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**Study Title: 'Exploring the psychosocial impact of alopecia on women'**

### **Information sheet**

You are being invited to take part in a research study for an MSc dissertation in Health Psychology. Before you decide to take part in this research study, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. If there is anything that is not clear or you'd like more information please feel free to ask me. Thank you for reading this.

#### **What is the purpose of the study?**

This study is concerned with female's experience of alopecia, exploring the psychosocial impact of Alopecia on females. The aim is to hear the voices of people who are living with Alopecia and enable them to express their thoughts and feelings about their lived experience. Additionally the purpose of the research is to also raise awareness about this topic area, particularly for health professionals involved in the diagnosis and treatment of Alopecia.

Alopecia can have a profound psychological impact upon the individual concerned and this can include issues around self-esteem, body image and overall quality of life. The condition can also impact on social interaction and engagement in relationships. Alopecia can change the way a person looks especially if there is hair loss of the eyelashes and eyebrows, it can also change the way a person thinks, feels and behaves. Because Alopecia can be associated with serious psychological consequences, the research seeks to understand what would be helpful or not helpful when offering support to those who live with this experience. Moreover, the study aims to provide new insight and build on existing research in this area.

#### **Why have I been chosen?**

You have been chosen because I am interested in finding out what it is like and what it means to you to have the experience of living with Alopecia. Your experience will help me to understand and gain insight into the consequences of living with Alopecia, what helped or did not help you cope and adjust to this change and how interventions and support can help others. It will also raise awareness to health professionals in this field.

#### **Do I have to take part?**

No, you do not have to take part if you do not want to. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form. If you decide

to take part you are still free to withdraw at any time, without having to give a reason and this will not affect your future care.

If you decide not to take part in this research study you will be given a consent form to read and sign. I will then make contact with you within a week to arrange a mutually convenient time and place to meet.

### **Who can take part in the study?**

Any female adult over the age of 18 can take part in the research study. The study is open to females of any ethnic group. English as a first language is required to take part in this study.

### **What will happen to me if I take part?**

To take part in the study you will be asked to attend an interview which will last up to an hour and it will be recorded by audio recorder. Before the interview takes place I will explain to you that I will be asking ten questions about what it is like to live with Alopecia as a female; exploring the impact that Alopecia has had on you. I will also check out that you are happy to proceed with the interview. I would also explain again that the information shared would be confidential and anonymized and that it would be the researcher Selina Edwards and Dr Amanda Visick, the dissertation supervisor only, who would have access to the information. You will also be given a debrief letter explaining what will happen after the interview has been completed.

### **What do I have to do?**

If you are interested in taking part in this study, please complete and return the consent form accompanying this information sheet. Alternatively, you may contact Selina Edwards, Health Psychology student who is the researcher conducting the study by email at [see0051@londonmet.ac.uk](mailto:see0051@londonmet.ac.uk) or Dr Amanda Visick at [A.Visick@londonmet.ac.uk](mailto:A.Visick@londonmet.ac.uk) who is the dissertation supervisor. You can also telephone the university on 020 71332574 and we will get in touch with you. If you do consent to taking part in this study Selina will contact you within a week.

### **What are the possible disadvantages and risks of taking part?**

Whilst I do not envisage any risks taking part in this study, talking about life experiences especially those that may have resulted from traumatic circumstances or caused you to experience difficult emotions can bring up difficult feelings. If you are currently receiving treatment for depression, anxiety, PTSD, or another psychiatric or psychological issue related to your experience with Alopecia, please ask your counsellor or therapist whether it is advisable for you to take part in this study before proceeding. If you have previously been on treatment, please carefully consider whether you feel psychologically stable enough to reflect on these matters without distress.

### **What are the possible benefits of taking part?**

The possible benefits of taking part in the study will mean that your contribution to the study will help others with the experience of Alopecia.

The study will give professionals and others a deeper understanding and insight into your experience which will hopefully lead to more interventions, support and awareness in the adjustment and making sense of the psychosocial impact of living

with Alopecia. Furthermore the personal accounts if from the participants will build on to the existing research in this topic area for reference.

### **What happens when the research study stops?**

When the study is finished and we have analysed all the information we will inform everyone who has taken part of what we have found. The recordings of the interviews will be securely held until they are transcribed, at which time the original recordings will be destroyed. The transcribed interviews will be securely held for a period of at least five years, in accordance with BPS and London Metropolitan University guidelines.

### **What if I want to withdraw?**

You can withdraw from the study anytime during your participation by asking to stop and saying you would like to withdraw. You can also withdraw up until 31<sup>st</sup> May 2017 by emailing me and saying you want to withdraw, and your data will be destroyed. After this date, I will have completed my analysis and it would no longer be possible to separate your data from that of other participants.

### **What if something goes wrong?**

I do not envisage any serious risk by taking part in this study. However, it is possible that someone would experience distress as a result of talking about difficult or traumatic experiences. As a researcher, I will at all times, be following the university's Distress Protocol to identify any signs of distress. Should any distress occur, I will ask you if you are alright; I will offer you the opportunity to take a break; and if necessary, I will end the interview and refer you to an organisation that can provide support. You are free to terminate the interview at any point. If you are harmed by taking part in this project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal London Metropolitan University complaints mechanisms will be available to you. Please direct concerns to Head of Psychology, London Metropolitan University, 116-120 Holloway Road, London N7 8DB.

### **Will my taking part in this study be kept confidential?**

If you agree to take part in the study, the process and information collected will be anonymised and kept confidential between the researcher Selina Edwards, Dr Amanda Visick dissertation supervisor and within the limits of the university.

### **What will happen to the results of the research study?**

When the study is finished, I hope to publish the results in academic journals and in various publications relating to alopecia. I also hope to present the findings of the study at conferences but I will ensure that no individual participants in the study can be identified.

### **Who is organising and funding the research?**

The research is being organised by the researcher Selina Edwards studying on the MSc Health Psychology Programme and London Metropolitan University. Both have

the responsible for ensuring that this research study is conducted safely, ethically and according to best practice has no financial interest in the program.

**Who has reviewed the study?**

The study has been reviewed by Dr Amanda Visick, dissertation supervisor and the University School of Psychology Ethics Review panel.

**Contact for Further Information**

If you are interested in taking part in the study please complete the consent form attached to this information sheet, and return it in the envelope provided. If you have any questions please feel free to contact Selina Edwards researcher or Dr Amanda Visick, dissertation supervisor from London Metropolitan University, by telephone on 201 74230000 or by email to [see0051@mylondonmet.ac.uk](mailto:see0051@mylondonmet.ac.uk) or [A.visick@londonmet.ac.uk](mailto:A.visick@londonmet.ac.uk) or by writing to us at: London Metropolitan University, 166-120 Holloway Road, London N7 8DB.

Thank you for taking the time to read this information sheet which is yours to keep, if you take part in the study you will be given a copy of your consent form for you to keep.