

The most bothersome aspects in patients with severe asthma and availability in the severe asthma registries

Patient Information Sheet

You are being invited to take part in a study that will be performed in several countries in Europe because you have asthma. Before you decide, it is important for you to understand why the study is being carried out and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

What is the purpose of the study?

Severe asthma impacts every single patient differently. You might think about asthma-related symptoms and other aspects of your life. In this study we ask 119 other patients like you to share their experience so that we can understand which symptoms or aspects of their asthma bother them the most. At the same time we ask your doctor what they think bothers you most about your asthma. Your doctor will not see your individual answers.

This study aims to get better insight into the differences in how patients and doctors perceive severe asthma. This can help improve treatment for patients in the future.

What will happen to me if I take part?

During your last visit with your doctor, you received information about this study and agreed to provide your email address to your doctor. Your doctor gave you a link to the study survey and a copy of this information sheet. You can download and save this information sheet.

After clicking on the link to the study survey and before starting the survey, you will be asked to provide your consent to participate in the study.

In the survey you will be asked two questions about what bothers you most about your asthma. You will also be asked your age, gender and the medications you take for your asthma.

You will not receive any financial compensation for taking part in this survey.

Sharing your experience of severe asthma may be stressful or upsetting. If this happens, you can choose not to share this information or stop answering the survey. You do not have to give a reason for stopping.

What does my doctor do in the study?

We are also going to ask your doctor the same two questions about what they think bothers you most about your asthma. The two survey questions will be anonymised and kept separate. You will not be able to find out your doctor's responses, and they will be unable to find out yours. The research team will be able to link the two questionnaires together (but they will be anonymous at this stage).

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you decide to take part, you will be asked to give your consent to participate. If you decide to take part, you are still free to withdraw at any time and without giving a reason by exiting the survey. A decision to withdraw or a decision not to take part will have no implications for your treatment or for your health insurance.

To withdraw from the study, please let the research team know by contacting the chief investigator: b.ainsworth@bath.ac.uk.

How will we use the data we collect about you?

All information that is collected about you during the course of this research will be kept strictly confidential and anonymised, and we will not hold any identifying data about you.

We will keep all information safe and secure. All data collected will be treated as confidential and kept in a locked cabinet in a locked room or on a password protected file on the University of Bath's secure server. This storage of data will be done in accordance with GDPR.

Once we have finished the study, we will keep some of the data so we can check the results. Recorded data will be kept for 10 years before it is destroyed.

We will write our reports in a way that no-one can work out that you took part in the study.

The results of this study may be presented at scientific meetings and published in scientific journals and on the SHARP project website (www.sharp-crc.org).

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 that we already have. Because the data is anonymous, we will not be able to remove your data from the study because we will not know which data is yours.

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/
- by asking one of the research team
- by sending an email to b.ainsworth@bath.ac.uk.

If you would like to find out more about the study findings, please contact the research team using the details above.

Complaints

If you have any concerns about your participation in the survey you have the right to raise your concern with the researchers who will do their best to answer any questions. If they are unable to resolve your concern or you wish to make a complaint regarding the project, please contact the Chair of the Research Ethics Approval Committee (Psychology):

Email: psychology-ethics@bath.ac.uk Tel: +441225384714

You can also contact the Complaints Department at the Belfast Health and Social Care Trust. Email: complaints@belfasttrust.hscni.net

Address: Complaints Department
Belfast Health and Social Care Trust
7th Floor, McKinney House
Musgrave Park Hospital
Stockman's Lane
Belfast
BT9 7JB

Tel: (028) 9504 8000 (Monday-Friday: 9am-4pm)

Who is organising and funding the research?

The survey is being organised by SHARP (Severe Heterogeneous Asthma Research collaboration, Patient-centred), which is a European Respiratory Society (ERS) Clinical Research Collaboration that is working to improve treatment for patients with severe asthma. SHARP is funded by the ERS.

The main sponsor of the research is the University of Bath. The project has been reviewed by the ethics committee at the University of Bath (ref: 20-256) and the NHS Research Ethics Committee (ref: 20/PR/0873).

Contact for further information

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The University of Bath privacy notice can be found here:

<https://www.bath.ac.uk/corporate-information/university-of-bath-privacy-notice-for-research-participants/>.

Thank you very much for taking the time to read and consider your participation in this survey.