

An exploration of the lived experiences of young individuals who have alopecia

INFORMATION SHEET (Over 16's)

My name is Amrit and I am a student at the University of Huddersfield. Thank you for being interested in taking part in this study. Please take the time to read the information below and decide if you want to take part (but you don't have to!).

You are being invited to take part in an online email interview to help learn more about what it is like as a teenager to experience alopecia. Before making the decision as to whether or not you would like to take part, it is important for you to understand why this study is being done and what you will have to do. Please take time to read this information and if you have any questions or need more information, you can email me using the email address below.

What is the study about?

We want to know what it is like for a young person to have alopecia. The study wants to explore how a young person manages their alopecia and the support that they receive. There are not that many studies out there that look at how a young person experiences alopecia, but we think it is important that young people with alopecia have a voice to talk about what it means to them. From doing this, we can look at how other young people can access the right help and support and improve their wellbeing.

Why I have been approached?

I am looking to get in touch with teenagers between the ages of 13-18 (up until their 19th birthday) who have (or who have had) alopecia. We think that the best way to try and understand what it is like for a young person to have alopecia, is to email the people who know the most about it... You! You have lots of valuable experience that you can share with us, such as what support you have received and how you deal with your alopecia.

What will I have to do?

First of all, you will have to send me your consent to tell me you are happy for the email interviews to take place. To do this, you will have to copy and paste the highlighted text below and email it to me using the email address below.

'I (insert name here), confirm that I have read and understood the information provided and that I consent to taking part in this study.'

The points you need to understand and consent to are these:

- I have read and understand the information sheet emailed to me by Amrit

- I have had the chance to email questions to Amrit about this study
- I understand the reason for this study and how I will be involved.
- I understand that taking part is my choice and that I can withdraw at any time during the interview without giving a reason, and one month after I have finished the interview. .
- I understand that direct quotes may be used in resulting research reports/publications, but that my identity will be protected using a false name and my personal information removed, and that no information could lead to me or anyone else being identified.
- I understand that all information disclosed within the interview will be kept confidential, in line with the Data Protection Act 1998, unless indicated that me or any other individual is at risk of serious harm. I give permission for the researcher to get in touch with an appropriate authority if I tell Amrit about harm to myself or others.
- I understand that the information collected will be kept in secure for 10 years in a password protected email system and that no other person apart from the Amrit will have access to this.
- I agree to take part in the study.

Once you have sent me your consent, I will email you with a question once a week for 6 weeks. It is your choice when you want to start receiving your questions, you can choose a day which you think is best for you to answer. You will be asked questions along the lines of what it is like to have alopecia, such as how you feel, what it is like at school and what it is like at home. Sometimes I might ask you more than one question, but it is only because I am really interested in your reply and I would like to know a little more about it. It is quite important that you do reply to my questions within the week. This is only so that you do not need to stay in the study any longer than needed. It is ok if you are busy or you have lots of school work- if you need more time to answer your questions you can just email me to let me know. If you forget to reply, I will send you a friendly email just to check everything is ok and that you are still happy to take part.

What will happen to the information?

All information from the interview will be kept confidential – this means that no one other than me will ever know that your information came from you. I will be writing a report using your interview, but I will change your name, other people’s names, and the names of places. Instead I will use made up names so no-one will know that this information came from you.

The only exception to this is if you tell me anything about hurting yourself or anyone else, or if something you say makes me think that you are in danger or someone else is hurting you. If this happens, I will have to inform the appropriate authority. For example if I think someone is hurting you, I will talk to the police or NSPCC. After the study has been published, the emails will be put away securely and then destroyed after 10 years.

Do I have to take part?

No, you do not have to take part if you do not want to.

It is entirely up to you whether you take part. Even if you do decide to be involved, you can change your mind and stop taking part at any time without giving me a reason while we are emailing. If you decide you have changed your mind after the emails, you can let me know up to one month after that you want to withdraw.

Please get in touch with me if you have any questions or want any more information.

Thank you for taking your time out to read this information sheet, I hope to hear from you soon. If you do want to take part in this study, contact me using the email address below. We really appreciate your help!

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