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TIDe: **T**raining to **I**mprove **D**yspno**e**a

ExPRes: **Ex**ploring the beliefs of patients and referrers to **P**ulmonary **R**ehabilitation mod**es** of delivery (Sub-study)

Healthcare Professional Information Sheet

Invitation

We would like to invite you to take part in a research study.

This study is student research project. It is being led by an employee from University Hospitals of Leicester NHS Trust who is undertaking an MSc at Aston University.

Before you decide if you would like to participate, take time to read the following information carefully and, if you wish, discuss it with others such as your family, friends or colleagues.

Please ask a member of the research team, whose contact details can be found at the end of this information sheet, if there is anything that is not clear or if you would like more information before you make your decision.

What is the purpose of the study?

Chronic Obstructive Pulmonary disease (COPD) is a chronic condition characterised by its disabling breathlessness. Pulmonary Rehabilitation (PR) is highly recommended as it improves breathlessness, emotional wellbeing, exercise ability and self-management skills. However, hospital-based PR is poorly attended.

To try and tackle this poor attendance, new methods of PR have been developed and put into practice at University Hospitals of Leicester NHS Trust (UHL). These include the COPD self-management manual (SPACE for COPD), a similar online version of this, Breathe Easy groups and the Active Lifestyles scheme. However, these new methods are not offered routinely, they are only offered if patients express concerns about attending the hospital-based PR.

The aim of this research is to find out what patients with COPD and healthcare professionals think about the current PR referral pathway and whether more of a ‘menu-based approach’ to PR would be suitable and acceptable. This research will help us to understand how the PR pathway currently works and if any changes could be made to improve it.

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Why have I been chosen?

You are being invited to take part in this study because:

1. You have agreed to find out more about this study
2. You are a healthcare professional who referrers COPD patients to PR

What will happen to me if I take part?

If you express an interest in taking part in the study, the researcher will contact you to arrange an appointment to meet with you.

Visit 1:
This appointment will be carried out at your place of work or over the telephone. At this appointment, you will have the opportunity to ask questions about the study before deciding if you would like to take part. If you agree, you will be asked to sign a consent form to confirm your participation in the study.

You will then be asked to take part in a one-to-one interview with the researcher. The aim of the interview is to find out what you think about the PR referral pathway and the introduction of a 'menu-based approach' to PR.

The interview will last for approximately 1 hour. You are welcome to take a break throughout the interview if you would like.

Visit 2:
After your interview has been transcribed and analysed, the researcher will ask you to look at the results to check they have been understood correctly. This visit can be carried out at your place of work, over the telephone or can be communicated by email, whichever method is easiest for you.

How will the conversation during the interview be recorded and the information I provide managed?

With your permission we will audio record the interview and take notes.

The recording will be typed into a document (transcribed) by a transcriber approved by University Hospitals of Leicester NHS Trust. This process will involve removing any information which could be used to identify individuals e.g. names, locations etc.

Audio recordings will be destroyed as soon as the transcripts have been checked for accuracy.

We will ensure that anything you have told us that is included in the reporting of the study will be anonymous.

You of course are free not to answer any questions that are asked without giving a reason

Do I have to take part?

No. It is up to you to decide whether or not you wish to take part.

If you do decide to participate, you will be asked to sign and date a consent form.

What if I change my mind?

You can withdraw from the study at any time before, during or up to 2 weeks after the interview. After 2 weeks your data will have been made anonymous and so you will no longer be able to withdraw it from the study.

Will my taking part in this study be kept confidential?

Yes. A code will be attached to all the data you provide to maintain external anonymity.

Your personal data (name and contact details) will only be used if the researchers need to contact you to arrange study visits or collect data by phone. Analysis of your data will be undertaken using coded data.

The data we collect will be stored in a secure document store (paper records) or electronically on a secure encrypted mobile device, password protected computer server or secure cloud storage device.

To ensure the quality of the research University Hospitals of Leicester NHS Trust may need to access your data to check that the data has been recorded accurately. If this is required your personal data will be treated as confidential by the individuals accessing your data.

What happens if I tell you something that concerns you about my health or welfare or that of the person I care for?

In the unlikely event of this happening, we will discuss with you how this should be addressed. If necessary, to protect you and the person you care for, we will report your concern to the appropriate person or bodies

What are the possible benefits of taking part?

While there are no direct benefits to you of taking part in this study, the data gained will help us to improve the way the PR programme is delivered in order to help us improve our patient care.

What are the possible risks and burdens of taking part?

There are no anticipated risks involved in taking part in this study, although, we appreciate the extra time commitment from you. We also appreciate that some people may find it difficult to talk about some topics. You will not be asked to talk about anything you are not comfortable with.

What will happen to the results of the study?

University Hospitals of Leicester NHS Trust is the sponsor for this study, based in the United Kingdom. We will be using information from you and your medical records in order to undertake 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. University Hospitals of

Leicester NHS Trust will keep identifiable information about you for 5 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study two weeks following the interview, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting the Lead Researcher, Amy Barradell on Tel: 0116 258 3035.

University Hospitals of Leicester NHS Trust, in collaboration with Aston University, will collect information from you and your medical records for this research study in accordance with our instructions.

University Hospitals of Leicester NHS Trust, in collaboration with Aston University, will use your name and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from University Hospitals of Leicester NHS Trust, Aston University and regulatory organisations may look at your medical and research records to check the accuracy of the research study. The only people in University Hospitals of Leicester NHS Trust who will have access to information that identifies you will be people who need to contact you to audit the data collection process.

University Hospitals of Leicester NHS Trust will keep identifiable information about you from this study for 5 years after the study has finished.

Procedures for handling, processing, storage and destruction of your data are compliant with the Data Protection Act 2018. Data will be electronically stored, securely in an encrypted format.

The results of this study may be published in scientific journals and/or presented at conferences. If the results of the study are published, your identity will remain confidential.

A lay summary of the results of the study will be available for participants when the study has been completed and the researchers will ask if you would like to receive a copy.

The results of the study will be used in Amy Barradell's MSc Project report for Aston University.

Expenses and payments

There are no expenses or payments for taking part in this study.

Who is organising this study and acting as data controller for the study?

University Hospitals of Leicester NHS Trust is organising this study and acting as data controller for the study. This study is an educational project working in collaboration with Aston University.

Who has reviewed the study?

All research that involves NHS patients and staff, information from medical records or uses NHS premises must be granted a favourable opinion from the NHS research ethics committee prior to commencement. A favourable opinion does not mean that you will not come to harm during the study, however it does mean that the committee is satisfied that your rights will be respected and that risks are reduced to the minimum. This study has been reviewed and given favourable opinion by the Leicester South Research Ethics Committee.

What if I have a concern about my participation in the study?

If you have any concerns about any aspect of this study, you should speak to the researchers who will do their best to answer your questions (0116 258 3035). There are no special compensation arrangements in the unlikely event that you are harmed through taking part in the research study. If you are harmed due to someone's negligence you may have grounds for legal action but may also have to pay costs for such 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 you can contact the NHS Patient and Information Liaison Service (PILS) by telephone: 0808 178 8337 or email: pils@uhl-tr.nhs.uk

Research Team

Lead Researcher:	Principal Investigator:	Co-Investigator
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Thank you for taking time to read this information sheet. If you have any questions regarding the study please don't hesitate to ask one of the research team