



Participant Information Sheet

Acne Care Online trial

Chief Investigator: Professor Miriam Santer

You are invited to take part in a research study. To help you decide whether you would like 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 and ask questions if anything is not clear or you would like more information – our contact details are at the end of this sheet. You may like to discuss it with others, but it is up to you to decide whether or not to take part. If you decide to take part, you will be asked to complete a form that shows you have agreed to take part.

What is the study about?

This study is trying to see if our new website, developed by doctors and young people, can help people aged 13-25 years to manage their acne. The whole study can be completed online and via any device, such as a smartphone.

This study is funded by the NIHR, which is part of the NHS, and is being run by the University of Southampton.



Why have I been invited?



You may have been invited to take part in the study if you have been affected by spots or acne in the past or because you are in the age range for this study (13-25 years), or you may have seen this study advertised through your school, on social media or elsewhere. Only one person per household can take part.

What do I have to do?



The study will last for 12 months. If you decide to take part, you will need to sign up online. Details on how to do this are at the end of this sheet. Once you sign up, we will ask if you are happy to take part as well as asking some questions about you and your acne – this will take about 10 minutes. The website will then randomly decide (by chance) whether you will either:

- **Try out the new website straight away.**
- **Try the new website after 12 months.** You will have access to the new website in 12 months time.

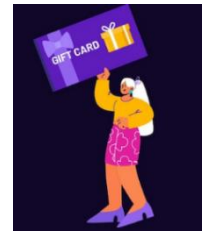
Everyone that takes part in the study will be able to access usual acne care. You will be asked to fill in a very short online questionnaire every 3 months throughout the 12-month study regardless of whether you access the website straight away or not. This will only take a couple of minutes. You will also be asked to fill in a longer online questionnaire after 3 months and again after 12 months. These will take around 10 minutes to fill in.

Optional interview

We may ask you to take part in a study interview which will take 30-60 minutes. This will involve a chat with a researcher (usually on the phone) about your views and experiences of using the new website or being in the study. It is up to you whether you take part. If you're happy for us to get in touch about the chat we may do so after a couple of months with full information and ask for your consent.

What are the benefits for me?

You will get access (either immediately or after 12 months) to a brand new website with advice and support about managing acne. The website includes videos and top tips from health professionals and other young people with acne, support with keeping on track with using treatments, and advice for seeking help and coping with acne. There is also a tool included that may help you to identify suitable acne treatments. Once you complete the study, you'll be entered into a prize draw to win one of 4 x £50 vouchers.



Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, we will ask you to complete a form that shows you have agreed to take part.

What happens if I am not eligible to take part?

When you complete the short online questionnaire, your answers may tell us that you the study may not be suitable for you at this time. If this happens, we will give you some useful website resources where you can find some helpful information about acne.

What happens if I don't want to carry on with the study?

That's fine. You can stop at any time, without giving a reason and without your rights or

routine care being affected.

Will my taking part be kept confidential?

Yes, all personally identifiable information about you (e.g. your name and any other information which could let others know who you are) will be kept strictly confidential. Information would only be shared outside the study if it seemed someone was in danger. Contact details will be held in a separate secure file on a University computer or locked in a filing cabinet.

What will happen to the results of the study?

We will use information from the study to write reports but this will not include any information that makes it possible for you to be identified. We will send you a summary of the results if you would like to see them.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee. This study has been reviewed and approved by North West - Greater Manchester East Research Ethics Committee 23/NW/0323. This study is also supported by the University of Southampton. Young people with experience of acne have been consulted throughout all parts of the study and have helped create the study documents, questionnaires and acne website.

What happens if there is a problem?

If you have a concern about any aspect of this study, you should speak to a researcher (acnecare@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 Head of Research Ethics and Clinical Governance (02380 595058, rgoinfo@soton.ac.uk).

How do I sign up?

For more information, please email the study team at: acnecare@soton.ac.uk

Thank you

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

Further information and contact details

Data Protection Privacy Notice – How will the University of Southampton use information about you?

We will need to use information from you for this research project. This information will include:

- Your name, age, gender, ethnicity, historical socioeconomic status and contact details
- Information you give directly to the ACO research team or online on the ACO website
- Sound recordings and written transcripts (the words you say written down) if you choose to do a telephone, online or face-to-face interview with the ACO research team

This information will be held securely at the University of Southampton. People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a Study ID number. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data for up to 10 years so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

We will use the email address and/or phone number you provide to send you emails or text messages from time to time. You can stop or change how often you receive these emails or text messages by changing your settings on the ACO website. Our team may also occasionally call you while you are taking part in the study. Your contact details will only be kept for the duration of your participation in the trial and to be able to inform you of the results of the study.

Where can you find out more about how your information is used?

You can find out more about how we use your information at:

- www.hra.nhs.uk/information-about-patients/ or
- ring the research integrity and governance officer on 02380 595058, or
- email the research team at acnecare@soton.ac.uk or
- read the University's data protection webpage www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page or
- email the University's Data Protection Officer (data.protection@soton.ac.uk).

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

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. A copy of the University's Privacy Notice for Research Participants can be found here: www.southampton.ac.uk/about/governance/regulations-policies-guidelines.page.

Julie Hooper, Trial Manager, Primary Care and Population Sciences, University of Southampton, Southampton, SO16 5ST, Email: acnecare@soton.ac.uk, Call: 02380 590742 or Message: 07584 865230

THANK YOU FOR YOUR TIME