



GRIDD Patient Data Verification Delphi

Participant Information

You have been invited to participate in the Global Research on the Impact of Dermatological Diseases (GRIDD) Patient Data Verification Delphi (the Delphi). Before you decide whether or not to take part, it is important for you to understand why the Delphi is being conducted, and what it will involve. Please take time to read the following information carefully and feel free to discuss it with others.

Project Description

Title of Project: GRIDD Patient Data Verification Delphi

The Delphi is a research process taking place in Phase 3 of the GRIDD project. It will help determine that the patient items (impacts) the GRIDD researchers have collected globally in Phase 2 are truly accurate, and they are being communicated in a way that makes sense to adult patients.

Name of Researchers: Ms Rachael Pattinson (Cardiff University), Professor Christine Bundy (Cardiff University), Ms Rachael Hewitt (Cardiff University), Ms Nirohshah Trialonis-Suthakharan (University Medical Center Hamburg), Professor Matthias Augustin (University Medical Center Hamburg).

What is the purpose of the GRIDD Project?

GRIDD is a multi-year, five phase project created and funded by the [International Alliance of Dermatology Patient Organizations](#) (IADPO, also known as GlobalSkin). GRIDD aims to develop a measure of the impact of dermatological conditions (skin, hair and nails) on people worldwide from a patient's perspective. By measure we mean scales and questionnaires used to assess the impact of living with dermatological conditions.

The GRIDD project is a response to the Global Burden of Disease (GBD) projects which have underestimated the burden of living with a dermatological condition. Data from the GBD projects are used to identify patient need, develop policies, and determine resource-allocation and research priorities on a global scale, so it is important that the full impact of having a dermatological condition is captured. Good scientific measures are needed to provide this



information. Unfortunately, research conducted as part of Phase 1 of the GRIDD project found that existing measures used both in research and clinical settings don't meet the scientific standards.

We want to find out more about the impact that dermatological conditions can have on peoples' lives. Currently, assumptions about the life impact of dermatological conditions are made based on limited knowledge. People may not discuss the full impact of dermatological conditions, even in the clinic setting. In order to get the clearest possible picture of the impact, we need highly skilled researchers with sufficient time to engage with people with dermatological conditions (this took place in Phase 2 of GRIDD).

We need a new patient-impact measurement tool (questionnaire) that identifies and reports what is really important to people with dermatological conditions: first, to assist with government decision making about the money and expertise dedicated to managing dermatological conditions; second, to accurately estimate any effects of new medicines that are developed. The best way to develop a new measurement tool to address this is to engage with experts, that is, people with dermatological conditions, the patient organisations that represent them, and the clinicians who care for them.

Why have I been invited?

You have been invited because you:

- Have a dermatological condition.
- Are aged 18 years or older.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do 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.

You are free to withdraw your consent at any time, without giving a reason, even after signing the consent form. If you would like to withdraw your data after taking part, you can do so by contacting Rachael Pattinson (pattinsonr@cardiff.ac.uk).

What would taking part in the Delphi involve?

Taking part in the Delphi will involve completing at least two of our surveys (each taking approximately 15 minutes). The surveys will be available online and you will be given up to



one month to complete each one. The first survey will provide you with a list of issues experienced by people with dermatological conditions and ask you to rate and rank how important they are to you. You will also be asked to identify any important issues you think are missing from the list provided. We will ask you to complete the second survey a month later. The second survey will feature an updated list of issues (based on the results of the first survey). This will help us to identify which issues people with dermatological conditions think are the most important to include in new measurement tool of the impact of dermatological conditions. We would also like to find out a little about you, such as which dermatological condition you have, how long you have had it for, and what country you live in.

Will I be paid anything for taking part?

No, there is no funding for your participation.

What are the possible benefits of taking part?

There are no specific benefits to you in taking part, but the research will help us to understand the impact of dermatological conditions and help us to raise awareness among decision-makers, clinician and researchers. This will, over time, improve the experience of patients and help us to understand how to improve care and treatment for people living with a dermatological condition.

What are the possible disadvantages and risks of taking part?

There are no specific risks in taking part in this research.

How will my information be kept confidential?

Disclosed information will be stored securely and used solely for research purposes. All information that is collected about you during the course of the research will be kept strictly confidential. All data collected will be anonymised and will not be individually identifiable. Made up names will be used in any oral or written reports or presentations from the Delphi, including any direct quotations from your questionnaire.

Only the research team will have access to the information that can identify and link you to your data. All electronic data will be kept on a password-protected server at Hamburg and Cardiff Universities in accordance with the European Data Protection Act and will only be accessible to the research team and regulatory authorities, including Cardiff University and



the University Medical Center Hamburg. Data will be kept for five years and then disposed of securely and may be used for additional analyses related to other aspects of the impact of dermatological conditions.

What will happen if I don't want to carry on with the Delphi?

You have the right to withdraw from the Delphi at any time without reason. If you decide to withdraw, you will not be penalized and your legal rights will not be affected. We will keep any existing data we have from you, unless you specifically ask for it to be destroyed.

What will happen to the results of this Delphi?

We plan to present the findings of this research at scientific meetings and publish in academic journals. The results of this research will also be included in the PhD theses of two members of the research team. Participants will not be identifiable in any report/publication but we may use some of the comments that you have provided in reports, publications and presentations.

What if there is a problem?

If you have any concerns about any aspect of the way that you have been approached or treated during the course of the Delphi please contact Rachael Pattinson (pattinsonr@cardiff.ac.uk) who is part of the GRIDD research team. Should you require independent advice, please contact Dr. Kate Button, Director of Research Governance, School of Healthcare Sciences (buttonk@cardiff.ac.uk). If you are harmed by taking part in this research there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for legal action, but you may have to pay for it.

Who is organising and funding the GRIDD project?

[GRIDD](#) is a project initiated and funded by GlobalSkin. It is being co-led by researchers from Cardiff University (Professor Chris Bundy) and Hamburg University (Professor Dr. Matthias Augustin). Prof Bundy is a Health Psychologist and world-leading researcher with extensive knowledge of inflammatory dermatology conditions and provides training for specialist dermatology clinicians. Prof Augustin is a world-leading dermatologist and researcher. Other



members of the research team are Rachael Pattinson (PhD candidate in Health Psychology, School of Healthcare Sciences, Cardiff University), Rachael Hewitt (Research Associate, School of Healthcare Sciences, Cardiff University) and Nirohshah Trialonis-Suthakharan (Research Associate, German Center for Health Services Research in Dermatology, University Medical Center Hamburg).

Who has validated this GRIDD Research?

The Delphi has been given ethical approval by the Research Ethics Committee of the School of Healthcare Sciences, Cardiff University.

Further information and contact details

If you have any further questions about the research, please contact Rachael Pattinson pattinsonr@cardiff.ac.uk

For additional information:

[About GRIDD](#)

[About GlobalSkin](#)

We thank you for considering to take part in this Delphi.

Click [here](#) to register for the GRIDD Patient Data Verification Delphi and complete the survey.

Thank you for taking the time to read this important information.