

Breathe4T (Breathe for teenagers)

Breathing exercises for teenagers with asthma using an online tool

Participant information sheet for younger teenagers [12-14 years old]

You are invited to take part in our research study. Before you decide to take part, it is important that you know what the study is about, why the research is being done, and what will happen if you take part.

Please read this sheet carefully (or ask someone to read it to you) and talk about it with your parents, legal guardians, carers, family, or friends.

What is the project about?



Teenagers tell us that it can be difficult to stay calm during an asthma attack. Our team have already made a programme to help adults use breathing exercises to stay calm and help their asthma. We now want to make this open for younger patients like you.

In this study, we want to find out:

- Can a new website help teenagers to **improve their asthma** and their **overall lives**?

We will compare a group of teenagers using the new website with a group of teenagers who are having their normal asthma care (when they see their doctor and nurse). The group you are put in will be decided at random by the website.

Do I have to take part?



No, it is up to you and your parents/legal guardians. If you do decide to take part then you and your parents/legal guardian will be asked to sign an online form to say you agree to take part (assent/consent form).

You can choose to stop taking part in the study at any time and without having to give a reason – just email breathe4t@soton.ac.uk to let us know. This will not affect your normal asthma care.

What will happen if I take part and what will I have to do?

The study will last 6 months. You'll also be able to use the website for another 6 months after that. If you decide to take part in this study:

- You will get an email with a special code. You will need to use this code to sign-up to the Breathe4T website and you will be asked if you would like to take part.
- You will be asked some questions about your asthma, general health and daily life.
- The website will then randomly put you into one of two groups.
 - **Group 1:** If you are put in this group you will be able to use the new website straight away. You will also carry on receiving your normal care from your doctor or nurse.
 - **Group 2:** If you are put in this group you will be able to use the new website in 6 months time. You will also carry on receiving your normal care from your doctor or nurse.
- After 2 and 6 months, both groups will be asked to answer some more questions.
- During the study you may also be asked to tell us how you found this study via a telephone call or online chat. You do not have to do this if you do not want to.
- You will be given a £10 voucher to thank you for your time.

We don't know which group you will be put in as the website will decide at random. Both groups are equally important and both groups will get to learn the breathing exercises.

What are the good and bad parts of taking part?



You may find out more about your asthma and learn breathing exercises. You could also help towards changing the care of teenagers with asthma across the UK.



The study will take up some of your time, however you can spend as much or as little time as you'd like to spend on the website. We will need you to answer some questions about your asthma. Both groups will be looked after by their asthma doctor or nurse as usual throughout the study.

Who will know I'm taking part?

We will need to let your GP know that you are taking part in the study. We will keep all information about you safe and secure.

What if there is a problem?



If you have any concerns, you or your parents/legal guardian should speak to us (details at the end) and we will do our best to answer your questions.

How long do I have to decide whether I want to take part?



It is completely up to you and your parents to decide if you would like to take part, however there are only 116 places and you should decide by August 2021.

Who can I speak to if I have a question?



Email: breathe4t@soton.ac.uk **Phone:** 07767 833924

Research nurse: Amber Cook (amber.cook@uhs.nhs.uk)

Chief Investigator: Prof Graham Roberts, Professor & Consultant, Paediatric Allergy and Respiratory Medicine, University of Southampton Faculty of Medicine & University Hospital Southampton NHS Foundation Trust. **Phone:** 02381 206160.

What's next? If you would like to take part, please see the "Ready to Get Started?" flyer which tells you how to find the Breathe4T website.

Data Protection Privacy Notice

How will the research team use information about you?

We will need to use information from you and your GP for this research project.

This information will include:

- Your name
- Your age
- Your gender
- Your contact details

This information will be held securely by the research team. 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 code number instead. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data 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.

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, but we will keep information about you that we already have. 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.

Where can I find out more about how my information is used?

You can find out more about we use your information:

- at www.hra.nhs.uk/information-about-patients/
- our GDPR leaflet from www.hra.nhs.uk/patientdataandresearch
- By asking one of the research team.
- By sending an email to dataprotection@uhs.nhs.uk
- By ringing us on 023 8120 4743.

THANK YOU FOR YOUR TIME