

## Participant Information Sheet for parents

### Acne Care Online trial

Chief Investigator: Professor Miriam Santer

Your teenager is invited to take part in a research study. To help you decide whether you are happy for them to take part, it is important that you understand why the study is being done and what it will involve. Please read the information below and contact us if anything is unclear 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 whether to pass information about the study onto your teenager for them to decide if they'd like 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, via any device with internet access, such as a smartphone.

This study funded by the NIHR, 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 acne in the past and because they are in the age range for this study (13-25 years), or you may have seen this study advertised through your teenager's school, on social media or elsewhere.

Only one teenager in each household will be able to take part.

#### What does my teenager have to do and what happens next?

The study will last for 12 months. If your teenager decides to take part, they will need to sign up online. Details of how to do this are at the bottom of this page. Once they sign up, we will ask them to complete a form to say they are happy to take part, as well as asking some questions about themselves and their acne – these will take about 10 minutes. The website will then randomly decide (by chance) whether your teenager will either:

- Try the new website straight away, OR
- Try the new website after 12 months

Everyone that takes part in the study will carry on receiving any usual acne care. Your teenager will be asked to fill in a very short online questionnaire every 3 months throughout the 12-month study regardless of whether they access the website straight away or not. This will only take a few minutes. They will also be asked to fill in a longer online questionnaire after 3 months and again after 12 months. This will take around 10 minutes to fill in.

### **Optional Interview**

We may invite your teenager to take part in a study interview which will take 30 and 60 minutes. This will involve a chat with a researcher (usually on the phone) about their views and experiences of using the new website or being in the study. It is up to you and your teenager whether they take part. We will contact you and them again when the interview is due with full information and ask for your consent.

### **What are the benefits for my teenager?**

Your teenager would 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 to identify suitable acne treatments. Additionally, once your teenager completes the study, they will be entered into a prize draw to win one of 4 x £50 vouchers.

### **Does my teenager have to take part?**

No, it is up to you and your teenager whether they take part. This information sheet can help you decide whether you are happy to pass the on information so that they can decide whether they would like to take part. Your teenager's current or future care will not be affected whether they choose to take part or not. They will be asked to sign a consent form if they agree to take part.

### **What happens if my teenager is not eligible to take part?**

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

### **What will happen if my teenager doesn't want to carry on with the study?**

That's fine. They can stop at any time, without giving a reason and without their rights or routine care being affected.

### **Will their taking part be kept confidential?**

Yes, all personally identifiable information about your teenager (e.g. their name and any other information which could let others know who they 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 your teenager to be identified. We will send your teenager a summary of the results if they 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 also been consulted throughout all parts of the study and have helped create the study documents, questionnaires and acne website.

### What if there is a problem?

If you are concerned about any aspect of this study, please contact the Research Team on [acnecare@soton.ac.uk](mailto:acnecare@soton.ac.uk) or **023 8059 0742** who will do their best to answer any questions you may have.

The University of Southampton is the research sponsor for this study. If you wish to complain, or have any concerns about the way you have been approached or treated during the ACO trial, please contact the Head of Research Ethics and Clinical Governance, on **023 8059 5058** or by email to [rgoinfo@soton.ac.uk](mailto:rgoinfo@soton.ac.uk)

### What next?

**If you received a paper leaflet about the study, you could pass this on to your teenager and they will be able to use this to find out more or sign up.**

Otherwise, for more information, please email the study team at: [acnecare@soton.ac.uk](mailto:acnecare@soton.ac.uk)

## Thank you

Thank you for taking the time to read the information sheet.

### **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/](http://www.hra.nhs.uk/information-about-patients/) or
- ring the research integrity and governance manager on 02380 595058, or
- email the research team at [acnecare@soton.ac.uk](mailto: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](http://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](mailto: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](http://www.southampton.ac.uk/about/governance/regulations-policies-guidelines.page).

## **Further information and contact details**

Julie Hooper, Trial Manager, Primary Care and Population Sciences, University of Southampton  
Southampton, SO16 5TU, Email: [acnecare@soton.ac.uk](mailto:acnecare@soton.ac.uk), Phone: 02380 591742

**THANK YOU FOR YOUR TIME**