



Asking asthma patients about how asthma affects their lives

Principal Investigator: Dr Chloe Bloom

You are being invited to take 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 others if you wish.

- You are invited to participate in a study about how your asthma affects your life
- You will be asked to participate in a short survey that is expected to last about 5-10 minutes
- The survey is broken down into three parts, some of these questions may seem familiar to you
- You will be asked to repeat the survey 2 to 4 times more in the next 12 months

What is the purpose of the study?

This study aims to find out how feasible it is to ask people with asthma to fill in a short survey regularly over a period of 12 months. Half the participants will be asked to answer the survey three times during the 12 months, and the other half will be asked to answer the short survey five times.

The survey will be sent to you in the beginning, 3 months later and 12 months later. Half of the participants will also be sent the survey at 6 months and 9 months after the first survey.

Understanding if patients are happy to answer these short surveys about how their asthma affects their lives will be used to set up a future trial. The future trial will assess how best to reduce asthma medication in people with stable asthma.

Why have I been invited?

We want to gather information from people treated for asthma that frequently use their inhalers

Do I have to take part?

No, it is entirely up to you. No, it is entirely up to you. If you would like to take part in the survey, by completing any of the questions we will assume you have given your consent.

Even if you do complete some of the survey, you are free to withdraw from the study at any time and your answers will not be used.

What will happen if I take part?

You will be asked to take part in a short electronic survey which will take about 5 minutes to complete.

All participants will be asked to fill in the same survey in 3 months and 12 months time. Half of participants will be asked to fill it in again at 3 months and 6 months.



What do I have to do?

There are no added requirements or restrictions associated with this research other than taking part in the surveys.

What are the possible benefits of taking part?

There will be no direct benefit to you from participating in this study. The information will be used to help design a trial to enable GPs to safely reduce asthma medication in the right people.

What are the possible disadvantages and risks of taking part?

The only disadvantage to taking part is that it will take time to do the survey. There are no risks in taking part. If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been treated during the course of this study then you should immediately inform the Investigator (Dr Chloe Bloom; chloe.bloom06@imperial.ac.uk). If you are still not satisfied with the response, you may contact the Imperial Joint Research Compliance Office.

How will we use information about you?

Research Study Title: STEPDOWN Feasibility: Asking asthma patients about how asthma effects their lives; IRAS ID 310465.

Imperial College London is the sponsor for this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly.

Imperial College London will keep your personal data for:

- 10 years after the study has finished in relation to data subject consent forms.
- 10 years after the study has completed in relation to primary research data.

We will need to use information from you for this research project, if you agree to participating in an interview. This information will include your contact details (telephone number and/or email). People will use this information only to contact you for the interview. 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 you find out more about how your information is used?



Hampton Hill Medical Centre

Participant Information

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 chloe.bloom06@imperial.ac.uk

What will happen to the results of the research study?

The results of the study will be published in medical literature and disseminated on to patient friendly websites such as Asthma UK. No participants will be identified in any report/publication.

Who is organising and funding the research?

This study is organised by Dr Chloe Bloom and sponsored by Imperial College London and is funded by the National Institute for Health Research. Your GP practice will receive some funding for their involvement in this research study.

Who has reviewed the study?

This study was given favourable ethical opinion for conduct in the NHS by the Research Ethics Committee XXXX that reviewed this study.

Contact for Further Information

You can find out more about how we use your information by contacting one of the research team, Dr Chloe Bloom; chloe.bloom06@imperial.ac.uk.

Thank you for participating in this study.



Legal basis

As a university we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the [UK Policy Framework for Health and Social Care Research](#)

International transfers

There may be a requirement to transfer information to countries outside the European Economic Area (for example, to a research partner). Where this information contains your personal data, Imperial College London will ensure that it is transferred in accordance with data protection legislation. If the data is transferred to a country which is not subject to a European Commission (EC) adequacy decision in respect of its data protection standards, Imperial College London will enter into a data sharing agreement with the recipient organisation that incorporates EC approved standard contractual clauses that safeguard how your personal data is processed.

Sharing your information with others

For the purposes referred to in this privacy notice and relying on the bases for processing as set out above, we will share your personal data with certain third parties.

- Other College employees, agents, contractors and service providers (for example, suppliers of printing and mailing services, email communication services or web services, or suppliers who help us carry out any of the activities described above). Our third party service providers are required to enter into data processing agreements with us. We only permit them to process your personal data for specified purposes and in accordance with our policies.

Complaint

If you wish to raise a complaint on how we have handled your personal data, please contact Imperial College London's Data Protection Officer via email at dpo@imperial.ac.uk, via telephone on 020 7594 3502 and/or via post at Imperial College London, Data Protection Officer, Faculty Building Level 4, London SW7 2AZ.

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO). The ICO does recommend that you seek to resolve matters with the data controller (us) first before involving the regulator