

Asthma & Breath Mastery: Developing a Learning Health System (LHS) and Trials within Cohorts (TwiCs) platform

Short Title: Asthma & Breath Mastery LHS

Summary Participant Information Sheet

Invitation

We would like to invite you to take part in a long-term project in asthma care. People referred to a hospital asthma service have persistent breathlessness. Many people find that being short of breath is frightening and has a negative impact on their quality of life. We are running a research study to understand the causes of this breathlessness and how best to help people living with breathlessness to master it.

What would I be asked to do if I took part in the study?

1. Give consent/ agree to take part in the study.
2. Agree that we can collect data relevant to the study from your medical records.
3. Provide information about your asthma/breathlessness and physical and mental health by completing some questionnaires.
4. Complete some of the questionnaires again at different timepoints throughout the study (some will be completed once or as a one-off; some may be completed once a year; and some may be completed at each clinic appointment or every quarter (three months)).
5. You will be asked if we can contact you for future research, and if we can share your data with other approved projects, to help get the best use out of the data we collect. This could result in being offered new treatments or interventions. This part is optional and is explained in more detail in the Participant Information Sheet.

How will we use information about you?

In this research study, we will collect data about your asthma/breathlessness, and broader physical and mental health. We will use information from you, your medical records, clinician assessments, and external sources (e.g. UK Severe Asthma Registry, NHS England and/or my local Integrated Care Board). We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study. Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules.

At the end of the study, we will save some of the data in case we need to check it and/or for future research. We will make sure no-one can work out who you are from the reports we write.

The information sheet tells you more details about the project.