

**The PERFORM Intervention Development Study: Personalised Exercise-Rehabilitation FOR people with Multiple long-term conditions**

**Participant Information Sheet**

This document explains exactly what would happen if you decide to take part in the PERFORM Intervention Development Study. If you would prefer to talk about this with a member of our team, please call Paulina Daw on 0759 555 0720 or email p.daw@bham.ac.uk

**What is this study about?**

The PERFORM Intervention Development Study is part of a wider programme of research (called the PERFORM programme) that will be running in many locations across the UK over the next six years. The overall programme is looking at ways to support older people with two or more long term health conditions (conditions like diabetes, heart disease, lung disease, depression, anxiety and many others) to improve their health and mental wellbeing. In particular, we are focusing on illnesses where exercise can be beneficial in helping to improve health and mental wellbeing. This is because we have a wealth of knowledge and experience in the use of exercise-based “rehabilitation” to help people with heart and lung disease and other conditions to recover some of their lost physical function, fitness and stamina. In addition to exercise we will include advice and planning on other important things that people can do to manage long term conditions, such as managing stress and low mood and managing medications.

The PERFORM Intervention Development Study will work with patients, their supporters (family and friends) and health professionals to plan the exercise and education programme to help people with long term conditions. We plan to do this by working closely with groups of people who have an interest in improving the health and wellbeing of people with long term conditions.

**Why have I been chosen?**

We want to work with people with experience of living with long term conditions AND their family or friends who have a substantial role in supporting them and this will be our Lived Experience Advisory Group (LEAG).

If you decide to take part in the study you will be able to invite a family member or friend to attend the LEAG meetings with you, so we can also understand the role of people who support those living with long term conditions. If you would rather not involve anyone else to take part in the study, that is also fine – you will be more than welcome to attend the LEAG meetings on your own.

We will also work with health professionals who treat or support people with long term conditions, such as nurses, GPs, physiotherapists, rehabilitation specialists and service managers who will become part of our Service Provider Advisory Group (SPAG). We will also work with people who commission (pay for) or organise health services for people with long term conditions.

We hope that the meetings will help us to understand the barriers and challenges that patients face when exercising and living with long term conditions (as well as the barriers to setting up and delivering services to support patients). We will then work together to develop an exercise and education programme that will help to overcome the challenges and support patients to manage their conditions better and improve their physical and mental wellbeing.

**Who is organising the study?**
The study is being organised by the School of Sport, Exercise and Rehabilitation Sciences, at the University of Birmingham, in collaboration with the University of Leicester and the Universities of Glasgow and York. It is being paid for by the National Institute for Health Research.

**Who is conducting this study?**

The researchers who will be doing this PERFORM Intervention Development Study are Paulina Daw (p.daw@bham.ac.uk 0759 555 0720) and Professor Colin Greaves (c.j.greaves@bham.ac.uk 0798 989 5165) of the University of Birmingham. The researcher responsible for the overall PERFORM project is Professor Sally Singh (sally.singh@uhl-tr.nhs.uk 0116 258 3388).

**If I volunteer, will I be guaranteed to take part in the study?**

No. We need to make sure that we select a diverse range of people for our advisory group. To do this, we will also ask you for some information about yourself, such as age, ethnic group, gender, long term conditions that you have. This will allow us to make sure that our LEAG meetings include patients affected by variety of long term health conditions. This will help to make sure that the exercise and education programme we develop works for a wide range of people.

**What will happen to me if I take part?**

If you agree to take part in the PERFORM study we would arrange for you, and (if you wish) your family member or a friend involved in your support, to attend between six and seven group meetings (or “workshops”) over a period of around 18 months and one final feedback meeting around 12 months. The meetings will be face to face providing there are no further COVID-19 restrictions. Each meeting will last around 2 hours and may require one or two hours of additional work (either pre-reading or making comments on the programme documents after the meeting). The meetings will help us to find ways to help people who have multiple conditions to engage in exercise and other actions to improve their health such as managing stress, anxiety or low mood and managing medications.

The LEAG meetings/workshops will be recorded to ensure that we don’t miss any important ideas that come up. Some of the things people say in these meetings may be used when we write reports about the study, but no quotes will be attributed to any individual person.

**Do I have to take part?**

Not at all, it’s up to you. Even if you agree to take part, you (and your support person) can drop out at any time and without giving a reason. If you change your mind about taking part, at any stage, you just need to let us know. If you decide to drop out of the study, the researchers can remove your contact details from their database, but comments you have made at the LEAG meetings cannot be removed, once the workshops have started.

**What are the possible risks of taking part?**

We do not anticipate there will be any risks in taking part in this study.

**What are the possible benefits of taking part?**

You will be contributing to a large study that will develop a programme which will help patients to find better ways of living with long term health conditions. This could change the way that the NHS is organised, especially for people with multiple long term conditions. If successful this may improve the health and wellbeing of many older adults in the future.

**Will I be paid for taking part?**

Yes. Lived Experience Advisory Group members will be offered an honorary payment of £60 per group meeting (plus local travel cost). This reflects the time input required both within and before or after the meeting. Payments may affect entitlement to benefits and the study team can provide advice on this if needed. If we are unable to hold face-to-face meetings/workshops and need to meet virtually instead, an additional small payment for data usage may also be paid on request if any extra costs are incurred. You can also chose to have payments reduced or donated to a charity of your choice if preferred.

**Confidentiality and data protection**

Your involvement in this project, anything you say and all the information you give us is confidential. Any personal data will be “anonymised” (by using a code instead of, for example, your name) so that the results cannot be linked back to you. All your personal data will be kept on password-protected computers and any paper information (such as your consent form) will be stored safely in lockable cabinets in locked rooms and would only be accessed by members of the PERFORM Intervention Development Study. Members of the Universities of Birmingham or Leicester (the location of the chief investigator for the overall PERFORM research programme) may be given access to data for monitoring and/or audit of the study to ensure we are complying with guidelines. With your consent, we will keep your personal information on a secure database in order to contact you for the purposes of organising this study. You may also consent (or not) for us to contact you about taking part in future studies.

**Who do I contact if I have any complaints?**

If you have concerns about the study and how it is being done, please contact Professor Colin Greaves (c.j.greaves@bham.ac.uk or 0121 414 8061) or Professor Sally Singh (sally.singh@uhl-tr.nhs.uk or 0116 258 3388). Any complaints will be dealt with through standard complaint procedures at the University of Birmingham.

**Who approved this study?**

This study has been reviewed and approved by the University of Birmingham Research Ethics Committee.

**What next?**

Before you decide whether to take part, we would be happy to answer any questions you might have. Please contact Paulina Daw at p.daw@bham.ac.uk or 0759 555 0720.

**With warm thanks from:** **The PERFORM research team**