***PARTICIPANT INFORMATION SHEET***

**Black women’s experiences of living with alopecia**

**STUDY BACKGROUND**

You are being asked to take part in a research study on your experiences of living with alopecia (either Alopecia Areata (AA), Alopecia Totalis (AT) and Alopecia Universalis (AU) in your daily life. The research aims explore Black and dual-heritage women’s experiences surrounding having alopecia and to gain a deeper insight into alopecia from your own perspective.

The research will be carried out by me, Paige Clarke-Jeffers, a Masters Health Psychology student at Birmingham City University. Dr Kathrina Connabeer, the Course Director in Health Psychology, will be supervising this dissertation research.

This project has received ethical approval from the Business, Law and Social Sciences Research Ethics Committee at Birmingham City University.

**WHAT WILL YOU NEED TO DO?**

In this study, you will be asked to firstly read the information on Qualtrics and to fill out the demographic form. Once this has been completed, you will have to be the first one contact the researcher as the researcher does not have your personal e-mail address to contact you on. Therefore e-mail [Paige.Clarke-Jeffers@mail.bcu.ac.uk](mailto:Paige.Clarke-Jeffers@mail.bcu.ac.uk) . And you could state ‘*I would like a arrange a suitable interview time with you and my preferred interview method is… (Skype or Microsoft Team’* then the researcher will contact you back.

* Researcher’s Skype name for you to add: [Paige.Clarke-Jeffers@outlook.com](mailto:Paige.Clarke-Jeffers@outlook.com)
* For Microsoft Teams, the researcher will create and send you a meeting (using your e-mail that you provided) which will redirect you to Microsoft Teams to get the interview started. The researchers e-mail address: [Paige.Clarke-Jeffers@mail.bcu.ac.uk](mailto:Paige.Clarke-Jeffers@mail.bcu.ac.uk)

**HOW LONG WILL THE STUDY LAST?**

On average, this study takes 1 hour. This first section is reading the information here on Qualtrics and filling out a demographic question which can take 10 minutes. Then the second section is taking-part in the interview which can take 35-45 minutes which will be completed in one session.

**ARE THERE ANY RISKS OF TAKING PART?**

As this study involves talking about your experience of having alopecia it may cause different emotions to arise but to minimise the risk if you are from the UK you can ring the Samaritans who offer 24-hour emotional support for individuals experiencing distress. They can be called on **116 123** or by e-mailing [jo@samaritans.org](mailto:jo@samaritans.org).

If you are from America, you can get in contact with the Samaritans on:

Rhode Island - (401) 272 – 4044  
New York - (212) 673-3000  
Boston – (617) 274-0220

Also, you can get support from an alopecia support group:

If you’re from the UK: Alopecia UK

<https://www.alopecia.org.uk>

If you’re from the USA: The National Alopecia Areata Foundation

<https://www.naaf.org>

Physical risk is minimal as face-to-face interviews are not taking place, due to the interviews being online.

**ARE THERE ANY BENEFITS OF TAKING PART?**

Although there are no direct benefits from taking part, it is hoped that this research has a chance to be published which will allow health care professionals and other people with alopecia to understand the experiences of Black people living with alopecia.

**YOUR RIGHT TO WITHDRAW AND WITHHOLD INFORMATION**

In line with the regulations outlined by the British Psychological Society, you can stop being a part of the research study at any time without explanation. You are still entitled to the same benefits as an individual who completes the study. You can also have your data withdrawn from the time you complete until 14 days after your interview has taken place, where your data will have been analysed and written up. Please see contact details below if you wish to withdraw.

During the study, you also have the right to omit or refuse to answer or respond to any question that is asked of you*.*

**YOUR RIGHT TO CONFIDENTIALITY/ANONYMITY**

The study will not involve the collection of any personal information about you except your age, gender, ethnicity and your e-mail address if you decide to contact the researcher to arrange a meeting to complete the interview section. Any personal information given will be unidentifiable to an external party – Your name and any other identifiable information will be kept separately from the main study data, which will be stored confidentially, using a personalised pseudonym (fake name) that you will create during this study. You will create your pseudonym (fake name) at the end of the questionnaire.

You can have the option if you want to remain anonymous in the online (Skype or Teams) interview. This can be stated when e-mailing the researcher to set up the interview. However, your information for both modes of interview types will remain confidential as the recording will be deleted off the online recording systems (Microsoft teams or screencast-o-matic) within 48 hours which will be uploaded onto One Drive and stored on the researcher’s password protected computer which will then be deleted after the study is completed and been through the exam board. The consent form and demographic information will be saved on Qualtrics which is an online platform that will be kept separate from the interview recordings.

All data will be entered into computer files, where they will password protected.

If you wish to withdraw then you will need to e-mail the researcher (myself) and simply state ‘Withdraw from study’ along with the pseudonym that you created. You can withdraw up until 14 days after you have completed the interview.

This study has a chance of being published and may be used in the future for conferences and as mentioned above all personal information will unidentifiable when presenting the date from the study.

**WHO IS ORGANISING THE RESEARCH?**

The study is part of the Masters Health Psychology Dissertation Module by the Psychology department (School of Social Sciences, Birmingham City University, The Curzon Building, 4 Cardigan Street, Birmingham, B4 7BD).

If you require any further information, you can contact myself, Paige Clarke-Jeffers on the following email address: [Paige.Clarke-Jeffers@mail.bcu.ac.uk](mailto:Paige.Clarke-Jeffers@mail.bcu.ac.uk)

You can also contact my supervisor Dr Kathrina Connabeer on the following email address:   
[Kathrina.Connabeer@bcu.ac.uk](mailto:Kathrina.Connabeer@bcu.ac.uk)

If you are unhappy at any point in the study, or if there is a problem, please contact the Psychology Department Research ethics committee directly at [psychethics@bcu.ac.uk](mailto:psychethics@bcu.ac.uk).