

Participant Information Sheet for parents

Acne Care Online interview study

Researchers: Prof Miriam Santer

Your teenager is invited to take part in a research study. To help you decide whether you would like them to take part or not, it is important that you understand why the study is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information. You may like to discuss it with others, but it is up to you to decide whether or not your teenager may take part. If you are happy for them to take part, you will be asked to sign a consent form.

What is the study about?

This study is to develop a website to support people with spots or acne. We would like to chat to people aged 13-25 to find out what they would find most helpful.

This study is funded by the NIHR Programme Grants for Applied Research, which is part of the NHS, and is being run by the University of Southampton.

Why has my teenager been invited?

Your teenager may have been invited to take part in the study if they have been affected by spots or acne in the past or because they are in the age range for this study, or you may have seen this study advertised through your teenager's school, on social media or elsewhere.

Does my teenager have to take part?

No, it is entirely up to you to decide whether or not they are invited. If you decide you are happy for them to be invited, we will ask you to sign a consent form to show you have agreed to this. We will then contact your teenager however you and they prefer (email/phone/text/post) to share information about the study and invite them to take part. They will have the chance to read about the study and to ask any questions before they decide if they wish to take part. They will also be asked to sign an assent form if they agree to take part.

What will happen to my teenager if they take part?

If your teenager decides to take part, the researcher will contact them to arrange a time that suits to have a chat about their experiences of spots or acne. This chat is usually one-to-one but if a young person would prefer to have a parent or carer present this is fine. This may be by phone or video conference (e.g. TEAMS/Zoom) depending on what suits best.

The interview will take 30 mins to an hour. With your and your teenager's permission, this conversation will be recorded and transcribed (to written text). All personal details will be removed and fully anonymised.

Are there any benefits in my taking part?

Your teenager will be given a **£15 gift voucher** for taking part in the study. The findings of this study will help researchers understand how to better support young people with spots or acne.

Are there any risks involved?

There are minimal risks to taking part in this study. Your teenager may find it upsetting to talk about their experiences. If this happens, we will stop the interview and give them details where they can get advice and support.

What data will be collected?

The interviewer will ask questions about your teenager's experiences of acne and acne treatment use. They will also ask about what support and advice your teenager has received from friends/family, online, or from health professionals such as GPs, school nurses or pharmacists. Data about themselves such as gender and ethnicity will also be asked to help us make sure we include the views of a wide range of people in this study, although your teenager does not have to give this information if they do not want to.

What happens to the data being collected?

After the interview, the recording will be put on a university password-protected computer and deleted from the recording device. The recording will be typed up by a professional transcriber or a member of the research team. They will keep everything they hear private and will type code names instead of your teenager's name and any other names or places, so no-one can find out who they are. We will delete all audio recordings as soon as the study team have checked and are happy with the quality of the written transcript. Only anonymised information will be analysed.

We will review what your teenager has told us and put that together with what other people tell us. This will help us understand people's views and experiences of spots or acne. Your teenager's personal details and code name will be stored separately from the typed-up interviews and audio-recordings; all this information will be stored securely on computers at the University of Southampton and will only be accessible by the research team. We will delete the personal details that match your code name at the end of the study.

Will my teenager's participation be confidential?

Your teenager's participation and the information we collect about you will be kept strictly confidential. We will not share your teenager's interview with anyone who is not a member of the research team. We follow strict regulations about how health research is carried out. At times, individuals from regulatory authorities may require access to the information we

collect about you to check that we are carrying out the study correctly. These people have a duty to keep your information strictly confidential. The only time we would not be able to keep something your child tells us confidential is if we had serious concerns about theirs or others safety. We would share this information with the most appropriate sources of further support and advice. We would try to get their permission before doing this, but would still proceed without it necessary.

What happens if my teenager or I change our minds?

You and your teenager have the right to change your mind and withdraw from the study at any time without giving a reason. If you or your teenager decide to withdraw, any data that's been provided will be deleted if you request this, unless it has already been used anonymously in the analysis or results of the study.

What will happen to the results of the study?

Your teenager's personal details will remain strictly confidential. The results of the study will be written up as a report for NIHR and will be published in scientific journals and presented at research conferences. We may use direct quotes from the interview but **none** of your teenager's personal details that could identify them will be used (like their name).

Where can I get more information?

If you have any questions about this study, please contact:

Mary Steele
Primary Care Research Centre
Faculty of Medicine
University of Southampton
Aldermoor Close
Southampton
SO16 5ST

Email: M.E.Steele@soton.ac.uk

What happens if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researcher (M.E.Steele@soton.ac.uk) who will do their best to answer your questions. If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

How do I sign my teenager up?

To get started with the study by giving permission for us to contact your teenager you can exit this document and fill in the rest of the form.

Thank you

Thank you for taking the time to read the information sheet and considering taking part in the study.

Data Protection Privacy Notice

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at <http://www.southampton.ac.uk/assets/sharepoint/intranet/Is/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf>

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research

study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).