

PARTICIPANT INFORMATION SHEET

Global Research on the Impact of Dermatological Diseases (GRIDD)

You are being invited to take part in a research project. Before you decide whether or not to take part, it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information carefully and discuss it with others, if you wish.

Thank you for reading this.

1. What is the purpose of this research project?

Over 2 billion people worldwide live with a dermatological disease or condition such as acne, atopic eczema, psoriasis, pemphigoid, or vitiligo. These conditions can have a huge impact on patients' lives, but patients can struggle to access care and treatment because decision-makers perceive them to be less burdensome than most other diseases. This is simply not accurate or fair for dermatology patients.

The Global Research on the Impact of Dermatological Diseases (GRIDD) study is the first global patient impact project in the history of dermatology. It aims to collect global data on the impact of diseases of the skin, nails, hair and mucosa, *directly* from patients – using a new questionnaire measure (called PRIDD) that has been developed in close partnership with patients. The GRIDD data will support local, national, and international patient advocacy work for more research, better treatments and healthcare policies, and, ultimately, improve the lives of dermatology patients.

2. Who is organising and funding this research project?

This research project is funded by the International Alliance of Dermatology Patient Organizations (also known as GlobalSkin). It is being conducted by researchers at Cardiff University (UK) and University Medical Center Hamburg-Eppendorf (Germany). Professors Chris Bundy (Cardiff) and Matthias Augustin (Hamburg) are leading the research. Prof Bundy is a health psychologist and world-leading researcher with extensive knowledge of inflammatory skin conditions and provides training for specialist dermatology clinicians. Prof Augustin is a world-leading dermatologist and researcher. Other members of the research team are Dr Rachael Pattinson (Research Associate, Cardiff University) and Nirohshah Trialonis-Suthakharan (Research Associate, University Medical Center Hamburg).

3. Why have I been invited to take part?

You have been invited because you are an adult (18 years or older) living with a dermatological condition. The survey is available in 17 languages. To take part in the study you must be able to read and understand at least one of the following languages: English, Arabic, Bengali, Simplified Chinese, Danish, Dutch, French, German, Hindi, Italian, Japanese, Portuguese, Russian, Serbian, Spanish, Swahili, or Vietnamese.

You are not eligible to participate if you are:

- Less than 18 years old,
- completing the survey on behalf of someone else,
- unable to read and understand one of the 17 languages listed above.

4. Do I have to take part?

No, your participation in this research project is entirely voluntary. If you decide to take part, we will ask you to sign a consent form. If you decide not to take part, you do not have to explain your reasons and it will not affect your legal rights. Please contact Dr Rachael Pattinson (pattinsonr@cardiff.ac.uk) if you would like to ask any questions before participating.

You are free to withdraw your consent to participate in the research project at any time, without giving a reason, even after signing the consent form.

5. What will taking part involve?

Taking part in the study would involve completing a survey. The survey will be available online and you will be asked to sign a consent form and register an account to the online platform to take part. The survey will include some questions about you (e.g. age), your dermatological condition, and your current contact with healthcare services, as well as a few widely used questionnaires. It will take approximately 10 to 20 minutes to complete and will be available from 25 May to 28 September 2023.

To test some aspects of the new PRIDD questionnaire, we will also ask you to complete a shorter version of the survey six weeks after you complete the first. This second survey is shorter than the first and will take approximately 10 to 15 minutes to complete. It will be available until 28 September 2023 and you will automatically receive an email invitation to participate. Only people who participate in the first survey before 17 August can participate in the second.

6. Will I be paid for taking part?

No, you will not be paid for taking part. You will not benefit financially in the future should this research project lead to the development of a new treatment/method/test/assessment.

7. What are the possible benefits of taking part?

There will be no direct advantages or benefits to you from taking part, but your contribution will help us to understand the impact of dermatological conditions on patients' lives and will help us to raise awareness among decision-makers, clinicians, and researchers. This will, over time, improve the experience of patients and will help us to understand the benefits of treatments.

8. What are the possible risks of taking part?

There are no specific risks in taking part in this research. The questions in this survey were developed by a group of patients, dermatologists, psychologists, and researchers. Patients have told us that they found completing similar surveys helpful but there is a chance that you might find reflecting on the impact of your dermatological condition to be upsetting.

9. Will my taking part in this research project be kept confidential?

All information collected from or about you during the research project will be kept confidential and any personal information you provide will be managed in accordance with data protection legislation. Please see 'What will happen to my Personal Data?' (below) for further information.

10. What will happen to my Personal Data?

To meet the aim of this study, we need to collect some personal data. This will include your initials (to sign the consent form), email address (to register to the online platform), age, gender, sex, ethnicity, and country of residence.

This project is compliant with the European Union's General Data Protection Regulation (GDPR). Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection legislation. Further information about Data Protection, including:

- your rights
- the legal basis under which Cardiff University processes your personal data for research
- Cardiff University's Data Protection Policy
- how to contact the Cardiff University Data Protection Officer
- how to contact the Information Commissioner's Office

may be found at <https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection>.

After both surveys are closed, the research team will anonymise all the personal data it has collected from or about you in connection with this research project, with the

exception of your consent form. To ensure that you will not be individually identifiable, we will store your initials and email address separately from your responses to the survey (survey data). We will assign a random personal identification number to your survey data. Only one research team member, Dr Rachael Pattinson, will have access to the password-protected key linking your initials and email address with your personal identification number. Once data cleaning is complete (approximately two months after the surveys close), we will delete your email address and the key linking this to your personal identification number. Your consent form will be retained for at least five years and may be accessed by members of the research team and, where necessary, by members of the University's governance and audit teams or by regulatory authorities. Anonymised information will be kept for a minimum of five years but may be published in support of the research project and/or retained indefinitely, where it is likely to have continuing value for research purposes.

Cardiff University will need to share your anonymised data with our research partners, University Medical Center Hamburg-Eppendorf, GlobalSkin and Swiss4ward, for the purposes of this research project. Data will be shared securely and using password protection, in line with Cardiff University's Information Classification and Handling Policy.

You have the right to withdraw from the study at any time without reason. We will keep any existing data we have from you unless you specifically ask for it to be destroyed. If you would like to withdraw from the study after submitting your survey, please email Dr Rachael Pattinson (pattinsonr@cardiff.ac.uk) with your request. Please note that it will not be possible to withdraw any anonymised data that has already been published. It will also be impossible to remove data once all participant email addresses are irreversibly removed as we will have no way of identifying which is your data within the dataset.

11. What happens to the data at the end of the research project?

The data collected during the research project will be stored securely using Cardiff University's Research Data Store. The data may be used by members of the research team for additional analyses regarding the impact of health conditions. The anonymised dataset will be used to build a website where dermatology stakeholders can explore impact trends in the data.

12. What will happen to the results of the research project?

It is our intention to publish the results of this research project in academic journals, present findings at conferences, and on the new website where users can view trends



University Medical Center
Hamburg-Eppendorf



in the data. GlobalSkin's network of patient organisations will also use the results for their advocacy work.

Participants will not be identified in any report, publication, or presentation. We will publish a summary of the results on GlobalSkin's website here: <https://globalskin.org/research>.

13. What if there is a problem?

If you wish to complain, or have grounds for concerns about any aspect of the manner in which you have been approached or treated during the course of this research, please contact Dr Rachael Pattinson (pattinsonr@cardiff.ac.uk) who is part of the GRIDD research team. If your complaint is not managed to your satisfaction, please contact Dr Jen Davies (daviesj@cardiff.ac.uk), Director of Research Governance, School of Healthcare Sciences.

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, you may have grounds for legal action, but you may have to pay for legal representation.

14. Who has reviewed this research project?

This research project has been reviewed and given a favourable opinion by the School of Healthcare Sciences Research Ethics Committee, Cardiff University.

15. Further information and contact details

Should you have any questions relating to this research project, you may contact Dr Rachael Pattinson during normal working hours:

Email: pattinsonr@cardiff.ac.uk

Address: 12.14 Eastgate House, 35-43 Newport Road, Cardiff, UK, CF24 0AB.

Thank you for considering taking part in this research project. Please download a copy of this Participant Information Sheet to keep for your records.