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CityCare are providing financial support to Sarah McCracken. The University of Nottingham is acting as the academic sponsor.

Study Title: NORDIC WALKING & PARKINSON'S DISEASE
Understanding the impact, accessibility, and diversity of Nordic
Walking in People with Parkinson's disease after the Covid-19
pandemic.

PARTICIPANT INFORMATION SHEET

Research Ethics Reference: FMHS 331-0821

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We would like to invite you to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. One of our team will go through the information sheet with you and answer any questions you have. Please take time to read this carefully and discuss it with others if you wish. Ask us anything that is not clear.

What is the purpose of the research?

The purpose of this study is to increase the accessibility of Nordic Walking following Covid-19 lockdown; for people who have Parkinson's disease. There is a growing body of evidence that Nordic Walking can help people walk better and have an improved feeling of wellbeing. The charity Parkinson's UK is working collaboratively with British Nordic Walking to train accredited Nordic Walking instructors in Nottinghamshire who have a special interest in Parkinson's. This study explores whether Nordic Walking improves walking ability, posture and wellbeing. It also aims to offer Nordic walking as a safe, outdoor, supportive exercise group after a period of Covid related restrictions. We would like to recruit people from diverse backgrounds; especially those who struggle to access exercise groups.

Why have I been invited to take part?

You have been invited to take part in this research because you have been diagnosed as having Parkinson's disease and have expressed an interest in Nordic Walking. You have indicated that you are physically capable of walking for an hour at a weekly class, without a walking aid, are over 18 years of age and can attend a Nordic Walking group.

Unfortunately, we are unable to accept people into the study who have the later stages of Parkinson's, complex or acute health problems or advanced dementia. We aim to recruit forty to sixty participants in this study.

Do I have to take part?

No. It is up to you to decide if you want to take part in this research. We will describe the study and go through this information sheet with you to answer any questions you may have. We will check that you will be able to take part. If you agree to participate, we will ask you to sign a consent form and will give you a copy to keep. However, you would still be free to withdraw from the study at any time, without giving a reason and without any negative consequences, by advising the researchers of this decision. This would not affect your legal rights.

What will happen to me if I take part?

A researcher will contact you to complete some simple assessments to measure your walking speed, posture and your feelings of wellbeing; taking about thirty minutes to complete. There is an optional extra measurement addressing balance (BERG) that takes a further twenty minutes. You will then be asked to join the Nordic Walking group which is led by a trained Nordic Walking Instructor.

You will need to attend the Nordic Walking class for one hour per week for 8 weeks. The first week will be a taster session/ introduction to Nordic Walking and then we will progress to being in a public space with a group of people who have Parkinson's disease. The poles and gloves/ straps will be provided, but you will have to provide walking shoes/ trainers and a raincoat. You will also need to get yourself to the Lakeside Arts Centre; University Park Campus, University of Nottingham, NG7 2RD or to an alternative venue; agreed by the research team. During the Nordic Walking sessions, the instructor will ask you questions about how you are finding it and she will write these in her field notes. These notes will be used in the research.

After 8 weeks of the Nordic Walking you will be asked to complete the same assessments on walking and well-being. You will then be given information about established Nordic Walking groups to give you the chance to continue. We'd like to follow and record your progress over the next 6-9 months and so will contact you to repeat the assessments you have done before and after the Nordic Walking programme.

What is Nordic Walking?

Nordic walking is a total body workout utilising 90% of skeletal muscles. It's a version of walking that is performed with specially designed 'sport' walking poles similar to cross country ski poles. It focuses on large movements through the arms and legs and is superior to 'just walking'. It's usually enjoyed in a group setting, outdoors in green spaces. It was one of the first outdoor sports to start again after the Covid-19 lockdown.

Are there any risks in taking part?

The main risks of taking part are that you may have slight muscle pain as you may be using muscles in a different way. You will be taught how to warm up and cool down as part of each session. The instructor will talk about this with you and tailor the walks to your ability. There is no evidence that Nordic Walking causes people to fall, but there is a slight chance that by walking more, you have more chance of falling. However, Nordic walking should improve your balance, posture and gait. The instructor is trained in falls prevention and will be undertaking risk assessments before each session.

Are there any benefits in taking part?

You may benefit from taking part in Nordic Walking as it is a tailored exercise programme and exercise has been shown to have a positive impact on mood and muscle strength. The researcher is an experienced Parkinson's Nurse Specialist and Nordic walking instructor.

Will my time/travel costs be reimbursed?

Participants will not receive an inconvenience allowance to participate in the study, but you are very welcome to keep the poles to support you continuing to Nordic Walk with established groups.

What happens to the data provided?

The research data will be stored confidentially. We will allocate each participant a number and all research data will be stored using that number so that none of the data will have your real name or other individual identifiers associated with them. Your name and any information about you will not be disclosed outside the study centre. Your personal data and consent form will be kept separate to the research data. The researcher and supervisor will have access to your personal and research data. We would like your permission to use fully anonymised direct quotes in research publications. All research data and records will be stored for a minimum of 7 years after publication or public release of the work of the research.

We would like your permission to use anonymised data in future studies, and to share our research data (e.g. in online databases) with other researchers in other Universities and organisations both inside and outside the European Union. This would be used for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. All personal information that could identify you will be removed or changed before information is shared with other researchers or results are made public.

What will happen if I don't want to carry on with the study?

Even after you have signed the consent form, you are free to withdraw from the study at any time without giving any reason and without your legal rights being affected. Any personal data will be destroyed. If you withdraw, we will no longer collect any information about you or from you but we will keep the anonymous research data that has already been collected and stored as we are not allowed to tamper with study records. This information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally identifiable information possible.

Who will know that I am taking part in this research?

Data will be used for research purposes only and in accordance with the General Data Protection Regulations. All such data are kept on password-protected databases sitting on a restricted access computer system and any paper information (such as your consent form, contact details and any research questionnaires) would be stored safely in lockable cabinets in a swipe-card secured building and would only be accessed by the research team.

Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (Prof Pip Logan) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate.

You can find out more about how we use your information and to read our privacy notice at:

<https://www.nottingham.ac.uk/utilities/privacy.aspx/>

Designated individuals of the University of Nottingham may be given access to data for monitoring and/or audit of the study to ensure we are complying with guidelines.

Anything you say during an interview/focus group will be kept confidential, unless you reveal something of concern that may put yourself or anyone else at risk. It will then be necessary to report to the appropriate persons. Due to the professional responsibilities of some University staff, if you mention something during the focus group which may require reporting the research team will discuss it with you and decide on a course of action. This may involve implementing the University of Nottingham, Safeguarding policy.

What will happen to the results of the research?

The research may be published in nursing or medical journals and will be presented at health-related conferences. A report will be written for Parkinson's UK and then disseminated to clinical teams in the East Midlands. All participants will be anonymous within the report and you will be sent a copy.

Who has reviewed this study?

All research involving people is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. There are three patient and public involvement representatives who have reviewed all the study documents and they actively contribute to research project meetings. The study papers have all been reviewed by an academic supervisor and the project team.

Who is organising and funding the research?

This study is being organised by Professor Pip Logan and Dr Vicky Booth through the University of Nottingham and partially funded by the National Institute for health research (NIHR) through their Capacity Development Scheme. Additional funding and support for this innovation has been granted by Nottingham CityCare partnership with mentor support from British Nordic Walking.

What if there is a problem?

If you have a concern about any aspect of this project, please speak to the lead researcher Sarah McCracken, Principal Investigator Professor Pip Logan or the Chief investigator, Dr Vicky Booth who will do their best to answer your query.

The researcher should acknowledge your concern and give you an indication of how she intends to deal with it. If you remain unhappy and wish to complain formally, you can do this by contacting the FMHS Research Ethics Committee Administrator, Faculty Hub, Medicine and Health Sciences, E41, E Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH or via E-mail: FMHS-ResearchEthics@nottingham.ac.uk.

Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

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