

Participant Information Sheet for Public Contributors

Diagnosing and monitoring airways disease

Public and clinicians' views and experiences of diagnosing and monitoring airways disease: a qualitative study

You are being invited to take part in a research study. Before you decide whether to take part, it is important for you to understand what the aim of the research is and what it will involve. This document contains important information that you should read before deciding to take part in the study. You are welcome to discuss the information with other people, and you may e-mail us to ask any questions if anything is unclear, or if you would like to request more information. Take time to decide whether you would like to take part.

What is the purpose of this study?

The purpose of this study is to gather people's views and experiences related to the diagnosis and monitoring of lung conditions affecting the airways (including COPD and asthma), as well as their experiences with, and views on, phone-based technology for these purposes. We are also seeking feedback on one of the apps that is currently being developed in this area. Your insights and opinions will help us improve the app and ensure it meets the needs of users effectively.

Who can take part?

We would like to speak to people who have a diagnosis of airways disease (Chronic Obstructive Pulmonary Disease (COPD) or asthma) or are a current or ex-smoker (more than 10 cigarettes per day for more than 10 years) meaning you are at higher risk of developing airways disease in future. We are hoping to recruit 15-25 participants for this study.

What will happen to me if I choose to take part in the research?

You will take part in an online or telephone interview e.g., using Teams, or a group discussion (focus group), depending on your preference. The meeting will be arranged at a time to suit your schedule and will last around 45minutes (interviews) or 90 minutes (focus group). This will be with the researcher (Marta Wanat) and will be audio recorded with your permission. In the interview we will ask you questions about your lung condition (if you have one) and how it was diagnosed, how you monitor it, and your views on the use of phone-based apps to manage your condition. If you do not have a lung condition, we will ask you for your views on screening for a lung condition or what you might do if you developed lung symptoms. We will also ask you for your views on a specific app that has been developed so we can improve it. We will also record some basic information about you to ensure we are including a range of people in the study.

You will be asked at the beginning of the interview to give consent to take part in the interview/group discussion, and the researcher will make a written record of this. You will receive a copy of the signed consent form via e-mail.

Public Contributor Information Sheet

Ethics reference: R95717/RE001 V1.0 (17th September 2024)

PI: Helen Ashdown helen.ashdown@phc.ox.ac.uk

Will I be reimbursed for my time?

To thank you for your time in taking part in our study, you will be offered a £20 high street gift voucher which will be sent to you via email after the interview has been completed.

What are the advantages of taking part?

There are no direct advantages for you if you take part. Talking and reflecting on your lung condition (if you have one) might help guide how you manage it or your future discussions with your usual health care professional. The researcher doing the interviews is used to talking to people about their health experiences but is not a health care professional, so any clinical concerns or queries about your condition should be directed to your usual health care professional. If you have questions or concerns about lung health you can visit <https://www.asthmaandlung.org.uk/>, which has lots of evidence-based resources for patients and carers. If you would like to access free help to give up smoking you can find details of your local NHS Stop Smoking service here: <https://www.nhs.uk/live-well/quit-smoking/nhs-stop-smoking-services-help-you-quit/>

Findings from the study will be used to help inform future strategies for delivering patient-centred healthcare in lung disease, so taking part in the study could help other people in future.

What are the possible disadvantages of taking part?

There are no real risks or disadvantages to taking part in this study. The main thing that you must consider is whether you're happy to take part in an interview to discuss how you manage your lung health. This could involve discussion about how it was diagnosed, or your views about the risk of having a condition in the future. You do not need to answer any questions you don't want to.

Do I have to take part?

No. It is up to you to decide whether to take part. You can withdraw yourself from the research, without giving a reason, by advising us of this decision at any time before or during the interview. Shortly after you have completed the interview, your data will be combined anonymously with other data for analysis, so it will not be possible to withdraw it.

What will happen to my data?

Your interview will be transcribed (typed up from the recording), but we will remove any identifiable information so that you cannot be directly identified from the transcript. The transcript is important so that we can look back at the answers that you gave, to analyse and interpret it. Original recordings, will be destroyed once we have checked the transcripts. Transcripts of interviews and information about you gathered in the interview will be stored electronically long-term on a secure University of Oxford server, and will be only labelled with a unique participant identifier.

Your name will only be on the consent form, which will be stored separately from your transcript/audio recording securely on University servers for three years after publication of the study.

Contact details for the purpose of this research, such as your e-mail address for arranging the interview and sending an online gift voucher, will be kept on a password-protected spreadsheet stored securely and deleted shortly after your interview has taken place. If you wish to receive study findings, we will keep your email address until we have completed the analysis. We will also keep your e-mail address for three years on a separate password-protected spreadsheet to invite you to future studies if you agree. We will keep a copy of your consent form with this database, as your consent is our legal basis for re-contacting you under UK data protection law.

The University of Oxford is the data controller with respect to your personal data and, as such, will determine how your personal data is used in the research. The University will process your personal data for the purpose of the research outlined above. Research is a task that we perform in the public interest. Further information about your rights with respect to your personal data is available from <https://compliance.web.ox.ac.uk/individual-rights>.

Who has reviewed this research?

This research has received ethics approval from a subcommittee of the University of Oxford Central University Research Ethics Committee.

Who is organising and funding the research?

This study is organised by Dr Helen Ashdown, who is a GP and Clinical Lecturer in the Nuffield Department of Primary Health Care Sciences, University of Oxford. The study is being carried out by Marta Wanat, an experienced researcher at the University of Oxford. The research is funded by National Institute for Health Research I4IFAST-588 Invention for Innovation (i4i) Programme (Reference number: NIHR 207332) The views expressed are those of the researchers and not necessarily those of the NIHR or the Department of Health and Social Care.

Who do I contact if I have a concern about the research, or if I wish to complain?

If you have a concern about any aspect of the research, please contact Dr Helen Ashdown (helen.ashdown@phc.ox.ac.uk), and she will do her best to answer any questions. If you remain unhappy and wish to make a formal complaint, please contact the University of Oxford Research Governance, Ethics & Assurance (RGEA) team at rgea.complaints@admin.ox.ac.uk or on 01865 616480.

Further information and contact details

If you would like to take part in the study, or to discuss the research further, please contact marta.wanat@phc.ox.ac.uk

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