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Appendix S1

Evidence of data saturation

Saturation was evaluated across the sample to determine data sufficiency for breadth and depth of analysis to meet the aim of the study. This evaluation was facilitated by a saturation matrix (Table A1), which summarized the new codes discerned during the workshop and subsequent individual interviews. The saturation matrix indicated that the workshop captured all codes. These codes were validated by the first two individual interviews conducted (PID 4 and 5). No new codes were added after the third interview (PID 7). The remaining individual interviews tested whether these codes were endorsed across clinical and demographic groups (e.g., dermatological conditions geographic location, type of healthcare system).

Table A1 Data saturation matrix

Code	Workshop	Individual interviews		
		PID 4	PID 5	PID 7
Cause	x	x		
Consequences	x	x		
Physical	x	x		
Cognitions	x	x		
Emotions	x	x		
Coping	x	x		
Social	x	x		
Financial	x		x	
Daily responsibilities	x	x		
Control/cure	x	x		
Identity	x		x	
Timeline	x	x		
Other	x	x		

Appendix S2

Focus group topic guide

Question type	Question wording	Prompts
Opening	Can you tell us who you are, which patient organisation you represent, and, if you feel comfortable, whether you have a skin condition yourself?	-
Introductory	What do you understand by impact?	-
Transition	How do skin conditions impact the people living with them?	-
Vignettes	What do you think the main impact of skin conditions are on this person?	Physical Social Psychological Economical Cultural Religious Access to medical care Age Gender Ethnicity Socioeconomic status
		-
		-
Ending questions	What are the key issues we've identified today?	-
	Is there anything we have missed that you would like to add?	-

Appendix S3

Individual interview topic guide

Stage 1: set-up (5 – 10 mins)

1. Briefly introduce self

Hi. Thank you for agreeing to take part in this interview. We really appreciate you giving your time. I'm Rachael and I will be interviewing you today. I'm one of the researchers on the GRIDD project and I'm based at Cardiff University.

2. Brief GRIDD overview

You will know a little bit about the GRIDD project already from the emails and documents you received from GlobalSkin. If you would like, I can give a brief overview of the project or answer any questions you might have.

If they would like an overview:

The GRIDD project aims to collect global data on the impact of skin conditions on people's lives. We need to create a new questionnaire that can be used to collect this data. So that the questionnaire captures the full impact of living with a skin condition from the patient perspective, we need to speak to people with skin conditions to find out how their skin condition has affected them. We will use the data to create the questions for the questionnaire.

We have already conducted several focus groups where we discussed this topic. Participants at those focus groups really highlighted the social and psychological impact of their skin condition. We would like to build on what we've learned so far by investigating some of the topics in more depth and also by asking about other topics which may be important but haven't come up yet.

3. Ground rules

I just need to run through a few things before we start the interview.

- We will have 50 minutes for the interview, but you can choose to end the interview any time you'd like; for example, if you feel you don't have anything more to say.
- There are no right or wrong answers to any of the questions – we are interested in **your** views and experiences so be as open and honest as you can. But please refrain from offering your medical history as I can't address that in this interview. We have a limited time to cover a broad topic, so it's important that we stay on topic.
- Please don't hesitate to ask for questions to be repeated or explained.

- Taking part in the interview is voluntary and you have the right to decide not to discuss any topic or stop the interview at any time.
- The interview will be audio recorded. The interview will remain confidential unless you reveal something that would be harmful to you or others. Any information that can identify you such as names of people or places will be anonymised and if we use quotes from you, they will not have your name on them.

Before we begin, are there any questions you'd like to ask me?

Let participant know that we are beginning the interview and I will start recording.

Stage 2: interview (50 mins)

Introductory question: 1. What does the term 'impact' mean to you? (5 mins)

Key questions: (30 – 40 mins)

2. What skin condition do you have?
3. What are the symptoms of your skin condition?
4. What do you think caused your skin condition?
5. In what ways has your skin condition impacted upon your life?
 - a. Social life
 - b. Relationships

Possible prompts:

We know from other measures, such as the DLQI, that some people are reluctant to talk about how their skin condition affects their ability to be intimate with others. Why do you think this is? **Further prompt:** Is this because it's not an issue or because they feel uncomfortable talking about intimacy? If it is an issue, how do you think we can approach this subject?

- c. Life at home
 - d. Work
6. How does your skin condition make you feel?
 7. Tell me about some of the ways you cope with your skin condition?

Possible prompts:

People cope with their skin condition in lots of different ways. Some participants have said that they've used drugs or alcohol to help them cope with living with their skin condition. Is this something you can relate to?

Or do you know how people with skin conditions who cope in this way?

8. To what extent do you think you can control your condition?
9. How do you see your skin condition in:

- a. Three months' time? Better or worse or staying the same?
- b. One years' time? Better or worse or staying the same?

Ending questions: 10. Of all the issues we discussed today, which ones are the most important to you (5 – 10 mins)

Possible prompts:

- If someone was to measure/assess the impact of skin conditions on a person's life, what questions do you think they should ask?
- If you were speaking to a friend with a different skin condition to you and were interested to know how their skin condition impacts on their life, what questions would you ask them/what would you ask them about?

Stage 3: ending (5 – 10mins)

We have now come to the end of our discussion.

Before we finish, is there anything we've missed that you would like to add or any discussions where you felt you didn't fully manage to state your opinion?

Thank you all so much for taking the time to participate in this discussion. Your opinions are very important in guiding the development of this new measure and further research. You can track the progress of this research on GlobalSkin's website where the research team will be posting updates.

Appendix S4

Vignettes for focus groups

Acne

Alice is an 18-year-old woman from the UK who has widespread acne. She currently lives in the family home. Her family regularly tells her to stop eating unhealthy food and not to wear makeup as they believe this clogs her pores and causes her acne. Alice will be starting university soon and will be moving out of the family home to live in halls. While at school, Alice was bullied and woke up extra early every morning to apply makeup in order to cover up her acne, which made it worse. Alice is looking forward to moving away to university because she wants to meet new people and start to meet boys, but the thought of this also fills her with dread. She is worried that people will react negatively to her acne. Alice won't be able to hide her acne from other students in university as she did in high school as she will be living in accommodation with a communal bathroom and kitchen.

Lok is a 49-year-old man who developed acne in his late 30s. He lives in a rural town in China where he works as a veterinary assistant. Lok's acne is typical of that which appears in Chinese skin: He has hardened bumps and reddening, which can lead to permanent scarring if they are not treated quickly and effectively. Lok isn't aware of this and thinks he'll 'outgrow' his acne. Lok has visited the local hospital which doesn't have specialist dermatology services for treatment. They have prescribed him a number of antibiotic courses which are costly and don't seem to work to clear the acne. Clinicians in the local hospital advised Lok to travel to a city hospital to receive specialist dermatology care. Lok travelled for three hours for his appointment. He was prescribed Roaccutane, a medication that needs careful monitoring. Lok has now been on this medication for some months but has not been able to get back to the city hospital since his first visit.

Alopecia

Logan is a 25-year-old man from Canada with alopecia. He was training to be a music teacher when his hair started to fall out. After completing his degree, Logan secured a job as a high school music teacher. He was worried about how the children would react to his bald patches so decided to shave his hair off. Previously, Logan had long hair. He plays in a heavy metal band and is now the only member of the band with a shaved head. He tried to grow a beard instead, but the school will not allow this. Hardly any of the children notice his appearance but Logan is very self-conscious, and this is beginning to affect his self-esteem.

Marie is a 38-year-old woman who lives in France. She is a single parent to an 8-year-old boy Marc and works part-time in a patisserie to support them. Marie's hair started to fall out when she was pregnant with her Marc. Her friends told her not to worry because it's "just hair, it will grow back" but it hasn't. The first

dermatologist Marie saw told her to “stop stressing” and prescribed her local steroids in the form of a sticky mousse. Marie had been considering quitting smoking but feels that it helps her when she's stressed. Marie hasn't seen so much of her friends recently and now is upset that Marc has asked her not to come to his school Christmas party.

Atopic dermatitis

Jana is a 24-year-old woman from Oman who has atopic eczema. She is not looking forward to the upcoming summer months as her eczema gets worse and she tends to scratch more when it's hot. Her sleep isn't as good as it once was and she wakes up every morning feeling unrefreshed from the sleep. Her husband is a surgeon. He works irregular hours and is often called out at night. He recently suggested that they start to sleep in separate beds so that he will not disturb her and vice versa. This has caused Jana some distress because they would like to have children. Jana is also worried that her child will inherit the eczema.

Ray is a 62-year-old man from the UK who has atopic dermatitis. He is a widower and lives alone. Ray worked as a skilled carpenter but lost his job a couple of years ago. He used to play football but doesn't anymore. He is now very overweight and has osteoarthritis in both knees, which has reduced his mobility. He struggles to get to his GP or pharmacy independently. Ray is prescribed two ointments, an emollient and topical steroid, for his eczema, but doesn't know what they are for or what they're called. He often gets them confused and applies the wrong medicines to the wrong areas. His back, in particular, is untreated since he can't reach it alone. The ointments create a mess on his clothes and bed sheets.

Psoriasis

Diane is an African-American lawyer in her 50s based in Chicago. She has had chronic plaque psoriasis since she was a teenager, but was only recently diagnosed. Diane has found that there is a general lack of knowledge in the medical community about psoriasis in people of colour. As a teenager, she was repeatedly told by general doctors that people of colour don't get psoriasis. She felt very alone because the only photographs of psoriasis she could find were on Caucasian people. Their psoriasis looked very different to hers which was very dark and thick. Because of this, Diane became a patient advocate. Her psoriasis has become more severe since she hit the menopause. Diane had managed her psoriasis using expensive creams but now needs medical treatment. She was initially prescribed creams that made her feel wet and greasy and made it difficult to dress and feel confident in her corporate job. More recently, she has been prescribed biologics, which are effective, but cost her US\$1,200 per month and she has to self-inject. Diane is finding this a big challenge.

Paulo is a 43-year-old man from Brazil who has psoriasis and psoriatic arthritis. He is the breadwinner in a family with four children. They do not have enough money to make ends meet each month. Until recently, Paulo worked in a popular restaurant but his manager didn't understand psoriasis and thought it was contagious. He forced Paulo to wear gloves before finally firing him. Paulo has started to drink every day. He has noticed that his psoriasis and psoriatic arthritis are getting worse. He believes that his conditions are stopping him from finding another job. He wants to see improvements and is currently managing his psoriasis with topical treatment. Biologics are not available through the public health system in Brazil and he can't afford to pay for them privately.

Rare skin disease

June is a 20-year-old with mild epidermolysis bullosa, which is often mistaken for other skin conditions. She dropped out of school aged 14 as it took a great deal of time every day to manage her condition. Until recently, June had a job working in a retail store, however, her skin deteriorated and she had to leave. Each morning, June goes through a routine of removing dressings, bathing, showering, draining blisters, applying creams, antiseptic gels, bandages and plasters, and removing dead skin which can take up to two hours. Despite this, June is an epidermolysis bullosa (EB) blogger and uses her platform to raise awareness of the condition.

Yaron is a 35-year-old man from Israel who lives with neurofibromatosis. He works for a cancer charity as a fundraiser. His employers understand that he needs to take regular breaks and time off to attend his many hospital appointments. Yaron is very knowledgeable about cancer and is hypervigilant about checking his tumours. After his most recent check-up in the skin department, Yaron received a letter to come back to discuss his recent results, so is very concerned.

Vitiligo

Raka is a 27-year-old laboratory-based scientist from India who lives with vitiligo. Vitiligo is not openly talked about and stigmatised in her community and Raka was told that she will find it very difficult to get married. This has affected her family's reputation and, since her white patches began to appear, they have been ostracised in their community. When she was a teenager, Raka's parents took her to a few doctors who sold pills, herbs, and lotions that didn't work to improve the condition at all. They next turned to Hindu astrology, which led them to believe that her vitiligo was karmic justice for actions in a previous life. Raka was banned from talking about her vitiligo by her family because they didn't want her to draw attention to her condition. It wasn't until Raka moved away to Delhi to go to college that she could see a conventional doctor about her condition and found she'd been living with several undiagnosed and mistreated conditions.

Jordan is a 52-year-old African-American man with vitiligo. He received a sports scholarship for college and was a promising basketball player. He followed this with a successful career as a sports reporter where he travelled around the world commentating on games and interviewing players. Being in the spotlight is the meaning of his life. Jordan has had white spots on his arms and scalp since he was a child but he has been able to cover them well. They have started to expand and now he has developed white patches on his face. Since these becoming visible, Jordan's employer has insisted that he take a more backstage role. He has begun to gain weight making it increasingly difficult to get back in front of the camera. Jordan hates being behind the scenes and is becoming less interested in his appearance. He now has to sit for long periods in work which he knows isn't good for his health. However, he feels that he can't quit his job because he needs the health insurance benefit to pay for his medication. Jordan is taking stock of his life because he is now the same age as his father was when he died.

Appendix S5

Evaluation of the study according to the COSMIN standards for evaluating the quality of the PROM design

COSMIN standard		Requirement	Rating	Details
1	Is a clear description provided of the construct to be measured?	Construct clearly described	Very good	A description of the construct to be measured is provided in the introduction. PRIDD measures the impact of dermatological conditions patients' lives.
2	Is the origin of the construct clear: Was a theory, conceptual framework or disease model used or clear rationale provided to define the construct to be measured?	Origin of the construct clear	Very good	A conceptual framework of the impact of dermatological conditions does not exist. The study findings were used to develop the first conceptual framework of impact, which will form the basis of PRIDD development.
3	Is a clear description provided of the target population for which the PROM was developed?	Target population clearly described	Very good	'Adults (≥ 18 years) living with a dermatological condition' (Table 1).
4	Is a clear description provided of the context of use?	Context of use clearly described	Very good	'Discriminative application to distinguish people according to the amount of impact their dermatological condition has had on their lives' (Table 1).
5	Was the PROM development study performed in a sample representing the target population for which the PROM was developed?	Study performed in a sample representing the target population	Very good	To identify how dermatological conditions impact the patients' lives and to select the most relevant issues for PRIDD participants were purposively sampled in order to achieve maximum variation according to dermatological condition and demographic factors: country of residence, gender, and age. Tables 2 and 3 demonstrate that the sample represented the target population.

6	Was an appropriate qualitative data collection method used to identify relevant items for a new PROM?	Widely recognized or well justified qualitative method used, suitable for the construct and study population	Very good	Relevant items were identified during qualitative interview study featuring focus groups and individual interviews.
7	Were skilled group moderators/interviewers used?	Skilled group moderators/interviewers used	Very good	All focus groups and interviews were conducted by a skilled interviewer (RP, RH, NTS, or EC). All interviewers had experience in conducting dermatological and qualitative research.
8	Were the group meetings or interviews based on an appropriate topic or interview guide?	Appropriate topic or interview guide	Very good	A topic guide, including the semi-structured interview guide, was developed to structure interviews (Appendix S2 and S3). The guide was continually adapted to reflect new topics or themes that needed further probing.
9	Were the group meetings or interviews recorded and transcribed verbatim?	All group meetings or interviews were recorded and transcribed verbatim	Very good	Each focus group and interview was recorded using a Dictaphone. Audio data were subsequently transcribed verbatim by a Cardiff University approved independent transcription provider.
10	Was an appropriate approach used to analyze the data?	A widely recognized or well justified approach was used	Very good	A framework analysis was conducted from an essentialist/realist standpoint.
11	Was at least part of the data coded independently?	At least 50% of the data were coded by at least two researchers independently	Very good	Each transcript was coded independently by at least two of the co-authors.
12	Was data collection continued until saturation was reached?	Evidence provided that saturation was reached	Very good	Data collection continued until saturation was reached. Evidence of data saturation is provided in Appendix S1.
13	For quantitative studies: Was the sample size appropriate?	Not applicable	-	-