Impact of Dermatological Diseases

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PRIDD

Patient-Reported Impact of Dermatological Diseases

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Project Team

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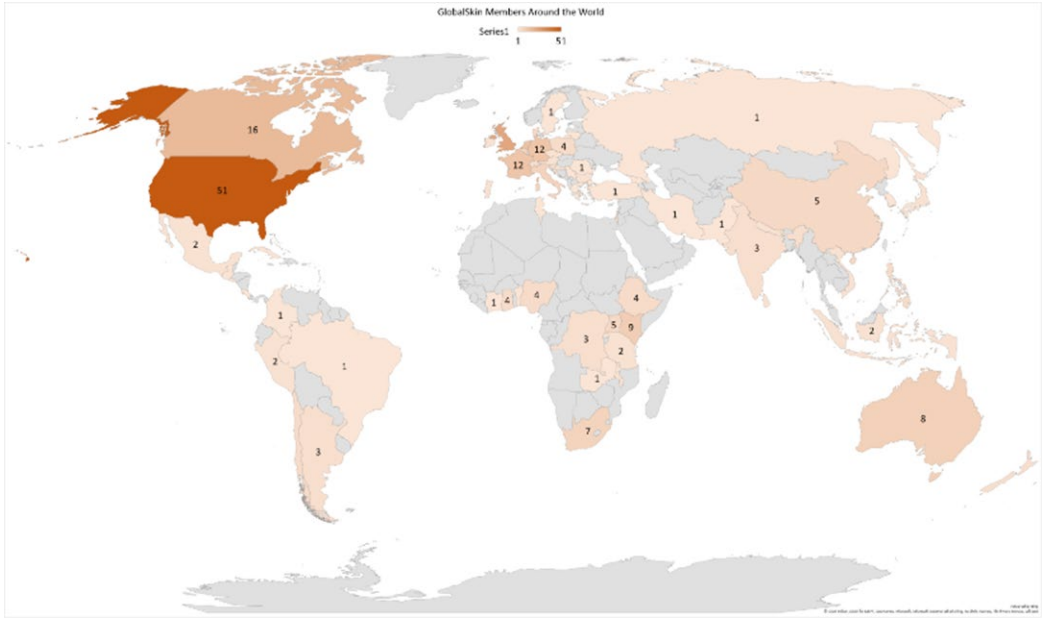
Who is GlobalSkin?

GLOBALSKIN.ORG
International Alliance of Dermatology Patient Organizations

300+ Members

74 Countries

59 Disease Areas

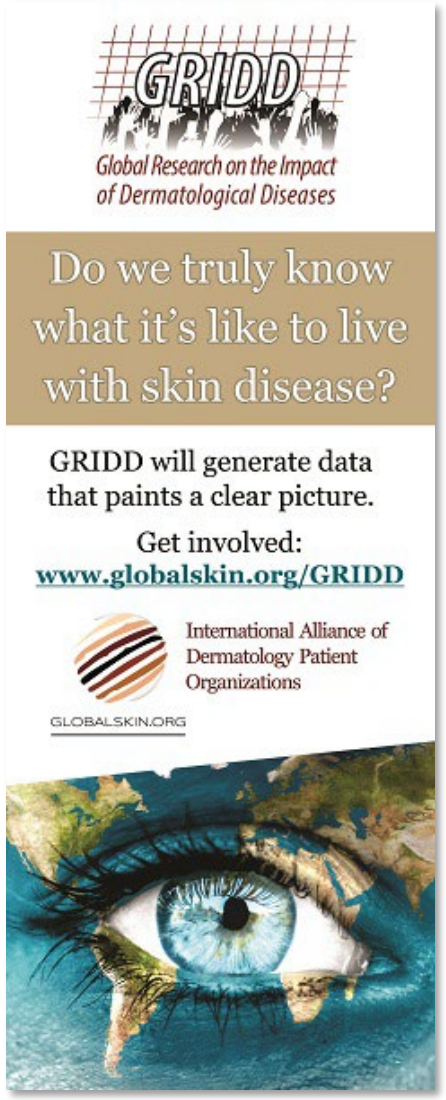


The International Alliance of Dermatology Patient Organizations (also known as GlobalSkin) is:

- A unique **global alliance** of dermatology patient organizations
- **Professionally-run** organization with staff located in Canada and Belgium
- Directed by a **global Board of Directors** comprised of patient organization leaders, governed by a rigorous code of ethics

Patient Advocacy Challenge

- Regulatory Agencies/Decision-makers/Payers/HTA want the patient voice
- They *do* and they *don't* want patient stories **BUT…their decision-making rubrics are based on DATA**



What if…

- Quality of Life was measured using a measurement tool *developed* by **patients**
- A **credible** patient voice could be built upon ***verifiable*** data
- Policy-makers wouldn't **ever** make a decision without including a ***patient-led*** **measure**

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Skin patient burden includes stigmatization and minimization.

That disgusts me!

Don't touch me. Don't come near me.

What's wrong with you??

It's only your skin.

I can't look away.

Is that contagious?

25.8% of patient respondents have thought about or attempted to take their lives.[1]

15-20% report feelings of stigmatization[2]

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Patient Inclusion in GRIDD: 5600+ patients

Item Gathering: 2019-2020 — Phase 2

- Workshop: **37** patients in **16** countries and **14** diseases
- Patient interviews: **28** patients in **11** countries and **5** diseases
- Outcome: ***263 items***

Delphi Surveys: 2020-2021 — Phase 3

- **1154** patients in **61** countries and **90** diseases
- Outcome: ***27 items***

Cognitive Interviews: 2021 — Phase 4

- **12** patients in **4** countries and **6** diseases
- Outcome: ***26 items***

Psychometrics Surveys: 2021-2022 — Phase 4

- Survey #1: **486** patients (Completed Dec. 2021)
- Survey #2: Test - **504** patients completed July 2022; re-test – **272** patients (Completed Sept. 2022)
- Outcome: **16** ***items***

GRIDD Study: 2023 used the 16 question PRIDD measure for the first time — Phase 5

- Survey #1: **4000+** patients (Closed Dec 31, 2023)
- Survey #2: Re-test **1230+** patients (Closed Dec 31,2023)

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Patient-Reported Impact of Dermatological Diseases

We know dermatological conditions impact people over a long period of time, but this questionnaire aims to measure how much your dermatological condition has affected your life **OVER THE LAST MONTH**. Please **consider each question in relation to your dermatological condition**. **Mark one box** only for each question. We have provided examples to give you an idea of the things you might consider, but these should not limit your answers. Dermatological conditions can affect the skin, hair, nails and/or mucous membrane. The word 'skin' here includes any of these aspects relevant to your condition.

Because of my dermatological condition…

		Never	Rarely	Sometimes	Often	Always
1	…I have experienced physical discomfort, soreness or irritation	○	○	○	○	○
2	…my sleep has been disturbed	○	○	○	○	○
3	… I have felt tired, fatigued or lacked energy	○	○	○	○	○
4	…my general physical health has been negatively affected	○	○	○	○	○
5	…my treatment has caused practical problems (for example, by taking up time or being messy)	○	○	○	○	○
6	…my leisure time (for example, hobbies, sports or exercise) has been negatively affected	○	○	○	○	○
7	…my everyday choices have been affected (for example, choice of clothes, hairstyle or products)	○	○	○	○	○

		Never	Occasionally	Often	Always
8	…I rely on others to help me with everyday tasks	○	○	○	○

		Never	Rarely	Sometimes	Often	Always
9	…I have had extra expenses	○	○	○	○	○
10	…I have felt anxious, worried or nervous	○	○	○	○	○
11	…my condition has dominated my thoughts	○	○	○	○	○
12	…I have felt depressed or low in mood	○	○	○	○	○
13	…my relationships with those close to me have been negatively affected	○	○	○	○	○
14	…my social life or social interactions have been negatively affected	○	○	○	○	○
15	…I have been prevented from or found it difficult to be intimate with another person	○	○	○	○	○
16	… I have struggled to perform roles important to me (for example, to be caregiver / parent / partner / employee / student)	○	○	○	○	○

Please make sure you have answered every question.

Thank you.

PRIDD assesses 4 domains:

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Psychometric testing – PRIDD results

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		Requirement	Rating	Results
Structural validity	Unidimensionality	- No violation of unidimensionality - No violation of local independence - Adequate model fit: χ^2 >0.01	+	PRIDD and all subscales unidimensional with no local dependency. χ^2 = 0.11
	Structural validity	CFI or TLI or comparable measure > 0.95 OR RMSEA < 0.06 OR SRMR < 0.08	+	CFI = 0.96; TLI = 0.97; RMSEA = 0.09; SRMR = 0.03
Internal consistency		Person Separation Index ≥ 0.7	+	Person Separation Index = 0.89
Hypothesis testing for construct validity		75% of hypotheses met	+	76% of hypotheses met
Test-retest reliability		ICC or weighted Kappa ≥ 0.70	+	ICC = 0.93
Measurement error		SDC or LoA < MIC	+	LoA (1.3) < MIC (4.14) Unable to determine anchor-based MIC
Responsiveness		The result is in accordance with the hypothesis OR AUC ≥ 0.70	+	Manuscript submitted, awaiting peer review
Floor & ceiling effects		Considered present when > 15% of the patients achieved the minimum or maximum possible score	+	< 0.9% with minimum or maximum score
MIC		N/A		Currently in process

"+" = sufficient, " –" = insufficient, "?" = indeterminate

CFI: Comparative Fit Index; TLI ; Tucker-Lewis Index; RMSEA: Root Mean Square Error of Approximation; SRMR: Standardised Root Mean Square; ICC: Intraclass Correlation Coefficient; SDC: Smallest Detectable Change; LoA: Limits of Agreement; MIC: Minimally Important Change

W = weak evidence; + = sufficient evidence; - = insufficient evidence; ? = indeterminate evidence

A= Recommended for use
B-Potential to be recommended for use, but they require further research
C= Should not be recommended for use

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The first **PROM** in dermatology to be developed and **validated** in partnership **with patients**

*"I've completed a lot of dermatological questionnaires, but I **don't think I've ever seen them all integrated like this** in such a questionnaire ... I'm very, very happy with this. It has stirred my heart ... **There are things here that I wanted to discuss with my dermatologist** ... I'm really, really impressed with this. It's very good, it's excellent." (Participant 5)*

Data from the psychometric study of the PRIDD English version.

SKIN MATTERS

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Psychometric testing: Comparison of Measures

PROM	Content validity	Structural validity	Internal consistency	Reliability	Measurement error	Construct validity	Responsiveness	Recommendation
DLQI	W	???	+++	?		+++	+++	B
PRIDD	++	+++	+++	+++	?	+++	?	A
Skindex	W	???	W	W		-	W	B
Skindex 29	W	???	+++	W		+++	W	B
Skindex 16	W	++	++			+	W	B

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Why use PRIDD in research?

It is the only **life impact measure** in dermatology that **meets all tested psychometric criteria** and is **recommended for use** according to the COnsensus-based Standards for the Selection of Health Measurement Instruments (COSMIN) standards.

Enhances
understanding of disease impact from a patient perspective

Supports
patient-doctor communication and shared decision-making

Informs
tailored treatments based on patient-reported outcomes

PRIDD
Patient-Reported Impact of Dermatological Diseases

Read our PRIDD Journal Articles!

ActaDV ACTA DERMATO-VENEREOLOGICA

frontiers

JEADV

BJD
British Journal of Dermatology
IMPROVING PATIENT OUTCOMES IN SKIN DISEASE WORLDWIDE

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Patient Experience and Measuring Patient Burden

- **Debilitating** (often chronic)
- **Co-morbidities** (e.g., diabetes)
- Impaired ability to **work** and advance **career**
- Difficulty meeting **family** responsibilities

Physical Impacts

Access to Treatments

- Treatments are **unaffordable** for many
- More **research** needed for new treatments and cures

"THE GOOD NEWS IS THAT NEW MEDICINE CLEARED UP THE SPOTS, BUT..."

Patient Experience and Measuring Patient Burden

Time to diagnosis

Psychosocial Impacts

- Misunderstanding and **minimization** of skin diseases
- **Stigma**, discrimination, social exclusion, human rights violations

Access to Care

- Lack of expertise among **general practitioner physicians**
- **Not enough dermatologists!**
- Long path to **diagnosis**

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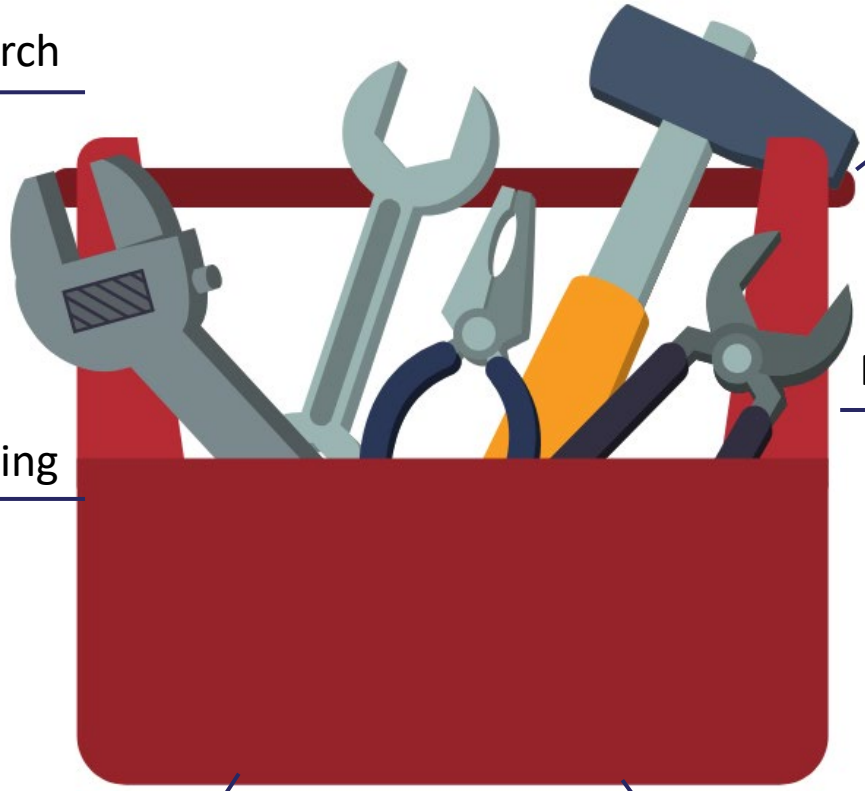
PRIDD is like a Dermatological QOL Multi-Purpose Toolbox



Quality of Life Research

Clinical Trial Endpoint

Patient intake triage tool

Shared Decision Making

Patient disease management

Patient Registry

There is a lot of excitement surrounding PRIDD
…. it will take time, partners and more research to discover its full value

PRIDD
Patient-Reported Impact of Dermatological Diseases

Valid and reliable

17 Languages

Multi-dimensional

The only fully **validated** dermatology **impact measure** applicable to all skin conditions!

"It's our new method for determining who we should treat first. We take people in order of how loud they scream."

License is free for use in non-industry funded research

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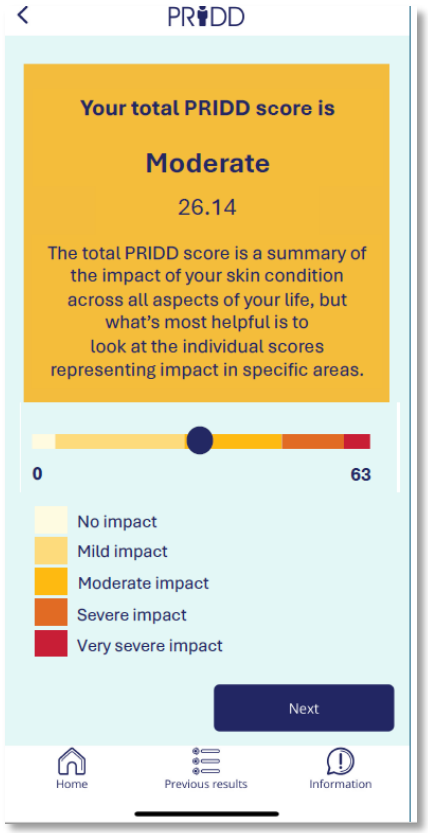
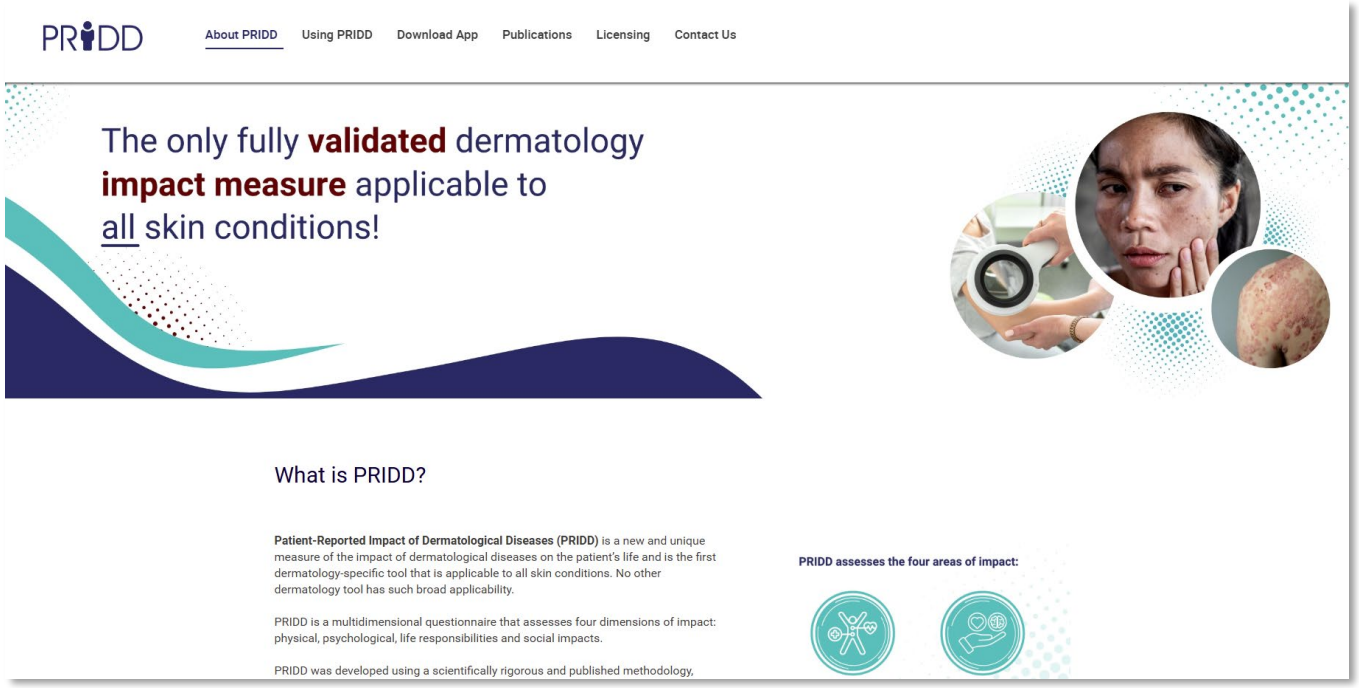
Visit our website: PRIDD.org

APP

Download on the App Store

ANDROID APP ON Google play





Questions?

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