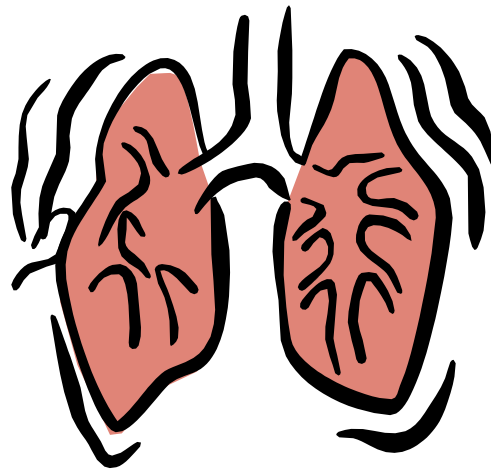
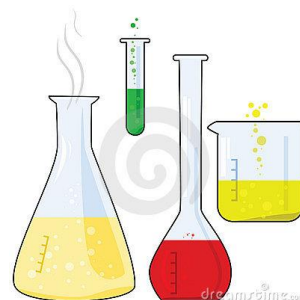
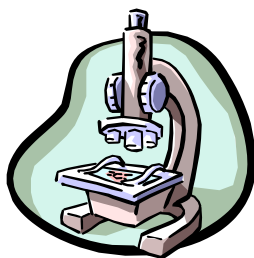


Predicting Progression to School Aged Asthma

Information sheet for the young person
Age 12-16years



Thank you for taking the time to read this leaflet, we hope it will help you to answer some questions about the study you have been asked to take part in.



Before you decide whether to take part you need to understand why the research is being done and what it would mean for you. Please take time to read this leaflet carefully. Talk to others including your family, friends, doctor and nurse about the study if you wish.

Why we are doing this research study

Asthma and wheezing are common conditions. When asthma or wheezing is severe, it can result in missing school and the need to stay in hospital. We are doing this research project to understand more about how changes in the lungs of very young children (pre-schoolers) affects their lung health later at school-age and if this makes them more likely to develop asthma. This will help us to one day understand how to better treat young children with breathing problems such as wheezing and target treatment differently for those who are likely to develop asthma.

Why have I been chosen?

You have been invited to join because when you were pre-school age, your parents kindly let you be part of a research study when you were having respiratory tests at the Royal Brompton Hospital. We looked at the fluid in your lungs that was collected when you had a camera test called a bronchoscopy. Our research team found very interesting changes in the pattern of infection and inflammation from the fluid sample of children with wheeze compared to those without.



We would like to see how you are doing now that you are older, to see if you have asthma or allergies and to check how your lungs are working. This will not involve another bronchoscopy, instead we would like to do some different tests that will be explained to you and can all be done in a short visit.

Do I have to take part?

Taking part in research is voluntary. This means that you can say yes or no to joining our study or change your mind at any time.

What do I have to do if I agree to take part?

If you agree to take part, we are asking if you would do the following:

1. That you come to the Royal Brompton Hospital so that we can meet you, ask you about your health and breathing and do some tests to see how your lungs are working.
2. That we can do some special tests to get samples to look for allergies, infection and inflammation.
3. That we can use any samples left over for future research rather than throw them away afterwards.
4. That we can look back on your old samples and information from when you were a pre-schooler to compare to your samples now.

You may not be asked to do all the tests or you can agree to do some of them and not others.

Questions about you

One of our research team will spend around 15 minutes speaking to you and your parent to ask about your breathing, medical and family history and any medicines that you are taking. We'll also ask you and your parent to complete a short questionnaire about asthma.

Induced sputum (Spit or Phlegm samples)

We would like to collect a collect a sample of sputum (spit, phlegm) that you cough up. We will give you a salty nebuliser which forms a mist to breathe in to help you to cough up the phlegm. We expect it to make you cough but sometimes this can cause chest tightness and this can easily be relieved with an inhaler at the time if needed. We will also adjust the salt concentration of the nebuliser based on your lung function results to make this test as safe as possible We will then look under the microscope at the phlegm to see what types of cells are there, and whether there is inflammation or infection.



Blowing tests

We would like to test how your lungs are working by asking you to blow into a machine. We have different ones that test your lungs in slightly different ways. We'll explain which ones need you to breathe into normally and which ones need you to breathe out really fast. These tests are also called Lung Function Tests. Very occasionally you might feel short of breath or light headed when trying to do the blowing tests, but we'll be checking you feel ok and you can pause at any time.

Nasal sample

We would like to collect some fluid from your nose. This will involve inserting a very small piece of filter paper in your nostril for about half a minute. It will be held in place using nose clips that may cause a little discomfort but isn't painful. We'd also collect fluid that will be washed through your nostrils, called a nasal-rinse, that we can use to look for any signs of infection. The fluid rinse can be a strange feeling and a little uncomfortable at but shouldn't hurt you in anyway.

Swabs

We would like to sample the back of your throat and your nose using a special swab that looks like a long cotton-bud. It has a soft end and will gently touch the back of your throat and nose and will be used to test for infection. This doesn't hurt but might make your nose or throat feel uncomfortable for a moment and might make you cough. Another swab test we do is called a cough-swab, and for this you just need to open wide and cough on it.

Blood sample

We would like to do a blood test, taking one small sample that will be tested for allergies and inflammation. We would also like to store a sample of your blood DNA for future research looking at genes related to asthma. We will not be doing any other genetic testing with you blood and you won't be contacted in future about your DNA sample or results. Very rarely after a blood test you might have a small bruise but this should heal quickly. Your arm might feel a little sore when having a blood test and so we will offer you numbing cream or spray beforehand to make sure it's as comfortable as possible.

Skin prick tests

Another way we test for allergies is called a skin prick test. This involves putting a drop of liquid containing bits of common things that people are allergic to (like pollen or cat and dog hair), on your forearm. A tiny scratch is made on your skin for each one and 20 minutes later your arm is checked. If you're allergic to anything we have tested, we'll know by seeing a small red swelling and can tell you this straight away! We can usually test for 6- 8 different allergens. The skin prick test doesn't hurt but it can make your arm feel itchy. If this happens and is uncomfortable we can give you a soothing anti-itch cream afterwards to help.

Your visit can take a couple of hours, so we will provide vouchers that can be used for food and drink snacks for you and you parent and you can have a break at any time.

Urine sample

We'll ask you to provide a urine sample in a pot that we will provide. The urine will be tested for signs of inflammation and exposure to smoking. You can do the urine sample at any time during your visit.

How will the samples be stored?

The samples will be stored for the research project without recording any details of your name so you cannot be identified.

Laboratory staff looking at these samples will not be able to tell who you are.



Do I have to take part?

You do not have to take part. You are also free to stop taking part at any time without giving a reason. If you decide to stop it will not affect the care you receive in the NHS.

Will I come to harm by taking part?

All the tests we do have been done in many times in children of all ages, are carried out regularly and are safe. You are very unlikely to have any side effects from the tests or suffer any harm by taking part. If you already have an appointment coming up at the Royal Brompton Hospital and you'd rather do the research visit on the same day, just let us know and we will try to arrange this for you.

What are the possible benefits of taking part?

You will be helping doctors to better understand why some children develop asthma. This will help us decide what is the best way to treat young children with wheeze and breathing difficulties.

We are also taking a closer look at how your lungs are working and checking for allergies, inflammation and infection in a way that you might not otherwise be tested for or know about. You will also be able to ask us lots of questions about your lungs and breathing.

What happens if I change my mind about taking part?

If you change your mind and want the samples destroyed, just let us know and we will do this. Any further information collection will also stop. You can choose whether or not to allow us to keep the data we already have for you or have collected so far. It is important to talk to your parents about whether or not you would like to take part in this research. If you decide not to take part or change your mind, that's fine and you will still be looked after by your regular doctors and your care in the NHS will not be affected in anyway.

Who is running the study?

Dr Louise Fleming, Professor Sejal Saglani and Professor Adnan Custovic are in charge of the study.

Further questions?

If you have any further questions, please contact our research team:

020 7352 8121 ex 82257

