



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

### **Physician Information Sheet**

You are being invited to take part in a study that will be performed in several countries in Europe because you care for people with 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. Patients might think about asthma-related symptoms as well as other aspects of their lives. In this study we will be asking 120 patients and their doctors which asthma symptoms they consider to be the most bothersome (for each patient).

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 do I need to do?***

Contained in this questionnaire pack is a list of 20 'collectors'. The 'collector' is a unique link to SurveyMonkey, paired for a physician and a patient. Only one collector will be used for each patient.

When you have discussed the study with the patient, and obtained verbal consent for each patient to involve them in the study, you can give them the patient information sheet (also contained within this pack) which has a unique collector ID. The patient will then complete the patient questionnaire.

You will use the paired physician collector ID to complete a physician questionnaire for each patient. Each questionnaire is only 2 questions and should take less than 5 minutes. You should complete a separate questionnaire, using a different collector ID, for each patients that is recruited in the study.

Please ensure you use the correct physician collector ID for each patient, or the study will not be able to link the data.

***Is the study safe for my patients?***

This is a low risk study with anonymous questionnaires. There are no risks to patients. We are hopeful that after the study, this will inform patient treatment to make sure asthma registries are recording the outcomes that are most important to patients.

***Do I have to take part?***

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 you.

To withdraw from the study, please let the research team know by contacting the chief investigator: [b.ainsworth@bath.ac.uk](mailto: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](http://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/](http://www.hra.nhs.uk/information-about-patients/)
- by asking one of the research team
- by sending an email to [b.ainsworth@bath.ac.uk](mailto: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](mailto: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](mailto: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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Sponsor contact: Professor Jonathon Knight  
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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.