



18/08/2016

PARTICIPANT INFORMATION SHEET University of Oxford Asthma Survey

Approved study:

We are asking you to consider taking part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with relatives, friends, and your doctor if you wish.

- Part 1 tells you the purpose of this study and what will happen to you if you decide to take part.
- Part 2 gives you more detailed information about the conduct of the study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this information section.

Nuffield Department of Clinical Neurosciences



Part 1: Purpose of the study

In the UK, 1 in 11 people have asthma, a condition that affects people in different ways. Some people find that things in the environment, such as pollen, or pollution in the air bring on their symptoms, whereas others find stress and worry bring on their symptoms, or make them worse.

We would like to investigate why some people experience asthma so differently from others.

As part of this study we will ask people to complete a short online questionnaire. This questionnaire is designed to help us identify a range of people who experience asthma differently, and who might be willing to take part in future research studies at the University of Oxford.

In the future, we would be interested in performing more detailed studies of asthma at the University of Oxford. If you would like to be contacted to participate in further studies, you will have an option to indicate this in the questionnaire. Future studies would help us better understand why different people experience asthma so differently, and will eventually help us design new treatments tailored to each individual person, rather taking the approach of "one size fits all".

Why have I been chosen?

You have been chosen to consider taking part in this study because you have asthma and you have seen one of our study advertisements. We are interested in hearing from a range of people, some who may be affected mildly by their asthma, and some more severely.

Am I able to take part?

We are hoping to recruit 500 volunteers who are over 18 years of age and have asthma.

Do I have to take part?

It is up to you to decide. We will ask you to read this information sheet and call us if you have any questions. If you are happy to take part, then please proceed to the questionnaire. You are free to withdraw at any time, without giving a reason.

What will happen to me if I take part?

If you take part, you will be asked to fill in a set of online questions, which will take no more than 10 minutes. We ask that you complete all the questions in one sitting. The questions are designed to assess how asthma affects your every-day life. We will also ask questions about your general mood.

In addition to your responses to our questions, we will also ask you for some personal information. This will include your name, date of birth and some questions regarding the medicines you take and the history of your asthma.

We will also ask whether you would be willing to be contacted regarding future

research studies that we will be running at the University of Oxford. Additionally, if you are interested in discussing future research with us (e.g. helping us design studies in the future in a way that addresses your needs), we would like to hear from you.

You are under no obligation to take part in future studies, even if you indicate that you would be interested to hear more about it.

Expenses and Payments

If you take part in this study we would enter you into a prize draw to win a £50 Amazon voucher. We will hold this prize draw once every 6 months.

What are the possible disadvantages and risks of taking part?

There are no known disadvantages of taking part.

What are the possible benefits of taking part?

There is no benefit to you if you take part in this study. We hope that the information we get from this study may help us to better understand asthma.

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

You are free to withdraw at any time, without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect you in any way.

Contact details for further information

You should contact Dr Sarah Finnegan for further information. You can contact her via email asthma@fmrib.ox.ac.uk or by phone 01865 234544

This completes Part 1 of the Information sheet. If the information in Part 1 has interested you and you are considering participating, please continue to read the additional information in Part 2 before making a decision.

Part 2: Conduct of the study

What if something goes wrong?

The University of Oxford has appropriate insurances in place to cover and claim for damages which may arise in connection with this research and for which the University of Oxford is legally liable.

Contact for making a complaint

If you have a concern about any aspect of this project, please speak to the relevant researcher via email (kyle.pattinson@nda.ox.ac.uk or by phone 01865 231 509), who will do his/her best to answer your query. The researcher should acknowledge your concern within 10 working days and give you an indication of how he/she intends to deal with it. If you remain unhappy or wish to make a formal complaint, please contact the chair of the Research Ethics Committee at the University of Oxford (Chair, Medical Sciences Inter-Divisional Research Ethics Committee; Email: ethics@medsci.ox.ac.uk <<mailto:ethics@medsci.ox.ac.uk>>; Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD). The chair will seek to resolve the matter in a reasonably expeditious manner

Will my taking part in this study be kept confidential?

All information that is collected about you during the course of the research will be kept strictly confidential. Any information about you that is shared between staff members outside our immediate group will have your name and address removed so that you cannot be recognised from it.

Responsible members of the University of Oxford, may be given access to data for monitoring and/or audit of the study to ensure we are complying with regulations.

If you consent to be contacted regarding future research studies then your details will be held in secure storage. If at any time you no longer wish to be contacted regarding future research studies then we will destroy your personal details from our database. If you do not consent to be contacted for future research then we will delete your personal details as soon as we are made aware of this.

What will happen to the results of the research study?

We hope to publish the results of this study in a scientific journal. We may also present the results at a scientific conference or a seminar in a university. We may also publish results on our website. We would be happy to discuss the results of the study with you and to send you a copy of the published results. It will not be possible to identify you in any report or publication.

Who is organising and funding the research?

The study is being run from within the Nuffield Department of Clinical Neurosciences, which is part of the University of Oxford and is based at the John Radcliffe Hospital. It is being funded by the NIHR Biomedical Research Centre in **Oxford**.

Who has reviewed this study?

All research is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by the Central University Research and Ethics Committee.

Future research studies.

If you indicate your willingness, then we may wish to get in touch with you in the future regarding a follow up study. Your participation is completely optional.

Does it matter if I am already participating in other studies?

No, this should not affect your ability to take part in this study.

Contact for further information

You should contact Ms Sarah Finnegan or Dr. Kyle Pattinson for further information. You can contact Ms Finnegan by email asthma@fmrib.ox.ac.uk or by telephone 01865 234544. You can contact Dr Pattinson via email kyle.pattinson@nda.ox.ac.uk or by telephone 01865 231509.

Further questions

If you wish to participate or have any further questions about the research, your rights as a volunteer or who to contact in the event of a research-related injury I would be happy to discuss them with you and can be reached at 01865 231 509.

Thank you for reading this information letter.

Yours sincerely,

Dr Kyle Pattinson