

APPENDIX S1: Online Registration Form

Global online group interview study - living well with a skin condition

Study background and aims

Researchers in the School of Healthcare Sciences at Cardiff University are working on a 3-year research project to develop a new mobile application (app) to support people with skin conditions to better understand their condition and live well in their own skin. The research team are organising online group interviews with people living with skin conditions (anywhere in the world) and you are invited to take part in **one** online group interview. The purpose of this study is to understand:

- Your views and experiences of managing your skin condition.
- The types and suitability of support that are currently available to you besides your medical care.
- The types of support that you want and need from a new app that you are not getting already.
- Your ideas for the new app and potential barriers and facilitators to using mobile apps.

Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. This online form contains information about the study. Please take time to read the following information carefully and discuss it with others if you wish.

Information about the study

Please use the the navigation buttons (previous and next) at the bottom of each page rather than those on your web browser to prevent losing the information you have provided.

Why have I been invited to take part?

You are invited to participate because you are:

- Aged 18 years or older.
- Have a condition that affects the skin.
- Able to read, write and speak English.

Do I have to take part?

No, your participation is voluntary and it is up to you to decide whether to take part. If you wish to participate in this study, you will be asked to sign a consent form before you are able to join a group interview. You will find the consent form in the next section of this online form.

You are free to withdraw your consent to participate at any time, without giving a reason, even after signing the consent form. Your decision to withdraw will not affect your legal rights or affect your medical care in any way. If you decide to withdraw, please notify the research team via email.

What will taking part involve?

Up to five online group interviews will be conducted. Each group will contain 8-10 people with different skin conditions. You have been invited to participate in **one** group interview. If you agree to take part in the study, you will be asked to give the dates and times that you are available for interview in a Doodle Poll at the end of this online form.

The group interview will take place on a secure online meeting platform called Zoom between March and June 2022. Once scheduled, you will be notified about the proposed date and time of your group interview via email invitation. The email will include the link and login details for the private Zoom meeting. The group interview will last approximately 90 minutes and will be audio recorded.

Will I be paid for taking part?

No, you will not be paid for taking part in this research study. If you are unable to participate because you do not have access to the internet, your Wi-Fi costs may be covered by Cardiff University. Please email the research team to discuss this.

What are the possible benefits of taking part?

You will have the satisfaction of knowing that you have actively contributed your knowledge, ideas, and experience of living with a skin condition to support the development of a new app that may become widely available to help individuals with skin conditions to lead healthier and happier lives. You will have the opportunity to meet other people living with different skin conditions who share the same goal of alleviating the physical, mental, and social burden of skin conditions.

What are the possible risks of taking part?

No major risks to you are anticipated because of taking part in this research. During the group interview, you may be asked to discuss your experiences and the impact of your skin condition, which you may find uncomfortable at times. However, you will not be obliged to answer all questions if you do not want to. If you feel distressed or upset during the interview, you can stop the interview at any time and the research team can signpost you to further support. If you live outside of the UK, the research team will work with patient organisations in your country to identify appropriate support services in your local area to signpost you to.

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

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

What will happen to my Personal Data?

Personal data, according to the General Data Protection Regulation (GDPR), means any information relating to you that someone could use to identify you. Examples of personal data include your name, addresses, email address or date of birth. For the purpose of this

project, you will be asked to provide the following details:

- Name
- Age
- Gender
- Ethnicity
- Country of residence
- Socio-economic status (education level and total household income)
- Occupation
- If you are a patient or patient representative
- Name of patient organisation (if applicable)
- Skin condition(s)
- Length of time living with a skin condition(s)
- Email address

Only the research team will have access to your personal information and will email you. Upon completion of the project in March 2024, your email address will be deleted.

The group interview will be audio recorded and the recording will be transcribed verbatim. Any personal information that you share during the group interview will be anonymised so that others cannot identify you from the data. Anonymised data will be kept for a minimum period of 15 years after publication of any findings based upon the data in accordance with the Cardiff University Records Retention Schedule (2020) 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. You will be able to withdraw your personal data up until the point your data are anonymised. It will not be possible to withdraw your data after the point at which it is anonymised.

Your interview data will be securely retained for a minimum period of 15 years after publication of any findings based upon the data in accordance with the Cardiff University Records Retention Schedule (2020). In this time, your data 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.

Cardiff University is responsible for the data collected through this project 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>.

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

It is now commonplace for researchers to make their data available via a data repository. When the study is published, others will be able to request access to the anonymised interview data. The research team may also use anonymised data for future research that relates to the current research project.

What will happen to the results of the research project?

The findings of this study will be published in scientific journals and presented at academic conferences. Only anonymised data will be published, so you cannot be identified. You will be emailed a brief summary of the study findings.

What if there is a problem?

In the case that you wish to make a complaint relating to this research project, please contact Dr Kate Button (Research Governance Officer) via email: buttonk@cardiff.ac.uk.

If you are harmed by taking part in this research study, 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 it.

Who is organising and funding this research project?

Researchers in the School of Healthcare Sciences at Cardiff University. Ms Rachael Hewitt is a PhD student at Cardiff University and is responsible for organising the online group interview study. Professor Chris Bundy (Principal Investigator) and Dr Catherine Purcell are supervising this research. The research project is funded by Beiersdorf AG.

Who has reviewed this research project?

This research project and the online group interview study has been reviewed and given

a favourable opinion by the School of Healthcare Sciences Research Ethics Committee at Cardiff University.

Further information and contact details

If you have any questions relating to this research, please contact Rachael Hewitt via email: hewitt2@cardiff.ac.uk.

Consent to take part

Please use the the navigation buttons (previous and next) at the bottom of each page rather than those on your web browser to prevent losing the information you have provided.

I confirm that I have read the information about the online group interview study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily

- Yes
- No

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my legal or medical rights being affected.

- Yes
- No

I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers

- Yes
- No

I agree for the conversations that take place during interviews to be audio recorded and analysed.

- Yes
- No

I agree for the use of quotations from my statements to be used in research reports, any quotations will be anonymised

- Yes
- No

I give my consent to the use of a written account of my experiences to be made available to others anonymously via the project website, social media, or in research publications and presentations

- Yes
- No

I understand that all personally identifiable information about me will be kept in a secure place and in a confidential way and destroyed once the study is completed.

- Yes
- No

I agree to take part in the above study

- Yes
- No

About me

Please use the the navigation buttons (previous and next) at the bottom of each page rather than those on your web browser to prevent losing the information you have provided.

What is your age?

What gender do you identify with?

- Male
- Female
- Other

If you selected Other, please specify:

What option best describes your ethnic origin or background?

- White (European descent)
- Black (African, Afro-Caribbean, African-Canadian descent)
- East Asian (Chinese, Korean, Japanese, Taiwanese descent)
- Latino (Latin American, Hispanic descent)
- Middle Eastern (Arab, Persian, West Asian descent, e.g., Afghan, Egyptian, Iranian, etc.)

- South Asian (East Indian, Pakistani, Sri Lankan, Indo-Caribbean, etc.)
- Southeast Asian (Filipino, Vietnamese, Cambodian, Thai, etc.)
- Other

If you selected Other, please specify:

In which country do you currently live? (If UK, please state the nation you live in)

Which skin condition(s) do you have?

For how long have you lived with your skin condition?

Are you a member of a patient organisation representing people with a skin condition?

- Yes
- No

If yes, what is the name of the patient organisation that you are a member of?



Scheduling your group interview

Please use the the navigation buttons (previous and next) at the bottom of each page rather than those on your web browser to prevent losing the information you have provided.

Please provide your full name and email address in the boxes below to enable the research team to contact you about arranging a group interview.

Please tell us your full name so that we can contact you about the study

Please provide your email address below so that we can contact you about study

Please enter a valid email address.

You are now ready to schedule a group interview. A member of our team will contact you via email. Please now go to the final page and submit this form.

Thank you for your interest

Thank you for your interest in this study. Please help the research team to improve by letting them know below why you chose not to participate in this study

Please state your reason(s) for not participating in this research study

Final page

On behalf of the research team at Cardiff University, thank you for taking the time to read and complete this form.

Please feel free to share the details of this online group interview study with anyone you know who may be interested in taking part.

If you have any questions or concerns regarding this piece of research, or you would like your data to be removed from the study, please contact the lead researcher, Rachael Hewitt, at: hewittr2@cardiff.ac.uk.
