Received: 2 June 2023 | Accepted: 24 January 2024

DOI: 10.1111/jdv.19903

ORIGINAL ARTICLE

JEADV JOURNAL OF THE EUROPEAN ACADEMY OF DERMATOLOGY & VENEREOLOGY

Patient prioritisation of items to develop the Patient-Reported Impact of Dermatological Diseases measure: A global Delphi study

Nirohshah Trialonis-Suthakharan[1] | **Rachael Pattinson**[2] | **Nasim Tahmasebi Gandomkari**[1] | **Jennifer Austin**[3] | **Christine Janus**[3] | **Nick Courtier**[2] | **Rachael M. Hewitt**[2] | **Chris Bundy**[2] | **Matthias Augustin**[1]

[1]Institute for Health Services Research in Dermatology and Nursing (IVDP), University Medical Center Hamburg-Eppendorf (UKE), Hamburg, Germany

[2]School of Healthcare Sciences, Cardiff University, Cardiff, UK

[3]International Alliance of Dermatology Patient Organizations, Ottawa, Ontario, Canada

Correspondence
Nirohshah Trialonis-Suthakharan, German Center for Health Services Research in Dermatology (CVderm), Institute for Health Services Research in Dermatology and Nursing (IVDP), University Medical Center Hamburg-Eppendorf (UKE), Martinistraße 52, Hamburg 20246, Germany.
Email: n.suthakharan@uke.de

Funding information
International Alliance of Dermatology Patient Organizations

Abstract

Background: The Global Research on the Impact of Dermatological Diseases (GRIDD) project is developing the new Patient-Reported Impact of Dermatological Diseases (PRIDD) measure. PRIDD measures the impact of dermatological conditions on the patient's life.

Objectives: This study aimed to seek consensus from patients on which items to prioritize for inclusion in PRIDD.

Methods: A modified, two-round Delphi study was conducted. Adults (≥18 years) with dermatological conditions were recruited. The survey consisted of a demographic's questionnaire and 263 potential impact items in six languages. Quantitative data used Likert-type ranking scales and analysed against consensus criteria. Qualitative data collected free text responses for additional feedback and a framework analysis was conducted.

Results: 1154 people representing 90 dermatological conditions from 66 countries participated. Items were either removed ($n = 79$), edited ($n = 179$) or added ($n = 2$), based on consensus thresholds and qualitative feedback. Results generated the first draft of PRIDD with 27 items across five impact domains.

Conclusion: This Delphi study resulted in the draft version of PRIDD, ready for psychometric testing. The triangulated data helped refine the existing conceptual framework of impact. PRIDD has since been pilot tested with patients and is currently undergoing psychometric testing.

INTRODUCTION

With no cure for many dermatological conditions, treatment focusing on reducing physical symptoms and improving quality of life, assessment of the full impact of dermatological conditions on patients' lives is crucial to effective management.

Two recent systematic reviews[1,2] evaluated the quality of existing dermatology-specific (can be used across conditions) patient-reported *outcome* measures (PROMs) against the gold-standard consensus-based standards for the selection of health measurement instruments (COSMIN) criteria.[3–5] Both reviews found that existing PROMs, including widely used measures such as the Dermatology Life Quality Index (DLQI)[6] and Skindex,[7–9] did not capture the full impact of dermatological diseases on patients' lives. The most common reason for poor quality assessment of PROMs was the lack of patient input during their development.[1]

In response, we are developing a new impact measure called PRIDD (Patient Reported Impact of Dermatological Diseases) in close collaboration with patients. PRIDD is

designed to measure the impact of living with a dermatological condition on patients' lives and is for use with all adults living with any dermatological condition.

As the first step in new measure development, the content validity phase,[10–12] we gathered data via a global qualitative interview study to develop a conceptual framework of impact (Figure 1).[13] We found that impact is a complex and multifaceted construct presenting across six domains: physical, psychological, social, financial, daily life and responsibilities and impacts of healthcare.

The next step in the process, item generation and reduction, is customarily achieved through statistical techniques (i.e. factor analysis and examination of item characteristics) but, without patient input at this stage, it is not clear whether the final measure accurately reflects the concepts that are most important to patients. Participatory methods have the advantage of providing this patient insight and additional evidence of content validity.

This study aims to identify which items patients would prioritize for inclusion in PRIDD. To maintain good content validity, we checked whether the impact factors identified were endorsed by a wider group of people with dermatological conditions and explored whether important items were missing from the item pool.

PATIENTS AND METHODS

Design

We conducted a modified, two-round Delphi study to elicit consensus from patients on the most important items to include in PRIDD. The Delphi study is a well-recognized consensus-seeking method in healthcare research,[14] which is increasingly applied to PROM development.[15] Ethical approval was obtained from Cardiff University School of Healthcare Sciences Ethics Committee (SREC:637). Informed consent was obtained from all participants.

Participants

We employed convenience sampling to recruit eligible participants through the International Alliance of Dermatology Patient Organizations' (IADPO) global membership network. Participants met the inclusion criteria if they were an adult (aged ≥18 years) living with a dermatological condition. Clinicians and patient proxies such as family members or carers were excluded (a) because evidence of content validity must come from the target population[3,4] and (b) to maintain patient-centredness in the item reduction process. To reflect PRIDD's target population, account for attrition and provide rigour for statistical analysis, we aimed to recruit up to 2000 participants but no less than 30.[16,17]

Materials

In lieu of a conventional idea generation round,[17] the online survey was developed based on the outcomes from the qualitative interview study.[13] Briefly, we proposed at least one working item for each of the identified impacts of dermatological disease. After checking for duplicates in the item pool, 263 items remained. The survey (Appendix S1) was conducted online and included a brief demographic questionnaire and a list of the 263 impact items.

To enable a sample representative of PRIDD's global target population, the survey was translated from English into German, Spanish, French, Arabic and Chinese. Professional translators employed back-translation methods to ensure cross-cultural construct equivalence.[18]

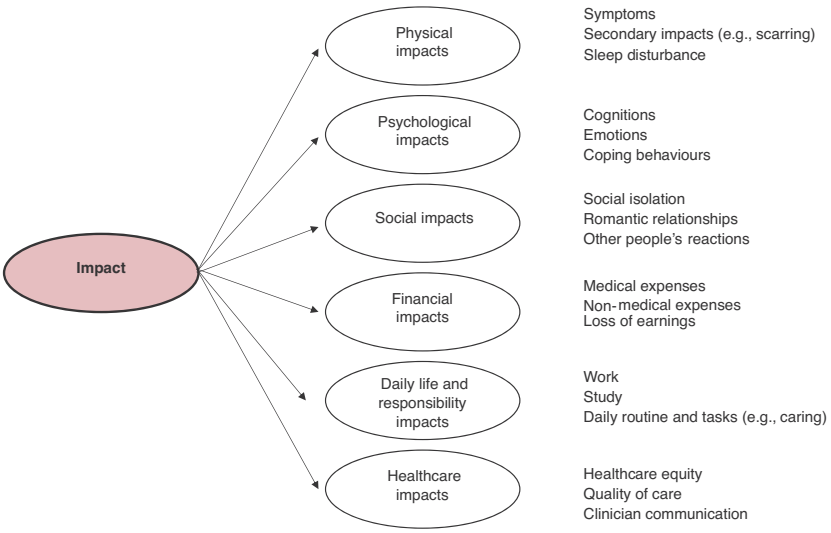

FIGURE 1 Conceptual framework of the impact of dermatological conditions with example concepts (Version 1).[13]

Procedure

The primary outcome of the study was the ranking of the items in terms of importance. In the first round, participants completed the demographics questionnaire and rated the importance of each of the 263 impact items using a 5-point Likert-type scale with responses: 'not at all', 'somewhat', 'moderately', 'quite a lot' to 'very much'. Respondents could also provide additional qualitative comments in the free-text space to identify any important relevant concepts that were missing. The results of this round were briefly summarized in reports to participants on the online platform at the start of Round 2. In the second round (Appendix S2), they rated the importance of the items using the same scale as Round 1 in the refined item pool. For both rounds, participants were given at least four weeks to respond. A reminder email was sent two weeks after the initial invitation email. Only participants who had participated in Round 1 were invited to participate in Round 2. Before launch, both Delphi surveys were pilot tested with public and patient involvement and with at least one native speaker for each of the survey languages for quality review.

Data analysis

Quantitative data were analysed with SPSS v. 26 (IBM, Armonk, NY, USA) and qualitative data were managed with NVivo 12 qualitative data software package (QSR International, Burlington, Massachusetts, USA). Missing data were handled using pairwise deletion. At the end of each round, simple item-specific descriptive statistics regarding the number of items retained (without alteration), removed, edited or added, based on a priori consensus criteria and free text responses were reported.

We defined consensus as follows: If ≥70% of participants score the item as 'critical' (options 'quite a lot' and 'very much') and if <15% of participants scored the same item as 'not important' (options 'not at all', 'not applicable' and 'somewhat'), the item should be prioritized. Items were removed if ≥70% of participants scored the item as 'not important' (options 'not at all/not applicable' and 'somewhat') and <15% of participants scored the same item as 'critical' (options 'quite a lot' and 'very much').[19] Consensus of middle ground items were retained or removed through a working agreement of researchers.

Subgroup analyses were conducted using Mann–Whitney *U*-tests to determine whether overrepresented conditions exerted undue influence on the results.

A framework analysis[20,21] was conducted on the free text responses following an inductive–deductive approach using our conceptual framework, which is part of the Common Sense Model of Self-Regulation.[22] This approach enabled the systematic exploration of both existing domains and items as well as novel impacts. The data for each domain and item were summarized in Microsoft Excel (Microsoft, Redmond, Washington, USA).

RESULTS

A total of 1154 participants completed Round 1 (from 14 December 2020 to 15 February 2021) and 493 (42.72%) completed Round 2 (from 12 May 2021 to 03 June 2021). Figure 2 shows the recruitment process. All demographic data collected in the first round and tracked during the study are shown in Table 1. In total, 90 dermatological conditions (Table 2) and 65 countries (Table 3) were represented. The number refers to the primary dermatological condition of the participants; 158 (13.7%) people reported multiple dermatological conditions.

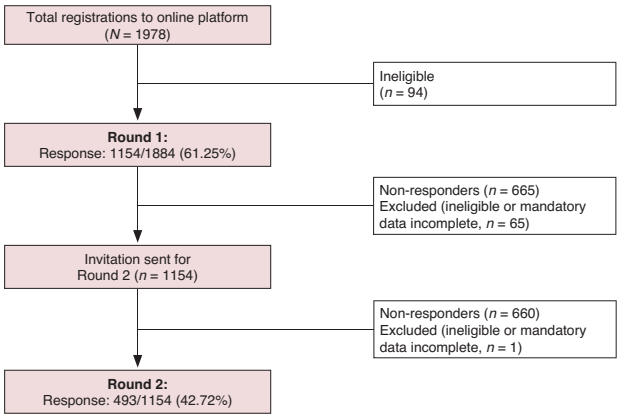

FIGURE 2 Flowchart showing responses to Delphi survey.

TABLE 1 Participant characteristics of Delphi Rounds 1 and 2.

	Round 1, *n* (%)	Round 2, *n* (%)
Total	1154	493
Gender		
Male	332 (29.2)	160 (32.5)
Female	802 (70.5)	325 (65.9)
Other	3 (0.3)	1 (0.2)
Age		
Overall	*M* = 49.34 (SD = 15.61, range = 18–94)	*M* = 52.27 (SD = 14.91, range = 18–85)
18–29	156 (13.5)	44 (8.9)
30–39	186 (16.1)	13.2 (13.2)
40–49	208 (18)	81 (16.4)
50–59	274 (23.7)	133 (27)
60–69	204 (17.7)	107 (21.7)
70–79	117 (10.1)	57 (11.6)
80–89	8 (0.7)	6 (1.2)
90+	1 (0.1)	0
Member of a patient organisation		
Yes	584 (50)	260 (54.2)
No	584 (50)	220 (44.6)

Round 1

Qualitative results

Overall, 515 (44.6%) participants provided at least one free text comment. Two overarching themes were developed: (1) *general feedback* and (2) *feedback on items and domains* grouped according to the conceptual framework (Table S1). These data contributed to both the shortlisting of items and edits to the survey instructions. However, it was impossible to implement all feedback as some conflicted with the purpose of PRIDD by, for example, suggesting disease-specific items. It emerged that, though important, the 'impact of healthcare' domain had a causal rather than a reflective relationship with impact and was therefore removed.

TABLE 2 Dermatological conditions represented.

Dermatological condition	Round 1, *n* (%)	Round 2, *n* (%)
Psoriasis	247 (21.4)	113 (22.9)
Atopic dermatitis	207 (17.9)	86 (17.4)
Pityriasis rubra pilaris	199 (17.2)	94 (19.1)
Alopecia areata	95 (8.2)	33 (6.7)
Pemphigus vulgaris	65 (5.6)	34 (6.9)
Vitiligo	38 (3.3)	16 (3.2)
Acne	34 (2.9)	12 (2.4)
Bullous pemphigoid	32 (2.8)	15 (3)
Lichen sclerosus	32 (2.8)	9 (1.8)
Cicatricial pemphigoid	22 (1.9)	0 (0)
Pemphigus foliaceus	15 (1.3)	5 (1)
Other	168 (14.6)[a]	76 (15.6)

[a]Actinic keratosis (solar keratosis), albinism, alopecia, alopecia areata, alopecia totalis, alopecia universalis, androgenetic alopecia, angioedema, autoimmune skin diseases, basal-cell carcinoma, birthmarks, burn injuries, candidiasis, corticosteroid addiction skin, cutaneous lymphomas, cutis laxa, dermatitis herpetiformis, dermatitis hypomelanosis, dermatitis seborrheic, dermatomyositis, dyshidrotic eczema, ectodermal dysplasias, epidermolysis bullosa, erythema nodosum, erythropoietic protoporphyria, frontal fibrosing alopecia, generalized pustular psoriasis, genital herpes, haemangioma, herpes simplex types 1 and 2 infection, hidradenitis suppurativa, hirsutism, HIV-associated skin diseases, hyperhidrosis, ichthyoses, keloid, keratosis pilaris, lichen planopilaris, lichen planus, lichen planus, lichen simplex, lipoma, lupus erythematosus, malignant melanoma, melanocytic naevus, melasma, miliaria, mycosis fungoides, nevus flammeus, pemphigus superficial, pityriasis lichenoides, pityriasis rubra pilaris, porphyria cutanea tarda, pressure sore, psoriasis arthritis, psoriatic spondylitis, pyoderma gangrenosum, Raynaud's, rosacea, sarcoidosis, scalp folliculitis, scarring alopecia, sebaceous hyperplasia epidermal cyst, Sjögren syndrome, skin allergy, squamous cell carcinoma, tinea pedis, chronic topical steroid withdrawal syndrome, urticaria and Wells syndrome.

Item-specific results

The decision to retain, remove, add or edit items was made on a case-by-case basis according to the consensus criteria and free-text responses (Table 4). Edited items include both single items that were reworded and the collapsing of two or more items.

The Round 2 survey was created from these findings; the shortlist comprised five domains with 76 items.

Round 2

The top 20 most important impacts of dermatological conditions according to patients are shown in Table 5.

Of the 76 items, 29 (38%) met the criteria to be prioritized for inclusion (Table 6) and 13 (17%) to be considered for removal. There was at least one item prioritized for inclusion in each of the five domains of impact, providing further support for our framework.

Subgroup analysis

Differences were found between the groups reporting psoriasis and atopic dermatitis (AD) compared with the sample overall on 24 (32%) and 15 (20%) items, respectively. Of these, only two items—'my life choices are affected (e.g. choice to have children)', $U = 13{,}763$, $z = -3$, $p = 0.003$ and 'I feel dismissed or abandoned by the healthcare system', $U = 25{,}096$, $z = 3.394$, $p = 0.001$—met the criteria to be

TABLE 3 Geographical spread of participants according to WHO regions.

WHO region	Countries represented	Round 1, *n* (%)	Round 2, *n* (%)
African region	Cameroon, Ghana, Kenya, Nigeria and Uganda	12 (1)	2 (0.4)
Region of the Americas	Argentina, Brazil, Canada, Chile, Colombia, Costa Rica, Cuba, Ecuador, El Salvador, Honduras, Mexico, Nicaragua, Panama, Peru, Puerto Rico, Trinidad and Tobago, Uruguay, US and Venezuela	565 (49)	237 (48.1)
South-East Asian region	Bangladesh, India, Indonesia and Nepal	8 (0.7)	2 (0.4)
European region	Austria, Belgium, Czech Republic, Denmark, Finland, France, Germany, Ireland, Israel, Italy, Kyrgyzstan, Liechtenstein, Netherlands, North Macedonia, Norway, Poland, Portugal, Serbia, Slovenia, Spain, Sweden, Switzerland, Turkey and United Kingdom	439 (38.1)	192 (38.9)
Eastern Mediterranean region	Lebanon, Pakistan, Qatar and Saudi Arabia	4 (0.3)	1 (0.2)
Western Pacific	Australia, China, Japan, New Zealand and Singapore	124 (10.8)	59 (12)

TABLE 4 Item-specific descriptive statistics regarding the number of items retained (without alteration), removed, edited or added (Round 1).

	n	Examples
Retained	5	'My sleep is disturbed' (physical) 'I am anxious' (psychological)
Removed	79	'I struggle to save money' (financial)
Edited	179	'I structure my day around my condition' (daily) 'I have medical expenses such as prescriptions' (financial)
Added	2	'I often feel disgusting' (psychological) 'My ability to be the person I want to be with others is affected' (social)

TABLE 5 Top 20 most important impacts to participants according to item means.

Rank	Item	Impact domain	Mean
1	My skin is sensitive	Physical	2.81
2	The quality, look and feel of my nails, skin and hair bothers me	Physical	2.76
3	I experience physical discomfort, soreness or irritation	Physical	2.52
4	I feel dismissed or abandoned by the healthcare system	Psychological	2.46
5	I cope by living a healthy lifestyle	Psychological	2.46
6	My leisure time/activities are affected	Daily life and responsibilities	2.35
7	I have been affected financially	Financial	2.34
8	My life choices are affected (e.g. choice to have children)	Psychological	2.33
9	I rely on others to help me cope	Psychological	2.32
10	My daily routine has had to accommodate my condition	Daily life and responsibilities	2.29
11	My education has been affected	Daily life and responsibilities	2.22
12	I worry about other health consequences	Psychological	2.22
13	I worry about social situations	Psychological	2.21
14	I am tired, fatigued or lack energy	Physical	2.09
15	My everyday choices are affected (e.g. clothes, food, drink and products)	Psychological	2.02
16	I cope by avoiding challenges	Psychological	2.02
17	I often feel unsure or uncertain	Psychological	2.01
18	My general health has been affected	Physical	1.96
19	I am stressed	Psychological	1.95
20	My sleep is disturbed	Physical	1.94

prioritized for inclusion after controlling for psoriasis and AD.

Mann–Whitney *U*-tests were run to determine whether there were any differences across the items between those with pityriasis rubra pilaris (PRP), who were overrepresented, and the sample overall. Statistical differences were found between the groups on 63 (82.9%) items (Appendix S3). Of these, six items reached the consensus threshold to be prioritized for inclusion and eight no longer met this threshold when PRP was controlled for (Appendix S3).

Item-specific results

The decision to retain, remove, add or edit items (Table 7) here was primarily driven by the item meaning, items that tapped the same underlying concept were collapsed. Again, edited items included both single items that were reworded and the collapsing of one or more items.

Based on the consensus criteria and subgroup analyses, a list of items prioritized for inclusion was created (Table 8). This list formed the basis of the first draft of PRIDD, which contained 27 items across five domains.

DISCUSSION

This Delphi study represents the second of three steps—concept elicitation, prioritisation of items and pilot testing—in the content validity phase of PRIDD development.[10,11] It aimed to achieve a consensus on the impacts that were most important to people living with a dermatological condition and consequently develop a list of items to prioritize for inclusion in PRIDD. We established consensus on the items for PRIDD through a two-round Delphi process. The results

TABLE 6 Items that met the criteria to be prioritized for inclusion and the percentage that deemed them 'critical'.

Item	%
Physical impact	
The quality, look and feel of my nails, skin and hair bothers me	78.9
I experience physical discomfort, soreness or irritation	72.4
My skin is sensitive	80.7
My sleep is disturbed	55.4
I am tired, fatigued or lack energy	58.0
My general health has been affected	56.5
The treatment for my condition causes me problems	54.0
Daily life and responsibilities	
My daily routine has had to accommodate my condition	65.3
My leisure time/activities are affected	68.8
Psychological	
I am stressed	63.0
I feel emotional pain or turmoil	56.5
I feel anxious	53.4
I am often worrying or feel nervous	52.0
I worry about social situations	55.0
I worry about other health consequences	65.6
I am always thinking about my skin, hair or nails	62.3
I often feel frustrated	49.4
I am self-conscious	51.8
I think that I'm unattractive	51.3
The course of my life has been affected	49.3
My everyday choices are affected (e.g. clothes, food, drink and products)	64.3
I have changed my appearance or how I chose to style myself (e.g. clothes, hair and makeup)	55.5
I am expected or expect myself to perform or function as though I don't have a dermatological condition	55.9
I cope by focusing on the positive	72.1
I cope by living a healthy lifestyle	68.8
I control all the things that I can	73.7
Social	
My social life has been affected	56.5
I tend to avoid social events or situations	50.6
Financial	
I have extra out-of-pocket expenses (e.g. medical appointments and prescriptions, wigs, creams and ointments)	66.2

generated the first draft of PRIDD, consisting of 27 items across five domains, ready for pilot-testing in the psychometric phase of development.

Data gathered from the free text responses validated and refined the conceptual framework of impact (Figure 3) generated in the concept elicitation study[13] as no new domains were suggested.

Mapping the first draft of PRIDD against the 36 PROMs identified in our group's systematic review[1] revealed that not one of the existing PROMs captured *all* of the impacts the study participants considered most important. Furthermore, refinements to our conceptual framework includes three impact concepts—abandonment, problems performing roles and pressure to perform—not captured in any of the existing measures. This supports the need for PRIDD that demonstrates wider impact and underlining its unique contribution to dermatology measurement.

The challenge of developing a dermatology-specific PROM

The data gathered reflect the challenges inherent in developing a dermatology-specific PROM compared to a disease-specific PROMs. With the ICD-10[23] classifying over 1000 dermatological conditions, dermatology patients are a particularly heterogeneous group in relation to age and condition type relative to other medical specialities. Therefore, finding issues shared across most conditions was challenging. Despite the heterogeneity of the sample, we were able to prioritize items for inclusion in PRIDD. This demonstrates that while each dermatological condition may have a unique impact profile, there are many similarities and, therefore, a dermatology-specific measure is appropriate.

Strength and weakness

This Delphi survey provided a systematic and transparent means of prioritising the items for inclusion in PRIDD. The online and anonymised nature of the survey allowed us to access the helpful aspects of group decision-making (e.g. obtaining expert input without geographical or temporal restraint) while limiting their unhelpful attributes (e.g. conformity to the dominant view). This enabled the recruitment of a large global sample to test and prioritize the concepts elicited in the previous study.

This study built on the strength of a systematic approach involving patients at each step of our concept elicitation study. An exploratory qualitative first Delphi round is recommended whereby a group of experts produces the initial items, thereby increasing reliability and validity.[17] This Delphi study consisted of two rounds using the results of the concept elicitation study in place of an initial qualitative round. By relying on our rich qualitative data, an arguably, more rigorous approach to Delphi item generation was followed than a traditional Delphi method.

To meet the assumption of unidimensionality in measurement instruments, the impact of healthcare domain was removed from the conceptual framework. Given the obvious importance of the impact of healthcare domain to patients, the data gathered thus far could form the basis of a separate, new measure of the 'quality of dermatology services', which

TABLE 7 List of items prioritized for inclusion in PRIDD.

Domain	Item
Physical	The quality, look and feel of my nails, skin and hair bothers me
	I experience physical discomfort, soreness or irritation
	My skin is sensitive
	I am tired, fatigued or lack energy
	My general health has been affected
	The treatment for my condition causes me problems
Daily life and responsibilities	My daily routine has had to accommodate my condition
	I have been treated differently by others regarding employment
Psychological	I feel anxious
	I am often worrying or feel nervous
	I worry about social situations
	I am always thinking about my skin, hair or nails
	I often feel frustrated
	I am self-conscious
	I think that I'm unattractive
	my life choices are affected (e.g. choice to have children)
	I feel dismissed or abandoned by the healthcare system
	I control all the things that I can
	I feel like I have lost some control
	I cope by avoiding thinking about my condition
	I cope by focusing on the positive
	I struggle to perform roles important to me, for example, as a caregiver or as a man
Social	My social life has been affected
	I tend to avoid social events or situations
Financial	I have extra out-of-pocket expenses (e.g. medical appointments and prescriptions, wigs, creams and ointments)

TABLE 8 Item-specific descriptive statistics regarding the number of items retained (without alteration), removed or edited (Round 2).

	n	Examples
Retained	23	'The quality, look and feel of my nails, skin, hair bothers me' (physical)
Removed	37	'I am concerned that people only see me as my condition' (social)
Edited	16	'I have found it hard to work or study' (daily life and responsibilities)

could be used to target quality improvement efforts at the local, national and global level.

The survey was professionally translated from English into five other languages enabling us to recruit from PRIDD's global target population. We used back-translation methods to ensure construct equivalence, the assumption that items in the translated version measure the same construct in the same way as in the original language.[18,24,25] Though some languages—and therefore populations—were missing, the variety of languages increased the validity and robustness of the data compared to an English version alone.

Because PRIDD items were prioritized for inclusion based on consensus thresholds, the first draft of PRIDD is unlikely to capture more extreme impacts that are very important but to relatively few people, for example, suicidality. The next phase of the process of measure development is to test the psychometric properties of PRIDD, this will enable us to test further the content validity of the items that arose from the Delphi and to establish their full-scale properties.

PRIDD is the only dermatology-specific PROM that has been developed with high levels of patient involvement during the item reduction stage.[1] There is evidence that the sample was not representative of the global population of people with dermatological conditions, with some conditions over- or under-represented relative to their prevalence. However, these conditions were prevented from exerting undue influence on the items prioritized for inclusion by checking for significant differences between these groups and the sample overall. Finally, as participants were recruited through IADPO, a global alliance of patient organisations focused on research, advocacy and support, these results may not represent the experiences of people who are not in contact with patient organisations. Nevertheless, half

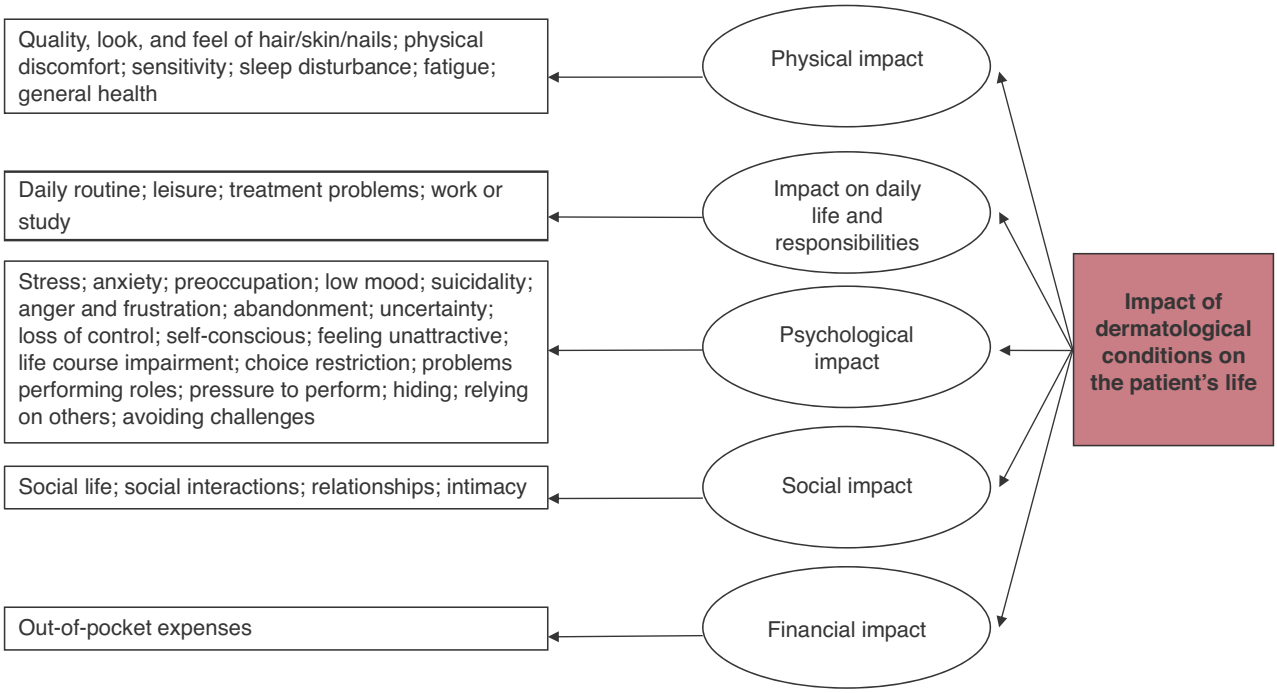

FIGURE 3 Conceptual framework of the impact of dermatological conditions on the patient's life with example concepts (Version 2).

of the participants were not members of a patient organisation, and the results were consistent across members and non-members, suggesting that they are applicable regardless of member status.

Implications for clinical practice

This phase established what people with dermatological conditions considered to be important issues impacting their lives (Table 5). Clinicians can use this knowledge to inform their management discussion with patients during consultations and to target interventions to improve quality of life. The results indicate that the psychological impact of dermatological conditions is profound, with this domain accounting for almost one-third of items in the first draft of PRIDD. Such data support calls for a biopsychosocial approach to dermatology,[26,27] suggesting that treatment should not focus exclusively on alleviating physical symptoms. Specialist psychological support should be available and integrated with the wider care of patients with dermatological conditions. An evidence-based training package already exists to allow clinicians to address the basic psychological needs of patients in dermatology consultation.[28,29] The list of top impacts identified here indicates the areas on which such training could focus.

Implications for research

James Lind Alliance's Priority Setting Partnerships have been conducted for acne,[30] alopecia,[31] eczema,[32] hidradenitis suppurativa,[33] psoriasis,[34] and vitiligo,[35] but none have been conducted for the global dermatology population as a whole. In its absence, the top-ranked impact items in this Delphi study could stand in by representing what patients prioritized the most important impacts of their condition and developing corresponding research questions and initiatives to address these.

Involving the target population during development is deemed a necessary part of creating a high-quality measurement instrument.[3] Patient insight during item reduction may be especially useful when developing speciality-specific measures like PRIDD, where the item pool is likely to be broader than disease-specific measures. Typically, item prioritisation is achieved through statistical techniques alone, but we involved patients in this step of the process also. The large reduction in number between the item pool (263 items) and the first draft of PRIDD (27 items) here highlights the utility of Delphi surveys in PROM development based on patient insight[36] and therefore, we recommend this approach. We have ensured that PRIDD is grounded in the lived experience and language of patients and captures issues important to them. For this reason, this study's methodology, building on our previous work,[1,13] provides a model for the development of quality PROMs in other therapeutic or disease areas.

This study produced the first draft of PRIDD. To complete the next and final step in the content validity phase of development, PRIDD is being, as complementary approach, pilot tested[4,11,37,38] with people with dermatological conditions to evaluate the measure's comprehensiveness, comprehensibility, relevance, acceptability and feasibility and make refinements accordingly in preparation for the final psychometric phase.

CONCLUSION

Through the support and engagement of patients, the item reduction process resulted in the first draft of PRIDD, ready for pilot-testing. Additionally, the data triangulated and refined the conceptual framework of impact and strengthened the evidence for the content validity of PRIDD. The results provide insight into what people with dermatological conditions from around the world consider to be the most important issues impacting their lives.

ACKNOWLEDGEMENTS

We would like to thank International Alliance of Dermatology Patient Organization for their efforts in conceiving of the GRIDD initiative, project management, and recruiting participants for this study. We are thankful for the generous involvement of participants for sharing their expertise and experiences with us. We also wish to acknowledge the input of those serving on the GRIDD project's Scientific Advisory Board: Prof. Andrew Finlay (Cardiff University, UK), Prof. Arnon D. Cohen (Clalit Health Services, Israel), Prof. Ncoza Dlova (Nelson R Mandela School of Medicine, South Africa), Dr Toshiya Ebata (The Jikei University School of Medicine, Japan), Dr Cristina Echeverría (ECHO Psoriasis, Argentina), Dr Alice Gottlieb (Icahn School of Medicine at Mt Sinai, US), Dr Luigi Naldi (Ospedale San Bortolo di Vincenza, Italy), Dr Lone Skov (University of Copenhagen, Denmark), Prof. Ramesha M. Bhat (Father Muller Medical College, India) and Marc Yale (International Pemphigus Pemphigoid Foundation, US). In addition, the authors thank the Scientific Communication Team of the IVDP, in particular Merle Twesten and Mario Gehoff, for copy editing. Open Access funding enabled and organized by Projekt DEAL.

FUNDING INFORMATION

This study was funded by the International Alliance of Dermatology Patient Organizations (IADPO) as part of its Global Research on the Impact of Dermatological Diseases (GRIDD) project. IADPO is a not-for-profit coalition of dermatology patient organisations worldwide. We recruited participants through IADPO's global network of patient organisations. IADPO were not involved in study design, data analysis or publication decision.

CONFLICT OF INTEREST STATEMENT

The authors report no conflicts of interest in this work.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ETHICS STATEMENT

Ethical approval was obtained from Cardiff University School of Healthcare Sciences Ethics Committee (SREC:637). Informed consent for participation and publication was obtained from all participants.

ORCID

Nirohshah Trialonis-Suthakharan https://orcid.org/0000-0002-6826-6951
Rachael Pattinson https://orcid.org/0000-0002-3145-3710
Nasim Tahmasebi Gandomkari https://orcid.org/0000-0001-6661-0264
Jennifer Austin https://orcid.org/0000-0003-0681-9124
Nick Courtier https://orcid.org/0000-0001-6098-5882
Rachael M. Hewitt https://orcid.org/0000-0002-3829-5604
Chris Bundy https://orcid.org/0000-0002-5981-3984
Matthias Augustin https://orcid.org/0000-0002-4026-8728

REFERENCES

1. Pattinson RL, Trialonis-Suthakharan N, Gupta S, Henry AL, Lavallée JF, Otten M, et al. Patient-reported outcome measures in dermatology: a systematic review. Acta Derm Venereol. 2021;101(9):adv00559.
2. Gabes M, Tischer C, Apfelbacher C. Measurement properties of quality-of-life outcome measures for children and adults with eczema: an updated systematic review. Pediatr Allergy Immunol. 2020;31(1):66–77.
3. Mokkink LB, de Vet HCW, Prinsen CAC, Patrick DL, Alonso J, Bouter LM, et al. COSMIN risk of bias checklist for systematic reviews of patient-reported outcome measures. Qual Life Res. 2018;27(5):1171–9.
4. Terwee CB, Prinsen CAC, Chiarotto A, Westerman MJ, Patrick DL, Alonso J, et al. COSMIN methodology for evaluating the content validity of patient-reported outcome measures: a Delphi study. Qual Life Res. 2018;27(5):1159–70.
5. Mokkink LB, Terwee CB, Patrick DL, Alonso J, Stratford PW, Knol DL, et al. The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: an international Delphi study. Qual Life Res. 2010;19(4):539–49.
6. Finlay AY, Khan GK. Dermatology Life Quality Index (DLQI)—a simple practical measure for routine clinical use. Clin Exp Dermatol. 1994;19(3):210–6.
7. Chren MM, Lasek RJ, Flocke SA, Zyzanski SJ. Improved discriminative and evaluative capability of a refined version of Skindex, a quality-of-life instrument for patients with skin diseases. Arch Dermatol. 1997;133(11):1433–40.
8. Chren MM, Lasek RJ, Quinn LM, Mostow EN, Zyzanski SJ. Skindex, a quality-of-life measure for patients with skin disease: reliability, validity, and responsiveness. J Invest Dermatol. 1996;107(5):707–13.
9. Chren MM, Lasek RJ, Sahay AP, Sands LP. Measurement properties of Skindex-16: a brief quality-of-life measure for patients with skin diseases. J Cutan Med Surg. 2001;5(2):105–10.
10. Apfelbacher CJ, Nelson PA. Patient-reported outcome measures and qualitative research in dermatology: the quest for authenticity. Br J Dermatol. 2017;176(2):285–7.
11. Brod M, Tesler LE, Christensen TL. Qualitative research and content validity: developing best practices based on science and experience. Qual Life Res. 2009;18(9):1263–78.
12. de Vet HCW, Terwee CB, Mokkink LB, Knol DL. Measurement in medicine. New York: Cambridge University Press; 2011.
13. Pattinson R, Hewitt RM, Trialonis-Suthakharan N, Chachos E, Courtier N, Austin J, et al. Development of the Patient-Reported Impact of Dermatological Disease (PRIDD) measure: a qualitative concept elicitation study. Acta Derm Venereol. 2022;102:adv00823.
14. Williams PL, Webb C. The Delphi technique: a methodological discussion. J Adv Nurs. 1994;19(1):180–6.
15. McLellan C, Frey MP, Thiboutot D, Layton A, Chren MM, Tan J. Development of a comprehensive quality-of-life measure for facial and torso acne. J Cutan Med Surg. 2018;22(3):304–11.

16. Chuenjitwongsa S. How to: Conduct a Delphi study. 2017 [cited 2022 July 25]. Available from: https://www.cardiff.ac.uk/__data/assets/pdf_file/0010/1164961/how_to_conduct_a_delphistudy.pdf
17. Iqbal S, Pipon-Young L. The Delphi method. Psychol Forsch. 2009;22:598–601.
18. Hawkins M, Cheng C, Elsworth GR, Osborne RH. Translation method is validity evidence for construct equivalence: analysis of secondary data routinely collected during translations of the Health Literacy Questionnaire (HLQ). BMC Med Res Methodol. 2020;20(1):130.
19. Diamond IR, Grant RC, Feldman BM, Pencharz PB, Ling SC, Moore AM, et al. Defining consensus: a systematic review recommends methodologic criteria for reporting of Delphi studies. J Clin Epidemiol. 2014;67(4):401–9.
20. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Med Res Methodol. 2013;13:117.
21. Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: Bryman A, Burgess RG, editors. Analyzing qualitative data. London: Routledge; 1994. p. 22.
22. Hale ED, Treharne GJ, Kitas GD. The common-sense model of self-regulation of health and illness: how can we use it to understand and respond to our patients' needs? Rheumatology. 2007;46(6):904–6.
23. World Health Organization. International statistical classification of diseases and related health problems. 10th ed. Geneva: World Health Organization; 2004.
24. Byrne BM, Campbell TL. Cross-cultural comparisons and the presumption of equivalent measurement and theoretical structure. J Cross Cult Psychol. 1999;30(5):555–74.
25. Beaton DE, Bombardier C, Guillemin F, Ferraz MB. Guidelines for the process of cross-cultural adaptation of self-report measures. Spine. 2000;25(24):3186–91.
26. Linder D. The biopsychosocial model in dermatology. 16th Congress of the European Society for Dermatology and Psychiatry. Saint Petersburg. 2015 [cited 2023 Dec 19]. Available from: https://www.researchgate.net/publication/303913870_The_Biopsychosocial_Model_in_Dermatology
27. Picardi A, Pasquini P. Toward a biopsychosocial approach to skin diseases. Adv Psychosom Med. 2007;28:109–26.
28. Hewitt RM, Pattinson R, Cordingley L, Griffiths CEM, Kleyn CE, McAteer H, et al. Implementation of the PsoWell™ model for the management of people with complex psoriasis. Acta Derm Venereol. 2021;101(4):adv00445.
29. Chisholm A, Nelson PA, Pearce CJ, Littlewood AJ, Kane K, Henry AL, et al. Motivational interviewing-based training enhances clinicians' skills and knowledge in psoriasis: findings from the Pso Well® study. Br J Dermatol. 2017;176(3):677–86.
30. Layton A, Eady EA, Peat M, Whitehouse H, Levell N, Ridd M, et al. Identifying acne treatment uncertainties via a James Lind Alliance Priority Setting Partnership. BMJ Open. 2015;5(7):e008085.
31. Macbeth AE, Tomlinson J, Messenger AG, Moore-Millar K, Michaelides C, Shipman AR, et al. Establishing and prioritizing research questions for the treatment of alopecia areata: the Alopecia Areata Priority Setting Partnership. Br J Dermatol. 2017;176(5):1316–20.
32. Batchelor JM, Ridd MJ, Clarke T, Ahmed A, Cox M, Crowe S, et al. The Eczema Priority Setting Partnership: a collaboration between patients, carers, clinicians and researchers to identify and prioritize important research questions for the treatment of eczema. Br J Dermatol. 2013;168(3):577–82.
33. Ingram JR, Abbott R, Ghazavi M, Alexandroff AB, McPhee M, Burton T, et al. The hidradenitis suppurativa priority setting partnership. Br J Dermatol. 2014;171(6):1422–7.
34. Majeed-Ariss R, McPhee M, McAteer H, Griffiths CEM, Young H. The top 10 research priorities for psoriasis in the U.K.: results of a James Lind Alliance psoriasis Priority Setting Partnership. Br J Dermatol. 2019;181(4):871–3.
35. Eleftheriadou V, Whitton ME, Gawkrodger DJ, Batchelor J, Corne J, Lamb B, et al. Future research into the treatment of vitiligo: where should our priorities lie? Results of the vitiligo priority setting partnership. Br J Dermatol. 2011;164(3):530–6.
36. Hepworth LR, Rowe FJ. Using Delphi methodology in the development of a new patient-reported outcome measure for stroke survivors with visual impairment. Brain Behav. 2018;8(2):e00898.
37. Patrick DL, Burke LB, Gwaltney CJ, Leidy NK, Martin ML, Molsen E, et al. Content validity—establishing and reporting the evidence in newly developed patient-reported outcomes (PRO) instruments for medical product evaluation: ISPOR PRO good research practices task force report: part 1—eliciting concepts for a new PRO instrument. Value Health. 2011;14(8):967–77.
38. Patrick DL, Burke LB, Gwaltney CJ, Leidy NK, Martin ML, Molsen E, et al. Content validity—establishing and reporting the evidence in newly developed patient-reported outcomes (PRO) instruments for medical product evaluation: ISPOR PRO Good Research Practices Task Force report: part 2—assessing respondent understanding. Value Health. 2011;14(8):978–88.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Trialonis-Suthakharan N, Pattinson R, Tahmasebi Gandomkari N, Austin J, Janus C, Courtier N, et al. Patient prioritisation of items to develop the Patient-Reported Impact of Dermatological Diseases measure: A global Delphi study. J Eur Acad Dermatol Venereol. 2024;00:1–10. https://doi.org/10.1111/jdv.19903