**Participant information sheet**

**PhD research study: An exploration of life with a chronic skin condition**

**This research is being conducted by:**

Khalid Al-Muhandis

07813 513045

khalid.al-muhandis.2014@live.rhul.ac.uk

**This research is being supervised by:**

Professor Jonathan Gabe Dr Leah Moyle

01784 276614 01784 276608

j.gabe@rhul.ac.uk leah.moyle@rhul.ac.uk

**Aims of the research**

This research aims to study experiences of living with a range of chronic skin conditions, such as acne, psoriasis and eczema, focusing on how people cope with and manage the physical, psychological and social difficulties that these conditions present. The findings from this research will provide valuable real-world understanding about life with a chronic skin condition from the perspectives of people affected.

I’m keen to find people who would be interested in speaking with me about their experiences. In addition, I am also interested in finding people interested in making some short video accounts exploring the impact of their chronic skin condition on day-to-day life.

If you decide you would like to be a part of this research, your participation will be entirely voluntary and you may withdraw from the research at any time, without giving a reason.

**What your participation means in practice**

Stage 1: Interview

We would find a time that is convenient to meet for a one-to-one interview at your home or another place suitable for a private conversation. The interview would last around an hour. We could also do an interview by Skype or by phone if a meeting in person is not possible.

The interview will provide an opportunity to have a conversation about life with a chronic skin condition. We will cover topics such as your personal history with the skin condition, what advice or guidance you have taken about treatment in this time, how you manage your skin day-to-day, and whether your skin condition impacts on your way of life.

Stage 2: Video accounts

Following the interview, I may invite you to take part in the second stage, which involves recording a few short video accounts of your daily life over a period of around a month.

I will supply you with a portable video camera, guidance about how it works and some suggestions about what you could record. This could include “video diary” type entries in which you talk about your feelings about any current treatment you may be undergoing for your skin, or a demonstration of how you use different creams, ointments or other medications to manage your skin condition. After around a month, I will arrange to collect the video camera.

Stage 3: Follow-up interview

With your agreement, we would then arrange to meet for a follow-up interview. In this second interview we will review and discuss some of your video clips together and talk about your experiences of producing video accounts related to your skin condition.

**Inclusion and exclusion criteria for this research**

If you are aged eighteen and over and have a chronic skin condition, such as psoriasis, eczema or acne, you are eligible to take part in this research. If you are under the age of eighteen and those who do not have experience of life with a chronic skin condition you will not be invited to participate.

**Risks, inconvenience or discomfort that you may experience as a result of taking part**

While it is hoped that your experience of participation in this project is a positive one, there is the possibility that discussing some aspects of life with a chronic skin condition may be lead you to feel distressed.

You will have the right to end an interview at any point without giving a reason. If you are taking part in the second stage of the research, there will be no obligation for you to make video recordings of any situation that causes you distress and you will have the right to delete any video recording without giving a reason. I will provide details of counselling services who can provide psychological support if required.

**How this research can benefit you**

You will receive an initial report of findings from the research and will then be given an opportunity to provide feedback. All feedback will be taken into account for a final report.

The findings produced with your participation will help to build an understanding about life with a chronic skin condition that will benefit others who share these conditions presently and in the future.

It is also hoped that you will find the experience of participation to be personally rewarding, and one which provides the opportunity to reflect upon your skin condition and the practices involved in its management in ways seldom presented in everyday life.

**Privacy and confidentiality**

Your anonymity and confidentiality will be maintained throughout the research, which will be conducted according to principles outlined in the British Sociological Association Code of Ethics and Social Research Association ethical guidelines. Ethical approval for this research has been granted by the University Research Ethics Committee (REC Project ID: 171), Royal Holloway.

All data will be held in a password-protected computer in the form of electronic recordings and transcripts. Only the researcher and academic supervisors will have access to these data. All data gathered during this research will be anonymised for the purposes of publication or any other use, such as presentations at academic conferences.

Data will be held for a period of up to five years following completion of this research before being destroyed.

Your consent form will be stored separately from the responses you provide.

You may retain this information sheet for reference and contact the researcher with any queries.