

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

INFORMATION SHEET (Under 16's)

Hello!

My name is Amrit and I am a student at the University of Huddersfield. Thank you very much for taking the time to read this sheet. It tells you all about a study I'm doing so you can decide if you'd like to take part (but you don't have to!).

I'm inviting you to take part in an online interview to help me learn more about what it is like as a teenager to experience alopecia. I'd like to email you some questions over a few weeks, and it would be really useful for me to find out about your experiences.

Before deciding whether you would like to take part though, it is important that you understand why I am doing this and what you will have to do. So please take time to read this information sheet, and talk with your parents/carers or anyone you feel will help.

If you have any questions or need more information, you can email me using the email address below. If you decide you want to take part, I also need your parent/carer to let me know that they are OK with this. They can contact me using the email address or telephone contact details at the end of this sheet.

What is the study about?

There are not that many studies out there that look at how young peoples' experiences of alopecia, and in this study, I want to explore how young people like you manage their alopecia and who supports them to do this. I hope that by 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 who have (or who have had) alopecia so that I can find out from them what it is like from people who know the most about it — people like YOU! You have lots of valuable experience that it would be really useful for me to find out about.

What will I have to do?

First of all, I will need to make sure that you and your parents/ guardians are happy for you to take part in the study.

Your parent/guardian will first need to give me the go-ahead by emailing me their consent. Then you can email me your consent. 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 assent 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
- If I had any questions about the study, I was able to email or ring Amrit.
- I know why this study is being done and what I will have to do.
- I know that I do not have to take part if I do not want to and that I can stop taking part at any time without giving Amrit a reason while we are emailing, and one month after.
- I know that my name and name of places will be changed so so no-one will know that any information came from me.
- I understand that anything I say will be kept private unless I tell Amrit about any harm to myself or others, or anything which suggests I am in danger. If this happens Amrit will contact the NSPCC.
- I understand that all the emails will be kept safe.
- I agree to take part in the study

Then 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 let me know when it is best for you. I will be asking questions about 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 emails, 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.

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 and your parent/ guardian 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. I really appreciate your help!

Amrit Bhatti

Email: teenagealopeciastudy@gmail.com

Telephone: 07578960271

Supervisors:

Dr Joanna Brooks

Email: J.M.Brooks@hud.ac.uk

and

Dr Alison Rodriguez

a.m.rodriguez@leeds.ac.uk