

We would like to take this opportunity to thank Arthritis Research UK for sharing their 'Taking part in research' booklet with us which has facilitated the production of this leaflet.

University Hospital of South Manchester **NHS**
NHS Foundation Trust



How to get involved in Chronic Cough Research



How to get involved in Chronic Cough Research

“DO YOU WANT
TO KNOW MORE?”

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- www.combatmycough.com
- ManchesterLungResearchSociety
- @ Lung-research

Information for patients and the public

This booklet has been designed
to answer your questions about
taking part in research



Dr Imran Satia
Clinical Research Fellow

“ALL YOUR QUESTIONS ANSWERED”

WHAT'S INSIDE? THIS BOOKLET.

- 1 What is research?
- 2 Why do we need research?
- 3 Who carries out research?
- 4 What types of research are there?
- 5 How do I get involved in research?
- 6 How do I know I'm taking part in a good research project?
- 7 How do I know I'll be looked after?
- 8 What if it's not right for me?
- 9 What happens after I have taken part?
- 10 Where can I find out more?

“WHAT IS RESEARCH?”

Research helps us to find out new things.

It is a process of collecting information about certain ideas or theories to improve our knowledge and understanding of something.

We do research in chronic cough to improve our knowledge of the symptom and to understand what might be causing it and how best to treat it. The answers that we get from our research can help to change the way medical professionals (such as doctors, nurses, therapists, etc.) manage patients with chronic cough, or improve the treatments that are currently available to you, which in turn can improve your quality of life.

Prof. Jacky Smith
Head of Cough Research



“WHY DO WE NEED RESEARCH?”

WHAT IS A CLINICAL TRIAL?

A type of study looking at drugs or medical devices in a large group of patients.

Research is needed for a number of reasons:

1 Developing treatments

There are currently no effective treatments for a chronic cough. As many of you will know, over the counter medicines simply do not help. We need to carry out research into developing new treatments that are effective for our patients and make sure they are safe. In order to do this, we ask patients if they are willing to take part in clinical trials of new medicines. Sometimes these medicines are taken as tablets and sometimes they are inhaled.



2 Developing new tests

Research helps us to develop new tests. This might be done in a number of different ways, from measuring how sensitive a person's cough is, to recording how frequently a person coughs during the day and night, or even developing new questionnaires to understand what might provoke your cough compared to other people.

3 Finding out causes

Sometimes a chronic cough is caused by underlying conditions such as asthma, nasal disease, or even as a side effect of medications for blood pressure but in around 40% of patients there is no underlying cause for their chronic cough. We need to carry out research to find out what causes a chronic cough in order to develop ways to control, prevent and hopefully cure it. If we want to learn more about different conditions then we need to continue to carry out research and learn from our experiences.

40% of patients
have no underlying
cause for their
chronic cough

“WHO CARRIES OUT RESEARCH?”

Before any research is carried out, the researcher must create a research question to be answered (called a hypothesis) and put together a plan to answer it (called a protocol). Research is carried out by different people such as doctors, nurses, scientists or healthcare researchers.

Chronic cough research in Manchester is carried out by a large team of doctors, nurses, research assistants and engineers. Our research is carried out at hospital clinics, universities or in clinical research facilities. Sometimes people take part in research from their own homes via telephone interviews or by completing questionnaires.

MEET THE TEAM



Prof. Jacky Smith
Head of Cough Research



Dr Imran Satia
Clinical Research Fellow



Dr Huda Badri
Clinical Research Fellow



Zbigniew Koziel
Research Assistant



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Kitty Ahern
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Shilpi Sen
Research Support Officer



Phil Turner
Cough Analyst



Danielle Birchall
Patient & Public
Involvement
Support Officer



Dr Kevin McGuinness
Clinical Engineer



Joanne Mitchell
Respiratory Physiologist



Suku Moyo
Research Nurse

“WHAT TYPES OF RESEARCH ARE THERE?”

There are many different ways of carrying out research. The types we most frequently conduct in the chronic cough research team are shown overleaf.

OBSERVATIONAL STUDIES

In observational studies researchers assess a condition on a single day or over a period of time (which could be a few weeks or several months). This helps researchers to understand patterns in health which in turn may help us to select suitable treatments for people. Some observational studies may require you to undergo some tests (such as a blood test or cough challenge test, etc.) but the type of test will depend on what question each study is trying to answer.

INTERVENTION STUDIES

There are different types of intervention studies. The most common one is called a randomised controlled trial. These studies usually involve taking a new treatment and comparing it with a dummy (placebo) treatment. The treatment people are assigned to is allocated at random.

QUALITATIVE STUDIES

Qualitative research is designed to understand the patient experience. For example, you might be interviewed individually or join in a group discussion about your experience of living with a chronic cough. The discussion is usually recorded and words and phrases from the discussion are looked at by the researcher to see what the common experiences are. Qualitative research may also involve completing questionnaires.



“HOW DO I GET INVOLVED IN RESEARCH?”

Every research project needs people to take part as a ‘subject’ of the study. You may be contacted directly by a researcher about helping them by taking part in a study, but you don’t have to wait to be approached. If you want to get involved in chronic cough research then speak to a doctor, nurse or researcher in clinic who will be able to tell you what studies you may be eligible for.

“HOW DO I KNOW I’M TAKING PART IN A GOOD RESEARCH PROJECT?”

Most research is looked at by a panel of people who are independent from the research team to ensure the study is scientifically appropriate. All research in the NHS is also looked at by a Research Ethics Committee. The Research Ethics Committee is made up of experts, non-experts and members of the general public. Together they review research applications to ensure your safety, rights, wellbeing and dignity are protected at all times.



“WHAT IF IT’S NOT RIGHT FOR ME?”

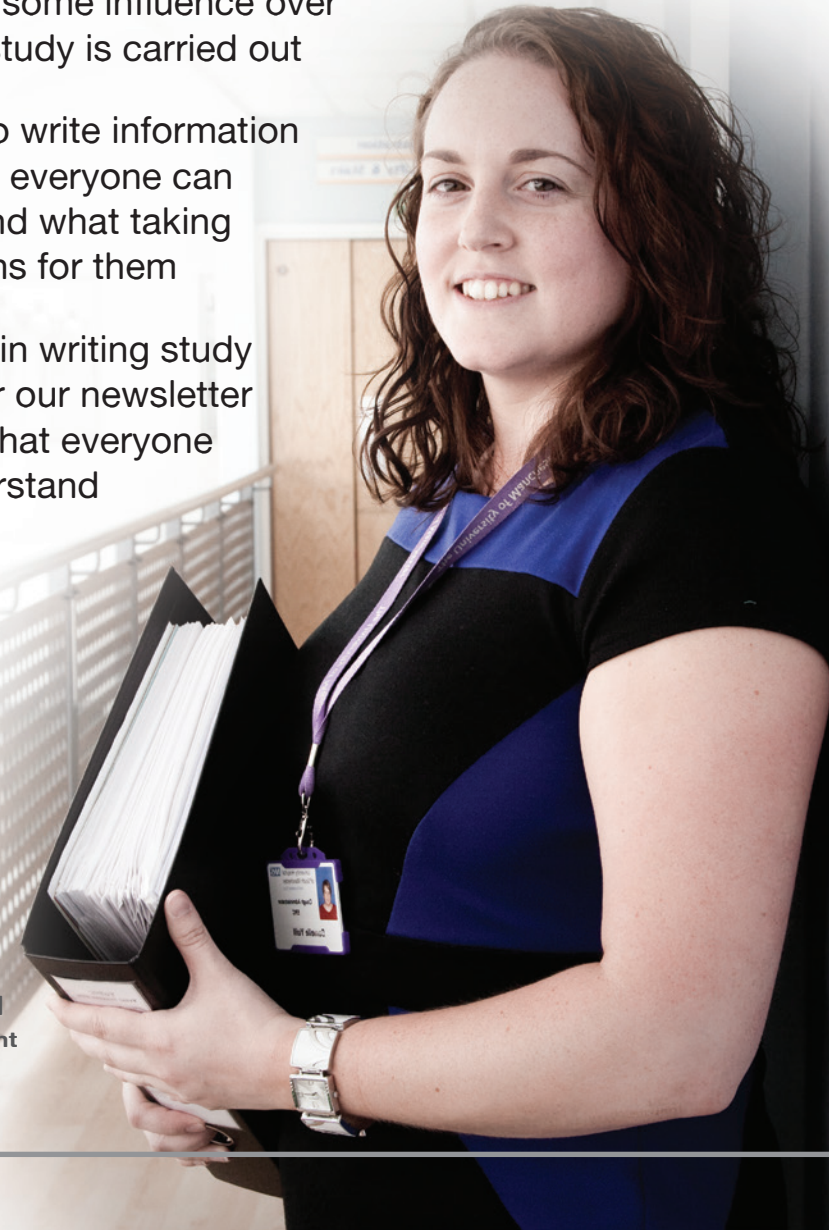
People often think that being involved in research means taking part in a study as a participant. Although this is an important role, there are many other things that you can do if being a study participant isn't for you, or if you find that you're not eligible to take part due to things such as your previous smoking history.

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Examples of other ways to get involved:

- Work with us to apply for funding for new research projects
- Join a study advisory group and have some influence over how the study is carried out
- Help us to write information sheets so everyone can understand what taking part means for them
- Assist us in writing study results for our newsletter in a way that everyone can understand

Danielle Birchall
Patient Involvement
and Engagement
Manager



“WHAT IF I CHANGE MY MIND ABOUT BEING INVOLVED IN RESEARCH?”

If you decide to take part in a study but later change your mind then you can choose to leave at any point. No one will be offended and you do not have to give a reason. Your decision will not affect your normal care and it doesn't mean you can't take part in a different study in the future if you want to.

The nature of research is that it can take a long time for the findings of a study to become available. We publish the results of our studies in our “chronic cough in focus” newsletter which we send out throughout the year.

If you take part in a study involving a new drug, even if the drug worked for you, it will not be available to use after the study until it has been licensed by the Medicines and Healthcare Products Regulatory Agency or the European Medicines Evaluation Agency who allow the manufacture of drugs in the UK. This can often take several years.

“WHAT HAPPENS AFTER I HAVE TAKEN PART?”

“WHERE CAN I FIND OUT MORE?”

For further information about the chronic cough research team, or taking part in research in general, please take a look at the following useful websites or contact us using the details on the back of this booklet.

