

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

INFORMATION SHEET (Parents/Carers)

Your child is 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. For your child to participate in this research study, it is important that both you and your child understand why this research is being done and what we are asking your child to do. Please read this information sheet carefully and then decide if you are happy for your child to take part if they want to. Your child must have permission from you to take part in this research. 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 looks at how a young person experiences alopecia, but we think it is important that young people with alopecia have the opportunity to discuss 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 has my child been approached?

Your child is being asked to participate in this study because I am looking to interview teenagers between the ages of 13-16 who had/ have alopecia.

What will my child have to do?

If your child agrees to take part in the study and you give them your permission to do so, I will need 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. It is important that you email me your consent from a separate email address to your child, to ensure that I have received consent from a parent.

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

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

- I have read and understand the study information (see attached document) and have had the opportunity to email or phone the researcher (Amrit) with any questions I have about the study.
- I understand the purpose of the project and how my child will be involved.
- I understand that I can withdraw my consent at any time during the interview without giving any reason, and up to one month after the interview has taken place.
- I understand that direct quotes may be used in resulting research reports/publications, but that my child's identity will be protected using a false name and my personal information removed, and that no information could lead to my child 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 an individual is at risk of serious harm. I give permission for the researcher to get in touch with an appropriate authority such as the NSPCC, if my child tells her about harm to his or herself or others.
- I understand that the information collected will be kept in secure conditions for a period of ten years in a password protected email system and that no other person apart from the researcher will have access to this.
- I agree that my child can take part in the study.

After you have sent me your consent, your child will send me their assent, and we can start the study. I will email your child one question once a week for 6 weeks. Your child can choose a day which is best for them to start receiving their questions. They will be asked questions along the lines of what it is like to have alopecia, such as how they feel, what it is like at school, the support they have received and what it is like at home. Although I would usually expect a reply within the week, if your child is busy or has lots of school work, they can just email me to let me know- so there is no time pressure for your child. I will also send a friendly reminder I do not hear from them within the week.

What will happen to the information?

All information from the interview will be kept confidential, in line with the Data Protection Act 1998, unless indicated that your child or anyone else is at risk of serious harm. In the unlikely event of this, I will contact the NSPCC. All email interviews will be kept safe in a password protected site and will only be available to the research team. Your child's direct quotes may be used in the publication of results, but a pseudonym will be used to protect their identity. Any information which may lead to them being identified will not be used. Following completion of the study, data will be archived securely at the University of Huddersfield and then destroyed after 10 years.

Does my child have to take part?

No, your child does not have to take part if they do not want to.

It is entirely yours and your child's decision if you wish to take part in this study. There are no consequences if you do not want your child to take part. If your child does decide to be involved and changes their mind during the interview, that is ok too- they can withdraw from the study at any time without giving a reason (and up to one month finishing the interview).

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 are happy for your child to take part in this interview, contact me using the email address below. We really appreciate your help!

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