

Participant Information Sheet

Introductory Statement

Research Study Title: “MoveWell Parkinson’s Programme’: A 6-week evidence-based hybrid (online and in-person) multimodal exercise programme for people living with Parkinson’s Disease in Ireland.

Researchers:

Dr Siobhán O’Connor, School of Health and Human Performance, Dublin City University, siobhan.oconnor@dcu.ie

Dr Diane Cooper, EduFIT, info@edufit.ie

Dr Kiera Ward, EduFIT, kiera@edufit.ie

Ruth Kavanagh ANutr. MSc., EduFIT, ruth@edufit.ie

Catherine Nicholl, BSc., School of Health and Human Performance, Dublin City University and EduFIT, catherine.nicholl7@mail.dcu.ie or catherine@edufit.ie.

What is this research about?

The purpose of this research study is to examine the feasibility, acceptability and benefits of a 6-week evidence-based hybrid (in-person and online) multimodal exercise programme for people living with Parkinson’s Disease.

Why is this research being conducted?

Multimodal exercise programmes incorporating strength, balance, flexibility, mobility, and aerobic exercise have been shown to improve motor and non-motor symptoms of PD. To our knowledge, there are currently no structured 6-week hybrid multimodal exercise programmes for people living with PD in Ireland, which are underpinned by clinical exercise physiology and incorporates exercise education. This research is being conducted to determine if there are benefits associated with the programme for people living with PD.

Why have you been invited to take part?

Male and female participants aged 18+ years who are living with PD and residing in county Laois and county Offaly are invited to participate in this research study. This includes people diagnosed with early-onset PD or those in stage 1.0 – 3.0 PD. Participants with additional injuries and clinical conditions (including cardiovascular disease, type 2 diabetes, arthritis, osteopenia, osteoporosis, back pain, and joint pain) will not be excluded from this study as they will benefit greatly from multimodal exercise training. Please note, if you have unstable angina and/or heart failure and/or Lewy body dementia, you will be unable to participate in this research study.

What will happen if you decide to take part in this research study?

Screening: If you are interested in taking part in this research study, you will be asked to complete the physical activity readiness questionnaire (PAR-Q & You). This questionnaire screens for injuries and illnesses. If you answer ‘yes’ to any of the PAR-Q questions, you will be required to obtain medical clearance from your local General Practitioner (GP) to take part in this study (a letter to confirm you are medically eligible).

Pre- and Post-Intervention Testing: Pre- and post-intervention testing will occur the week before and the week after the 6-week intervention (week 0 and week 7) respectively, in a community hall in Portlaoise, county Laois. Following detailed explanations, you will be asked to perform a MiniBEST (balance), 10-meter walk test (walking speed), 5 sit-to-stand (lower-body muscle strength), timed up and go test (mobility), 6-minute walk test (aerobic capacity), and 30-second bicep curl test (upper-body muscular strength and endurance). The testing session will be structured accordingly, to ensure you have rest periods between the tests. You will also be asked to complete an online questionnaire on Qualtrics before and after the 6-week intervention (week 0 and week 7, respectively) which will examine your physical activity participation, multimodal exercise participation, freezing of gait, fatigue,

confidence to complete activities of daily living, quality of life, and wellbeing. The research team will be contactable if you need assistance with the completion of online questionnaires.

6-Week Intervention: Following the completion of pre-intervention testing, you will start your 6-week intervention of multimodal exercise training. You will be asked to attend 2 * 60-minute in-person community-based multimodal exercise classes per week and 1 * 40-minute live online multimodal exercise class per week. The live online exercise classes will be delivered using Zoom by trained exercise professionals and will be additionally monitored by a clinical exercise physiologist. You will be asked to turn on your camera during the live online exercise classes so we can monitor your technique. You will also be asked to attend 1 * 10-minute in-person exercise education workshop every week, after one of your in-person exercise classes. These will also be recorded and made available in an on-demand library. There will be substitute multimodal exercise classes available in your on-demand library if you cannot complete any of the live exercise classes in a particular week. The research team will be contactable if you need assistance with accessing the on-demand exercise videos.

How will your data be used?

All information collected during this study will be handled safely and in line with GDPR rules. At the start of the study, you will be given a unique research ID number. Your name will not appear on any study data. Instead, all information collected, whether on paper or electronically, will be labelled using this ID number. A secure electronic file that links your name to your research ID, email address, and phone number will be stored in a password-protected DCU Google Drive folder. Only the research team can access this file, using secure login and multi-factor authentication. This file will be deleted when the study ends. Any paper records will be kept in a locked filing cabinet in a locked staff office in Dublin City University. These paper records will be securely shredded once the study is finished.

All study data that does not include your name (called “pseudo-anonymised data”) will be stored securely on a password-protected DCU Google Drive folder and used only by the research team to analyse the results. After the file linking your name to your ID is deleted (on 2nd April 2027), the data will become fully anonymous. Anonymous data may be kept indefinitely to support future research publications. It may also be shared with other researchers for further analysis (for example, as part of a larger research review) or placed in a public research data repository. You will not be identifiable in any shared data.

The results of this study will be published in scientific journals, presented at conferences, and shared through social media, media outlets, and Local Sports Partnerships. Only combined group data will be reported. No individual participant will be identified. Dublin City University (DCU) is responsible for managing your data for this study. The study follows GDPR regulations. If you have any concerns about how your data is being used or protected, you may contact: DCU Data Protection Officer, Mr. Martin Ward – (data.protection@dcu.ie Tel: 01-7005118/01- 7008257). An individual also has the right to report a complaint concerning the use of personal data to the Irish Data Protection Commission: <https://www.dataprotection.ie/>

How will your privacy be protected (including any legal limits to confidentiality)?

Confidentiality and privacy are of utmost importance. While we collect personal information (e.g., name, email address, phone number, etc.), these will not be published in an identifiable manner. You will be provided with an individualised research study code that will be used throughout the study. The electronic document containing your name, corresponding research ID number, email address and phone number will be deleted at the completion of this research study and will not be published in any form. Confidentiality of information provided can only be protected within the limitations of the law. It is possible for data to be subject to subpoena, freedom of information claim or mandated reporting by some professions.

What are the benefits of taking part in this research study?

Following the completion of the 6-week intervention, you will be provided with a full report of your results from the pre- and post-intervention tests, which will include feedback on the changes, if any, that occurred. You may experience improvements in balance, lower- and upper-body muscle strength and endurance, mobility, aerobic capacity, physical activity participation, multimodal exercise participation, freezing of gait, fatigue, confidence to complete activities of daily living, quality of life, and wellbeing. All the tests and exercise classes will be provided free of charge and will be delivered by trained professionals.

What are the risks of taking part in this research study?

There are minimal risks to participants who are involved in the research project. Exercise does carry a risk of injury, such as a pulled muscle, muscle soreness or in extreme cases abnormal heart rhythm, heart attack or death. To minimise these risks, you will be asked to complete a PAR-Q to determine your suitability for the study. You may need to obtain medical clearance from your GP if you answer 'yes' to any of the questions on the PAR-Q form (a letter to confirm you are medically eligible). All in-person pre- and post-testing sessions and exercise classes and online exercise sessions will include an appropriate warm-up and cool down (15 minutes) and stretching to reduce the risk of injury. This also significantly reduces the risk of adverse events for people who have cardiovascular conditions. You will also receive education on exercise intensity and be advised to exercise at an intensity that is appropriate for you. You will be provided with colour coded rate of perceived exertion (RPE) cards (green = low intensity, orange = moderate intensity, red = high intensity) and instructed on how to use these during the online exercise sessions when exercise instructors ask for an exercise intensity check. You will be monitored throughout pre- and post-testing and during in-person and online exercise classes by a team of trained professionals, including a clinical exercise physiologist and phase IV cardiac rehabilitation specialist. You will also be asked to have your phone with you during testing and the in-person classes, and when you're exercising at home in case, we need to contact you privately. If you have any complex cardiovascular conditions, you will be provided with a heart rate monitor and taught how to record your heart rate and be given advice on the heart rate ranges you need to stay within during the online exercise classes.

Can you change your mind at any stage and withdraw from this study?

Your participation in this research study is voluntary. You may withdraw from the research study until the point at which this research is published or following completion of the project (2nd April 2027) as your name and linked unique ID code will be permanently deleted at that point. You can withdraw by contacting any of the study investigators by email or phone. Changing your mind or not taking part in this research will not affect your relationship with DCU, EduFIT or Laois Sports Partnership.

How will you find out what happens with this project?

If you would like information on the results of this research study, this information will be provided once you email any of the researchers using their contact information below.

Is this study free to participate in? Who is funding this project?

Yes, this study is free to participate in as it has received funding from Sport Ireland in partnership with Laois Sports Partnership (LSP).

Contact details for further information:

If you have any questions at any time, please contact:

Dr Siobhán O'Connor, FT215, School of Health and Human Performance, Polaris, Dublin City University, siobhan.oconnor@dcu.ie, 017008579.

Dr Diane Cooper, info@edufit.ie

Dr Kiera Ward, kiera@edufit.ie

Ruth Kavanagh ANutr. MSc., ruth@edufit.ie

If you have concerns about this study and wish to contact an independent person, please contact:

The Secretary, Dublin City University Research Ethics Committee, c/o Research and Innovation Support, Dublin City University, Dublin 9. Tel 01-700 8000, e-mail rec@dcu.ie