# Understanding the impact, accessibility and diversity of Nordic Walking in People with Parkinson’s Disease

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I have had wonderful opportunities to share my research with NHS colleagues, partners in industry (BNW, PUK), and recently, I represented the National Rehabilitation Centre (NRC) for two days at the Royal Society summer science exhibition in London (July 2023). I published a paper in 2021, as a result of the pilot Nordic walking for Parkinson's study (McCracken et al., 2021). I was asked to speak at a conference for over one hundred British Nordic walking instructors in 2021 and 2022. The Parkinson's Disease Nurse Specialist Association (PDNSA) invited me to speak to 130 of their members at Warwick University in October 2022. I addressed 50 senior academics and partners in industry, including the NRC, in July 2023, at the University of Nottingham School of Medicine. I have presented my research to fellow MPhil and PhD students as well as my community neurology team, stroke team, a carers' event and to physiotherapy colleagues.

In July 2022 I had an opportunity to run a stall at a Community Arts festival at Wollaton Park. We offered NW taster sessions for the public and had incredibly positive feedback. I am thankful to councillor Cate Ward for the opportunity. Thank you to Alison Clarke from BNW who volunteered at the arts festival, and who has been my mentor and friend for four years.

I was inspired by a local GP who encouraged her patients to exercise and led by example. She started a local 'Couch to 5K' inclusive group and ran with her patients after work. At a similar time, a local oncologist and a person who was diagnosed with cancer at the age of 24 co-founded the charity '5K Your Way'. This community-based initiative promotes exercise for anyone living with and beyond cancer. Families, friends and those working in cancer services are encouraged to walk, jog, run, cheer or volunteer on the last Saturday parkrun event every month.

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# Abstract

## Background

Nordic Walking (NW) is an enhanced walking technique that uses special poles to increase the effort of the arms and legs. NW provides an all over body workout that is reported to improve posture and gait, strengthen the back and abdominal muscles, reduce the impact on joints and burn 20% more calories than walking without poles (British Nordic Walking, 2023b). There is a growing body of research supporting the use of NW as a means of regular, outdoor exercise for people of all ages and for those with a range of physical and mental health challenges. Research of NW shows promising outcomes for people with Parkinson’s (PwP), with significant improvements in walking speed and stride length, postural stability, gait, and in cognitive aspects of movement preparation (Ebersbach et al., 2014). However, the effectiveness and results of NW research in this population are inconsistent as there is heterogeneity of participants, various methodologies, no standardised model of NW delivery, and little data about the longer-term physical and psychological implications of NW.

This MPhil aimed to address this gap by exploring the impact of NW as a novel form of neurorehabilitation, taking the perspective of PwP on their quality of life/non-motor symptoms (NMS) into account, as well as measuring quantitative physical health outcomes. This study was conducted as society emerged from the Coronavirus (COVID-19) pandemic. PwP, with a diverse range of symptoms and backgrounds, were searching for safe ways to exercise outdoors, in a group, guided by an instructor with experience of Parkinson’s Disease (PD) and exercise. The data from this MPhil could inform new models of NW intervention, which might be suitable for larger effectiveness trials.

## Aims

1. Explore the motor (physical) and non-motor (psychological and quality of life) impact of an eight-week programme of NW for PwP, by establishing the short-term and longer-term (after six months) impact of NW as a means of neurorehabilitation in this population.
2. Determine the feasibility and accessibility of the NW intervention for a diverse sample of PwP.
3. Understand the core components needed to implement a NW group intervention for PwP in a community rehabilitation setting.

## Methods

A narrative literature review explored the impact and effectiveness of NW in PwP, with results presented in Chapter 1.

A quantitative repeated measures study is presented in Chapter 2. PwP were assigned to receive an eight-week course of NW intervention delivered by a trained NW instructor (NWI) who was also a Parkinson’s Disease Nurse Specialist (PDNS). Timed up and go (TUG), 10 metres and 20 metres walk tests (MWT), Tragus to wall distance (posture), Berg Balance (BB) and the Non-Motor Symptoms Scale (NMSS) questionnaires were recorded at baseline (T0), week eight (T1), and at month six (T2). Data were analysed using descriptive statistics

and the mean change over time explored using two tailed paired t-tests. Field notes were written at the end of every NW session and were an adjunct to the main pre-post repeated measures study.

Three focus groups (FGs) were conducted to understand the core components and characteristics required to implement outdoor community NW rehabilitation groups for PwP (Chapter 3). Two FGs for PwP and one for NWIs and a walk leader (WL) were conducted. Participants were recruited from the first study, employing the same eligibility criteria. Participants were recruited via a research call from Parkinson's UK, from local Parkinson's Disease (PD) support groups, and via NHS colleagues. Data were analysed using thematic analysis (TA) methods and reviewed by a second researcher (Braun and Clarke, 2006). The Behaviour Change Wheel (Mitchie, 2011) was used as a theoretical framework for organising the themes and facilitated recommendations for future research, policy, and clinical practice. These recommendations were reported as core components.

**Results**

The literature review provided the following definition of NW: "*An intensification of regular walking thanks to the active use of a pair of specially designed NW poles, whilst maintaining the characteristics of natural, bio-mechanically correct walking and appropriate posture*," (Mass, 2023), p33. Previously published studies confirmed the potential for NW as a novel form of neurorehabilitation (Cugusi et al., 2017), (Silverberg and Prejserowicz, 2018), (Salse-Batán et al., 2022). Theories of rehabilitation for PwP were defined and explored, including a health psychological approach and practical exercise recommendations (Parkinson's UK's excellence network, (Ramaswamy et al., 2018)). Engagement (or lack thereof) with therapy programmes was examined, in the context of health psychology and behaviour change theories, such as Michie's behaviour change wheel (BCW) (Michie et al., 2011).

The repeated measures study recruited 49 PwP and of this sample, 40 PwP (n=27 males) completed eight weeks of NW intervention. PwP ranged from 47 to 83 years, mean age 66. Mean Hoehn and Yahr (H&Y) stage of PD was 2.20, (range 1-4). Thirty-nine PwP (n=24 males) completed eight-week follow-up physical assessments and 34 (n=19 males) returned for six month follow up data collection. The return rate for NMSS questionnaires at baseline was (n=24, 61.5%), at week eight (n=13, 33.3%) and month six (n=20, 51.3%). Of 39 PwP who completed the intervention and assessments, statistically significant improvements were observed in the following motor assessments: 10 MWT and 20 MWT (gait speed and cadence), TUG, Tragus, all with p values <0.001. The mean change in Tragus was -2.03 cm after eight weeks and this improved six months post intervention (-2.73 cm). These improvements (p <0.001) indicated continued benefits of a NW programme after the period of intervention. Improvements were recorded in NMS, especially dimensions of sleep and fatigue, mood and cognition and some urinary symptoms. All motor and some of the non-motor improvements persisted after six months. Data from nine participants who did not complete eight-weeks of NW intervention (NMSS and field notes) were analysed and explored. There was a mean reduction in the total NMSS of -10.08 points after eight weeks of NW (p value 0.03). This sample of PwP appeared to have improved NMSS across all domains and most notably sleep and fatigue (p value 0.006), cognition and mood (p value 0.77), and urinary symptoms (p value 0.24). These improved quality of life dimensions were substantiated in the field notes. This was a diverse sample and some participants had high baseline scores for cognition, mood, and urinary symptoms. An unanticipated result was a general improvement in reported urinary symptoms after the intervention (-2.46), (p value

0.25), which could have clinical implications if NW was found to positively impact core stability and pelvic floor musculature. This warrants further exploration in the literature and additional studies. Combined with improvements in speed of walking, posture and confidence, this sample of PwP articulated a reduced fear of falls, which they attributed to NW. There were no adverse events.

Fifteen participants were recruited into the three FGs, including 11 PwP (n=6 males), three British Nordic Walking Instructors (BNWI) (n=1 male) and one walk leader (WL, n=0 male). PwP ranged in age from 51 to 80 (median 72) years. Analysis of the FG data highlighted six main themes: physical benefits, social interaction, core practical components, qualities and characteristics of the NWI, risk management and safety, and other facilitators for delivering community NW groups. PwP reported physical and psychological benefits from participating in an eight-week programme of NW. Optimising safety was an important theme, utilising COVID-19 screening tests and health screening risk assessments (PARQa) for PD and complex comorbidities. Core components required to deliver community PD rehabilitation groups include practical facilitators: parking, public transport (access), toilets and café (amenities), an instructor with knowledge and experience of PD, and effective partnerships with PUK and BNW. Opportunities to NW with friends and family at groups and parkrun may promote a change in behaviour or lifestyle that has a longer-term impact. Within this study, PwP enjoyed peer support and appreciated NW outside in the park.

**Conclusion**

These studies suggest that an eight-week programme of NW improves mobility, upright posture, NMS domains including cognition, mood, sleep, fatigue, and some urinary symptoms in PwP. Results from the repeated measures study indicate that further trials are needed to explore NW effectiveness and implementation in the NHS. Future studies could employ a randomised controlled trial (RCT) design comparing NW to routine care or to specialist, supervised community exercise or physical activity-based interventions. Results from both studies demonstrate that the aims of the MPhil were fulfilled, and recommendations were made for future research and practice. Future NW community rehabilitation groups for PwP could seek NHS, social values funding, social prescribing (NHS England), or third-party sources, in partnership with BNW and PUK.

**Key words.** Nordic Walking, Parkinson’s, Parkinson’s Disease, motor symptoms, non-motor symptoms, repeated measures, focus group, community rehabilitation.

**Ethical considerations.** Ethical approval was granted in September 2021, by the University of Nottingham, Faculty of Medicine Research Ethics Committee. REC ref: FMHS 331-0821 (Appendix 1).

**Table of Abbreviations**

| Abbreviation | Meaning |
|---|---|
| AMED | Allied and Complementary Medicine Database |
| APA | American Psychological Association |
| BB | Berg balance |
| BCW | Behaviour Change Wheel |
| BNW | British Nordic Walking |
| BNWI | BNW Instructor |
| CI | Confidence Interval |
| CINAHL | Cumulative Index to Nursing and Allied Health Literature |
| COM-B | Capability, Opportunity, Motivation-Behaviour change |
| COM | Capability, Opportunity, Motivation |
| COVID-19 | Coronavirus-19 pandemic |
| CPD | Continuing professional development |
| DBS | Deep brain stimulation |
| Dr | Doctor |
| FG | Focus group |
| FoG | Freezing of Gait |
| H&Y | Hoehn and Yahr (Stage of Parkinson's) |
| HEP | Home Exercise Programme |
| $I^2$ | The percentage of variance across studies that is due to heterogeneity rather than chance. |
| INWA | International Nordic Walking Association (federation). |
| JBI | Joanna Briggs Institute |
| LSVT | Lee Silverman Voice Training |
| LSVT BIG | LSVT Big |
| MDT | Multi-Disciplinary Team |
| MPhil | Master of Philosophy |
| MWT | Metre Walk Test |
| NHS | National Health Service |
| NICE | National Institute for Health and Care Excellence |
| NMS | Non-Motor Symptoms |
| NMSS | Non-Motor Symptoms Scale |
| NMS Quest | NMS Questionnaire |
| NSF | National Service Framework |
| NW | Nordic Walking |
| NWI | Nordic Walking Instructor |
| NRC | National Rehabilitation Centre |
| PARQ | Physical Activity Readiness Questionnaire |

| | |
|---|---|
| PARQa | PARQ adapted for PwP |
| PEMRIG | Parkinson’s East Midlands Research Interest Group |
| PIP | Personal Independence Payment |
| PRISMA | Preferred Reporting Items for Systematic Reviews and Meta-Analyses |
| PubMed | Free full-text archive of biomedical and life sciences. |
| PD | Parkinson’s Disease |
| PDNS | PD Nurse Specialist |
| PPE | Protective personal equipment |
| PUK | Parkinson’s UK |
| PwP | People with Parkinson’s |
| RA | Rheumatoid Arthritis |
| RAND | Health related Quality of life questionnaire (RAND-36). |
| RCT | Randomised Controlled Trial |
| SCT | Social Cognitive Theory |
| SM | Sarah McCracken |
| SMD | Standardised Mean Difference |
| SPSS | Statistical Package for Social Sciences |
| TA | Thematic Analysis |
| TTM | The Transtheoretical Model |
| TUG | Timed up and go |
| TWD | Tragus to wall distance |
| UoN | University of Nottingham |
| WHO | World Health Organisation |
| WL | Walk Leader |

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# CHAPTER 1 INTRODUCTION

## 1.1 Overview

In March 2020, the Coronavirus (COVID-19) pandemic resulted in many services for Parkinson’s Disease (PD) being stopped (World Health Organisation, 2021). NHS hospital clinics moved to virtual telephone or video appointments, and gym and physiotherapy rehabilitation units closed for many months (Dorsey et al., 2020). Community PD services adapted quickly, using personal protective equipment (PPE), robust risk assessments and novel ways of working, as described by Ellis et al, (2022). Many PwP experienced physical deconditioning due to reduced levels of activity (Ellis et al., 2022) and there was a tangible impact on well-being, mental health and social isolation (Brooks et al., 2021). Many PwP became more sedentary or fearful of leaving home (Dommershuijsen et al., 2021). Some PwP chose to keep active by walking, cycling, gardening or walking their dog. This data was collected as part of a pilot study, exploring the barriers and benefits of NW for PwP (McCracken et al., 2021). In this study, NW was offered outdoors, at the University of Nottingham (UoN) in July 2020, by a Parkinson’s Disease nurse specialist (PDNS)/lead researcher (SM), when people were permitted to exercise in small groups outside, following strict COVID-19 government guidelines (www.gov.uk, 2021). This small proof-of-concept study with ten participants (McCracken et al., 2021), indicated that it was possible for PwP to NW, but what was not known were the requirements to implement these groups in a community rehabilitation setting or the impact the intervention would have on their health.

As COVID-19 restrictions lifted, many PwP were looking for safe ways to exercise and to maintain fitness, alone or in community rehabilitation groups (Yang et al., 2022). Some individuals attended new PD physiotherapy exercise classes over ‘Zoom’ or other social media platforms (Neuro Heroes, 2023). There was a rise in telemedicine and novel technologies (Dorsey et al., 2020). A question posed by Domingos was ‘*Is being physically active enough, or do PwP need structured supervised exercise? Lessons learned from COVID-19’* (Domingos et al., 2022b). This question was explored in more detail in this MPhil study in the context of a community rehabilitation NW intervention, delivered by a PDNS.

NW is a growing area of research interest, owing to its global rise in popularity over the past 20 years; as a sport, leisure activity and a novel rehabilitation intervention (Pellegrini et al., 2015, International Nordic Walking Federation, 2023). Current literature focusses on the physical impact on posture, walking speed, balance, and gait. There is a gap in qualitative research on NW from the perspective of people living with neurological conditions, such as PD. One question that warrants further exploration is, ‘What do PwP believe to be the core features of NW and how, as an intervention, can it be done in practice?’ Physical rehabilitation for PwP is usually delivered by neurological physiotherapists rather than PDNS, in a gym, rehabilitation unit, clinic or at home, with NHS waiting lists for therapy. This study investigates a NW intervention, delivered in a group by a PDNS, which has potential to be more cost-effective, accessible, and timely than current service provisions. The study explores whether it is feasible, and if there is any indication of benefit.

## 1.2 Parkinson's Disease (PD)

### *1.2.1 PD definition and symptoms*

PD is caused by degeneration of nerve cells in the substantia nigra area of the brain (De Santis and Kaplan, 2020). This leads to a reduction in the neurotransmitter, dopamine, which is an important chemical for movement, mood, memory, attention, motivation, and pleasure (Rogers et al., 2017).

The widely accepted criteria for a diagnosis of Parkinson's are the presence of bradykinesia (slow movements) with one or more of the following symptoms: tremor at rest, rigidity, and postural instability (Bloem et al., 2021). Tremor can impact upon daily life (Silva et al., 2016) and lead to reduced dexterity, difficulties with work, operating machinery, computers, technologies, activities of daily living such as personal care (Abate et al., 2017), feeding, and some hobbies. Rigidity for some PwP can be painful, unpleasant and might have an associated dystonia or clawing of the hands and feet (McDonald et al., 2018). In addition, PwP may experience slow or reduced movements, including micrographia (small handwriting) (Behrman et al., 2020). In the lower limbs, bradykinesia can lead to a shorter stride, shuffling gait, poor balance (Wróblewska et al., 2019), and an increased risk of falls (Ellis et al., 2022). Bradykinesia in the hands and fingers could result in reduced grip power and dexterity (Yang et al., 2022). Postural instability is a complex and challenging feature of Parkinson's as it may lead to impaired balance and, ultimately falls (Franzoni et al., 2018).

### *1.2.2 PD incidence and prevalence*

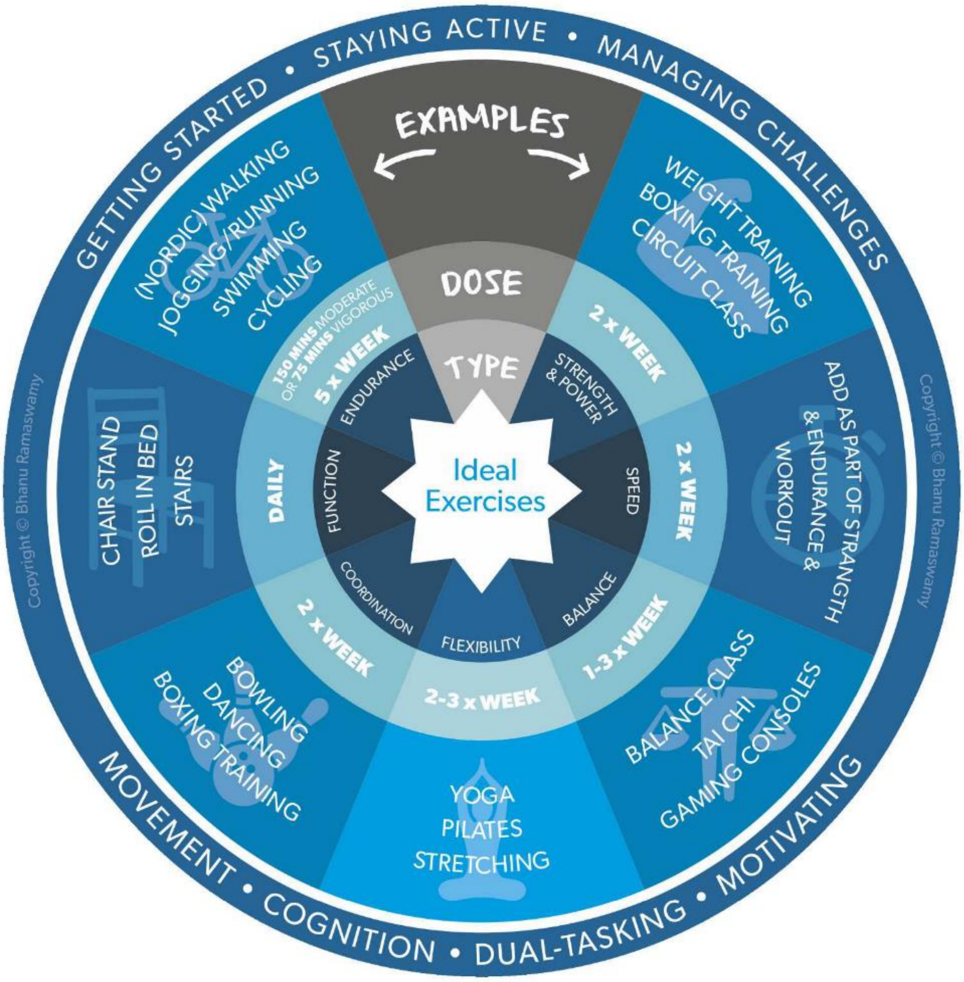
PD is the fastest growing neurological long-term condition globally (Dorsey et al., 2018a). There are around 145,000 people living with PD in the UK according to data from PUK (Parkinsons.org.uk, 2023a). The global prevalence of PD doubled between 1990 and 2015, that is the proportion of the population living with PD increased two-fold over a 25-year period (Abate et al., 2017). An international study that completed a systematic analysis of the burden of neurological diseases, estimates that there are over 6.2 million individuals who currently have PD (Abate et al., 2017). The incidence of new cases rises with age, and it is recognised that the world's population is ageing (Bloem et al., 2021). Prospective data analysis, from the Global Burden of Disease study, estimates that the prevalence of people living with PD will rise to 12.9 million people by 2040 (Abate et al., 2017).

### *1.2.3 PD treatment interventions*

Medication and, for some, deep brain stimulation (DBS) surgery serves to reduce the symptoms of PD and drugs can replace some of the 'lost' dopamine. There is no single cure. PwP are looking for non-drug therapies to complement their complex treatment plans (Bloem et al., 2015). Research indicates that lifestyle adjustments, including exercise has many benefits, both physical and non-motor/ psychological (Ramaswamy et al., 2018).
Dr Ramaswamy, a doctor of physiotherapy, cited exercise as a means of taking control and fighting back against PD. Her research captured qualitative quotations from PwP in addition to exploring the literature. In other animal model studies, there was a suggested neuroprotective impact of exercise, indicating a halt or slowing down of disease progression (Schenkman et al., 2018). NW was included as part of Ramaswamy's Parkinson's Exercise Framework (Parkinsons.org.uk, 2023b).

The output from her studies were recommendations for the design, type and intensity of exercise for PwP as shown in Figure 11 (Ramaswamy et al., 2018).

**Figure 11 Types, dose and examples of ideal exercise for PwP**



Source: Ramaswamy et al., 2018

PD is a neurodegenerative, long-term condition. Symptoms usually deteriorate over many years, but the rate of disease progression does not follow a linear pattern. The age of the person at the onset of diagnosis is somewhat indicative of the trajectory of deterioration (Bovenzi et al., 2023), and yet every PwP is different and no two age matched pairs are the same (Dorsey et al., 2018a). However, physical exercise has been shown in some studies to moderate symptoms and PwP who exercise frequently have been found to require less medication, have better balance (Bloem et al., 2016), improved gait (Gougeon et al., 2017), and postural stability (Reuter et al., 2011). They might experience fewer non-motor symptoms (De Santis and Kaplan, 2020, Chaudhuri et al., 2006) and enjoy a better quality of life (Bullo et al., 2018). Exercise can therefore form part of the rehabilitation process or programme for PwP.

## 1.3 Rehabilitation Theory

### *1.3.1 Rehabilitation defined*

NHS England (2016) defines rehabilitation as "*a philosophy of care that helps to ensure people are included in their communities, employment, and education rather than being isolated from the mainstream and pushed through a system with ever-dwindling hopes of leading a fulfilling life. It is increasingly acknowledged that effective rehabilitation delivers better outcomes and improved quality of life and has the potential to reduce health inequalities and make significant cost savings across the health and care system*" (N.H.S., 2016, p.5). Rehabilitation can be used for prevention or early intervention. It is also important for the maintenance of function and to address dynamic and changing health and psychosocial needs. The scope of rehabilitation interventions is broad and needs to be tailored to the individual (person-centred), as described by Seale et al (Seale et al., 2013).

### *1.3.2 Rehabilitation for Parkinson's Disease*

When people with a long-term medical or neurological condition, such as PD, become unexpectedly ill or have an exacerbation, they benefit from specialist rehabilitation interventions to help them regain or maximise their independence. This was described in detail in the National Service Framework (NSF) for long term conditions (National Service Framework, 2005). Usual NHS service provision for PD varies across the country (Brock et al., 2019) but most PwP have access to a consultant neurologist or specialist geriatrician, a PD Nurse Specialist (PDNS), and some members of a multi-disciplinary team (MDT), as described in the National Institute for Health and Care Excellence (NICE) guidelines for Parkinson's (NICE, 2017). An ideal MDT for PwP comprises the patient, Parkinson's Disease Nurse Specialist (PDNS), neurophysiotherapist, occupational therapist, speech and language therapist, neurologist, specialist geriatrician, clinical neuropsychologist, cognitive behavioural therapist, assistant practitioner, dietician, social care services, the voluntary sector and palliative services. The 'ideal' MDT for PwP was described in a recent book by Lindop and Skelly (2022), and included a chapter contribution from local PDNS, lead researcher, McCracken (2022) (Lindop and Skelly, 2022). Rehabilitation needs to be holistic and tailored to the individual's physical or non-motor needs. Physiotherapy is usually delivered in an NHS rehabilitation unit with access to gym equipment, long wide corridors, and space to practice a tailored exercise programme (Schirinzi et al., 2020). A home exercise programme (HEP) complements the activities in the gym and the aim is for self-management and maintenance or improvement in function, as cited by Tuijt (2020).

The intervention within this MPhil focused on NW, a novel sport that could be harnessed as a means of rehabilitation for PwP. In the following literature, NW was found to be effective at treating several motor symptoms: freezing of gait (Wróblewska et al., 2019), falls (Yang et al., 2022) balance (Salse-Batán et al., 2022) posture (Lindholm et al., 2021) shuffling gait (Szefler-Derela et al., 2020) and slow speed of walking (Monteiro et al., 2017).

However, PwP need to engage in rehabilitation for it to be successful, and there are many barriers to exercise that are intrinsic and extrinsic to the PwP (White et al., 2023). Internal factors include a lack of drive or motivation to exercise, that may be worse due to lower levels of the neurotransmitter, dopamine (Radder et al., 2020). Apathy is cited as a non-motor symptom (NMS) of PD and coupled with slow physical movements and the challenge of PD medication timing, exercise can become another 'chore' (Domingos et al., 2022b). Further barriers include: fear of falling, cost, transport, accessibility of classes, and lack of available activities to suit personal choice (Ramaswamy et al., 2018). Depression, low mood, and pain (three more NMS) can also contribute to reasons not to engage in rehabilitation programmes (De Santis and Kaplan, 2020). PwP may struggle to find exercise interventions that they enjoy and there are groups of PwP who never exercise at all, either through choice or lack of opportunity, ability, or motivation (Ellis et al., 2013).

Health psychology plays an important role in rehabilitation, including the role of self-efficacy and behaviour change theories (Tuijt et al., 2020). Health psychology examines how biological, social, and psychological factors influence health and illness. Health psychologists use psychological science to promote health, prevent illness and improve health care systems (American Psychological Association, 2022). This approach corresponds with a holistic or integrated approach to rehabilitation and PD management, adopted by many specialists in this field. Facilitating PwP to change their habits, and to start new exercise activities, is multi-factorial as the PD population is heterogenous, made up of complex individuals, who make choices about their health and lifestyle. Many PD researchers are keen for all PD professionals, including PDNS, to promote healthy lifestyle options from diagnosis onwards (Ramaswamy et al., 2018). Bloem's study (2015), of 33 RCT's, advocated non-pharmacological treatments such as exercise, dance and music therapy, as positive adjuncts to medication and advanced therapies for PD (Bloem et al., 2015). Two hundred years after James Parkinson wrote his seminal paper on the shaking palsy, McDonald et al wrote a biographical account of Dr Parkinson. They documented that he was a strong believer in the role of integrative medicine, "to go beyond treating the disease and to recognise the importance of holistic care." (McDonald et al., 2018).

Theories of behaviour and behaviour change across the social and behavioural sciences were defined and explored by Davis et al (2015). Davis's study preceded the study by Tuijt et al (2020) and resonated with the definition of behaviour change theories in health psychology above, by the American Psychological Association (APA) (Davis et al., 2015, American Psychological Association, 2022). Davis discussed change health-related behaviours and stated that most public health interventions focus on individual capabilities and motivation, rather than the local context and social factors (Glanz and Bishop, 2010). Davis suggested that the effectiveness of an intervention may be improved by examining a wider range of theories that influence behaviour: social, cultural, and economic factors (Glanz and Bishop, 2010). Glanz and Bishop (2010) stressed the importance of theoretical models in public health and health promotion, as an important means of bridging the divide between theory, practice, and research. Michie et al developed the application of theory to a behaviour change framework, described below (Michie et al., 2011). Other behaviour change models include: The Health Belief Model (HBM), The Transtheoretical Model/Stages of Change (TTM), Social Cognitive Theory (SCT) and The Social Ecological Model. However, only the Behaviour Change Wheel (BCW) will be discussed as an example of how health psychology can be utilised.

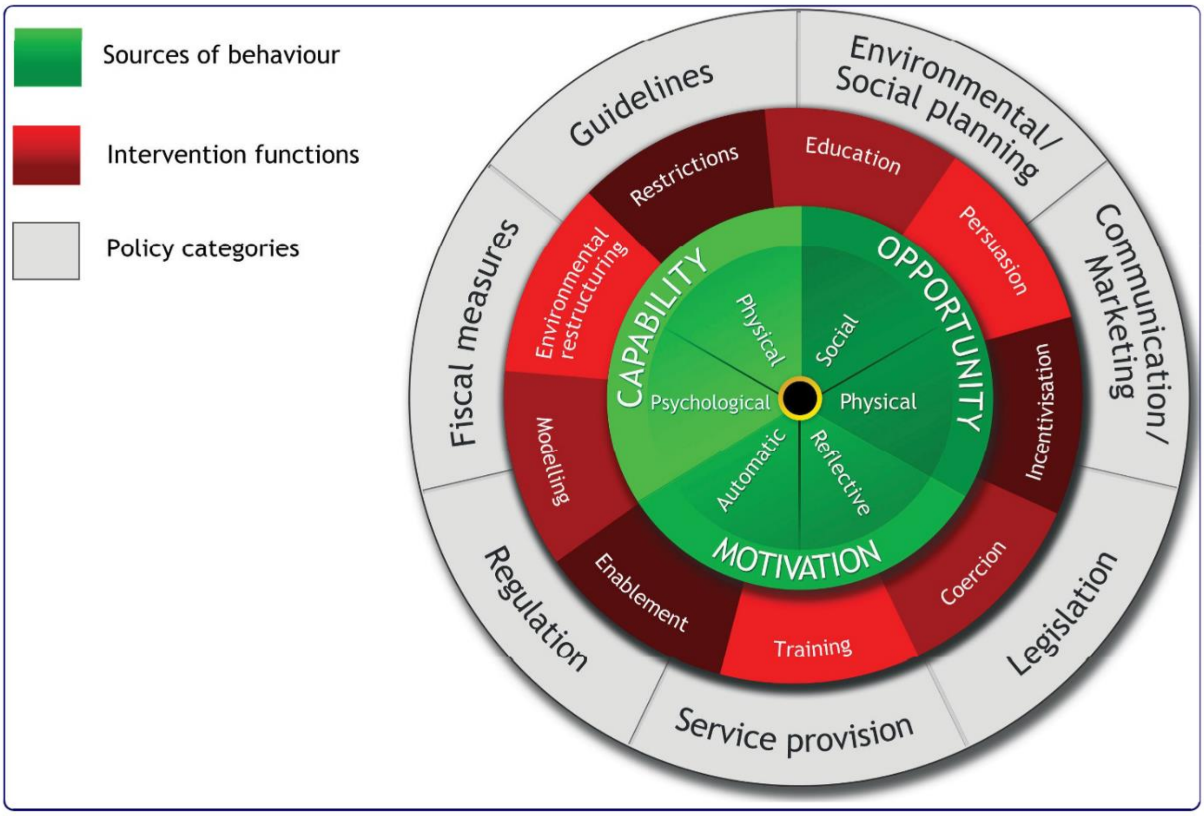
### *1.3.3 Behaviour Change Wheel*

The BCW framework was devised by Michie et al, following a systematic review of electronic databases and consultation with behaviour change experts (Michie et al., 2011). They evaluated 19 frameworks according to three criteria: coherence, comprehensiveness, and a clear link to an overarching behaviour change model. The hub of the BCW, (Figure 22) is the COM-B change system: capability, opportunity, and motivation. Around the centre are nine intervention functions aimed at addressing one or more of the COM deficits. The outer ring comprises seven policy categories that could facilitate the interventions.

Michie's BCW (Michie et al., 2011) provided a framework to investigate complex factors in evidence-based practice, public health, and engagement with rehabilitation. This MPhil focused on NW sessions, and there was potential to use Michie's theory to help understand the rationale for PwP to attend a NW group and the motivation to change and continue to exercise (lifestyle factors). Motivation to exercise, and to embed this into routine, are key features in maintaining fitness (White et al., 2023). Some PwP are apathetic and lack drive so there is a barrier to initiating and engaging with rehabilitation programmes (Bovenzi et al., 2023). A study conducted by Aliberti investigated the motivation of women to NW after the COVID-19 pandemic. They cited physical and psychological benefits as drivers for change; and the motivation of exercising in a group, outdoors (Aliberti, 2023).

BCW provided an integrated approach to behaviour change. Other frameworks focussed on the individual or the disease, but few addressed the psycho-social aspects of change. A recent study by Ahern et al cited Michie's approach but did not specify the BCW. Ahern's systematic review protocol (Ahern et al., 2022) synthesized the available evidence about interventions for PwP by addressing barriers to exercise, self-efficacy and exercise adherence. However, to the best of knowledge from available literature, there were no previous studies that adopted the BCW in the presence of NW for PwP.

**Figure 22 Behaviour Change Wheel**



Source: Michie et al., 2011

## 1.4 Nordic Walking

### *1.4.1 Background to Nordic Walking*

Nordic Walking (NW) started in the 1930's when Finnish cross-country skiers used their ski poles for summer training. In 1967 Leena Jääskeläinen, a professor in sport sciences, introduced walking with ski poles and within a few years had rolled it out as a recognised sport in Finnish schools  (Mass, 2023). Nordic walking poles can facilitate a more upright posture, which in turn activates the core muscles of the torso, to improve postural stability (Gougeon et al., 2017). Poles are placed at a 45-degree angle to the body, and they propel the person forward, using exaggerated big amplitude movements (Cugusi et al., 2017). NW provides an all over body workout using 90% of skeletal muscle and burns more calories than conventional walking, (Reuter et al., 2011). The INWA (International NW Association) ten step method of NW is taught by a qualified INWA instructor (NWI) to individuals or groups (Mass, 2023).

The evidence base for NW as a form of rehabilitation and maintenance of function is growing. Several good quality studies suggest it may be suitable for people with a range of disabilities including neurological diseases like Parkinson's (Silva et al., 2016), arthritis (Domaille et al., 2020), leg amputation, people recovering from breast cancer surgery (Fischer et al., 2015), back pain, hip pain (Silverberg et al., 2016) and mental illness (Liu et al., 2022). NW has been endorsed by the UK Chief Medical Officer (Gibson-Moore, 2019).

### *1.4.2 Evidence for Nordic Walking for Parkinson's Disease*

#### *A narrative review of the current literature*

A narrative review of international research was conducted, using these search terms: 'NW', 'PD', 'exercise', 'mobility' and 'rehabilitation'. The aim was to find studies that provided outcome measure data that was repeated (usually six to eight weeks) on the effect of NW as an intervention (according to INWA method, if possible) within PwP (any stage of diagnosis). Studies with longitudinal follow-up data (at six months or longer) were important to ascertain whether there were any longer-term benefits after the period of NW intervention. The following databases were searched from 2003-2023, because of the global rise in NW popularity, as a novel sport, over the past 20 years: CINAHL, the Cochrane library, PubMed and AMED. High quality papers were selected and critically appraised using the Joanna Briggs institute (JBI) appraisal tools for randomised controlled trials (RCTs) and systematic reviews (Dos Santos et al., 2018). RCTs, cohort studies, systematic reviews and meta-analyses were included. Single case design studies and those with low fidelity were excluded. Eighteen studies were critically reviewed; two were excluded due to a lack of longitudinal data and in one study the NW technique did not follow the INWA method, leaving 15 studies in the final review.

A summary table of comparative NW studies is included in Appendix 2. Trends and themes were identified across the studies, with many researchers employing the same, or similar, physical and non-motor outcome measures. The Timed up and go (TUG) (Podsiadlo and Richardson, 1991), Ten metres walk test (10MWT) (Watson, 2002) and non-motor symptoms scale (NMSS) (Chaudhuri et al., 2007) are established, standardised, and validated outcome measures that are well-suited to this area of neurorehabilitation. Some recent studies have built upon the results of earlier NW research, by replicating study design or adopting recommendations for improving the research methodology (Cugusi et al., 2017, Granziera et al., 2021, Salse-Batán et al., 2022).

Many of the studies of NW showed an immediate benefit to physical and psychological health in PwP. A Dutch study (van Eijkeren et al., 2008) tested subjects at baseline and after six weeks of twice weekly NW intervention. This was a longitudinal study with follow-up at 6 weeks and 5 months. Their findings indicated that there were improvements in the 10 MWT (Watson, 2002) and TUG (Podsiadlo and Richardson, 1991) as well as improvements in the quality-of-life questionnaire PDQ 39 (Peto et al., 1998). These results persisted up to five months, but there were few longitudinal studies available in this population.

Using a different design, Reuter conducted an RCT where 90 participants were randomised into three different exercise groups: flexibility exercises with relaxation, NW and ‘just walking’ (a guided walk, without poles). Their data suggested that NW was superior to the alternative exercise forms in improving stride length, gait, and balance (Reuter et al., 2011). Cugusi’s RCT with 20 participants (Cugusi et al., 2015), comparing NW with conventional care/no exercise had similar findings. Their study reported improvements from baseline for the NW arm of the study in TUG, and the NMS ‘Quest’ questionnaire (NMSQ), (Appendix 11), (Chaudhuri, 2007), and improvements in the six-metre walk test. The duration of NW was 60 minutes, twice per week for 12 weeks with PwP at Hoehn and Yahr (H&Y) stages 1-3 (early to moderate disease) (Hoehn and Yahr, 2001).

However, when these individual studies were combined in review format, the results were not as consistent. A large systematic review by Cugusi identified 66 studies and 221 participants. They critically appraised six RCTs with inconclusive results. Their main finding was that there was too much heterogeneity (differences) between subjects regarding the age of participants, disease duration and stage of disease. There were also discrepancies in research design to draw meaningful conclusions from the data, despite large numbers of studies and participants (Cugusi et al., 2017). Their paper included a table of comparative studies as well as recommendations for the standardisation of future research in the context of PD. They concluded that NW was feasible, affordable and that further studies should explore whether NW could be an adjunct therapy to conventional rehabilitation models. Despite the positive outcomes found in the small number of NW studies, there is still a gap in empirical evidence that this intervention is, or is not, better than others.

The Ebersbach studies were among the first to explore the impact of large amplitude (big movements) training programmes for PwP (Ebersbach et al., 2010, Ebersbach et al., 2014). Physiotherapists based their new rehabilitation programmes on previous studies in the field of specialist speech and language therapy, where a PwP is intensively trained and supported over four weeks to use their loud voice, by repeating prescribed vocal exercises and singing. A specialist practitioner delivers the course. An example is Lee Silverman Voice Treatment (LSVT) (Sapir et al., 2011). Ebersbach carried out an RCT comparing LSVT BIG (a physiotherapy standardised programme of augmented exercises) to NW and a home exercise programme (HEP) (Ebersbach et al., 2010). LSVT BIG was found to be superior to NW and HEP and this has had an impact on current physiotherapy clinical practice (Ramaswamy et al., 2018, Lindop and Skelly, 2022). However, the Ebersbach studies (2010) compared different intervention frequencies:

- NW intervention = 60 minutes, twice per week, for 8 weeks
- LSVT BIG intervention = 60 minutes, four times per week, for 4 weeks
- HEP intervention = one hour per week, once per week, for 4 weeks

One might argue that there were too many variables, and it was not realistic to compare such disparate interventions. In addition, LSVT BIG was delivered by physiotherapists and the NW programme was delivered by a NW instructor, who was not a clinician. This is a recurring theme in many NW studies in this population.

A similar rehabilitation intervention, widely adopted for PwP is PD Warrior©, although there are few studies available as it is a novel programme (Warrior, 2023). Launched in Australia in 2012 it is gaining popularity with PwP, and health professionals, due to its growing evidence base and parallel findings with the LSVT BIG studies (Ramaswamy et al., 2018). Like these interventions, NW emphasises and reinforces large, exaggerated movements of the arms and legs. Bilateral arm-swing (in a PD population with unilateral reduced arm-swing) is encouraged by using two lightweight, specially adapted NW poles with a technique that promotes 30 degrees forward and backward, pendulum-like motion from the shoulder joint (Leal-Nascimento et al., 2022). In addition, the correct use of NW poles, placed at a 45-degree angle to the body to promote an upright posture, can augment the cadence or stride, resulting in longer, fewer steps over a measured course (Leal-Nascimento et al., 2022).

Bombieri's study (2017) 'Walking on four limbs: A systematic review of NW in PD', suggested that the NW poles could spread the load and effort of walking by recruiting more movement in the arms and legs (Bombieri et al., 2017). They extrapolated that impact on the joints would be reduced in the hips, knees, and ankles. This is supported by earlier studies on people without PD (Farnsworth and Burtscher, 2010). One assumption is that NW reduces the likelihood of injury, compared to other high impact sports or exercise modalities such as running or tennis. This is a popular concept for older adults or PwP who might not enjoy traditional exercise programmes, or for whom their previous hobbies and sports have had to be adapted, due to disease progression. This is gaining some traction in the literature, and in recent podcasts, within the PD community (Movers and Shakers, 2023), as there appears to be a range of positive physical outcomes when comparing NW to walking without poles (Reuter et al., 2011). The augmented arm movements serve to increase upper body strength and core stability. The poles can increase the base of support and enhance confidence in a PwP with impaired balance (Bang and Shin, 2017, Giardini et al., 2018).

Radder's study was a recent meta-analysis of physiotherapy rehabilitation interventions for PwP (Radder et al., 2020). A total of 191 trials with 7,998 participants were included. Traditional physiotherapy was compared to novel sports and hobbies including dance, martial arts, dual tasking, exergaming (technology-driven physical activities such as a static exercise bike while using a virtual reality headset or video of a mountain), hydrotherapy, NW, and resistance training. The individual sports were not compared to each other, only to routine physiotherapy. Their meta-analysis provided a comprehensive overview of the evidence base for these novel forms of rehabilitation, giving the clinician and PwP choice about a tailored, individualised programme of therapy. NW, along with dance and martial arts, showed favourable changes in motor symptoms, balance, and gait.

Few of the papers in this chapter described the NW intervention in detail. Several reported a period of warm-up exercises, learning the technique, practising the NW movements and a period of cool-down stretches e.g., Radder et al., 2020 and Yang et al., 2022. This resonates with the INWA ten step technique (described in Chapter 2, methods), but it was not always specifically named. It is assumed that there was uniformity of NW delivery, by a suitably qualified instructor, following a standardised protocol, but other pole-walking methods that use Activator poles or trekking poles might have been included in these studies. Not all pole walking is NW, and it is beyond the scope of this MPhil to study the different NW poles and their action, nor to comment on their efficacy.

The results of the narrative literature review informed an evidence base for this MPhil study, using the same validated, specific outcome measures from larger clinical trials, in the context of Parkinson's Disease (PD).

### 1.5 Context of the Study: Coronavirus (COVID-19) Pandemic

A thread that runs through this MPhil study is the COVID-19 pandemic (WHO, 2021), its impact upon PwP and PD services. On 11th March 2020, a global pandemic was declared by the World Health Organisation (WHO), that brought society to an abrupt halt. Schools and businesses closed for several months, care homes were closed to visitors and deaths attributed to COVID-19 totalled 229,150 people in the United Kingdom (www.gov.uk, 2021). The societal challenges faced by PwP were described in Brooks' study (2021), a scoping review addressing the social and psychological well-being of PwP (Brooks et al., 2021). When PD clinics stopped and gyms closed, PwP struggled to access their multidisciplinary team (MDT) for specialist support, advice, and physiotherapy. Some PwP, who were physically active, continued to exercise within COVID-19 guidelines. They demonstrated self-efficacy (reflecting confidence, resilience, and motivation despite the social environment) and self-management.

A model of self-management and peer support for PD was formally adopted in 2013 by PUK. A systematic review, and synthesis of qualitative literature in 2020 by Tuijt, explored self-management components as experienced by PwP and their carers (Tuijt et al., 2020). Six papers were included in their thematic synthesis and seven main themes were derived. Physical exercise was a strong theme alongside medication management and psychological strategies. This is supported in other studies where exercise (non-pharmacological treatment) is used therapeutically to ameliorate symptoms, to compliment medications and advanced PD treatments such as apomorphine, duodopa, and deep brain stimulation (Bloem et al., 2015). As previously described, NW has the potential to be included as a physical activity, or exercise element, of a PwP self-management programme. It also has scope to be incorporated into a guided, group-delivered PD rehabilitation intervention.

An initial proof-of-concept study (McCracken et al., 2021), was conceived in 2019 after the lead researcher (SM) trained to become a BNWI and could see the value in its use in PwP to manage their symptoms. The NW intervention was delivered in 2020 and a research paper was published in the British Journal of Neuroscience Nursing (2021). As the pandemic receded an opportunity arose for a bigger study with a larger sample, using lessons learned from the previous research and available literature.

## 1.6 Aims of the Study

This MPhil seeks to:

1. Explore the motor (physical) and non-motor (psychological and quality of life) impact of an eight-week rolling programme of NW for PwP, by establishing the short-term and longer-term (after six months) impact of NW as a means of neurorehabilitation in this population.

2. Determine the feasibility and accessibility of the NW intervention for a diverse sample of PwP.

3. Understand the core components needed to implement NW groups for PwP in a community rehabilitation setting.

## 1.7 Structure of the MPhil

### *1.7.1 Quantitative repeated measures pre-post study*

A longitudinal, repeated measures, feasibility study design was chosen to explore the physical impact of an eight-week NW intervention for PwP. Motor outcome measures were recorded at baseline, eight weeks, and six months. The non-motor score scale questionnaire (NMSS) was completed at the same time points. Two-tailed paired t-tests (within the same group) calculated the mean difference in score over time. The method, results and discussion of the quantitative study were described in Chapter two. This study was designed to explore the first two aims of this MPhil: The motor and non-motor impact of NW following the COVID-19 pandemic, and the feasibility and accessibility of NW for a diverse sample of PwP.

### *1.7.2 Qualitative focus group study*

A FG study served to evaluate the eight-week NW intervention, by gaining the perspective of PwP, NWI and a walk leader (WL). The FGs were recorded, professionally transcribed, and analysed using thematic analysis. The method, results and discussion were written into Chapter 3. The three FGs sought to understand the third aim of this MPhil: To understand the core components and characteristics required to set up NW classes for PwP in a community rehabilitation setting.

# CHAPTER 2 REPEATED MEASURES FEASIBILITY STUDY

## 2.1 Methods

### *2.1.1 Research design*

This longitudinal, repeated measures, feasibility study design, evaluated a novel intervention delivery, outcome measures and patient satisfaction. In this chapter of the thesis the methods, results, and discussion are reported.

This method was chosen because few studies have addressed the longer-term impact of a NW rehabilitation intervention for PwP. Previous NW studies in this population have focussed on physical outcome measures and reported on data after the period of intervention, usually six to eight weeks. The repeated measures design was chosen so that all participants had the opportunity to gain experience of a new skill (NW), without delay and all the outcome measures could be recorded for the same participant at three time points: baseline (week zero), eight weeks, and six months. Analysis was then conducted between the three time points (baseline-eight weeks, baseline-six months, eight weeks-six months) with an intention to reduce individual differences/variables.

A repeated measures feasibility design was chosen over a randomised controlled trial (RCT) because the aim of this study was to evaluate whether it was feasible to deliver NW in an NHS/community group setting, recruit participants and collect data. An RCT is proposed for the next stage, if found feasible in this study. The RCT study design is described by Hariton and Locascio, (2018) as the gold standard for effectiveness research, measuring the success or efficacy of a novel intervention. Randomisation reduces bias and provides a rigorous tool to study cause and effect relationships between intervention and outcome (Hariton and Locascio, 2018). Due to the need to assess the feasibility of NW with PwP in an NHS setting, the repeated measures, within subjects' design was considered the right experimental method.

The primary hypothesis was:

- That an eight-week NW intervention, delivered in a group setting according to INWA guidelines, improves gait, speed and cadence, posture, and TUG on PwP.

Secondary hypotheses were:

- That an eight-week NW intervention, described as before, improves non-motor symptoms (NMS).
- That an eight-week NW intervention has long term benefits for up to six months after the intervention period, on both motor and non-motor symptoms.

### *2.1.2 Recruitment*

#### *Identifying participants*

The lead researcher (SM) identified participants through clinical and professional networks. An advert (Appendix 3) was sent via professional networks or given to individuals directly by their own clinician. Twitter, email, and websites were used to advertise the study via these professional networks. The Parkinson's East Midlands research interest group (PEMRIG) and BNW placed adverts on their websites and sent emails directly to their members. Professionals working with PwP, namely PDNS and neurological physiotherapists were sought via email and Tweets and asked to distribute to their networks. Participants were also identified through local PUK branches, PUK website and the national PUK research network. The PUK branch chairs distributed study materials to their members via email. A 'snowballing' approach to participant identification was used to distribute information through PwP communities (Bryman, 2004).

#### *Participant recruitment*

The advert for social media (repeated measures study) (Appendix 3) included the contact details of the lead researcher. Interested people were invited to make direct contact with the lead researcher using email or telephone. Upon doing so a meeting was arranged in person at the University grounds, the location of the study and NW group intervention.

The participant information sheet, for the repeated measures study (PIS) (Appendix 4), was sent to the individuals at least 24 hours prior to the meeting, via the contact email address given. At the meeting, the eligibility criteria were checked, and participants' questions were addressed before gaining informed consent, as per the study protocol (Appendix 5).

#### *Eligibility*

#### *Inclusion criteria*

- People with a diagnosis of idiopathic Parkinson's disease, as confirmed by the participant and who attended a movement disorders clinic for PwP.
- Over 18 years of age.
- Stage four or below on the Hoehn & Yahr scale (Hoehn and Yahr, 2001), determined by the PD nurse specialist (SM) before recruitment.
- Could walk for up to an hour without a walking aid as reported by the participant.
- Able to follow verbal and practical instructions.
- Able to participate in a weekly one-hour training session.
- Could provide written consent.

### *Exclusion criteria*

- Complex comorbidities including frequent falls and significant postural hypotension (reduction of 20mmHg systolic or greater, with adverse symptoms), assessed by SM with the adapted physical activity readiness questionnaire (PARQa) (Appendix 6).
- H&Y stage five (Hoehn and Yahr, 2001).
- Advanced dementia.

### *Justification for inclusion and exclusion criteria*

People with Parkinson's classified as having disabilities aligned to the Hoehn and Yahr (1967) stages one to four were chosen to help compare the results of this study with previous research. Only in the study by Reuter was the criteria narrowed to participants in stages two and three. (Reuter et al., 2011). Most NW papers cite that the study will investigate PD characteristics for people in stage one to three (early disease, unilateral involvement to mild to moderate bilateral disease; some postural instability, physically independent), (Bang and Shin, 2017, Cugusi et al., 2015, Ebersbach et al., 2010). PwP with severe disease including advanced dementia, frequent falls or those who frequently used a wheelchair were excluded, as they could not participate in the hour-long NW intervention. However, PwP with early cognitive changes were included. The previous study by McCracken was a useful pilot, facilitating PwP to engage with the NW intervention if they were supported by a partner, carer or walk leader (McCracken et al., 2021).

### *Sample size*

As this was a feasibility study no formal sample size was required to power the study (Kirkwood, 2003). However, to assess the expediency of a single staff member (SM/Lead Researcher) delivering the intervention, and to collect data to inform the acceptability of outcome measures, it was acknowledged that at least 40-60 participants were needed. This was in line with recommendations by (Elsworth et al., 2011) and other similar feasibility studies in people with complex long-term neurological conditions living in community settings. Elsworth et al, 2011 studied the practicability and safety of supported exercise in a community gym, for adults with long-term neurological conditions. Their assumption was that this population had reduced levels of physical activity and they engaged less with standard rehabilitation programmes. Their study recruited participants either to a community gym or to standard physiotherapy interventions. Their sample size was circa 50 people in each arm of the study (n=100 in total), as they were investigating numbers needed to treat (NNT), that is the number of patients needed to treat to prevent one additional bad outcome (death, stroke, injurious fall). The planned sample size in this MPhil study was 40-60 participants and 53 PwP were recruited.

### *Consent*

The consent procedure took place in person at the University grounds, during the initial recruitment meeting. Participants were asked to give their written, informed consent (Appendix 7). A health questionnaire adapted for PwP (PARQa, Appendix 6) was completed during this meeting as part of screening measures for complex comorbidities, advanced dementia and to provide an individual baseline assessment prior to the NW intervention.

This was adapted from a standardised risk assessment, provided by BNW and every NWI uses this assessment tool (Appendix 8). This questionnaire was adapted to include PD specific questions such as medication timing, allergies, falls history and problems due to high or low blood pressure. Baseline data collection was measured and recorded following the consent and screening procedure.

### *2.1.3 Intervention*

The intervention, offered to all participants, was an eight-week programme of NW instruction, delivered by the lead researcher (SM). SM was an experienced PDNS and an INWA accredited BNWI. During this study no other dual qualified experts were identified in the UK, although some physiotherapists had recommended NW to their patients with PD. A walk leader (MB) assisted SM, for the purposes of group safety and to help slower walkers. MB was an experienced NW who had taken an extra NW qualification, to support the lead researcher in delivering the intervention, two classes per week over 13 months.

Participants were given new NW poles (as equipment was not shared, due to infection prevention and control measures, and to satisfy COVID-19 guidelines) at the consent meeting but asked not to use them before the first intervention lesson. Spouses, partners, and carers were invited to join the classes and they borrowed NW poles. Health screening questionnaires (PARQ) were completed for their safety, but no outcome measures were recorded as this was not planned for in the protocol.

Participants were assigned to a beginners' 'blue group' or an advanced 'red group,' according to their walking speed, balance, and mastery of the INWA technique as assessed at baseline and the first NW session. All participants started in the blue group and were assessed by the NWI during each class. Some people, who displayed increasing confidence and accuracy with the NW ten step technique, and who were faster walkers, were moved to the red group.

All participants, family members, friends and carers attended a warm-up group exercise at the start of each class and participants were encouraged to practise their loud voice for introductions, so that people could learn the names of other group members. People with Parkinson's can have soft, quieter voices, and this volume diminishes over the years as the muscles of the larynx become weaker and the air passing over the vocal cords has a reduced speed (Sapir et al., 2011). Some specialist speech and language therapists promote 'Loud' or 'Speak Out' voice programmes, to encourage PwP to exercise their vocal cords and to project their voice. Such programmes include Lee Silverman Voice training, LSVT Loud (Sapir et al., 2011), and the recently launched Parkinson's Voice project 'Speak Out!' (Behrman et al., 2020). It was beyond the scope of this study to comment on, or measure, the volume of speech but was useful as an ice-breaker exercise when people were socially distanced at two metres outside, due to COVID restrictions.

Participants were asked to inform the instructor of any new injuries, infections or changes to treatment or medication, which might impact upon their performance of the NW tasks. An attendance register was maintained for both groups: blue (beginners and slower walkers) and red (advanced or faster walkers). All participants and the research team, including a BNW walk leader, were advised to conduct a COVID-19 lateral flow test if they had any symptoms of coronavirus and not to attend if they had a positive result. They were asked to inform the NWI by email.

The INWA standardised ten step method, described in the new INWA manual for instructors, was taught to each participant and revised, in a progressive manner from steps one to ten, at the start of each session (Mass, 2023). The technique was embedded with drills and balance exercises during the one-hour lesson. All participants completed a ten-minute warm-up session, which included an ice breaker activity. The table of ten steps (Table 11) indicates how NW may be beneficial for PwP, by mapping the step to a particular PD symptom or area of deficit such as reduced arm-swing.

**Table 11 INWA Ten steps method and relationship to PwP.**

| Step number | Description of step | How it relates to PwP |
|---|---|---|
| 1. Posture | Stand with feet hip-width apart and aligned. Upright posture, not hyper-extended. Shoulders in mid-position, relaxed. Knees slightly bent, neutral position of pelvis and chin. | Some PwP stoop. Adopting correct NW posture helps activate core muscles and strengthens trunk stability. Helps to reduce stooping. |
| 2. Lean forwards | Subtle lean forwards, as one active unit from feet to head. Maintain chin up, with eyes on the horizon; avoid looking down. Like the start of a ski jump. | Relates to step one, correcting stoop and promoting good posture. Lean is not over-emphasised for PwP in case it encourages centre of gravity to shift forwards. |
| 3. Walk | The basic movement for NW. March with opposite arm and leg. Land on heel and roll onto ball of foot. Push off from ball of foot. Swing the arms from the shoulder. Maintain a natural bend in the elbow as the arm swings forwards. Remember posture and rotation. | NW is exaggerated walking with augmented movements in the arms and legs. This is useful if a PwP has a short, shuffling gait, narrow base of support and poor balance. NW can facilitate a longer stride, wider base of support and bilateral arm-swing. |
| 4. Rotate | Keep head looking forwards and rotate the upper spine naturally with each step. As the left foot pushes off the right shoulder moves forward. Rotation in the upper spine results in gentle rotation in the lower back. | PwP can experience rigidity in their joints. Stiffness in the neck and spine can result in pain. Gentle rotation of the upper and lower spine may ameliorate back pain. |
| 5. Drag | A key step for acquiring the correct position of the poles, 45 degrees from the body to the ground, tips facing backwards. Helps with coordination of opposite legs and arms. Poles are strapped to the wrist and hands are open and relaxed, with palms facing inwards. Continue regular walking and ignore the poles dragging behind. Establish a natural stride length and rhythm. | A useful step for PwP, with or without poles. A foundation to good posture, rolling through the foot and arm-swing. Enhances normal walking in preparation for the main NW technique. |
| 6. Place | Find traction or ‘biting’ point of the pole in the ground through the natural arm-swing as the arm swings backwards. Close hand softly around the grip to place the pole on the ground. Don’t grip tightly. Find a rhythm by matching the placed pole with the opposite heel strike. | Placing the pole can help with balance and core stability. Using two poles can increase confidence. |

| Step number | Description of step | How it relates to PwP |
|---|---|---|
| 7. Push | Place the pole then push backwards through the pole, moving the body forwards. Use smooth, steady pressure with active muscle action around the shoulder, without raising the shoulders. The body is propelled forwards. Maintain an upright posture, remember the shoulder rotation. | Pushing through the poles moves the body forwards. The repetitive action of placing and pushing can improve coordination and facilitate smooth movement without (FoG). Pushing poles provides power and increases the effectiveness of walking. This may increase speed of walking and build confidence. |
| 8. Extend fully | This maximises the effect of the pole. Keep the tip of the pole on the ground for as long as possible. Push hand past the pelvis and extend the arm at the elbow. Maintain pressure on pole until the end of the movement. The fingers should be pointing towards the bottom of the pole at the end of the backward movement. | This movement facilitates bilateral arm-swing and exaggerated backwards arm movements in a pendulum like motion, from the shoulder. Can help to alleviate stiffness and tension in the shoulders. It may promote improved arm swing when poles are not in use (walking). |
| 9. Release actively | Creates impulse to start forwards arm swing. Open hand at the end of full extension. Keep fingers softly together. Place hand actively against strap and push off from balls of feet at the same time. Push off strongly so that pole tip clears ground. Feel how the pole flies away and how it returns like a spring. Avoid hyperextending the elbow. | A difficult technique to master for some PwPs. Involves letting go of the pole at the end of extension phase. Augments backwards arm swing. Important for the next step and is beneficial for arm swing, shoulder mobility, stiffness, and natural movement forwards. |
| 10. Swing forward | The spring effect in step 9 results in a dynamic arm swing forward. Keep the pole tip airborne as the arm reaches forward to place the pole. The top of the pole leads the movement. The hand will gently grip automatically as the pole flies forwards. The little finger will collect and lift the pole. Place the pole again using the correct 45-degree angle and a gentle hand grip. | An essential forward movement of arm and pole with natural bend at elbow. Encourages pendulum motion of the arm from shoulders. Opening/ closing hands correctly helps circulation and serves to avoid pencil-like arthritic hand posture. |

The ‘blue group’ took a slower paced shorter NW, approximately one km, around the lakeside, on level gravel pathways, stopping for balance exercises and rests, taking approximately 40 mins of walking time. The ‘red group’ took a faster paced longer NW, covering level gravel paths and grass covered hills around the university campus, approximately two kms for 50 mins. Despite the difference in walking time, all participants were active (e.g., standing, doing the warm-up or cool down) for a full hour.

Both groups commenced with a ten-minute warm-up session, which included an ice breaker activity. The one-hour class concluded with a set of predetermined cool down stretches and breathing exercises. Stretches were modified for those with balance/ coordination problems. Some participants attended with a partner, carer, family member, friend who walked with them and assisted with putting on gloves, straps and supporting them with the exercises.

The terrain and route were varied for both groups to add interest and increase physical exertion. Hill repetitions added to the cardiovascular workout, in addition to enhanced effort for the upper body, by intentionally pushing through the poles. Balance exercises and multi-tasking exercises challenged the red group and were modified for the blue group.

All participants were signposted to the weekly, free, 5km parkrun events in their locality and a monthly group NW at parkrun with other PwP. Quirk’s qualitative study explored how to involve more people with long term conditions in parkrun (Quirk and Haake, 2019).

The NW intervention was offered to each participant for eight weeks, but people were welcome to continue to attend the programme and they were invited to join local, established mixed groups (people without Parkinson’s or individuals with other disabilities such as osteoarthritis, older adults, and some highly active individuals). New participants joined the class most weeks. Where possible, the intervention was delivered consecutively over eight weeks. However, if participants were unable to attend a week (e.g., due to holiday or ill-health), they were offered an additional class to complete the full number of sessions.

### *2.1.4 Assessments*

Assessments were completed at baseline (same day as screening and consent was taken), after eight weeks of NW intervention and again six months later. The lead researcher (SM) completed all assessments. Physical outcome measures included the Timed up and Go test (TUG), ten and a separate twenty metres walk test (10 MWT and 20MWT) (time and cadence) and Tragus (Tragus Wall Distance, TWD). The primary outcome measure was the TUG.

#### *Timed Up and Go test (TUG).*

The TUG was chosen as it is a simple screening test that can be used as a predictor of falls risk and measures the progress of balance in PwP (Goswami et al., 2015). The TUG records the time taken to stand from a chair without assistance, walk three metres, turn around a marker, return three metres and sit down again. Participants had a trial of the TUG test and in the repeated TUG, data was recorded (Podsiadlo and Richardson, 1991). This outcome measure has been used for over 30 years and has good psychometric properties: demonstrating reliability (it is repeatable inter-rater and intra-rater), and validity (measuring what it is designed to assess). It is recognised in literature as a useful tool for measuring functional mobility in elderly people (Podsiadlo and Richardson, 1991), in younger adults with Parkinson’s (Goswami et al., 2015) and for people who have had a stroke (Persson et al., 2014). In the Podsiadlo and Richardson, 1991 study, participants were scored as being independent for transfers (changing position) if they took <20seconds, they could manage independent bathing and could climb stairs. Participants who took >30 seconds to complete the TUG were more dependent and some required assistance with personal care, toileting, and stairs. This assessment tool is simple to set up and takes approximately five minutes to teach and complete. As recommended in this study the same chair, tape measure, marker and researcher were employed for all baseline and repeated measures.

### *Ten-metre walk test (10 MWT) (Watson, 2002)*

The ten MWT is a validated tool measuring walking speed (velocity) and number of steps (cadence) over a 14-metre course to assess gait (Watson, 2002). This measure has been used in several PD studies (Bang and Shin, 2017, Ebersbach et al., 2010, Granziera et al., 2021), and has been found to be reliable, reproducing the same results multiple times (Salse-Batán et al., 2022). The 14-metre course is set out with cones and a two-metre acceleration and deceleration phase is highlighted. Only the ‘middle’ ten metres data is captured. The participants were asked to walk at a brisk, but comfortable pace and a stopwatch was used to record the time taken. They repeated the timed walk three times, and an average score was calculated for the time taken and number of steps. The mean score was used in the analysis.

### *Tragus test (Tragus Wall Distance, TWD) (Shipe et al., 2013)*

The Tragus test (TWD) is a validated tool used to assess head position and posture, by measuring the horizontal distance from the tragus point of the ear (the cartilaginous flap anterior to the external auditory meatus) to the wall on the right and left ear, separately (Shipe et al., 2013). This test was chosen as there is some evidence that NW can have a positive impact on posture (Silva et al., 2016). Although this measure was employed by Giardini in their study of PwP, rehabilitation of balance and gait (Giardini et al., 2018) this test has not been used in previous PwP studies of NW. The mean score of the right and left tragus was used at each of the three time points.

### *Twenty-metre walk test (20 MWT) (Alldridge, 2019)*

The pilot study by the lead researcher (SM), (McCracken et al., 2021) established that some PwP take time to initiate movement so their TUG and 10 MWT scores were impacted by freezing of gait (FoG), (Wróblewska et al., 2019). Due to this a decision was taken to include a newer, twenty metre walk test (20 MWT), using a 24-metre course and recording the ‘best’ 20-metre walking speed and number of steps. Like the 10 MWT, the 20 MWT has a two-metre walk to the starting line, a timed 20-metre walk using a stopwatch, while the researcher counts the number of full strides over the 20-metre course. There is a two-metre deceleration zone once the clock has stopped. This newer outcome measure is being used for personal independence payment (PIP) applications (Alldridge, 2019). A mean score from three measured walks was used in the data analysis.

### *Berg balance scale (BBS) (Berg et al., 1992)*

The BBS is a measurement of the quality of balance capacity during a series of physical tasks (Berg et al., 1992). The fourteen physical tasks incorporate nine items that assess static balance in sitting and standing, and five items that assess anticipatory balance during common daily activities: including turning, reaching, transferring weight, and retrieving objects from the floor. Each item is scored from zero (unable) to four (able to perform) and the final score is the sum of the task scores. This test was more time consuming to execute than previous measures and it was anticipated that few participants would demonstrate impaired balance, due to being at stage H&Y one, two or three. However, several individuals presented with difficulties with balance, some falls and moderate disease progression (15 years) and a BBS score was recorded.

### *Non-motor scale questionnaire (NMSS) (Chaudhuri et al., 2007)*

This questionnaire is a validated tool, developed by a panel of international experts in PD and published in 2007 (Chaudhuri et al., 2007) (Appendix 9). It was used, free of charge, with written permission from the Movement Disorders Society (Appendix 10). Usually there is a fee of around $1,000, but as this was a research project for PwP the fee was waived. Non-motor symptoms (NMS) in PD are often under reported and they impact upon quality of life. A previous NMS questionnaire (NMS Quest) developed by the same team of experts, identified 30 NMS and this validated tool (Appendix 11) is routinely used in a clinical setting, where PwP tick yes or no to each symptom (Chaudhuri et al., 2006). One might argue that NMS Quest is easier to administer as it is simple, clear and many PD specialists use it as part of their toolkit for tailored, holistic assessments (Clayton et al., 2006). However, it does not assess frequency and severity of these symptoms. Thirty NMS were categorised into nine dimensions on the NMS scale questionnaire (NMSS): cardiovascular (two items), sleep/fatigue (four items), mood/cognition (six items), perceptual problems/ hallucinations (three items), attention/memory (three items), gastrointestinal (three items), urinary (three items), sexual function (two items) and miscellany; pain, taste/smell, weight change, sweating, (four items). A total score is calculated, for each dimension, by multiplying the scores for frequency (1-4) and severity (0-3). The NMSS was used to explore which non-motor dimensions were impacted by the NW intervention and whether there would be long-term carry over after the period of NW intervention.

### *2.1.5 Fidelity of the intervention*

Fidelity is described as the extent to which an intervention follows the intended research model (Silverman, 2022). Fidelity to the intervention is important for the reliability, validity, replicability and potential scaling-up of the results of an intervention study (Feely et al., 2018). In evidence-based studies that are adapted to a local context, fidelity can preserve the components that make the model effective (Feely et al., 2018). Several steps were taken to attempt to maintain the fidelity of the intervention. The programme was delivered by an experienced PDNS who had a NWI qualification. The standardized (INWA) warm-up and cool down activities were delivered at each session and tailored to the needs of individuals, to optimize safety. These activities were recorded in the INWA manual (Mass, 2023). The INWA ten step technique model (Table 11) was delivered by the same NWI and revised orally, rehearsed and demonstrated practically by participants at every session. Step number two, a subtle lean forward, was taught to each participant with caution, to avoid over-reaching and forward falls. In this study the NW programme was adapted to a local context (PwP) but delivered according to the protocol (Appendix 5). Fidelity to this protocol was checked by recording the number of sessions attended by each participant in a diary. In this study, eight out of eight sessions were pre-determined to demonstrate excellent fidelity.

### *2.1.6 Data storage*

Each participant was assigned a study number, for use on study documents and the electronic database. Study documents were held securely in accordance with regulations. The lead researcher (SM) made a separate confidential record of the participant's name, study number and contact details, to permit identification of those enrolled in the study in case additional follow-up was required. Most documents were electronic and stored according to the data management plan (DMP). All paper forms and questionnaires were filled in using black ballpoint pen. Source documents were filed at the lead researcher's (SM) site and included consent forms, health risk assessments, environmental risk assessments, emergency contact details, pole length details, study records, field notes, paper, and electronic questionnaires. Only study staff had access to study documentation.

In compliance with the Good Clinical Practice guidelines, regulations and in accordance with the University of Nottingham Code of Research Conduct and Research Ethics, the Chief Investigator (the lead researcher's primary supervisor, Dr Vicky Booth), maintained all records and documents regarding the conduct of the study. These will be retained for at least seven years or for longer if required. If the responsible investigator is no longer able to maintain the study records, a second person from the research team will be nominated to take over this responsibility. The study documents held by the Chief Investigator shall be archived at secure archive facilities at the University of Nottingham. This archive shall include study databases and associated meta-data encryption codes.

### *2.1.7 Data analysis methods*

Data from the outcome measures was stored on a Statistical Package for Social Sciences (SPSS) database (IBM SPSS Statistics Version 28.0, Chicago) and analysed initially using descriptive statistics (mean, median, range and standard deviation) and then used to compare changes over time.

Data was first analysed using descriptive statistics. The sample was described as a group using their personal non-identifiable characteristics (e.g., age, gender, time since Parkinson's diagnosis and H&Y stage of Parkinson's).

Data from participants, who completed eight weeks of NW intervention, was assessed for normal distribution and then two-tailed paired t-tests (within the same group) were used to compare results from baseline to week eight, from week eight to month six and from baseline to month six (Kirkwood, 2003). The p-value was set at 0.05 with confidence interval (CI) set at 95%. A p-value of 0.05 or less was considered statistically significant. Comparing the scores at the three time points provided useful data about the longitudinal impact of NW across specific motor and non-motor domains. Data from participants who did not complete eight weeks of intervention were recorded, but it was not possible to calculate paired t-tests for this sample.

The qualitative data from the field notes were an adjunct to the main study and were not analysed in detail.

### *2.1.8 Ethical approval*

Ethical approval was granted in September 2021, by the University of Nottingham, Faculty of Medicine Research Ethics Committee (ref: FMHS 331-0821) (Appendix 1).

### *2.1.9 Public and patient involvement*

Two PwPs, who were not participants, and one spouse contributed to the Patient and Public Involvement (PPI) of this study. There were no known conflicts of interest. One gentleman with PD (JP) was a participant in the previous proof-of-concept study, (McCracken et al, 2021). One PwP (SJ) and his wife (JJ) chaired the local PUK branch and disseminated study adverts and emails to their members during the recruitment phase. A BNWI (AC) was also part of the PPI group and subsequently joined the FG for Instructors and walk leaders.

All PPI members helped with proof reading, commented on all documents, and lay summaries. They attended project meetings and were sent updates on the research every three to four months. Their knowledge, perspective and experience of Parkinson’s added depth to the study and they continued to support the NW group after the period of data collection.

## 2.2 Results

### *2.2.1 Recruitment*

Recruitment commenced once ethical approval had been granted (September 2021). In total, 50 emails/ adverts were sent to professional colleagues, three emails to PUK, three emails to the local PUK branches, two emails to the Parkinson’s East Midlands research interest group (PEMRIG), and three to the national PUK research team. BNW signposted PwP to the study and the lead researcher (SM) promoted the study by speaking at BNW conferences in November 2021 and 2022. The lead researcher also spoke at a PD nurse specialist association (PDNSA) conference at Warwick University (130 people) to raise awareness of NW for women with PD (Conference title: *EVEolution-A Woman’s Journey with Parkinson’s*; lecture title: *Exercise and Lifestyle*).

The number of participants recruited was; professional sources n=17, BNW n= 4, PUK local branches n=15, PEMRIG n=2, national PUK research advert n=5, participants who completed the previous pilot study n=6 (McCracken et al., 2021), and from indirect/snowball effect (e.g., participants telling their friends) n=4. The enrolment period ran from November 2021-September 2022.

During this time 53 PwP, who matched the inclusion criteria, expressed an interest in participating. However, four PwP chose not to consent, leaving 49 PwP in the final sample. Five PwP, who expressed an interest in the study, did not meet the inclusion criteria.

### *2.2.2 Participant characteristics*

**Table 22 Demographic characteristics of participants.**

| Variables | Total sample (N=49) | Normal distribution |
|---|---|---|
| Age median (years)<br>Mean (± SD)<br>Range<br>IQR | 69<br>66.41 (± 9.98)<br>47-83<br>59.50-74.50 | No<br>Positively skewed |
| Sex, male | N=27 (55.1%) | |
| Years from diagnosis median<br>Mean (± SD)<br>Range (years)<br>IQR | 4<br>5.47 (± 3.95)<br>1-17<br>3-6.5 | No<br>Negatively skewed |
| H&Y median score<br>Mean (± SD)<br>Range<br>IQR | 2<br>2.20 (± 0.96)<br>1-4<br>1.00-3.00 | No<br>Negatively skewed |

Abbreviation: H&Y=Hoehn and Yahr scale, IQR=Interquartile range from 25th percentile to 75th percentile, SD=Standard Deviation

Demographic data are reported in Table 22. The median age was 69, (mean 66 years) with an interquartile range from 59.3 to 74.5 years (standard deviation (SD) of 9.97 years). The range was 47-83 and age was not distributed normally (Figure 33). Twenty-seven participants (55.1%) were male. The overall H&Y mean value was 2.20 (± 0.96), placing the group at a mild to moderate disease with recovery on the balance pull test (Lindholm et al., 2021). The distribution curve for H&Y was negatively skewed, with a long kurtosis, indicating potential outliers or extreme values, as there were four participants at H&Y stage four. H&Y for all participants ranged from one to four, median value three, with H&Y interquartile range from one to three (Hoehn and Yahr, 2001).

**Figure 33 Histogram of age of participants (years)**

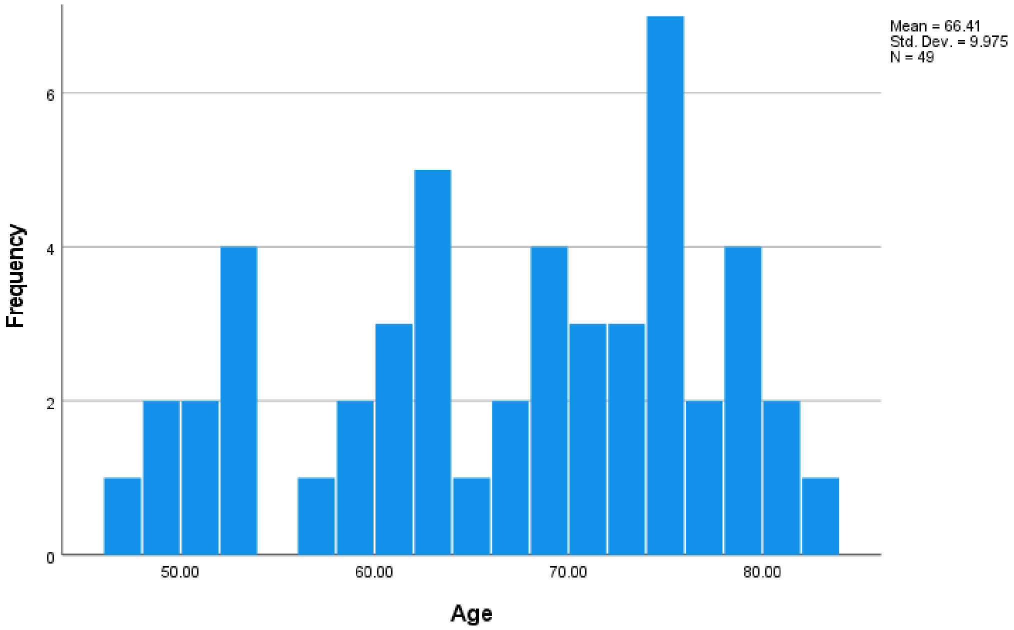


Figure 33 represents the spread of ages with the histogram, positively skewed, with a peak value of 77 years, a group of younger PwP aged 48-54, and another peak at 65 years.

### *Missing participant characteristics data*

All 49 participants provided baseline data for characteristics, H&Y, and time since diagnosis (Table 22).

### *2.2.3 Attrition and intervention fidelity from field notes*

Forty participants completed at least eight weeks of NW training. Reasons for attrition included: cause unknown (n=2), inclement weather (n=1), distance from home too far (n=1), increasing frailty and pre-existing back pain (n=2), struggling with menopause (n=2), poor sleep (n=1). One participant did not complete outcome measurements after their eighth lesson due to fatigue.

Reasons for stopping the programme early were reported and recorded in the field notes. After three lessons, one participant reported that the weather was too cold and wet (n=1). One participant attended twice and then stopped as the journey was too far on the train and tram (n=1). Two participants had long-standing back pain and stopped attending after three lessons each. An older participant (eighty-three years old) said that he enjoyed NW and the support of the group, but his PD was deteriorating, and he stopped due to increased frailty after attending four lessons. Two women in their late forties attended three lessons each but reported that they were struggling with peri-menopausal symptoms: poor sleep, pain, and fatigue. They said that they enjoyed the physical exercise of NW and the group support. However, they did not return to the group despite several email reminders. (The group was emailed if the class was cancelled due to extreme weather conditions). One participant stopped attending after three lessons due to growing workload demands after the COVID-19 pandemic. She was complimentary about her experience of NW, very keen to improve her physical fitness, and said she was disappointed to stop the classes.

Field notes document the people who accompanied the participant and were invited to learn the NW technique. Their outcome measures were not recorded but field notes documented that they continued to NW after the eight-week programme. At the class there were usually one or two partners or a personal assistant. In total 20 people without Parkinson's joined the eight-week programme, including a neurological physiotherapist, a neurology nurse specialist, and a nursing student. These individuals, or NHS 'guests,' attended for one week to observe the intervention.

Field notes reported that 37 PwP continued to NW weekly after the eight-week course. Of the study sample, 22 participants continued to attend the NW classes after the eight-week intervention. Nineteen participants joined a new NW group, led by a PwP who trained to be a NWI, who was a physical education teacher before retirement. Three participants joined local NW groups, led by an NWI. Twenty-five PwP reported in the field notes that they planned to NW regularly with their partner, friends, or on their own after the study ended. Twelve PwP reported that they were going to regularly NW at parkrun with their friends and family.

### *2.2.4 Outcome measures*

#### *Missing data baseline and follow-up data*

Twenty-four people (60%) returned baseline NMSS questionnaires (week zero). Thirty-nine (79.6%) of the initial 49 participants, completed the eight-week follow-up outcome measurements (Table 33). Thirty-four participants (70%) completed six-month follow up physical assessments. Of the six participants who did not return after six months, one PwP reported having several appointments due to waiting for deep brain stimulation (DBS) for PD (n=1). Three people had other commitments (moving house, caring for grandchildren, medical appointments). One PwP missed his outcome measures appointment due to emerging cognitive impairment (he missed the tram stop), but his wife facilitated a meeting two weeks later. The cognitive deficits were evident in his NMSS questionnaire, and his wife reported that she was thankful for this information, to inform the consultant at their next hospital PD review. Two participants failed to reply to the email invitation for follow-up measurements. Twenty participants returned a non-motor symptoms scale (NMSS) questionnaire after six months. Thirteen participants returned the NMSS after eight weeks and nine participants returned three NMSS questionnaires after both time points: eight weeks and six months (Table 55).

#### *Baseline data*

Baseline outcome measures data is presented in Table 2. Initially, the sample had an average gait speed over ten metres of 6.29 seconds, over 20 metres of 12.42 seconds, stepping cadence over ten metres of 13.68 steps, over 20 metres of 26.51 steps and TUG of 7.76 seconds. Tragus, a measurement of posture had a mean score 18.82 cm. The total NMSS score averaged 43.77 (out of a total 360). Data for all outcomes at baseline was normally distributed.

#### *Comparison of baseline to eight-week data.*

As reported in Table 33, after eight weeks of NW intervention, there appeared to be an improvement of the following motor scales: 10 MWT (time and cadence), 20 MWT (time and cadence), TUG and Tragus. After calculating the mean difference between the two time points, data was analysed and found to be normally distributed (Figure 33). The mean difference (± SD) between time zero (baseline) and time one (after eight weeks of NW intervention) of motor and non-motor variables were computed with a two tailed paired sample t-test (confidence interval 95% and an alpha or p value =0.05). Non-motor symptoms scale (NMSS) scores were lower at week eight (indicating a potential improvement in symptoms), particularly the total NMS score ($p < 0.03$) and the score for sleep/ fatigue ($p < 0.006$).

**Table 33 Effect of eight-week intervention (NW) in PwP from week 0 to week eight**

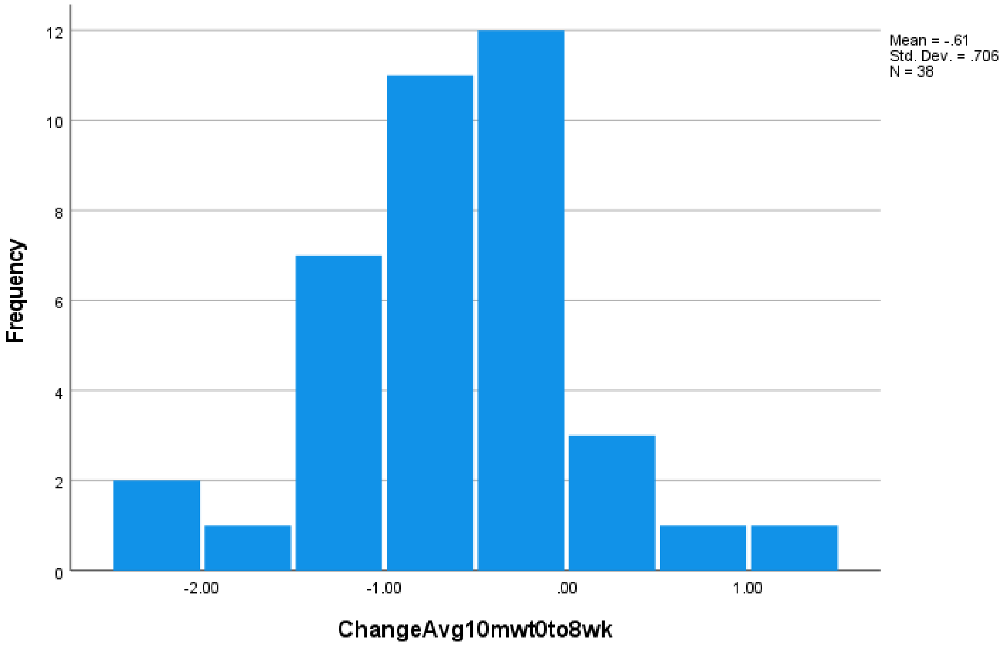
| Variable (n=39) | Mean (SD) baseline (T0) | Mean (SD) 8-weeks (T1) | Mean difference (SD) T1-T0 | 95% CI around mean difference | p value | Cohen's d effect size and its 95% CI |
|---|---|---|---|---|---|---|
| 10 MWT (secs) | 6.29 (0.90) | 5.68 (0.96) | -0.61 (0.71) | -0.84 to -0.38 | <0.001 | 0.86 (0.49 to 1.23) |
| 10 MWT (steps) | 13.68 (1.55) | 12.84 (1.56) | -0.83 (0.95) | -1.15 to -0.52 | <0.001 | 0.88 (0.50 to 1.25) |
| 20 MWT (secs) | 12.42 (1.66) | 11.14 (1.80) | -1.29 (1.13) | -1.66 to -0.91 | <0.001 | 1.14 (0.73 to 1.55) |
| 20 MWT (steps) | 26.51 (2.83) | 25.17 (3.01) | -1.34 (1.41) | -1.81 to -0.87 | <0.001 | 0.95 (0.56 to 1.34) |
| TUG (secs) | 7.76 (2.05) | 6.61 (1.31) | -1.15 (1.43) | -1.61 to -0.69 | <0.001 | 0.81 (0.44 to 1.17) |
| TRAGUS (cm) | 18.82 (4.27) | 16.79 (4.15) | -2.03 (2.33) | -2.78 to -1.27 | <0.001 | 0.87 (0.50 to 1.24) |
| NMSS Total score | 43.77 (32.80) | 33.69 (24.02) | -10.08 (15.11) | -19.21 to -0.94 | 0.03 | -0.67 (-1.26 to -0.05) |
| NMSS sleep/fatigue | 7.77 (5.29) | 5.80 (4.64) | -2.00 (2.16) | -3.31 to -0.69 | 0.006 | -0.93 (-1.57 to -0.26) |
| NMSS Mood/cognition | 6.62 (8.77) | 6.23 10.03) | - 0.38 (4.70) | -3.22 to 2.45 | 0.77 | -0.08 (-0.61 to -0.46 |
| NMSS Urinary | 9.62 (10.81) | 7.15 (9.39) | -2.46 (7.38) | -6.92 to 2.00 | 0.25 | -0.33 (-0.86 to 0.23) |

Abbreviations: CI= confidence interval, MWT=metre walk test, n=number of participants, NMSS=non-motor scale score, SD= Standard deviation, T0= Week 0, T1= Week 8, TUG=Timed Up and Go

### *10 MWT, speed and cadence*

The mean difference between the average mean values of the 10 MWT over eight weeks of intervention was normally distributed as shown in the histogram (Figure 44).

**Figure 44 Histogram showing the change in mean time for 10 MWT from week 0 to week eight (seconds)**



The mean change was -0.61 seconds for speed and -0.83 steps, indicating that on average the sample walked quicker and took fewer steps (cadence) at the end of eight weeks. The confidence interval (CI) between -0.38 and -0.84 did not span zero and the p value was <0.001. Therefore, the null hypothesis was rejected, this was not a chance finding. The primary hypothesis can be accepted: that an eight-week NW intervention, delivered in a group setting according to INWA guidelines, improves gait, speed and cadence on PwP. There appeared to be a positive effect on mobility following the period of NW intervention. The effect size was on average, 0.86 (with 95% CI around Cohen's d correction 0.49 to 1.23). The potential clinical implications and confounding factors are points for discussion in the next section of this chapter.

### *Timed up and Go (TUG).*

The mean change in TUG after the eight-week intervention was -1.15 seconds. Most participants showed improvements at this sit to stand test and walked faster. The CI (-1.61 to -0.69) around the mean difference (-1.15 seconds) had an effect size of 0.81 and p value < 0.001. Again, the null hypothesis was rejected as there seemed to be a positive impact following the NW intervention.

### *20 MWT speed and cadence.*

The mean difference between average mean values of the 20 MWT following eight weeks of NW was -1.29 seconds and -1.34 steps. Outliers were not excluded from the data set. On average, each participant walked faster with longer, fewer steps (cadence) after the intervention. The CI around the mean difference was -1.66 to -0.91 seconds, with a p value of <0.001. In this instance, the null hypothesis can be rejected. There appeared to be a positive effect with mean effect size 1.14 applying Cohen's d correction.

### *Tragus Wall Distance (TWD).*

The mean change in Tragus after the eight-week NW intervention was -2.03 cm. The CI (-2.78 to -1.27) did not span zero and the p value was <0.001. The effect size, applying a Cohen's d correction was 0.87. This sample of PwP appeared to have improve posture and were more upright after the intervention.

### *Non-motor symptoms scale (NMSS) (0-8 weeks).*

There was a mean reduction in the total NMSS score of -10.08. The CI did not span zero and the p value was <0.05. This sample appeared to have improved non-motor symptoms across all domains following eight weeks of NW intervention. Of the nine dimensions (groups of non-motor symptoms) on the scale, three (sleep, cognition, and urinary symptoms) had higher scores at baseline, indicating greater impact to the participant (frequency multiplied by severity of symptoms). These domains were analysed separately. The mean difference between the score for sleep/ fatigue was -2, with CI (-3.31 to -0.69) and p value of 0.006. There appeared to be compelling evidence for improvements in sleep following eight weeks of NW as p was less than 0.05. (This was also reported in the field notes by several participants over consecutive weeks). The mean change in mood/ cognition was -0.38 with a CI around the mean difference of -3.22 to 2.45. The CI spanned zero with a p value of 0.77. This was not statistically significant, but the general trend was maintenance or a slight improvement in mood and cognition. Outliers were included and some participants, with complex or later stage PD, had higher scores for cognition and mood at baseline.

An unexpected result was the improved NMSS score for urinary function after eight weeks of intervention. The mean change in score was -2.46 with a p value 0.25. Although this did not meet the threshold for statistical significance, it was included in the discussion as there were potentially clinical implications.

### *Comparison of baseline to six-month data.*

As reported in Table 44, six months after the NW intervention, the data suggests an improvement of the following motor scales: 10 MWT (time and cadence), TUG, Tragus and 20 MWT (time and cadence). Data was normally distributed. The mean (± SD) at time 0 (T0 baseline) and time 2 (T2 six months after the NW intervention) of motor and non-motor variables were computed with a two-tailed paired sample t-test (confidence interval 95% and an alpha or p value =0.05).

Field notes supported the physical improvements in speed, cadence and posture as participants reported that they could walk faster, with a longer stride. For some participants (n=5) their relatives had remarked that they were standing taller, with notable improvements in posture. Many participants (n=15) remarked that they felt more confident due to using two poles and expressed a reduced fear of falling.

All motor scores in this table had a p value of <0.001, suggesting longer-term benefits of the NW intervention. This p value contrasts with the interim paired t-tests, between eight weeks and six months, where p values ranged from 0.049 to 0.93 (Table 55).

**Table 44 Effect of eight-week intervention (NW) in PwP from week 0 to month six**

| Variable (n=34) | Mean. (SD) baseline (T0) | Mean. (SD) 6-month (T2) | Mean. (SD) difference T2-T0 | 95% CI around mean difference | p value | Cohen’s d effect size) (95% CI) |
|---|---|---|---|---|---|---|
| 10 MWT (secs) | 6.26 (0.93) | 5.44 (0.99) | -0.82 (0.67) | -1.06 to -0.59 | <0.001 | 1.22 (0.77 to 1.66) |
| 10 MWT (steps) | 13.71 (1.57) | 12.60 (1.75) | -1.11 (0.98) | -1.45 to -0.76 | <0.001 | 1.13 (0.69 to 1.55) |
| 20 MWT (secs) | 12.40 (1.73) | 10.69 (1.87) | -1.71 (1.20) | -2.13 to -1.29 | <0.001 | 1.43 (0.94 to 1.90) |
| 20 MWT (steps) | 26.53 (2.85) | 24.98 (3.45) | -1.55 (1.73) | -2.15 to -0.95 | <0.001 | 0.90 (0.49 to 1.29) |
| TUG (secs) | 7.54 (1.80) | 6.55 (1.87) | -1.00 (1.45) | -1.50 to -0.49 | <0.001 | 0.69 (0.31 to 1.06) |
| TRAGUS (cm) | 18.24 (3.94) | 15.51 (3.74) | -2.73 (2.20) | -3.49 to -1.96 | <0.001 | 1.24 (0.79 to 1.69) |
| NMSS total score | 47.94 (44.32) | 39.67 (37.42) | -8.28 (28.81) | -22.61 to 6.05 | 0.24 | -0.29 (-0.76 to 0.19) |
| NMSS sleep/ fatigue | 7.22 (5.63) | 8.89 (8.15) | 1.67 (7.23) | -1.93 to 5.26 | 0.34 | -0.23 (-0.24 to 0.70) |
| NMSS mood/ cognition | 9.39 (13.76) | 6.72 (9.19) | -2.67 (9.32) | -7.30 to 1.97 | 0.24 | -0.29 (-0.75 to 0.19) |
| NMSS Urinary | 10.61 (10.47) | 9.94 (8.18) | -0.67 (6.93) | -4.11 to 2.78 | 0.69 | -0.10 (-0.56 to 0.37) |

Abbreviations: CI= confidence interval, MWT=metre walk test, n=number of participants, NMSS=non-motor scale score, SD= Standard deviation, T0= Week 0, T2= Month 6, TUG=Timed Up and Go

### *10 MWT, speed and cadence*

The mean difference between the average mean values of the 10 MWT, six months after eight weeks of intervention was normally distributed. The mean change (± SD) was -0.82 (±0.67) seconds for speed and – 1.11 (± 0.98) steps. So, on average each participant walked faster with fewer steps (cadence) at the end of six months. The CI for 10 MWT steps (between -1.45 and -0.76) did not span zero and the p value was <0.001. Therefore, the null hypothesis can be rejected, this was not a chance finding. There was an emerging positive effect due to this intervention, the effect size was on average, 1.13 (applying Cohen’s d correction).

### *Timed up and Go (TUG)*

The mean change in TUG six months after the intervention was -1.00 seconds. The CI around the mean difference was -1.50 to -0.49 seconds. Again, the null hypothesis can be rejected as there seemed to be a positive effect, with mean average effect size 0.69.

### *Tragus*

The mean Tragus six months after the eight-week NW intervention was -2.73 cm. The CI (-3.49 to -1.96) did not span zero and the p value was <0.001. The effect size, applying a Cohen's d correction was 1.24. The overall effect suggests that NW positively influenced posture for PwP, and this appeared to be maintained up to six months after the period of NW rehabilitation.

### *20 MWT, speed and cadence*

The mean difference between average mean values of the 20 MWT, six months after eight weeks of NW was -1.71 seconds and -1.55 steps. Each participant, therefore walked faster with fewer steps (cadence) after the intervention. The CI (-2.13 to -1.29) seconds did not cross zero, with p value of <0.001. Again, the null hypothesis can be rejected. There was an emerging positive effect with mean effect size 1.43 (with Cohen's d correction).

### *Non-motor symptoms scale (NMSS) (0-six months)*

Twenty-four NMSS questionnaires (60%) were returned at baseline, 13 (32.5%) were completed after eight weeks and 20 (50%) NMSS were posted to the researcher after six months of NW intervention. Most of the improvements in the NMSS were recorded after eight weeks of NW. However, the total NMSS score had a mean difference of -8.28 after six months and a p value of 0.24. There appeared to be a small improvement in mood and cognition in a population where these domains can fluctuate or deteriorate after six months. The mean difference in urinary scores was -0.67 with p value 0.69. None of the NMS on this table achieved strong statistical significance, but their potential implications for clinical application were points for discussion.

Field notes corroborated with the non-motor improvements, in particular the domains of mood and cognition, sleep, and fatigue. One female participant remarked that she always slept better on Thursdays after NW, even if the weather was poor. She expressed that she felt motivated by other people in the group and was always pleased that she had made the effort to attend. This was a recurring theme in the field notes: the motivating impact of exercising outdoors with fellow PwP. Participants rarely discussed urinary symptoms during the lesson. However, some male participants required a bathroom break during the one-hour session (n=4). Female participants (n=15) discussed sleep, fatigue and motivation, and the positive impact that NW had on their sleep pattern.

In addition to the NW sessions in the study, some participants chose to set motivational, personal goals such as a five km parkrun or parkwalk (parkrun, 2023), NW on holiday in the lake district or NW on the beach. These goals were recorded in the field notes. Some participants (n=19) introduced a friend or partner to NW and some partners (n= 10) joined the eight-week NW intervention. Their results were not recorded as this was not in the study protocol.

### *Comparison of eight week to six-month data*

As reported in Table 55 there was a small improvement or maintenance of function across most outcome measures between week eight and month six, apart from TUG. Changes in this dataset were not specific to the research question, so were not reported in detail. However, the net effect from baseline (week 0) to month six was useful and the p value for all physical outcome measures was $p < 0.001$. The results indicated that there was no deterioration in outcome measures and that PwP continued to demonstrate small improvements, after the eight-week period of intervention. By applying a Cohen’s d correction (1.43) for the 20 MWT (time) and for the Tragus measurement (1.24), these outcomes had the largest effect size in this sample of PwP. Maintenance of function in this population would be considered a positive outcome.

**Table 55 Effect of eight-week intervention (NW) in PwP from week eight to month six**

| Variable (n=34) | Mean (SD) 8-week (T1) | Mean (SD) 6-month (T2) | Mean difference (SD) T2-T1 | 95% CI around mean difference | p value | Cohen’s d effec size (95% CI) |
|---|---|---|---|---|---|---|
| 10 MWT (secs) | 5.63 (0.98) | 5.44 (0.99) | -0.19 (0.67) | -0.04 to 0.42 | 0.109 | 0.28 (-0.06 to 0.62) |
| 10 MWT (steps) | 12.84 (1.59) | 12.60 (1.75) | -0.25 (0.78) | -0.03 to 0.52 | 0.08 | 0.31 (-0.03 to 0.66) |
| 20 MWT (secs) | 11.10 (1.87) | 10.69 (1.87) | -0.41 (1.18) | -0.82 to 0.00 | 0.049 | 0.35 (0.00 to 0.69) |
| 20 MWT (steps) | 25.25 (3.01) | 24.98 (3.45) | -0.27 (1.39) | -0.21 to 0.76 | 0.26 | 0.20 (-0.14 to 0.54) |
| TUG (secs) | 6.53 (1.22) | 6.55 (1.87) | 0.02 (1.22) | -0.44 to 0.41 | 0.93 | 0.01 (-0.35 to 0.32) |
| TRAGUS (cm) | 16.11 (3.48) | 15.51 (3.74) | -0.60 (1.75) | -0.01 to 1.21 | 0.053 | 0.34 (-0.01 to 0.69) |

Abbreviations: CI= confidence interval, MWT=metre walk test, n=number of participants, NMSS=non-motor scale score, SD= Standard deviation, T1= Week 8, T2= Month 6, TUG=Timed Up and Go

### *Missing data due to attrition*

Quantitative data from nine participants, who did not complete eight lessons, was not included in the analysis. Their follow up eight-week and six-month outcome measures were not recorded and uploaded to SPSS; therefore, two tailed paired t-tests could not be calculated. However, their reasons for not attending eight sessions, as recorded in field notes, provided rich qualitative data about adherence to an exercise intervention for PD rehabilitation. The participant who stopped attending due to harsh weather reported that she was also juggling a growing workload, following the pandemic. She felt tired on Thursdays (NW session) due to working long hours and other family commitments. A participant who stopped attending after two lessons reported that the one-hour travel time on public transport (train and tram) was very tiring, and he asked to join a local NW group. He was given information about an established, regional PD NW group, but he did not communicate with the research team again, so his follow-up data was not recorded. Of the two participants who stopped attending due to pre-existing back pain, one PwP returned to NW after a few weeks and said that he found it beneficial. His other PD symptoms were deteriorating, and he chose to stop the lessons. His back pain had been recorded on the health questionnaire, PARQa (Appendix 6), and may have been a reason to exclude him from the study, but his NHS physiotherapist had recommended NW, and he was keen to learn the technique. He contacted the research team after the study and expressed his gratitude for the early introduction to NW. The 83-year-old participant who stopped attending after four lessons, due to increased frailty, reported (in the field notes) that he was disappointed to withdraw from the programme. He enjoyed meeting other PwP who were active, especially as he enjoyed hill-walking and exercising outdoors. He returned to the lessons after a break of several weeks, but his PD symptoms were progressing, and he said that he lacked stamina for a one-hour session. Another participant expressed her disappointment at stopping NW as her full-time job, for which she could work flexibly during the pandemic, was returning to an office-based routine with increasing demands on her time. She said that she had enjoyed learning how to NW and she valued exercising with other PwP who were also active and motivated.

Overall, there was good adherence to the NW intervention and most participants (80%) were willing, and available, to return to the University for repeated measures. There was a fair return rate of the NMSS questionnaires, either in person or by post. Twenty-four (60%) people returned baseline NMSS questionnaires (week 0), 13 people (32.5%) returned them after eight weeks and 20 (50%) were posted after six months. Nine participants (22.5%) returned all three NMSS questionnaires. A stamped-addressed envelope was provided at the six-month follow-up assessment, and this might account for the higher return rate of NMSS, compared to those who returned them in person (at the next session) after eight weeks.

## 2.3 Discussion

### *2.3.1 Principal findings*

Nordic Walking, as a novel form of rehabilitation in PwP, was successfully implemented in a group community setting, and delivered with fidelity, with 40 out of 49 participants (81.6%) completing the eight-week intervention. Participants engaged with the intervention and appropriate outcome measures were collected on time and to target.

In participants who completed all eight sessions, the intervention appeared to deliver improvements in speed of walking and stride length, timed up and go (TUG) from a chair and posture. The improvements were statistically significant after eight weeks ($p < 0.001$) and there were further small improvements observed at the six-month assessment. The greatest improvement was seen in the Tragus, and 20 metre walk tests (speed). Participants in this sample walked with an improved gait speed, better upright stance, and with fewer steps (longer strides) than before the intervention. These findings were corroborated in the field notes.

These results could have positive clinical implications for PwP as the study sample reported feeling more confident with walking, with better balance and a reduced fear of falls due to using two NW poles. In addition, non-motor (quality of life) scores for sleep and fatigue, cognition and mood improved after eight weeks. An unexpected result was improved urinary symptoms, possibly due to enhanced engagement of core muscles including the pelvic floor during NW. These improvements were seen in a population that would routinely be expected to decline over time. The study results suggested that the benefits were due to NW as they were all outcomes related to the intervention, but a fully powered RCT is needed to evaluate clinical and cost-effectiveness. Field notes found that some participants continued to NW outside of the study sessions which could have been a motivator towards increased NW and exercise.

### *2.3.2 Strengths and weaknesses of the study*

A strength of this study was that the NW intervention was delivered according to a protocol, and it had fidelity against pre-defined components: eight weeks of NW in a group with PwP, outside, following the INWA ten steps model, with a qualified BNWI for one hour.

The intervention included INWA defined warm-up and cool down exercises, tailored to meet the needs of individuals and the group for their safety.

Another strength was that almost 80% of outcome measures (79.6%) were completed on time. Once in the study, participants stayed in the study, although inclement weather during the initial recruitment phase (Winter 2021) and throughout could be viewed as a weakness. During the NW intervention that ran for 13 months twice per week, only one participant reported that cold and wet weather was a factor in their withdrawal from the programme. PwP were keen to take part and easy to recruit from a range of geographic locations, PD branches, PD research interest groups and professional sources. There were strong partnerships with PUK, BNW and NHS teams in the hospital and community.

A strength of the study was that p values were extremely low across all motor domains after eight weeks of NW intervention ($p < 0.001$), so these results were unlikely to be a chance finding. A further strength was that this statistical significance was maintained after six months and there appeared to be a further improvement or maintenance of function from eight weeks to six months.

Confounding factors should be considered in the light of these results. There were extraordinary external circumstances due the timing of the intervention from November 2021-December 2022. The Coronavirus (COVID-19) pandemic had a major impact on PwP and the provision of routine clinical and other support services. During the study lockdown measures were gradually lifted, with caution for at risk groups. PwP were keen to get outside, to meet other people, but they remained anxious about contracting Coronavirus or experiencing longer term complications of COVID, e.g., Long-COVID (Leta et al., 2021). Additional confounding factors were other health services and facilities that restarted, such as in person PD clinics. There was a possibility that medications might be radically changed, or new treatments started. One participant was commenced on a clinical pathway for deep brain stimulation (DBS) but did not undergo surgery during the data collection period. No participant undertook a new sport or treatment; however, some did resume previous exercise habits/routines. One PwP returned to golf, one enjoyed table tennis and a PwP who ran most days continued to do so. Another strength was that some PwP who had been inactive before the study became more active and this continued six months after the intervention, as if taking part in the NW programme was a stimulus for becoming more active.

A further strength was using a repeated measures design, thereby having the same sample throughout the study. This reduced the potential for variability within the group. The same sample was measured at three time points, so it was possible to draw comparisons and derive inference from the results. A weakness was the time commitment from each participant as there were eight weeks of face-to-face intervention (one hour per week) as well as a pre-study screening meeting and post-study repeated measures, and three NMSS questionnaires.

One might argue that there was potential for selection bias during recruitment, as PwP who volunteer to participate in exercise research studies might be more motivated than those who do not take part in either research or exercise (Smith and Noble, 2014). So, was this a representative sample and could these results be extrapolated or generalised to a wider population of PwP? A weakness of the study was that this was a motivated group who had all shown an interest in NW and therefore, not representative of all PwP.

Very few participants, who initially took part, stopped attending the programme after two or three lessons. If NW were provided as part of an NHS programme, to a wider cohort of PwP, there might be more who would not complete the eight-week intervention.

A weakness was that the quantitative data from the nine participants, who did not complete all eight sessions, was not included in the analysis. However, their reasons for attrition provided rich qualitative data about adherence and motivation regarding an exercise intervention for PD rehabilitation. This data was captured in the field notes.

A potential weakness of the study was information bias (Bryman, 2004). There could have been discrepancies or differences in the way that outcomes were measured. A strength was that the same person, using the same equipment (e.g., chair, stopwatch, measuring tape) at the same venue, at a similar time of day, recorded all the outcome measures. Another potential source of bias was that the lead researcher delivered the NW intervention and conducted the measurements. To mitigate this risk the protocol was followed with fidelity and integrity. A second researcher (FA) checked data and statistical analysis.

A further potential weakness of the study were the subjective measures recorded in the field notes, as participants' feelings, mood or fatigue were noted after each class. However, they were not formally reported in this study and served mainly as an adjunct to the NMSS questionnaire and physical measurements. Many participants expressed that they 'felt better' at the end of the eight-week NW intervention, but this could be attributed to many factors, not least their re-emergence into the community after the COVID-19 lockdown. The NMSS was recorded at the three time points, and there could have been subjective bias as the participant might have believed that the intervention contributed to some improvements. However, a strength was that the NMSS was a robust and appropriate questionnaire that has demonstrated consistency (reliability) and accuracy of measurement (validity) since its inception in 2007 (Chaudhuri et al., 2007). It was devised by a panel of international experts in PD and complex non-motor symptoms. It was the first comprehensive assessment of the range of NMS that occur in PD and was useful for the identification of problems and measurement of the impact of an intervention, as employed in our NW study. The NMSS was developed after the NMS Quest (NMSQ, Appendix 9). A weakness was that the NMSS was complex (30 questions with a frequency multiplied by severity rating scale from 0 to 4). Some questionnaires were completed inaccurately, and others were not returned. A strength was the specificity of symptoms in the questionnaire helped to elicit useful data, including emerging mild cognitive impairment in three participants.

The time of the day for recording outcome measurements was important for the participants due to Parkinson's medication efficacy and 'on-time' (the period when PD medication is most efficacious, yielding optimal motor symptoms). A weakness of the study was the restricted availability of the lead researcher to meet participants at various times of the week, according to their schedules and medications. This was ameliorated by the researcher adopting a flexible approach, to accommodate the needs of the participants and their partner or carer wherever possible. For example, an anxious participant, who struggled emotionally with the larger group, attended with their spouse for two NW lessons and then recorded outcome measurements at a time when their medication was optimal. Another PwP moved from the 1pm class to 2.30pm as their medications were more efficacious after 2pm.

### *2.3.3 Results in relation to other studies*

It was useful to explore the literature to compare these findings to previous studies, discussing particularly any differences in results.

The study design (methods, outcomes, and materials) resembled previous studies in this population, although results were different. It was difficult to compare such studies as there was heterogeneity of participants regarding H&Y stage, age, time since diagnosis and baseline motor function (Bang and Shin, 2017, Cugusi et al., 2017, Ebersbach et al., 2014, Monteiro et al., 2017).

It was difficult to compare these findings with similar research as few human subject research studies were conducted during the COVID pandemic in this population. However, a systematic review and meta-analysis was published that reviewed 12 studies conducted before the pandemic (Salse-Batán et al., 2022). In 2021 they studied the effects of NW in PwP by reviewing the available literature, using the preferred reporting items for systematic reviews and meta-analyses (PRISMA) guidelines. A strength of this study was the adherence to rigorous methods of critical appraisal of the literature. Salse-Batan (2022) included RCTs with a wide scope of outcome measures, using the Physiotherapy Evidence database (PEDro). The Cochrane collaboration's risk of bias tool was also employed. A potential weakness of their study was the discrepancy between the NW intervention frequency and intensity, between four and 24 weeks. There was also a bias towards physiotherapy interventions rather than those delivered by other members of the multi-disciplinary rehabilitation team. Despite differences in the study designs, most physical outcome measurements were comparable with the current study. For example, seven studies analysed data between pre- and post-intervention in basic functional mobility and reported significant effects due to NW. In this meta-analysis, comparing baseline with post-intervention data (TUG in the intervention group), significant improvements were obtained (n=190; WMD = 1.75 seconds faster; 95% CI [1.33,2.18]; $I^2$ =94.1%), and included an assessment of heterogeneity. That is, an estimate of the proportion of variability that is explained by differences in the trials rather than sampling error (Kirkwood, 2003). The meta-analysis, pooling the standard mean difference (Cohen's effect) for the TUG showed a medium effect size (SMD = 0.77; 95% CI, 1.09; $I^2$ = 89.3%). This was like the Cohen's effect size in this study 0.81 (0.44 to 1.17) and mean difference -1.15 seconds (TUG).

In contrast with the larger systematic reviews, a small study with 11 PwP, measured the biomechanical impact of NW on arm-swing (Leal-Nascimento et al., 2022). The sample in their feasibility study was small (n=11) so it was difficult to generalise their results to a wider population of PwP. However, if the NW technique has potential to improve bilateral arm-swing in PwP with unilateral impairment, this study could provide baseline material and outcome measures for further biomechanical research in this field. Our study did not measure arm-swing and could be an important additional outcome to consider in future NW research.

Few studies have employed the Tragus measurement in the context of PD (Giardini et al., 2018). The initial paper (Shipe et al., 2013) set out to assess the intra- and inter-rater reliability of the Tragus measurement in non-pathological participants aged 18-34. This contrasts with the current study where all participants have PD, representing an older cohort, who may experience concurrent spinal or postural challenges. A strength of the Tragus measurement was that it was simple to assess, using the same metal tape measure, wall, and researcher. A weakness was the participants understanding of a natural, relaxed stance at each time point, if they thought that an upright posture was a positive outcome. A strength was calculating an average (mean) of the right and left ear Tragus to wall distance as cited in this study for PwP (Giardini et al., 2018).

Heterogeneity of participants' stage of PD, as described by H&Y (Hoehn and Yahr, 2001), was a confounding factor to comparing studies. Even in comparative studies, with a narrow range of H&Y stages (De Santis and Kaplan, 2020), participants varied in their clinical presentation. This was supported by a further small study with 11 participants, (stages 1-1.5) by Leal-Nascimento and colleagues (Leal-Nascimento et al., 2022). The De Santis and Kaplan study (2020) contrasted with the current study as it set out to systematically review 318 participants with early to moderate PD, (stages 1-2) across thirteen studies. The current study set out to recruit participants from a wide range of PD stages (1-4) as the NW intervention could be tailored to meet the needs of a diverse population, the individual and the group. The results indicated that this was achieved. A comparative study was conducted by Monteiro et al, (2017) who also recruited PwP at stages 1-4, although, with a lower sample size (33 participants compared to 49 in the current study). Monteiro's study was a small RCT, comparing NW to free walking (without poles). Outcome measures were similar, and in both studies PwP participants demonstrated significant improvements in TUG and walking speed (Monteiro et al., 2017). TUG was measured at a self-selected speed by participants in both studies and p values were the same ($p< 0.001$). Monteiro also recorded TUG at a forced speed and recorded data in a control group, in contrast to this study ($p< 0.001$). Their results indicated that NW was superior to walking (without poles) and NW could be considered a valuable method of rehabilitation for some PwP (Monteiro et al., 2017).

The Granziera (2021) study was like the current study as it employed a similar repeated measures method (single-blind RCT) and data was analysed using paired t-tests (Granziera et al., 2021). Thirty-two PwPs were recruited with H&Y stages 2-3, and NW was compared to walking. In their study, NW was found to be 'not superior' to walking. However, they documented that there was a beneficial effect of open-air exercise and guided group walking activities for PwP. This resonates with the non-motor improvements in the current study.

The use of NMSS questionnaire in this population was low in other studies (Chaudhuri et al., 2007, Cugusi et al., 2015, Ebersbach et al., 2014). Despite a well-recognised, reliable, and valid non-motor symptoms scale there may have been barriers to its use in studies for PwP. One weakness was the potential barrier of cost to the researcher. The fee would have been $1,000, but as this was a postgraduate PD research study the cost was kindly waived by the Movement Disorders Society (MDS). A further weakness was the complexity and length of the questionnaire with nine non-motor domains comprising 30 questions. Some domains were of a sensitive nature, so participants may have felt uncomfortable disclosing personal information about their sexual drive or urinary symptoms, in the context of an exercise intervention. Similar studies utilised a range of non-motor assessment tools including the PD quality of life questionnaire (PDQ-39) (Peto et al., 1998) and the Unified Parkinson's Disease Rating Scale (UPDRS) (Goetz et al., 2008), so different scores and outcomes could not be compared directly.

In summary, the results from this study have built upon previous literature regarding the potential impact of NW for PwP. Other studies in this population have not measured the longer-term benefits on physical and psychological outcomes, following a global pandemic. Radder's meta-analysis of 191 trials with 7,998 participants (Radder et al., 2020) provides a comprehensive guide to treatment modalities for PD, from a physiotherapy perspective. They scrutinised the evidence for a range of novel, non-drug therapies and concluded that dance, Nordic walking, balance and gait training, and martial arts improved motor symptoms, balance, and gait. Exergaming improved balance and quality of life (Radder et al., 2020). In conclusion, Radder (2020) suggested that the evidence from their meta-analysis could allow policy makers, clinicians, and patients to make an evidence-based choice about specific treatment modalities. They recommended that further research was required to directly compare the various rehabilitation interventions, which this study contributes towards.

### *2.3.4 Conclusion*

The study achieved its main aims and recruited 49 PwP (the target was 40-60), from a diverse population according to age, H&Y stage of PD, number of years since diagnosis and background. The NW intervention was delivered on time, to target, with fidelity and within resources allocated to it. The lead researcher (SM) delivered two NW sessions (one hour each) every week for 13 months. Participants came to the group every week and almost 80% of the outcome measures were collected (79.6%). PwP demonstrated motor and non-motor benefits, and these persisted up to six months post intervention.

Once we established that NW was feasible for PwP and there were benefits, the next stage was to explore the participants' opinions of the intervention. A qualitative FG method was chosen to ascertain the perceptions of PwP who undertook the repeated measures NW study. The aim was to determine facilitators and core components for future community NW groups and to build on the findings from the quantitative study.

Policy makers could consider a wider roll-out of NW instructor training for NHS PD specialists, to equip clinicians with the skills to deliver community rehabilitation groups in social and clinical settings. The cost for NWI instructor training is £485 per person (British Nordic Walking, 2023a). Once PwP have had guided specialist instruction they may feel confident to join mixed NW groups or NW with a partner or alone, as illustrated by the maintenance of improved outcomes and field notes from this study. This will be explored further in the FG study (Chapter 3).

Unanswered questions, and suggested future research, are considered in the context of the whole MPhil and will be included following the FG results in the overall discussion (Chapter 4).

# CHAPTER 3 FOCUS GROUP STUDY

## 3.1 Methods

### *3.1.1 Research design*

This FG study sought to evaluate an eight-week rolling programme of NW being delivered to PwP in a community rehabilitation setting, to better understand the characteristics and core components needed for further implementation. The aspiration was to understand the practical, safety and individual aspects of setting up NW groups through the opinions and experiences of PwP, NWIs, and NW walk leaders (WL). The FGs intended to answer the research question: “What are the characteristics and core components needed to implement NW groups for PwPs in a community rehabilitation setting?”

The aim, as set out in Chapter 1, was to establish the characteristics and core components needed to implement NW groups for PwPs in a community rehabilitation setting.

An exploratory qualitative approach was employed to establish the facilitators/core components required to set up NW groups for PwP. A FG study design and thematic analysis (TA) were used to explore characteristics and enablers inductively, as reported by Braun and Clarke (Braun and Clarke, 2006).

FGs were chosen over individual interviews to facilitate interactive conversations between participants, with an aspiration to elicit a range of strong themes and subthemes. The strength of this method was to establish group dynamics, stimulate dialogue and elicit opinions about group norms. Three, one hour-long FGs had potential to yield a broad range of themes, in a brief period. An individual interview for fifteen participants would have been more time-consuming to deliver, to transcribe and to analyse. The subject matter was not emotive, nor sensitive, and the FG study captured the groups’ experiences, rather than an individual’s opinions or feelings. Had the subject been of a personal, sensitive nature, a different methodology would have been employed (e.g., individual interviews).

Kruger’s study in 2019 was with undergraduate women and their disclosed feelings about body image. Kruger’s research question was, “Individual interviews or focus groups? Interview format and women’s self-disclosure”, (Kruger et al., 2019). The subject matter was sensitive (body image). The results of the study suggested that individual interviews in a supportive environment were more conducive to disclosing sensitive feelings, compared to a FG design. A further study by Schuster et al aligned with Kruger’s study. The subject was gender-based violence against women and the criminal justice system (Schuster et al., 2023). The lead researcher regarded the NW FG study as not sensitive and unlikely to elicit sensitive emotions. This qualitative approach, asking patients or participants about their opinions and experiences of a treatment plan, is growing rapidly in the field of medicine and dentistry research (Gill and Baillie, 2018).

### *3.1.2 Recruitment*

#### *Identifying participants*

PwP and any partners who were able to NW, having accompanied their partner with PD in the NW intervention study, were invited to attend one of two FGs. NWI and WL were invited to join the third group. The aim was to encourage discussion from a variety of experiences and perspectives, to add to the richness of data. A decision was taken to convene all three FGs, irrespective of whether saturation was achieved after two groups. Homogeneity of participant characteristics was partially achieved as most participants had an interest in NW. However, there was sufficient variation in background, age, disease duration and H&Y stage to allow for contrasting opinions, as suggested by Willig et al (2017).

#### *Participant recruitment*

The PwP participants (and one spouse) were a sub-group/sample from the main NW for Parkinson's study (n=53, Chapter 2). The spouse had accompanied throughout the eight NW sessions and had learned the NW technique (their physical outcome measures were not recorded as this was not specified in the protocol). It was not initially planned for them to attend the FG, but they provided transportation, a one hour journey each way, to the NW sessions. The spouse added their perspective to the FG discussion. Other partners and carers were invited to join the FG study, but they chose not to attend.

All the NW research participants from the pre-post measures feasibility study were emailed and invited in person, at the end of the NW class, to establish expressions of interest. Any participant who was interested, and available, was invited to join the FG. PwP were offered one of two FG times (am or pm).

NWI and WL were recruited via the BNW regional and national networks via social media (a closed Facebook group for NWI and WL). Prospective participants sent an email to the lead researcher, expressing an interest to take part in the study.

#### Consent

Once a participant had shown interest in attending a FG, they were given a participant information sheet (PIS, Appendix 12), 24 hours before the FG. In addition to the electronic copies, sent via email, at the start of each FG, hard copies of the PIS were available. Additional time was given to consider the contents of the PIS and ask questions. Signed, informed consent was obtained at the beginning of each FG from all participants.

#### *Setting*

The FGs were held in a meeting room, at university premises, close to the location of the NW intervention.

### *3.1.3 Eligibility*

***Inclusion criteria (PwP)***

- Eligibility criteria included experience of NW, by attending the NW intervention sessions, as well as meeting the inclusion criteria for the pre-post measures feasibility study (Chapter Two).
- Any spouse/ partner who had accompanied a PwP for the whole eight-week NW intervention.

***Inclusion criteria (NWI/WL)***

- Inclusion criteria for the NWI was an instructor's qualification with BNW and recent experience of running NW groups for PwP. The WL also had a BNW qualification.

***Exclusion criteria (PwP)***

- Complex comorbidities including frequent falls and significant postural hypotension (reduction of 20mmHg systolic or greater, with adverse symptoms), assessed by SM with the adapted PARQ (Appendix 6).
- H&Y stage five (Hoehn and Yahr, 2001).
- Advanced dementia.

***Exclusion criteria (NWI/WL).***

- No experience of leading NW groups for PwP.
- No continuing professional development (CPD) or professional qualification for PD***.***

***Sample size***

The ideal number of participants in a FG is deemed to be between five and eight (Willig, 2017). In the marketing sector, numbers could be between ten to 12 people, according to the Sage Handbook (Willig, 2017). However, this number would be too large for a healthcare setting, especially with PwP who may have quiet, dysarthric voices and might be hard of hearing (Bloem et al., 2020).

### **3.1.4** ***Process during the FG***

The lead researcher (SM), with support of the supervisory team (VB and FA), hereafter called the research team (RT) compiled the FG interview schedules (Appendix 13). A separate schedule (Appendix 14) was developed for the NWI/WL FGs, based upon the experience of the RT, and current research about NW groups for PwP.

A member of the RT, not the lead researcher (SM), took the lead during the FG and asked an ice-breaker question. This served to facilitate the transcriber, as participants said their name and gave some background information. The discussion was audio recorded and each FG lasted one hour. The lead researcher interjected, when appropriate, but did not ask leading or prompt questions, to reduce introducing bias (Silverman, 2022). Participants were encouraged to engage and conduct peer discussion. Quieter members of the group were actively encouraged to contribute to the discussion to ensure that their views and opinions were heard. There was no break during the FG, but refreshments were served beforehand and a light meal afterwards, during a debriefing period (30 minutes). Travel expenses were reimbursed.

### *Data analysis*

Each FG was recorded on a digital voice recorder and audio files were electronically transferred to a University of Nottingham approved transcriber for transcription. The audio was transcribed verbatim. Three separate, pseudonymised transcripts were returned securely to the researcher for detailed coding. A pseudonym name was given to each participant and used as identifiers on the transcript.

Transcripts were shared with a second researcher (FA) for scrutiny and to complete independent data analysis. The additional researcher served to increase the credibility and validity of the research findings. Triangulation in research was described by Helen and Roberta and this study adopted investigator triangulation for the FG study and methodological triangulation for the MPhil studies (Helen and Roberta, 2019). Triangulation aimed to reduce researcher bias and helped to explore complex human behaviour by employing a variety of methods for data collection.

Thematic analysis was utilised (Braun and Clarke, 2006). Coloured highlighters, and the comments feature, were used on the electronic documents. Sub-themes were distilled and poignant quotes, captured. Thematic analysis was chosen for this qualitative research, following Braun and Clarke's (2006) six step approach. Data familiarisation (step one) was embedded by reading the transcripts several times, checking for errors, and accurately matching the quotations to the participants. Two researchers coded inductively for characteristics and core components to implement NW groups for PwP (step two). The researchers then reviewed and refined the codes and identified initial patterns or themes (step three). Further discussion involved reviewing the themes, to ensure that they answered the research question (step four) and in step five the themes were named and defined, including subthemes for each overarching theme. Themes from all three groups were combined and checked with the original transcripts for accuracy. Inductive codes and themes came from the data but were considered in the context of available literature. Step six was the formal report, the synthesis of the data, including a comparison with existing literature, methods, results, observation and recommendations for future practice or research.

Michie's BCW provided a framework as main themes were mapped onto the behaviour change model (Michie et al., 2011). Michie's BCW, Figure 22, found in Chapter 1 (Michie et al., 2011) provided a framework to investigate complex factors including: the *capability* of the participant to engage with NW classes, the *opportunity* to attend the group and the *motivation* to change and continue to exercise (lifestyle factors). Motivation to exercise and to embed this into a routine are key features in maintaining fitness (White et al., 2023). Some PwP are apathetic, and lack drive, so there is a barrier to initiating and engaging with rehabilitation programmes (Ramaswamy et al., 2018).

### *3.1.5 Ethical approval*

Ethical approval was granted in April 2022 (Appendix 15), by the University of Nottingham, Faculty of Medicine Research Ethics Committee (Ref: FMHS 331-0821).

### *3.1.6 Public and patient involvement*

The FG study was supported by the same PPI team who proof-read the lay summaries and documents for the repeated measures feasibility study (see section 2.1.9). They represented PUK, PwPs, carers, BNW and a retired senior nurse in the NHS. The phrasing on one document (participant information sheet, PIS, Appendix 12) was changed following feedback from the PPI team.

## 3.2 Results

### *3.2.1 Description of the sample*

In total, 15 participants were recruited into three FGs; groups one and two for PwP (and one spouse), and group three for instructors/walk leaders (WL) (Table 66). Six participants attended the first FG (n= 5 males), five PwP attended the second (n=1 male) and four NWI/ WL the third (n=1 male). The mean (SD) FG duration was 60 (5) minutes. The groups were conducted in May and June 2022.

**Table 66 Focus group study. Description of the sample.**

| Participant number (n=15) | PwP/NWI/WL/ Spouse PwP | Male/Female | Time since PD diagnosis (years) | Group type | Group number | am/pm FG |
|---|---|---|---|---|---|---|
| **1** | PwP | F | 1 | PwP | 1 | pm |
| **2** | PwP | M | 7 | PwP | 1 | pm |
| **3** | PwP | M | 5 | PwP | 1 | pm |
| **4** | PwP | M | 13.5 | PwP | 1 | pm |
| **5** | PwP | M | 4.5 | PwP | 1 | pm |
| **6** | PwP | M | 6 | PwP | 1 | pm |
| **7** | PwP | F | 4 | PwP | 2 | am |
| **8** | PwP | F | 3 | PwP | 2 | am |
| **9** | Spouse PwP | M | - | PwP | 2 | am |
| **10** | PwP | F | 2 | PwP | 2 | am |
| **11** | PwP | F | 3 | PwP | 2 | am |
| **12** | NWI | F | - | NWI | 3 | am |
| **13** | NWI | F | - | NWI | 3 | am |
| **14** | NWI | M | - | NWI | 3 | am |
| **15** | WL | F | - | WL | 3 | am |

Abbreviations: PwP=People with Parkinson’s, NWI=Nordic Walking instructor, WL=Walk Leader, PD=Parkinson’s Disease, FG=Focus group, F=Female, M=Male, pm=post meridiem, am=ante meridiem.

### *3.2.2 Thematic analysis*

Six over-arching themes were distilled from the multiple codes. Table 77 shows the six themes and minor sub-themes. Quotations from the participants highlight the sub-themes. How these themes related to Michie's Behaviour Change Wheel are identified in brackets.

**Table 77 Focus group themes and sub themes**

| Themes | Sub-themes |
|---|---|
| **1. NW is physically beneficial for PwP**<br>**(Capability)** | Improves mobility by facilitating an increase in upright posture, gait, balance, and improved arm-swing<br>A whole person approach rather than medical model of therapy, full body workout<br>Compliments other forms of exercise |
| **2. NW facilitates group interaction**<br>**(Motivation)** | Social interaction in a relaxed environment<br>Peer motivation to engage and continue to exercise<br>Parkrun/ Parkwalk |
| **3. Practical aspects of implementing NW groups for PwP**<br>**(Opportunity)** | Accessibility, parking, public transport, amenities<br>Time of class and medication.<br>Location, weather, and terrain.<br>Funding. |
| **4. Qualities and characteristics of the NW Instructor**<br>**(Motivation & Opportunity)** | Specialist experience of Parkinson's and other disabilities builds confidence.<br>Communication and motivation.<br>WL enhances group safety. |
| **5. Optimising the safety of the group & risk management.**<br>**(Opportunity)** | Outdoor exercise after lockdown.<br>Risk assessments: Health, Parkinson's & COVID-19. |
| **6. Facilitators for setting up community rehabilitation NW groups for PwP.**<br>**(Capability, Opportunity & Motivation)** | Adaptable to diverse levels of ability, age, disease severity.<br>Publicity, equipment, and partnerships.<br>Accessibility and inclusivity.<br>Lifestyle and enjoyment. |

Abbreviations: NW=Nordic Walking, PwP=People with Parkinson's, COVID-19= Coronavirus.

Six main, strong, recurring themes were identified across the three FGs. These themes point to the characteristics and core components required to set up NW groups for PwP in a community rehabilitation setting. The main themes are supported by 19 sub-themes (represented below in italics).

### *Theme one: NW is physically beneficial for PwP (Capability).*

*NW improves mobility by facilitating an increase in upright posture, gait, balance, and improved arm-swing.*

Most of the FG participants reported improvements in their overall, physical health and were positive about many motor benefits of NW. Some people indicated that they struggled with other forms of exercise, running, or going to a gym. In addition, some reported that their families noticed that they were more upright, had improved confidence and better balance when walking. They intentionally moved both arms, even when poles were not present, and this improved bilateral arm swing. This was reflected in these comments:

> *"The big thing with the poles is that it gets your arms working. I had stopped swinging my left arm, but I swing it now when I walk with poles." (PwP 4).*
>
> *"You feel more confident with the poles. It is energising I think." (PwP 5).*
>
> *"The thing I take away is step number one, posture. See, I have remembered something. I do think it makes a difference. My family have noticed a difference." (PwP 8).*

*A whole person approach rather than medical model of therapy, full body workout.*

Several participants (n=5) expressed a view that they believed NW could potentially improve the body and mind. They talked about exercise as a form of therapeutic treatment, in addition to medication and lifestyle choices. They spoke positively about a full body workout and one participant spoke with passion about alternative, non-drug therapies. She concluded:

> *"I was bit anxious about being seen with PD because I didn't really want to go down too much of a medical route. For me I wanted to find alternative ways. Once I heard exercise was the key component to keep on going, I thought I would give it my best shot." (PwP 8).*

*Compliments other forms of exercise.*

Several participants enjoyed other sports and NW was part of their array of activities. As restrictions lifted one participant returned to golf and two others increased their running goals. On-line exercise classes were available during lockdown but getting outside with others was very appealing. As one participant exclaimed:

> *"It was the fact that we could all meet up and be outside, get fit, it put us in a different position to a lot of other activities. Much better than Zoom!" (PwP 2).*

The NW instructors were knowledgeable about adapting exercises for older people or those who have disabilities. One NWI explained that NW uses two special poles and so the mechanical load of the body is spread over four limbs. He said that this lowers the impact on knees and hips, so NW is deemed to be a relatively safe sport that could be beneficial for PwP. Another instructor explained:

> *"I have a painful knee, so sometimes I need to walk slowly, and the poles help me to keep moving. We run a Nordic Amblers group with a gentler pace." (NWI 13).*

### *Theme two: NW facilitates group interaction (Motivation)*

*Social interaction in a relaxed environment*

Most participants (n=12) expressed that the social aspect of meeting others with PD was motivating. Some felt that they would not attend a PD social gathering or formal support group, yet they felt comfortable meeting PwP at an exercise class. Two participants were recently diagnosed with Parkinson's and remarked that they found discussing PD with friends and family an emotive topic. This view was echoed by another participant who reported:

> *"This is a bit more relaxed and that's why I joined was to meet other people, but not in a let's all sit down and talk about Parkinson's because I think I would find that a bit daunting at the moment." (PwP 1).*

Walking and talking was conducive to rich conversations as most participants expressed that they felt more relaxed outside, in nature, in the fresh air. Several people commented that they were grateful to meet others and for the opportunity to exercise together. As one individual stated:

> *"I think the other thing that strikes me is the actual social aspect of this is quite important as well because I think with any sort of illness you can get rather down about it and just to meet other people and have a bit of natter as you walk without being self-conscious and worrying about things." (PwP 11).*

*Peer motivation to engage and continue to exercise.*

The NW participants who attended the FGs were motivated to be there. Many had completed the eight-week programme of NW intervention and continued to attend the classes. A common view amongst the participants was that they wanted to increase their fitness, particularly after the COVID-19 lockdown, but they valued the motivation of others as a stimulus to continue and persevere. For example, this comment was frequently expressed, even if the weather was inclement:

> *"Yes. It is the kind of encouragement or peer pressure depending on which way you look at it from anything from when you are here, if you feel a bit tired you keep going because that is what everyone else is doing." (PwP 5).*

However, the same participant added balance to the group dynamic, by expressing an opposing view. He felt that some people may find it difficult to attend the NW classes. He argued that:

> *"We are a self-selecting group. It would be useful to get feedback from the people who are not here! We are people who have flexibility in our work so that we can attend the Nordic walking class some weeks and attend work meetings on other weeks. Other people might be excluded from joining the Nordic walking for Parkinson's classes, because they have work or family commitments". (PwP 5).*

Some of the participants were of working age (n=2), but the range was from 51-80 years, with some older participants remaining highly active (enjoying yoga, Pilates, and running). Meeting other people, who were regularly active, was motivating and there was a strong sub-theme that peoples' mental health, motivation and mood were elevated by attending the NW classes, as expressed here:

> *"Yes, it worked both physically and mentally, yes. It has been good to meet up with people, to meet other people that are active." (PwP 10).*

*Parkrun/parkwalk*

Three participants commented that NW gave them motivation and confidence to take part in other exercise settings, specifically, NW weekly at parkrun. They were positive about regular NW with a group of friends and set personal goals re distance and frequency. They reported that NW was the stimulus to get them outside and exercise after lockdown, and NW opened new opportunities and adventures. As one participant reported:

> *"And I did a parkrun didn't I? But I am lucky because this friend is taking early retirement and is looking for some interests so when I said I was doing the pole walking, she said she might be interested. She is going to be quite a good motivation." (PwP 8).*

This was echoed by a PwP in the other FG who was keen to set achievable goals, but who disliked running. They enjoyed the atmosphere and the peer support at parkrun and one participant commented:

> *"I feel if I do something like parkwalk, I have achieved a goal to do some activity each day. If you have got a motivation for doing it, then that is always a good thing. You want a bit of variety; running is not my thing." (PwP 4).*

***Theme three: Practical aspects of implementing NW groups for PwP (Opportunity)***

*Accessibility, parking, public transport, amenities.*

These practical subthemes resonated strongly across all three FG's and stimulated a rich discussion. If there was inadequate parking on a sunny day during the school holidays, participants expressed their disappointment and rising stress levels. Three people arrived early to secure a parking space or chose to travel on public transport. The location was accessible by tram, bus and car and a minority of participants travelled for over an hour (n=2). When they arrived for class, there was a café and easy access toilets. Without these core components in place, the NW group would not function smoothly. Several participants commented:

> *"It has got decent parking, can be a bit crowded, good public transport, so you can come on the tram or the bus and there is a café and toilets, without those things it would be difficult for some people." (PwP 6).*

Access to the toilet in a timely manner is of paramount importance, especially in a mixed group of participants with PD at various stages. One instructor expressed their concerns:

> *"If they need to stop at the toilet. In a normal mixed abilities group, they might feel embarrassed"*
> *(NWI 13).*

*Time of class and medication*

The participants chose a morning or afternoon FG, and factors included the timing and impact of their medication. Three participants commented that they wanted more flexibility in the time of NW classes as they were more ’active’ in the morning. Some reported that their medication regimen worked well in the afternoon and one participant chose to join the later (red/advanced) group as his medication ‘kicked in’ by 2.30pm. One NWI explained:

> *“I have a lady who jabs (Apomorphine injection), and she will be half-way through the walk, and you see her winding down. We stop, want a water break? “Yes” and she will slip off, do her injections. She is like clockwork again.” (NWI 12).*

Another NWI for PwP emphasised that flexibility was important, by listening to the needs of her group. Consensus was reached several years ago that they preferred an earlier class. In response to their requests, she commented:

> *“Mine are in the morning because they are up and ready and took all their pills and their system is working properly, so we go at 11 o’clock”. (NWI 12).*

*Location, weather, and terrain*

When asked about the location, the participants were unanimous in their view that the central, free access, parkland setting was ideal for NW. There were flat areas for warm up exercises and cool down stretches. A beginner’s group could do all their NW on level ground and there was a variety of terrain, on the downs (hills), the lake and through the woodland area. Short, dry grass was preferable to muddy paths and participants preferred sunny, dry days to cold, wet afternoons. Despite the seasonal changes, participants attended the classes all year round, with a few class cancellations due to weather risk assessments (extreme heat wave, high winds or electric storm). Three participants expressed that rainy days were energising and helped them to sleep better. They discussed the feel-good factor of exercising outdoors in all weathers and one participant commented:

> *“But even not on a day like this, some days have been horrible, haven’t they? Even then it still felt good.” (PwP 1).*

This was echoed by another participant who spoke positively about the location:

> *“And when you think about the variety you have got from this end of University Boulevard to that end through the park, the walk with stepping-stones. Parkinson’s can affect you and this is a good place to use your poles when going up a hill. The terrain, I think is great for it.” (PwP 2).*

*Funding*

A question that several participants asked and discussed was “who pays for the NW groups?” As this was a research project the participants were provided with the NW intervention/ tuition and poles for free. There were different models of funding across the region, and it was beyond the scope of this study to answer this question. One instructor volunteered her perspective:

> *"I think it just depends, because like with C, she is getting paid, so she may well be charged to use the venue. For me because I am a volunteer and I only take enough to cover my expenses which is the other thing about organising it, who is running it, what is their status in the organisation, are they paid, or unpaid?" (NWI 12).*

***Theme four: Qualities and characteristics of the NW Instructor (Motivation and Opportunity).***

*Specialist experience of Parkinson's and other disabilities builds confidence.*

Almost two-thirds of participants, who took part in the FGs, reported that the NWI was pivotal to the success of the group. Six PwP indicated that the personality, motivation, and experience of the lead researcher (SM) as a NWI was crucial. Their specialist, NHS, clinical experience of PD and other disabilities enhanced the study's quality and authenticity. They 'trusted' the instructor because she had a wealth of knowledge about PD at all stages. The comment below illustrated this point:

> *"I think you feel comfortable about asking about Parkinson's because of the knowledge that she has. I would be quite open to have people without Parkinson's walking in the same group. I think to normalise it is an issue to try and be part of life. You want that understanding but primarily yes, we want someone who will take control of and understands Parkinson's." (PwP 11).*

*Communication and motivation*

The NW research groups received information in written and verbal form most weeks from the lead researcher, in their role as a NWI. This included news about dedicated community events, parkrun with the NW group, cancelled classes and FGs. The NW participants were encouraged and motivated by the NWI to set personal goals regarding distance, a parkwalk, NW with family members and taking NW poles on holiday. They were motivated by the NWI and spurred on by others. They thanked the instructor for the email reminders and said that they enjoyed the special events. As one participant remarked:

> *"You have been a good motivator, incredibly positive person that I can spot straight away now in that red outfit at parkrun or our sessions. So, I never thought, where is this group?" (PwP 8).*

*WL enhances group safety.*

The NWI and WL FG expressed strongly that a WL was essential for the safety of the group. This could be a mixed abilities group for people with or without PD. Sometimes carers or relatives joined the NW groups. A skilled NWI has experience of a range of disabilities and can tailor the exercises, and structure the NW programme, to suit the group. Several models of NW delivery exist, and it was beyond the scope of this paper to define best practice. As one instructor emphasised:

> *"I have worked with Parkinson's only groups, and I have worked with mixing them into other groups, and I find both works well. I had some reservations about doing Parkinson's only groups especially if they are seeing people further along the line. I think the main*

> *issue for me is having worked with people with a range of illness and health problems you do need a walk leader or a helper. So, in all my groups, I have a helper." (NWI 14).*

The WL, in response, offered her perspective. This was inciteful as she had supported both research NW groups for PwP every week since the start of the project (eight months). She illustrated this point:

> *"It does mean as a walk leader I have done the warm-up and cool down training and so if people do arrive late, I can be dealing with that while SM is getting on with the group. And there has been on at least one occasion when somebody needed to stop and go back and so we did the cool down together and I made sure they were safe to get home." (WL 15).*

She explained a further point:

> *"You can go to the Nordic walking instructor level, it teaches you how to teach the Nordic walking strategies, how to manage the groups, how to do a risk assessment. Then if you go on to the Parkinson's CPD modules they give you a better awareness of what is normal, if you call it 'normal' to a range of Parkinson's symptoms. That is useful because then you think, this must be their Parkinson's or is it something else? So, you have graded awareness and a lot of it comes from experience as well". (WL 15).*

***Theme five: Optimising the safety of the group and risk management (Opportunity)***

*Outdoor exercise after lockdown*

PwP were pleased to start exercising together in groups as they emerged from the COVID-19 lockdown. Some PwP had spent months indoors, 'shielding from the virus' away from family and friends. This had resulted in physical deconditioning, and it impacted upon their well-being. To optimise safety, risk assessments were conducted for the venue, the group, the individual, and COVID-19. The NW for PwP classes started in November 2021, so COVID was still a potential threat to health and welfare. Participants met outside, near the café and the group maintained social distancing, two metres apart. All NW classes were delivered outside and the overall response from participants was positive. This participant summarized the sentiments of the group:

> *"I think it was picking up from where you stopped. The first activity when you found out everybody had been living the sense all their lives in lockdown and were glad to be heading out and getting back to normal, whatever normal is going to be. It was the fact that we could all meet up and be outside and get fit!" (PwP 2).*

*Risk assessments: Health, Parkinson's & COVID-19*

The NWI and WL group discussed safety and risk assessments, in particular the specific health assessment for PwP. Two PwP participants expressed their gratitude that they felt safe, and this enabled them to walk further and to participate in 5k community events. The PD risk assessment contained more detail about falls, medication, blood pressure (low or high) and cognition. One NWI voiced her concerns about the standard physical activity readiness (health) questionnaire (PARQ) (Appendix 8) for PwP:

> *"I always fill in the back of it and say the person has told me this is their norm, I have observed this when I have been walking with them, so I have made additional notes on*

> *the back of the assessment because you don't get it all on the straight-forward PARQ health risk assessment". (NWI 13).*

***Theme six: Facilitators for setting up community rehabilitation NW groups for PwP (Capability, Opportunity and Motivation).***

*Adaptable to diverse levels of ability, age, disease severity*

The practical facilities of transport, toilets and location were noted in theme three. In addition, participants commented that NW was adaptable for people with diverse backgrounds. Having a choice between the beginners' (blue) group and the faster paced (red) group provided a flexible approach. One participant brought a personal assistant with her, and a gentleman with mild cognitive impairment, was accompanied by his partner. A man who was very anxious had two 'private' NW lessons with his wife in the morning, as he struggled in a group setting. The participants were appreciative of this approach and one PwP commented:

> *"I have been to other walking groups but sometimes the pace is a little bit fast, but when it is set for a Parkinson's group the leader knows the level to set it for and it is more appropriate with the warm and cool down is more specific to the needs of Parkinson's." (PwP 7).*

*Publicity, equipment, and partnerships.*

Several FG participants (n=5) commented that publicity and partnerships with Parkinson's UK, Parkinson's East Midlands research interest group (PEMRIG), BNW and NHS physiotherapists had motivated them to take part in the study. Publicity from the local chair of a PD group was raised by three participants:

> *"Nordic walking is something I have always wanted to try, and I was interested, looking at the fun point. I was told about this trial by S who is someone who has PD and very active in the community so he sent out emails to those that might be interested." (PwP 11).*

NW requires little equipment, but special NW poles are essential. Most participants expressed gratitude that NW poles were provided. A quieter PwP joined the conversation at this point:

> *"They are quite sporty they don't look like a walking aid and that is a real sale it is more of a sporty image than a disability. You feel confident with them. It is energising, I think". (PwP 10).*

*Accessibility and inclusivity*

Accessibility and availability of classes were reported as major factors and participants commented that choice was important regarding the time, day, and location. Some participants found alternative NW classes, nearer to home on a different day of the week. Two people joined an evening group, after work and there were classes on offer at the weekend at beautiful country parks. A walk leader made this valid point:

> *"I had a gentleman who swapped from a one o'clock class to two thirty, because his medication worked better by then and he enjoyed the company of the other participants." (WL 15).*

*Lifestyle and enjoyment*

The NW intervention was inclusive and potentially enjoyable for people with mixed abilities and backgrounds. Some members of the FG reported that they had started to attend parkrun and enjoyed taking part with others who did not have PD. They also commented that they were motivated to include NW as part of their lifestyle by an enthusiastic NWI and friends, in a group.

A subtheme to conclude this section was that most of the participants said that NW was fun. They enjoyed the group interaction, the warm-up and cool down exercises, the variety of conversation and the physical exercise. In summary, the NW classes were relaxed, accessible, suitable for people with diverse backgrounds and they were fun. Two couples attended the FG and NW class together. They have both adopted NW into their weekly routines and left this parting comment:

> *"I think what P is trying to say there is the embarrassment of walking with sticks. I wouldn't walk around the village on my own but to come to a group and do it and enjoy it and I don't feel embarrassed at all. This got me out of that anyway." (PwP 7).*

### ***Summary of themes***

Following thematic analysis of the FGs, the lead researcher summarised the key themes and subthemes regarding the core characteristics and components needed to implement a NW intervention in the community for PwP. An acronym table of subthemes and recommendations for future practice is discussed in 3.3.4. (Table 88).

## 3.3 Discussion

### ***3.3.1 Principal findings.***

Three FGs were successfully conducted and delivered according to the protocol. Participants engaged with the FGs, and appropriate themes and subthemes were derived from the transcripts of the discussions captured. The six main themes as reported by PwP and NWI/WLs were: 1) NW is physically beneficial for PwP, 2) NW facilitates group interaction, 3) Practical aspects of implementing NW groups for PwP, 4) Qualities and characteristics of the NW instructor, 5) Optimising the safety of the group and risk management, 6) Facilitators for setting up community rehabilitation NW groups for PwP.

### ***3.3.2 Strengths and weaknesses of the study***

A strength of the FG study design was that there was an opportunity for conversation among participants about a shared experience of a novel intervention. However, the lead researcher, who delivered the NW classes, was in the room, so participants may not have felt that they could freely express negative comments. This may have led to information bias (Smith and Noble, 2014). A strength was that all FGs were facilitated by experienced researchers in qualitative methods. Themes and subthemes were therefore checked by a second or third researcher (FA and VB), to add validity and reliability to the study.

Confounding factors to this study, delivering the NW intervention, was the COVID-19 pandemic. It would be hard to replicate this FG study in its entirety as the environment and situation were impacted by the lockdown and fear of the virus. A weakness of the FG study could be that participants were incredibly positive about exercising in a social setting, outdoors as a group. As discussed in Chapter 2, PwP may have self-selected to participate due to preconceived ideas or attitudes towards NW, therefore giving a skewed perspective of the intervention. The NW intervention met a need for PwP to exercise in a safe space, with robust risk assessments in place, during a difficult and unusual time. This was reflected in the FG discussion and therefore can be considered a strength for the novelty of the study.

The participants were recruited from another study (Chapter 2) and so only a subset of these (n=11) were involved. A weakness in this study was the time commitment required from each participant, specifically attending eight weekly one-hour classes of NW and contributing to the FG. Both points might have led to selection bias (Smith and Noble, 2014) as the sample, who contributed, had time to attend the study, and were motivated to do so, whereas people who were working, or who had other responsibilities, were excluded. A strength was that the people in the FG had recent lived experience of attending, or leading, a NW group and they spoke with first-hand knowledge about the NW intervention.

A further strength of the study was having a second researcher (investigator triangulation), who checked the FG transcripts, assisted with coding, and checked themes with the lead researcher (Helen and Roberta, 2019). A limitation to triangulation was the time commitment for both researchers. This was fundamental to thematic analysis and yielded strong themes and subthemes (Braun and Clarke, 2006).

### *3.3.3 Results in relation to other studies*

#### NW is physically beneficial for PwP (Capability)

Improvements in physical health found in the literature were also experienced and reported by FG participants. They received oral feedback from their families that they had notable improvements in their posture, balance, and bilateral arm-swing (often lacking on one side by PwP) (Granziera et al., 2021). The FG participants reported enjoying a full body workout (Cugusi et al., 2017), that complimented other forms of exercise (Yang et al., 2022). Previous studies in this population have reported a growing trend towards a whole person approach to treatment, rather than a traditional medical model of therapy for PwP (Salse-Batán et al., 2022).

Another strength was that the integrated approach to PD treatment, found in the literature, was reported by PwP in the FG study. However, this could be a biased sample, as the intervention on offer was a novel NW intervention that was not routinely provided by the NHS. The physical impact of NW is well documented in the literature for PwP with many studies reporting improvements in health outcome measures (Granziera et al., 2021). The specific health outcomes include; increased walking speed (Monteiro et al., 2017), improvements in adopting the correct upright posture (Berg et al., 1992), balance (Bullo et al., 2018), gait (Silva et al., 2016), upper body strength and core stability (Fischer et al., 2015), augmented arm-swing (Bombieri et al., 2017), and better coordination (Monteiro et al., 2017). Other FG studies, exploring NW as an intervention for rehabilitation in this population found similar themes, such as benefits for PwP using the NW poles in daily life, belonging to a therapeutic NW group, group support to cope with perceptions about PD, and facing the future with PD (Casarotto et al., 2022).

### *NW facilitates group interaction (Motivation)*

Social interaction in a relaxed environment was a strong subtheme from this FG study and was supported by previous studies involving community exercise groups (Lamont et al., 2012, Yang et al., 2022). Lamont's qualitative study used a similar research design of FGs and TA (Braun and Clarke, 2006). Yang's comprehensive meta-analysis addressed community exercise on motor symptoms in PD, involving 22 studies and 809 participants. The heterogeneity of participants was cited as a confounder, and this is echoed across many studies, including (Szefler-Derela et al., 2020). No two PwP are identical, even if they are a similar age with the same disease duration (Radder et al., 2020).

A strength of the FG study was that peer motivation was important, and participants were inspired by meeting others who were highly active, in the weekly NW exercise classes. This is echoed in a recent qualitative paper (Dabkowski et al., 2021), who carried out a thematic analysis of the perceptions of a community exercise programme for older adults. Their results, like the current FG study, reinforce the need for exercises to be adapted to the needs of the group, to promote inclusivity and accessibility. A weakness of this study could be that PwP with higher levels of motivation participated in the study and had a desire to take part in parkrun or other community events. The results might not be representative of the wider PD population, as some PwP have reduced levels of motivation.

Parkrun/parkwalk was raised by three FG participants and is a growing area of research interest for PwP and other disabilities (Quirk and Haake, 2019, Newson, 2022). It is outside the scope of this MPhil study to discuss this in detail but parkrun, as a weekly, accessible, free, community running or walking event (parkrun, 2023) has potential to contribute to ongoing engagement with exercise for this population. A recent study employed semi-structured interviews with people with long-term health conditions and explored the public health impact of parkrun (Quirk and Haake, 2019, parkrun, 2023). It was found that inclusivity and accessibility are key to the success of parkrun. A recent initiative, launched in October 2022, parkwalk, demonstrates this ethos well as people are welcome to walk, NW and use mobility aids (parkrun, 2023).

### *Practical aspects of implementing NW groups for PwP (Opportunity)*

The location of the NW intervention at a university campus, next to a lake, with public amenities, accessible by public transport and with parking facilities, were strong subthemes across the three FGs. A strength of the FG study was the results compared to previous studies, regarding the practical aspects of setting up community exercise groups (Domingos et al., 2022a). However, a weakness was that few studies had a Parkinson's specific focus. This is an emerging novel area of rehabilitation for PwP.

The flexibility of the instructor to hold two classes, at separate times, for a diverse range of abilities and demographics, were important practical considerations for this feasibility study, identified by the FGs. It was found that the NW group was sensitive to the needs of its members (such as when they needed to stop for medication or to use the bathroom).

Other practical elements, such as completing risk assessments for the terrain and adverse weather, increased the safety for those participating. Communication was another crucial element identified in the FGs (e.g., emails were sent if a class was cancelled, due to high winds or a heatwave). Some of these practical components were described in Elsworth's study (2011), a facilitated community exercise programme for people with diverse long-term neurological disorders (Elsworth et al., 2011). However, the context and setting were different to our NW study as they examined the feasibility and safety of using inclusive fitness gyms for supported, supervised, community exercise programmes. The population was heterogeneous; people living with a range of long-term neurological conditions, including multiple sclerosis, cerebral palsy and motor neurone disease, not solely PD.

#### *Qualities and characteristics of the NW Instructor (Motivation and Opportunity)*

The FGs identified that the NWI was pivotal to the success of the group. Their knowledge and experience of Parkinson's at every stage of the disease was acknowledged and reported by several participants. This finding was echoed in the literature in a newly published paper by White et al, where they described the social context of exercise and the motivating role of the instructor (White et al., 2023). The expertise of a physiotherapist, as a NWI, was acknowledged in the 2019 paper regarding NW and freezing of gait in PD (Wróblewska et al., 2019). Several papers cite physiotherapists delivering a NW intervention (Bassett et al., 2012, Domingos et al., 2022b, Ebersbach et al., 2014, Radder et al., 2020). Following a thorough literature search, only one paper cited a Parkinson's Disease Nurse specialist (PDNS) who trained as an INWA NW instructor, and who delivered NW for PwP, (McCracken et al., 2021). This was the proof-of-concept study that preceded the current research project. This lack of comparable literature could be interpreted as a weakness of the current study. However, it demonstrates a gap in research that this MPhil aims to address. It also opens new opportunities and avenues for NW intervention delivery that could be further explored.

#### *Optimising the safety of the group and risk management (Opportunity)*

NW remains a novel area of research interest for rehabilitation in PwP. The timing of the study, after the COVID-19 lockdown, may have influenced participant recruitment and motivation to exercise, in a group setting. Participants in the FGs expressed that they preferred exercising outside, rather than in a gym or indoor rehabilitation setting. They reported that they felt protected from harm because the relevant safety measures were in place to mitigate risk. This was echoed in the literature by similar studies, (Schirinzi et al., 2020) although, to the best of knowledge, this was the first FG study for PwP who NW in a community rehabilitation setting.

### Facilitators for setting up community rehabilitation NW groups for PwP (Capability, Opportunity, Motivation).

The partnerships between the lead researcher and PUK, BNW and NHS colleagues, facilitated broad sources of recruitment to the repeated measures study and in turn to the FGs. However, it was also identified, within the FGs, as a core aspect by the participants for offering authenticity to the intervention. Despite a thorough literature search, there were few comparable studies that identify this novel finding.

Studies that were published with a similar population, employed different methods and materials. For example, an RCT of a community exercise study for people with long-term neurological conditions recruited a sample of 99 participants but did not use utilise professional networks to do so (Elsworth et al., 2011). The intervention group (n=51) received 12 weeks of supported exercise in a community rehabilitation setting. The control group (n=48) received standard care for 12 weeks and were then offered the intervention. Main measures included physical activity, adherence to exercise, measurements of mobility, health, and well-being. Elsworth concluded that people with long-term neurological conditions can safely exercise in community gyms if they receive practical and physical support. They may achieve similar attendance/ adherence to standard exercise schemes. However, they may reduce other hobbies and activities to attend a supported place at a community gym (Elsworth et al., 2011).

These practical facilitators, for setting up community rehabilitation interventions, had similarities to our study. The results were comparable as the attainment of a physically active lifestyle benefited mobility, health, and well-being. This in turn had potential to reduce the impact of disease burden and reduce health care costs in people living with neurological conditions (Elsworth et al., 2011).

Another aspect about setting up the NW groups was that there were minimal overhead costs as the venue (outside, in a park on university grounds) and the intervention, were free to the participants. The main cost would have been the cost of the NWI, but this was covered by the research budget. Other studies cited low cost of NW and ease of access to a variety of locations as compelling reasons to take up this form of exercise (Salse-Batán et al., 2022). In their systematic review and meta-analysis, Salse-Batan (2022) conducted an in-depth review of high-quality literature, to guide practitioners in prescribing NW for PwP. They concluded that NW appeared to improve walking ability and quality of life. They recommended further research in the latter outcome.

Eight participants from the FG study continued to NW regularly as well as all the instructors and NWL. This served to highlight potential lifestyle choices for the participants; to continue to exercise and maintain fitness. Having fun was important for engagement, resilience, and perseverance and this was echoed in similar studies, (Bloem et al., 2015, Dabkowski et al., 2021, Farnsworth and Burtscher, 2010).

### *3.3.4 Meaning of the study: possible mechanisms and implications for clinicians or policymakers*

This was a small qualitative study with three FGs that were held during a COVID-19 pandemic. Participants were easy to recruit from the main pre-post measures study and engaged with the research schedule. The study has started to answer this research question, “What are the characteristics and core components needed to implement NW groups for PwP in a community rehabilitation setting?”

By using the derived themes and subthemes, a service model could be designed for third sector organisations, clinicians, and policymakers for the roll out of further community NW groups for PwP, in various locations, led by appropriately trained NW instructors, with knowledge and experience of PD. The six main themes could help to provide a replicable framework or model. A clinician could train to become a NWI, in order to deliver NW according to the ten step INWA method (International Nordic Walking Federation, 2023).

The clinician would motivate and encourage PwP to start NW and signpost or accompany them to parkrun/parkwalk community events. The clinician, as a NWI would address the practical aspects for implementing NW in a suitable location that is accessible for people with mixed abilities. The clinician could offer sessions to suit the group regarding their medication efficacy and timing, PD symptoms and stage of disease. The clinician would have specialist knowledge of PD and would conduct appropriate risk assessments (Appendix 6). The PD specialist would have an established clinical and professional network and could partner with PUK, BNW, and social prescribing, for the sustainability of future NW groups in the community. Some subthemes were grouped under the initial letters of the word Parkinson's and became a useful aide-memoire, for teaching and disseminating results (table 8).

**Table 88 Parkinson's acronym of subthemes.**

| |
|---|
| **P= Physical activity** |
| **A= Adventure and not Apathy** |
| **R= Reconditioning** |
| **K= Kindred spirits. Exercising with new friends/spouses/ partners** |
| **I= Inclusive. Available to people of all ages and diverse backgrounds** |
| **N= Non-motor benefits (improved sleep, mood, motivation, less pain, and constipation)** |
| **S= Sporty poles, not walking aids** |
| **O= Outdoors and the benefits of exercising in the green gym/ healing balm effect** |
| **N= Nature and well-being** |
| **'= Belonging. Some PwP felt very isolated during lockdown. NW was one of the first activities to re-start as well as golf. They enjoyed meeting people outside with a shared interest** |
| **S= Spouses and friends** |

## 3.4 Conclusion

PwP reported physical and psychological benefits from participating in an eight-week course of NW during a series of three FGs. They enjoyed the social aspect of exercising as a group with like-minded, motivated peers. Practical facilitators included access to public transport, parking, café and toilet facilities, NW poles and varied terrain with beautiful scenery. The personality, motivational skills, and PD expertise of the NWI were key to the delivery of the NW intervention. Risk assessments for PD, complex comorbidities and COVID-19 optimised the safety of the group. Overhead costs were minimal and future NW community rehabilitation programmes for PwP could seek NHS, social values, social prescribing, or third-party funding sources, in partnership with BNW and PUK.

# CHAPTER 4 DISCUSSION

## 4.1 Statement of Principal Findings

The overarching research question for this MPhil was explored through a narrative literature review, a quantitative repeated measures feasibility study (involving motor and non-motor outcomes) and a qualitative FG study. The aspiration was to understand the impact and accessibility of NW for PwP from a diverse background regarding age, stage and duration of disease, following the COVID-19 pandemic. The repeated measures study recruited 49 participants. Qualitative data from three FGs (n=15) reinforced and complimented quantitative statistical analysis. Previous studies recorded motor and non-motor outcome measures following a NW intervention in PwP (Cugusi et al., 2015), (Salse-Batán et al., 2022). However, few used FGs to understand the impact and core components of such an intervention and fewer were conducted during the COVID-19 pandemic (McCracken et al., 2021).

## 4.2 Comparison of Findings to Other Literature

Previous studies reported the immediate benefits, after a short intervention of NW (six to eight weeks), in this population (Reuter et al., 2011, Cugusi et al., 2015). Few NW studies researched the longer-term impact (six months or more) of a NW programme (van Eijkeren et al., 2008). Some studies delivered the NW intervention over a longer period (up to 24-weeks) (Reuter et al., 2011, Salse-Batán et al., 2022), but did not report on the longer-term impact of that extended 24-week intervention. This study found that an eight-week intervention was sufficient time to identify a change and that change remained in some outcomes at six months. For instance, the outcomes of improved posture (Tragus), speed and cadence over 10 and 20 metres, TUG and some NMS.

PwP often have a shorter stride, shuffling gait, and reduced arm-swing in one or both arms (initially unilateral) (Bloem et al., 2016). This NW intervention aimed to address some of these motor deficits. This study was like the Ebersbach study (Ebersbach et al., 2010). They reported on large amplitude movements, comparing the Lee Silverman 'Big' intervention to walking and NW (Ebersbach et al., 2010). Data from their studies shaped and continues to influence current PD rehabilitation delivery models, by focussing therapy interventions on exaggerated and augmented limb movements (Ebersbach et al., 2014).

A popular, current intervention facilitating large movements, delivered by neuro physiotherapists is PD Warrior© (Warrior, 2023). The NW intervention delivered in this MPhil study also emphasises exaggerated movements of both the arms and legs, with the potential to optimise the benefits of walking by intentionally pushing through the NW poles, as described by (Silva et al., 2016). Therefore, it could be argued that NW is a non-healthcare delivered intervention, that uses these same 'big' movement principles, which is accessible in the community. Further research, that directly compares the effectiveness between these interventions, is needed.

Heterogeneity of PwP in the repeated measures study (age, years since diagnosis, H&Y stage) was a confounding factor in comparing similar studies (Appendix 2). This MPhil aimed to recruit participants from a diverse background as shown in participant characteristics in Chapter 1. There was a wide range of ages (48-82 years), years since diagnosis (1-15 years) and stage of disease (H&Y 1-4). Therefore, it was feasible to deliver a NW intervention in a diverse sample of PwP, but the sample was equally heterogeneous compared to other literature in this field. Future effectiveness trials or RCT studies would need to take this into account in the design.

Persuading or motivating PwP to exercise, or start a novel sport, was explored through Michie's research, knowledge and experience of health psychology and sociology. The BCW served to shape intervention delivery and policy, by understanding the capabilities, opportunities, and motivation of PwP to change, or in the case of this study to undertake a NW intervention (Michie et al., 2011). Radder's meta-analysis of physiotherapy interventions for PwP (191 trials with 7998 participants) served to inform policy makers and clinicians about the merits and potential scope of NW as a rehabilitation intervention (Radder et al., 2020). Radder concluded that NW has a beneficial effect on motor symptoms, balance, and gait. The evidence base facilitates clinicians and PwP to make choices regarding treatment modalities, and the uptake of novel sports (Radder et al., 2020). Ramaswamy's (2018) practical approach to exercise, provides clinicians and policymakers with a choice about rehabilitation interventions for PwP at various stages of PD (Ramaswamy et al., 2018). It is hoped that this MPhil study can be used to help change practice.

A further practical approach, whose goal was to enable and facilitate PwP to exercise, was the health risk assessment performed before the NW intervention (Appendix 6). This assessment served to reduce risk, for example, falls as cited by (Reuter et al., 2011), but also to anticipate and manage risk and to encourage PwP to start new challenges and activities. Positive risk taking is widely cited in literature for adults with intellectual disabilities (Seale et al., 2013), and indeed was found to be important in the field notes and FGs. Therefore, this study corresponds with existing literature in the field and adds to the evidence base to support changes in practice.

The context and challenges of the COVID-19 pandemic (World Health Organisation, 2021) played a significant role in recruitment, intervention delivery (two NW groups per week for 13 months) and data collection of the 49 participants, in this repeated measures study (Chapter 2). It also makes this study difficult to replicate as the societal influences at that time were impacted by fear of coronavirus and the inevitable disruption to NHS service provision. This was corroborated in the FGs findings (theme 5) which found that participants appreciated the safety measures, and regular risk assessments, which had been put in place to mitigate the spread of infection. That said, one aspect of COVID-19's legacy could be its influence on the resilience, determination, and innovation of the PD community and of those delivering PD services.

This claim was supported in the literature by Dorsey et al (2020) and Bloem et al (2021). Bloem, a Dutch neurologist, researched personalised management of PD for many years. He described an optimal multidisciplinary (MDT) approach from diagnosis, in addition to tailored medication and non-pharmacological interventions, such as novel sports, exergaming and NW (Bloem et al., 2021). Dorsey et al, (2018b) acknowledged the rise in the incidence and prevalence of PD and a call to action to be ready for a potential PD pandemic (Dorsey et al., 2018b). The same authors collected data, made observations and recommendations for PwP following the COVID-19 pandemic regarding telemedicine and innovative interventions, that would reshape care for people with movement disorders (Dorsey et al., 2020). This MPhil study adds to this body of research with a novel rehabilitation intervention, delivered outdoors by an NHS clinician, with the potential for psycho-social benefits of the ‘green gym’ and ‘healing balm’ effect (Priest, 2007).

Priest (2007) wrote about the experiences of participants who used a walking group for their well-being, by exploring the psychological benefits of a physical activity outdoors. Priest collected data via interviews, a group discussion and participant observation. Their grounded theory approach, as defined by Glaser and Strauss (1967), served to develop the model ‘Healing Balm Effect’ (Glaser, 1967). This model had seven categories that were comparable to the results of the FG study and NMSS questionnaire; 'closer to what is more natural,’ ‘feeling safe’, ‘being part’, ‘striving’, ‘getting away’, ‘being me’, and ‘finding meaning’. The first three categories mirrored the FG study as safety, being outdoors in nature, and being part of a group were strong themes and subthemes. Getting away and finding meaning were also articulated during the FG study, particularly as NMSS scores for mood and cognition, sleep and fatigue improved after the eight weeks NW intervention.

Principal findings, from the repeated measures study, were statistically significant improvements in the following motor assessments: 10 MWT (speed) and cadence (steps), TUG, Tragus (posture), 20 MWT (speed) and cadence (steps), all with p values <0.001. The mean change in posture (Tragus) was -2.03 cm after eight weeks and this appeared to improve further, six months post intervention (-2.73 cm). These improvements (p <0.001) indicated potential longer-term benefits of a NW programme, after the period of intervention. These findings of improvement in motor outcomes are comparable to other studies, such as (Bang and Shin, 2017, Monteiro et al., 2017, Cugusi et al., 2017, van Eijkeren et al., 2008).

There was a mean reduction in the total NMSS of -10.08 points after eight weeks of NW, which showed statistical significance (p value 0.03). Specific NMSS domains showing improvements included sleep and fatigue (p value 0.006), cognition and mood (p value 0.77) and urinary symptoms (p value 0.24). These quality-of-life improvements were substantiated in the field notes and persisted, six months after the NW intervention.

A similar study, investigating the motor and non-motor impact of exercise for PwP, recruited 44 PwP and employed the NMSS questionnaire (Schaible et al., 2021). The NMSS results were comparable to our study after an eight-week period of exercise intervention, with intensive LSVT Big exercise being superior to routine care. However, our repeated measures study did not compare NW to other exercise modalities.

In another similar study, in the presence of PD, the effectiveness of NW on functional performance, gait quality and quality of life was reported (Szefler-Derela et al., 2020). In contrast, their study assessed quality of life with the PDQ-39 questionnaire and not the NMSS, so it was difficult to compare the studies and they did not report on urinary symptoms. There could be a positive clinical impact if NW were found to improve core stability and pelvic floor musculature. Pellegrini et al, (2018) explored muscular and metabolic responses to different NW techniques and described the influence of NW on pelvic movement and muscle activities (Pellegrini et al., 2018). This warrants further exploration in the literature and additional studies.

Results from the FGs elicited six main themes, or components required to deliver NW as an intervention in this population. A similar qualitative study addressed the perception of PwP practicing NW and its potential impact upon daily life in different contexts and cultures

(Casarotto et al., 2022). The Casarotto FGs had similar findings to this MPhil study. Five main themes included: NW benefits for PwP, using the NW poles in daily life, belonging to a therapeutic NW group, group support to cope with perceptions about PD, facing the future with PD (Casarotto et al., 2022). Similar qualitative studies with different populations yielded similar themes and results.

A study in 2015 delivered NW as an intervention for breast cancer survivors (Fischer et al., 2015). Participants were invited to attend a group interview six months after the ten-week NW intervention. They reported physical and psychological benefits, their vitality had improved, and they had measurable improvements in upper body strength and condition. They concluded that participant selection and risk assessment should take place under (para)-medical supervision and NWI should have knowledge and skills to work with this patient group (Fischer et al., 2015).

These findings were echoed in the 2020 NW intervention and FG study with people with rheumatoid arthritis (Domaille et al., 2020). Their use of FGs yielded similar themes: enjoyment, walking taller, better posture, better balance, and improved well-being. Participants expressed their appreciation that rheumatology specialists and physiotherapists had contributed to the design of the intervention.

There were no adverse events reported during the MPhil NW intervention nor in the FGs. This contrasts with a systematic review and meta-analysis by Salse-Batán et al (Salse-Batán et al., 2022) who reported adverse events in the following studies (Cugusi et al., 2015, Monteiro et al., 2017, Szefler-Derela et al., 2020). Hypotension after a brisk uphill NW in hot weather and falls, but no significant injuries were reported in a RCT comparing three treatment modalities (NW, flexibility and relaxation, and walking) (Reuter et al., 2011).

Taking the results from both studies, the aims were fulfilled, and recommendations were made for future research and practice.

### 4.3 Strengths and Weaknesses of the MPhil

The lead researcher (SM) delivered the NW intervention and helped to facilitate the FG study, so there was a risk of researcher bias (Smith and Noble, 2014). To mitigate this risk, the lead researcher used the same methods and materials to record the outcome measures. The FGs were led by a different member of the research team, and all data, statistical analysis, codes, and themes were checked by a second and third researcher (VB, FA, and PL). Despite this potential limitation, a strength was the consistency of the lead researcher, throughout the various stages of the MPhil. This approach accumulated knowledge from each study, with the pre-post study experience leading into the FGs.

The MPhil comprised a narrative literature review in addition to quantitative and qualitative research methods. A weakness of the study design was the length of time required to deliver a NW intervention over 13 months, to collect and analyse the data and deliver three FGs. These challenges for the researcher, collecting and analysing written and numeric data, and being familiar with quantitative and qualitative research, were described in Creswell's book (Creswell, 2018), p205. Silverman reported the complexities of mapping one data set onto another by combining different methods: interviews, observation, recording. He warned the novel researcher against multiple methods as they may not reveal the bigger picture and may lead to incomplete or *"scrappy research and under-analysed data",* (Silverman, 2022, p. 99). However, despite these challenges, FG quotations, themes, subthemes, and field notes complimented the physical outcome measures and NMSS questionnaire findings. Data triangulation, as described by Rooshenas (Rooshenas et al., 2019), facilitated complex interpretation of the data. In addition, involvement of multiple researchers added depth and reliability to the studies (Helen and Roberta, 2019). The benefit of this approach yielded complimentary quantitative and qualitative results that add to the growing body of research in this field.

A weakness of the study was that physical measurements were not recorded for all participants (nine PwP did not complete eight weeks of NW; n= four males). These participants were reminded via email but chose not to attend for follow-up intervention sessions or measurements. This level of attrition was not considered when writing the study proposal. There had been an intention to treat 40-60 participants, and 49 PwP consented to take part in the study. All participants received regular emails about the NW sessions and were encouraged to engage with the programme. Despite not returning for physical measurements, qualitative data was captured in the NMSS and field notes. Reasons for stopping the programme early were described in Chapter 2, and they gave useful insights into why PwP might struggle to engage with, and commit to, a weekly exercise class. Examples given were cold weather, travel time to class, too far, other family and work commitments, poor sleep, and menopausal symptoms. This was supported by Ellis's study, addressing barriers to exercise in PwP (Ellis et al., 2013). They reported that regular physical exercise declined with increasing age and that women over 65 years old were less likely to engage with, and adhere to, an exercise programme (Ellis et al., 2013). A recent study into the unmet needs of women with Parkinson's raised important issues facing women of all ages (Subramanian et al., 2022). Exercise adherence, lifestyle and personalised medicine were cited as key factors for meeting the clinical and psychosocial needs of women with PD. Whilst not all the participants who left the study were women, there is comparable literature which has similarities and provides additional rationale for this attrition.

Aliberti's study (2023) explored the push-pull motivational framework for engagement in physical activity (Aliberti, 2023). Similarities with the MPhil study were NW post COVID-19, but, by contrast, their study addressed perceptions on motivations and future intentions regarding NW in women, without PD. They acknowledged that COVID-19 had led to a reduction in psychological, social, and physical well-being which they attributed to sedentary behaviours and social isolation. They recommended ecological exercise (outdoors, in a group) and reported many benefits (e.g., improved humour, self-esteem, physical fitness, reduced anxiety and depression). In contrast to our study, Aliberti's methods did not involve an interventional study. Their research methods included a literature review and semi-structured interviews with 65 women (50.07 ± 7.85 years old). In conclusion, Aliberti recommended that future studies could address an innovative NW protocol, which was not focussed on exercise performance. Instead, the goal of NW could be to improve social and mental well-being. This in turn could provide information to wellness instructors who might motivate more women to participate in physical exercise (Aliberti, 2023).

A strength of the MPhil was the professional network of the lead researcher (a PDNS for 18 years) with strong links to partners in industry, PUK, and BNW. Their endorsement and support facilitated recruitment to a wide audience and may have assured the participants. A potential weakness was organisational bias towards BNW as this was the not-for-profit organisation that trained the lead researcher. Other NW providers (e.g., Nordic walking UK) offered groups for PwP, but it was not in the scope of this MPhil to comment on the structure, evidence base or ethos of different NW organisations. A strength for BNW was its founder and chief executive officer (CEO), Dr Hughes, who had a PhD in Chemistry and maintained a scientific approach to the vision and leadership of BNW. However, future research needs to consider different organisations involved in NW.

A further strength was the patient and public involvement (PPI) team who supported the MPhil study. They read all study documents, lay summaries, attended meetings, and received regular research updates. An additional strength was the collective experience of the PPI team. One member was both a NWI and a retired NHS senior nurse manager. Two PPI representatives were living with PD and a married couple were the chair and secretary of the local PUK branch. However, there are no PPI data included in this MPhil and their involvement was not formally documented. This could be viewed as a limitation of the whole MPhil and would need to be addressed in future research.

A strength of the MPhil was its timing, as lockdown restrictions were gradually eased, following the COVID-19 pandemic (World Health Organisation, 2021). Several similar studies were published after the pandemic (Aliberti, 2023, Domingos et al., 2022b, D’Iorio et al., 2022, Dommershuijsen et al., 2021), but to the best of knowledge, none delivered a practical, outdoors NW intervention for PwP, by a PDNS, within this context. An opportunity arose to trial a novel exercise modality in this population. A weakness was that the lead researcher was working clinically, so balancing studying and clinical responsibilities during the uncertainty of a pandemic was challenging. However, as described by the PwP FGs, this clinical expertise was important so that the intervention could be tailored to the needs of PwP, by focussing on large amplitude movements and adapting some balance exercises, to reduce the risk of falls. The knowledge and skills of the lead researcher, as a PDNS, built confidence and participants reported that this was a motivating factor (Chapter 3). Another strength was the research funding that was allocated to buy equipment (Nordic walking poles, hand sanitizer and cleansing wipes) so the intervention was widely accessible, relatively safe, and inclusive. Participants were invited to keep the NW poles after the period of intervention.

A further strength of the MPhil was harnessing the growing interest in NW for PwP over the past ten years and building upon results of previous studies. In 2014, a PwP attended an international Parkinson’s conference and asked her local PUK branch in Herefordshire to pay for a NWI (Bradley Blake) to teach their PD group. Blake (2014) consulted neurological physiotherapists and PUK, recorded TUG and 10MWT measurements and delivered an eight-week NW intervention for PwP. Results from this feasibility study were presented as a poster at a BNW conference for instructors, an article in a PUK magazine and the BNW website (Blake, 2014, Blake, 2015a, Blake, 2015b). Blake’s research was the inspiration for the proof-of-concept study by McCracken et al (2021). BNW established a continuing professional development (CPD) teaching programme for NWI in 2019, led by Blake and Hughes (Chief executive officer for BNW). This was a further trigger for the lead researcher to investigate the potential for NW as a rehabilitation intervention. A proof-of-concept study, exploring the benefits and barriers for NW indicated that it was conceptually feasible for PwP to NW (McCracken et al., 2021). During lockdown, many NWI undertook PD training and subsequently new groups for PwP were established. It could be viewed as a weakness for future implementation, that few clinicians are trained in NW instruction, and it remains a novel exercise intervention. Proof of concept in an NHS setting, including clinical and cost effectiveness justifies further exploration through a randomised controlled trial (RCT).

## 4.4 Meaning of the Study: Possible Mechanisms and Implications for Clinicians or Policymakers

A question that warrants further exploration is, 'What have we learned from this MPhil, what is the consequence of this research and its application to future practice?'

Improvements in posture (Tragus) combined with faster speed of walking (20 MWT and 10 MWT) appeared to have a positive impact on upright stance and core stability. This could lead to improved core strength, balance and more confidence with mobility and fewer falls. The National Institute for Health and Care Excellence (NICE) reports that the cost of falls to the NHS amounts to more than £2.3 billion per annum, which equates to over £6 million every day (NICE, 2023). This MPhil study did not set out to measure falls risk reduction, but future effectiveness studies could significantly contribute to the NHS regarding rehabilitation, maintenance of mobility and function (activities of daily living) in this population.

The improved scores for 20 MWT (time and cadence) seemed to complement the Tragus scores and there appeared to be a cumulative positive effect, in the context of improved NMS benefits (sleep, cognition and mood). The cost of NMS to the NHS is high, but hard to quantify precisely. Depression, low mood, back pain, social isolation, and poor sleep contribute to a lower quality of life for PwP. This is well documented by Abate et al, (2017) in their study about the global burden of neurological disorders, taking a global, regional, and national perspective (Abate et al., 2017). Nordic walking appeared to improve many of these NMS, so there could be potential cost savings to the NHS if quality of life, sleep and mood are elevated, as reported by De Santis (2020).

A further implication for NW was its potential longer-term impact as a driver for positive change (in behaviour) towards exercise engagement (Domingos et al., 2022b). Outcome measures were recorded immediately after the eight-week period of NW, to establish whether the intervention had any impact on function, and this mirrored previous studies (Ebersbach et al., 2010, Monteiro et al., 2017, van Eijkeren et al., 2008). However, the six-month follow-up data was suggestive of longer-term benefits as the NW intervention might have been a stimulus for increasing activity. This was supported by the FG participants who spoke about NW on holiday and parkwalk with friends. Encouraging PwP to exercise, and to remain active throughout their disease trajectory, is well documented as being crucial to living well with PD, physically and psychologically (Ramaswamy et al., 2018). Finding an exercise programme that is enjoyable, accessible, effective, adaptable, and sustainable remains a challenge for the providers of rehabilitation programmes (Radder et al., 2020, White et al., 2023).

Previous studies have investigated NW in the presence of a range of long-term health conditions including chronic back, knee, and hip pain (Silverberg and Prejserowicz, 2018). Silverberg's 12-week NW study with 100 participants (aged 60 or more) indicated a reduction in pain on walking and an increase in the distance walked, which they attributed to the use of NW poles. They questioned why health care providers did not offer, signpost, or provide NW as part of a treatment plan. They concluded that NW held promise for the effective treatment of chronic pain and recommended further RCTs (Silverberg et al., 2016). As found in this MPhil, NW appears to hold promise for PwP. Further studies are needed to establish NW as part of an exercise prescription that has potential to be endorsed or delivered by the NHS. Ramaswamy cites NW on the PUK excellence network as an exercise modality, with recommendations for frequency of NW, up to three times per week (Ramaswamy et al., 2018).

Domaille's study (2020), for individuals living with rheumatoid arthritis (RA) cited NW as both an exercise and a support network, and people were 'plotted' on a bell-shaped normal distribution curve, somewhere between sport and support (Domaille et al., 2020). The Domaille study resonated with the core findings of this MPhil. Domaille suggested that interventions delivered in a clinical setting had measurable short-term benefits, but sustaining longer term physical activity posed several challenges. Their abstract was presented at a UK physiotherapy conference in 2019. The aim was to establish the acceptability of a tailored NW intervention for people with RA (Domaille et al., 2020). In contrast to the MPhil pre-post measures study with 49 participants (n=27 males), Domaille did not record physical outcome measures and their study sample was smaller, 24 participants (n=6 males). In their study, participants with RA completed a quality of life (RAND) health questionnaire and attended a FG or interview. It was difficult to compare the studies due to heterogeneity of subjects with different long term health conditions (RA and PD). However, the themes from Domaille's FG and interviews were similar: participants enjoyed exercising together outdoors, they reported walking taller with better posture, balance, and improved well-being. Participants expressed their appreciation that the intervention was tailored to the needs of each small NW group. They were reassured that rheumatology specialists and physiotherapists had been consulted regarding the design, methods, and delivery of the intervention. Peer support was cited as a motivating factor and people living with RA preferred to NW with others with RA, rather than a mixed group. There appeared to be longer term engagement after the RA NW intervention as at least ten participants (41.7%) purchased NW poles and continued to NW independently (Domaille et al., 2020). Their recommendations for future research and practice resonated with this MPhil study findings, to establish whether the NW intervention was replicable and scalable. This warrants further exploration.

Another question that merits further discussion is which FG themes could have the most influence on current healthcare services and in the future? The specialist Parkinson's knowledge of the NWI (theme four) and their experience of managing health risks (theme five) were important to healthcare services. Controversially, facilitating some PwP to become more active could augment their risk of falls, due to their overall increase in activity (Goswami et al., 2015). However, the NW intervention addressed and appeared to improve posture, core stability and gait, so the risk of falls was mitigated. As a further safety measure, the group were instructed, and supervised, by a NWI and WL, both of whom were experienced with PD at various disease stages. Encouraging PwP to be more active, and to exercise outside, had measurable and statistically significant benefits regarding improved physical and mental health outcome measures. These findings corroborated with previous studies (Cugusi et al., 2015, Reuter et al., 2011).

A challenge for policymakers and clinicians could be the cost of delivering NW to PwP, especially, as budgets in the NHS are scrutinised, and models of self-care and self-efficacy are widely promoted (Bloem et al., 2015, Tuijt et al., 2020). The intervention was free to the participants at time of delivery as it was part of a research study. Subsequently, if PwP chose to attend an established NW group with a BNWI it would cost around £6.50 per person for a one-hour session, unless the instructor was a volunteer (British Nordic Walking, 2023b). Other models of NW service delivery are suggested in the conclusion, and this is a rapidly evolving area of research interest following the COVID-19 pandemic with new technologies (Bloem et al., 2020, Dorsey et al., 2020), and innovative models of acute and community PD service provision (Yang et al., 2022). It is likely to cost more if an NHS physiotherapist, or PDNS, are INWA trained and deliver NW, approximately £15 per person, per hour depending on the number of PwP in the NW group (British Nordic Walking, 2023a). However, a suggested model could be that the PwP receives eight weeks of NW instruction from their NHS specialist, who has experience of the complexities of PD. The clinician would conduct the necessary health risk and physical activity assessments (Appendix 6) thereby facilitating reassurance to the individual. After eight sessions they could be signposted to established NW groups and adopt a model of self-efficacy (Tuijt et al., 2020) or self-care (Bloem et al., 2015). They might choose to set up their own NW group for PwP, with support from PUK, BNW and third-party funding.

## 4.5 Unanswered Questions and Future Research

Future research could address the health economics of establishing community rehabilitation groups for PwP. This MPhil did not set out to calculate cost implications nor savings to the NHS. However, NW groups tend to have low overhead costs as one NWI and one WL can instruct a group of several PwP to NW outdoors (n=2, up to n=15, depending on H&Y stage and other comorbidities). The cost savings to the NHS could be significant if PwP were found to have a reduced risk of falls (due to improved mobility, confidence with walking, coordination, balance, and gait: theme one). Another cost implication was that the NW groups seemed to be adaptable to people at different stages of PD, were accessible and inclusive. This could facilitate more PwP to become, and remain, active and enjoy their local area, using the NW poles. These PwP might be ‘seldom heard’ in research contexts or individuals who do not enjoy traditional exercise settings (gymnasium, using equipment, team sports or running). Well-being and lifestyle choices are of paramount importance to good mental health (theme six) and the cost of depression, low mood and anxiety is high in this population (De Santis and Kaplan, 2020, Szefler-Derela et al., 2020).

An unanswered question from the FG study was, ‘How generalisable were the results (themes) of the study to PwP in different geographic locations, stages of PD and local contexts?’ Could NW be delivered in different locations, using the enablers and facilitators described in this study? Theme six included practical components such as publicity and partnerships with BNW, PUK and the NHS. Subthemes included the adaptability and inclusivity of NW for PwP with a diverse range of symptoms, stage of disease and demographic background. Enjoyment and lifestyle changes were important for engagement with future NW groups. Theme three (practical, core components: toilets, parking, café, public transport, accessibility) complemented theme six and both were deemed essential to implement NW groups successfully, in future community rehabilitation settings.

As many BNW instructors have undertaken specialist PD courses after the COVID-19 pandemic, the time might be right for a national, multi-site RCT with a larger sample of PwP. NW could be compared to standard treatment or to a facilitated community walking intervention without NW poles.

Reflecting on the repeated measures study, one may enquire which outcome measurements were the most appropriate for the sample population? The Tragus measurement for posture, 20 MWT (speed of walking and cadence) and the NMSS appear to be appropriate outcome measurements for studies of NW in PwP. These measures had the greatest effect after applying a Cohen's d coefficient (standardizer) to all the outcome measures used in this study. The TUG and 10MWT were secondary, reliable, and valid outcomes and were useful for comparing this study to previous studies, using similar or the same health measures. However, no data was collected on the acceptability of these measures, or exploration of what other measures could have been used. Future research could use PPI members, or other PwP, to identify which measures are most meaningful to them.

A further question to explore at the conclusion of both studies was, 'overall, what was important for the participants?' This was partly explored with the FG participants and the six themes derived from their data were underpinned and corroborated with improved NMSS scores, physical measurements, and field notes (data triangulation) as described by (Rooshenas et al., 2019). Most participants were keen to improve, or maintain, their fitness. They were keen to know whether their scores for posture, speed of walking, and TUG had improved after the physical outcome measures were recorded. Some participants expressed that NW poles improved their balance, confidence and posture and reduced their risk of falls. Others reported improved sleep and well-being after the NW class (as reported in field notes and NMSS questionnaires). Future research could incorporate other qualitative methods, such as interviews, to explore at an individual level what is important, particularly for those that didn't engage in the NW intervention, or who are from a more diverse background or those with protected characteristics that are seldom heard.

## 4.6 Conclusion

The data from these studies will inform new models of NW delivery, which will be suitable for larger effectiveness trials (RCTs). Future research could consider an RCT, using a control intervention, to address the efficacy (under ideal circumstances) and effectiveness (under 'real-world' conditions) of NW. A suggested control intervention could be a community rehabilitation walking group, without walking poles, but with similar warm-up exercises and cool down stretches, facilitated by a NHS clinician. Similar community exercise group intervention studies have been delivered (Lamont et al., 2012, Elsworth et al., 2011), but to the best of knowledge, none have addressed the impact and accessibility of NW for PwP with diverse backgrounds, age, and stage of disease following the COVID-19 pandemic.

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# CHAPTER 6 APPENDICES

| | |
|---|---|
| Appendix 1. | Ethical approval letter. September 2021. |
| Appendix 2. | Comparative NW studies. |
| Appendix 3. | Advert for social media. |
| Appendix 4. | Participant information sheet (PIS). |
| Appendix 5. | Study protocol. |
| Appendix 6. | PARQa (adapted) for PwP. |
| Appendix 7. | Consent form repeated measures study. |
| Appendix 8. | PARQ standard. |
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| Appendix 10. | Written permission from Movement Disorders Society. |
| Appendix 11. | NMS Quest (30 NMS). |
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| Appendix 14. | FG Interview schedule (NWI/WL). |
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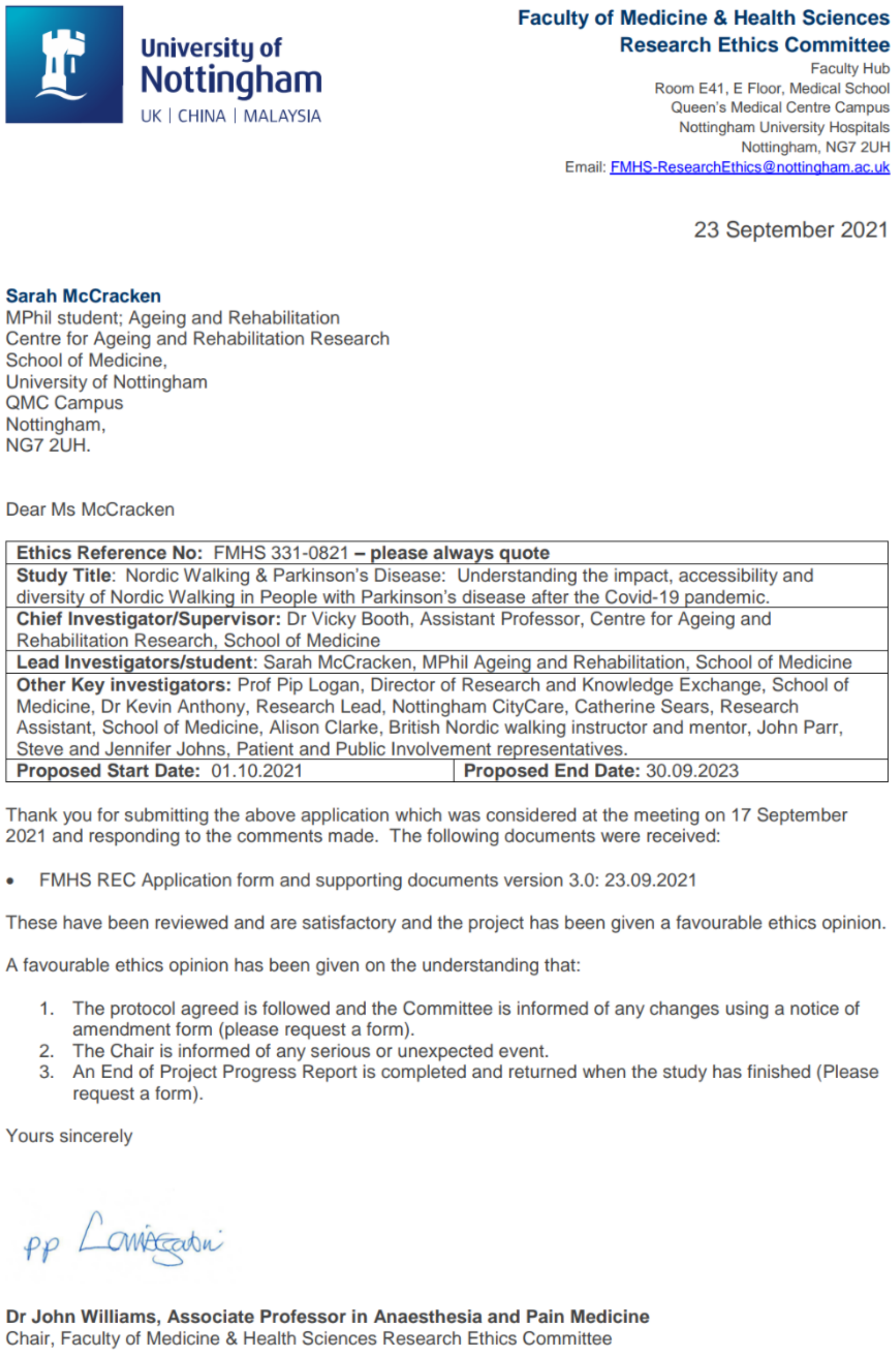
## Appendix 11. Ethical approval letter. September 2021.



University of Nottingham
UK | CHINA | MALAYSIA

**Faculty of Medicine & Health Sciences**
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23 September 2021

**Sarah McCracken**
MPhil student; Ageing and Rehabilitation
Centre for Ageing and Rehabilitation Research
School of Medicine,
University of Nottingham
QMC Campus
Nottingham,
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Dear Ms McCracken

| | |
|---|---|
| **Ethics Reference No:** FMHS 331-0821 **– please always quote** | |
| **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. | |
| **Chief Investigator/Supervisor:** Dr Vicky Booth, Assistant Professor, Centre for Ageing and Rehabilitation Research, School of Medicine | |
| **Lead Investigators/student**: Sarah McCracken, MPhil Ageing and Rehabilitation, School of Medicine | |
| **Other Key investigators:** Prof Pip Logan, Director of Research and Knowledge Exchange, School of Medicine, Dr Kevin Anthony, Research Lead, Nottingham CityCare, Catherine Sears, Research Assistant, School of Medicine, Alison Clarke, British Nordic walking instructor and mentor, John Parr, Steve and Jennifer Johns, Patient and Public Involvement representatives. | |
| **Proposed Start Date:** 01.10.2021 | **Proposed End Date:** 30.09.2023 |

Thank you for submitting the above application which was considered at the meeting on 17 September 2021 and responding to the comments made. The following documents were received:

- FMHS REC Application form and supporting documents version 3.0: 23.09.2021

These have been reviewed and are satisfactory and the project has been given a favourable ethics opinion.

A favourable ethics opinion has been given on the understanding that:

1. The protocol agreed is followed and the Committee is informed of any changes using a notice of amendment form (please request a form).
2. The Chair is informed of any serious or unexpected event.
3. An End of Project Progress Report is completed and returned when the study has finished (Please request a form).

Yours sincerely

**Dr John Williams, Associate Professor in Anaesthesia and Pain Medicine**
Chair, Faculty of Medicine & Health Sciences Research Ethics Committee

**Appendix 22**. **Comparative NW studies**

| Author | Country | Number of participants and if split into groups | Level of disability | Duration of NW | Comparator | Main findings |
|---|---|---|---|---|---|---|
| Bang and Shin 2016<br>Intensive NW intervention on the balance function and walking ability of individuals with PD. An RCT | Republic of Korea | 20:<br>10 NW<br>10 TT | H&Y 1-3 | 60 min<br>5 times/ week<br>4 weeks | Treadmill training<br>(Nordic walking was carried out on treadmill) | All outcomes improved. Significant improvement of NW over treadmill in UPDRS, BBS, 10mWT, TUG, 6MWT |
| Monteiro et al 2016<br>Nordic walking training on functional parameters in PD: a randomized controlled clinical trial | Brazil | 33:<br>16 NW<br>17 FW | 1-4 | 35-50 min<br>2 times / week<br>6 weeks | Free walking | All outcomes improved. NW significantly more improvement in TUGSS, TUGFS,<br>SWS |
| Cugusi et al 2015<br>Effects of a Nordic walking programme on motor and non-motor symptoms, functional performance and body | Italy | 20:<br>10 NW<br>10 controls | 1-3 | 60 min<br>twice / week<br>12 weeks | Conventional care/ no exercise | NW group showed significant improvement in all tests:<br>Motor symptoms<br>UPDRS-III H&Y scale<br>Functional performance<br>6MWT, FTSST, HGT, BBS, |

| Author | Country | Number of participants and if split into groups | Level of disability | Duration of NW | Comparator | Main findings |
|---|---|---|---|---|---|---|
| composition in patients with PD | | | | | | TUG, SRT, BST<br>Anthropometric profile<br>and body composition<br>QOL and non-motor symptoms<br>PFS-16, BDI-II, SAS,<br>NMSS |
| Ebersbach et al 2010<br>Comparing exercise in Parkinson's disease- the Berlin LSVT®BIG study,<br>Ebersbach et al 2014, Impact of physical exercise on reaction time in patients with Parkinson's disease | Germany | 58:<br>19 NW<br>20 LSVT BIG<br>19 Home | 1-3 | NW:<br>60 min<br>2 times / week<br>8 weeks<br>LSVT:<br>60 min,<br>4 times / week<br>4 weeks<br>Home: 60 min | LSVT BIG and similar home exercise programme | UPDRS improved by LSVT BIG and mild deterioration in NW group.<br>LSVT BIG superior to NW in TUG and 10MWT. No sig difference in QOL. Sig difference in cRT between LSVT BIG group and home group and between NW group and home group. No sig. difference between LSVT BIG and NW in cRT.<br>Supervised physical exercise with LSVT Big or NW is associated with improvement in cognitive aspects of movement preparation. |

| Author | Country | Number of participants and if split into groups | Level of disability | Duration of NW | Comparator | Main findings |
|---|---|---|---|---|---|---|
| Reuter et al 2011<br>Effects of a flexibility and relaxation programme, walking, and Nordic walking on PD | Germany | 90:<br>30 NW<br>30 F&R<br>30 W | 2-3 | 70 min<br>3 times / week<br>24 weeks | Walking<br>Flexibility and relaxation | All reduces pain, increase QOL. W and NW significantly<br>improved stride length,<br>gait variability, 12MWT,<br>24MWT, MWS at exercise test, and UPDRS-III score. NW was superior to the F&R and W in improving postural stability, stride length, gait pattern and gait variability. |
| Monteiro et al 2016<br>Nordic walking training on functional parameters in Parkinson's disease: a randomized controlled clinical trial. | Brazil | 14 | 1-4 | 60 min<br>2 times / week<br>9 weeks | Free walking | NW superior to free walking in improving TUG and SSW |
| Van Eijkeren et al 2008<br>Nordic Walking improves mobility in PD | The Netherlands | 19<br>10 NW<br>9 NW + 5-month retest | 1-3 | 60 min<br>2 times / week<br>6 weeks | Baseline, 6 weeks and 5 month follow up | Significant improvement in 10MWT, TUG, 6minWT and QOL (PDQ-39) in NW arm. Improvements persisted in follow up testing after 5 months |

| Author | Country | Number of participants and if split into groups | Level of disability | Duration of NW | Comparator | Main findings |
|---|---|---|---|---|---|---|
| Salse-Batan, 2022.<br>Effects of NW in PwP: a systematic review and Meta-Analysis. | Spain | 12 papers/ studies in the final analysis<br>Studies assess motor and non-motor symptoms. |  | 4-24 weeks.<br>Different intensity and frequency of NW | Shown in a table. | Potential benefits of NW seem to be limited to improvements in walking ability and Quality of life. |
| Leal-Nascimento, 2022.<br>Biomechanical responses of Nordic walking in people with PD. | Brazil | 11 PwP | H & Y<br>One to 1.5. |  | 9 healthy controls | NW can be a useful strategy in rehab for PwP due to potential for improving functional mobility, increasing the pendulum-like mechanism in PD. |
| Granziera 2021<br>NW and Walking in PD: A randomized single-blind controlled trial.<br>Bombieri 2017 | Switzerland | 32<br>Nine studies, including 4 RCTs.<br>127 subjects. | H & Y<br>Two-three |  | NW v Walking<br>Paired t-tests<br>General linear models<br>repeated measure. | NW was not superior to walking in this population.<br>However, there was a beneficial effect of open-air exercise and guided group walking activities for PwP.<br>Most studies reported beneficial effects of NW on either motor/non-motor symptoms or |

| **Author** | **Country** | **Number of participants and if split into groups** | **Level of disability** | **Duration of NW** | **Comparator** | **Main findings** |
|---|---|---|---|---|---|---|
| Walking on four limbs: A systematic review of NW in PD | | | | | | both. Further large RCT's were recommended. |
| Gougeon 2017.<br>NW improves trunk stability and gait spatial-temporal characteristics in PwP. | Canada | 12 PwP<br>No control group | | | NW with or without a verbal fluency task.<br>To assess gait rehabilitation with cognitive impairment. | NW improved stride length and increased the base of support, to stabilize the upper body. Use of poles can assist with balance despite mild cognitive impairment. NW poles might help PwP to remain physically active and have a beneficial impact upon their independence and quality of life. |
| De Santis 2020<br>The motor and the non-motor outcomes of NW in PD: A systematic review.<br>(and three observational studies with cross-over designs). | Germany | 318 | Early stages of PD.<br>H & Y<br>1-2 | | Large table of comparative studies, including recent papers. | NW may contribute to the maintenance of overall mobility in addition to pharmacotherapy.<br>NW may require regular and supervised training. |

| Author | Country | Number of participants and if split into groups | Level of disability | Duration of NW | Comparator | Main findings |
|---|---|---|---|---|---|---|
| Radder 2020<br>Physiotherapy in PD:<br>A meta-analysis of present treatment modalities. | 191 trials | 7998 participants | H& Y<br>1-4 | | Meta-Analysis of 191 trials. | NW has a beneficial effect on motor symptoms, balance, and gait.<br>The evidence base allows clinicians and PwP to make a choice regarding treatment modalities. |

**Key to outcome measures & terms**

| | | |
|---|---|---|
| Hoehn & Yahr stage (H&Y) | 24 metre walking tests (24MWT) | PD quality 39 (PDQ-39) |
| Unified Parkinson's disease rating scale (UPDRS) | Five Time Sit to Stand Test (FTSST) | Berg balance scale (BBS) |
| 6 min walking test (6MWT) | Hand grip-strength evaluation (HGT) | Parkinson's fatigue scale (PFS) |
| 10 metre walking tests (10MWT) | Sit and Reach Test (RST) | Beck depression inventory (BDI) |
| Timed up and go test (TUG) | Back scratch test (BST) | Starkstein apathy scale (SAS) |
| Sit to stand performance (STS) | Self-selected speed (SSW) | Non-motor symptoms scale (NMSS) |
| 12 metre walking tests (12MWT) | Locomotor rehabilitation index (LRI) | Cued reaction time (cRT) |

## Appendix 33. Advert for social media

**We are seeking volunteers to participate in a research study on the benefits of Nordic walking to people with Parkinson's disease.**

Study title: Understanding the impact, accessibility and diversity of Nordic Walking in People with Parkinson's disease after the Covid-19 pandemic.

### What is Nordic walking?

Nordic walking is a style of walking using 2 poles, utilising both the upper and lower body. It uses up to 90% of the main muscles and is more efficient than just walking. It began in the 1930s when Finnish cross-country skiers would train with their poles during the summer.

There is a growing body of research supporting the use of Nordic Walking as a means of regular, outdoor exercise for people with a variety of physical and mental health problems. Prior research into people with Parkinson's has shown Nordic walking to improve quality of life, their pattern of walking, posture and cognition of movement preparation. Nordic Walking has been endorsed by Parkinson's UK and British Nordic Walking .

### What are the aims of the study?

This study aims to add to the body of research, determining the impact of a Nordic walking programme on the physical and mental wellbeing of people with Parkinson's. We'd like to recruit people from a variety of backgrounds and start new Nordic walking classes in Nottinghamshire.

### What is involved?

The study involves 8 , weekly, one hour group sessions with a trained instructor, with data on your physical and mental wellbeing collected before and after the programme. There will be short questionnaires as well as some physical measurements regarding walking and posture. We'd like to follow up your progress after six and nine months. The study is based in Nottinghamshire.

Participant information sheet

### Am I eligible?

If you are an adult with Parkinson's disease, who is able to walk for up to an hour without a walking aid and have no other major health conditions, you may be eligible for this study. This study has obtained approval from the FMHS Research Ethics; 331-0821

**If you are interested in participating please contact Sarah McCracken**

**Email: sarah.parkes007@gmail.com** **https://nordicwalkingforparkinsons.org.uk/**

**Appendix 44. Participant information sheet (PIS).**

**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.
Version 3.0 16/07/2021

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 well-being. 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 well-being. 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 40 to 60 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 well-being; taking about 30 minutes to complete. There is an optional extra measurement addressing balance (BERG) that takes a further 20 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 eight 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 David Ross Sports village; Main 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 eight 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 six to nine 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 seven 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 on-line 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 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. Ref: FMHS 331-0821.

**Contact Details**

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

Lead researcher: Sarah McCracken
Community Neurology Team
The Meadows Health Centre
1, Bridgeway Centre, The Meadows
Nottingham, NG7 2UH
Tel: 0755 758 9080. 0115 8834830.
Email: sarah.mccracken1@nottingham.ac.uk

**Appendix 55. Study protocol**

## 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. REC ref: FMHS 331-0821

### Abstract.

There is a growing body of research supporting the use of Nordic Walking as a means of regular, outdoor exercise for people with a variety of physical and mental health problems. Research shows promising outcomes for people with Parkinson's disease, with significant improvements in quality of life, increased walking speed and stride length, postural stability, gait improvements and in cognitive aspects of movement preparation. Although the benefits appear reasonable, there are several barriers to Nordic Walking for people with Parkinson's, such as accessibility and availability of specialist training, time, stigma of using two poles, cost of poles and it being predominantly an activity for middle-aged females and older adults.

Nordic Walking has been endorsed by PUK and BNW. There is currently a roll-out programme through this partnership; training instructors nationally to deliver Nordic Walking specifically to people with Parkinson's. The East Midlands is an early pilot site, and one Parkinson's disease nurse specialist is an accredited Nordic Walking instructor. However, there has been little research to explore the wider implementation, or benefits, of such programmes.

A quasi-experimental pre-post study of Nordic Walking for people with Parkinson's Disease (PwP) (n= 40-60) at The University of Nottingham and at Gedling Country Park will be conducted. Standard outcome measures of walking (ten metre and twenty metre walk test) timed up and go test, the Tragus test for posture, the Parkinson's non-motor scale questionnaire and field notes will be recorded before, and after, the eight-week programme of Nordic Walking. Participants will be recruited from the Nordic Walking group, which will be advertised via PUK branches and website, British Nordic walking website/social media and Social prescribers. A small sample (n=10-15) will complete optional advanced outcome measures for PD: the Berg balance test; to explore acceptability and feasibility of completing a wider range of measures in this population. This will take an additional 20 minutes per participant.

The cost of the programme will be calculated, and all the data will be used to inform either an implementation strategy, or a larger randomised controlled trial protocol. An overarching

aim is to develop referral pathways from the NHS and to set up a new Nordic Walking service in the Nottinghamshire area for people with Parkinson's disease.

## Ethics and dissemination.

Ethical approval is being sought from the School of Medicine, University of Nottingham, Ethics Committee.

The results of the study will be presented in a report to the funder and community neurology team; as well as a presentation at a Nottingham CityCare Partnership Nurses and Allied Health Professionals event.

Results will be presented at relevant conferences: a Parkinson's nurse specialist forum (100 people) and British Nordic Walking Instructors' convention (80 people). Results will be shared with all participants, and via an article in CityCare communications, and a short report to the research and audit team. A paper will be published in a peer reviewed journal.

## Introduction

Nordic Walking (NW) started in the 1930's when Finnish cross-country skiers used their ski poles for summer training. In 1967 Leena Jääskeläinen, a Professor in sport sciences, introduced walking with ski poles and within a few years had rolled it out as a recognised sport in Finnish schools.

In 1997 the name Nordic Walking (NW) was coined (britishnordicwalking.org.uk) and International Nordic Walking Federation (INWA inwa-nordicwalking.com) celebrated 20 years in 2020 with a plethora of global sporting events. The INWA is the global governing body promoting Nordic Walking. It collaborates with international scientific and medical communities to offer research resources and teaching. Nordic Walking is an evidence-based sport and is suitable for people with a range of disabilities including neurological diseases, arthritis, leg amputation, people recovering from breast cancer surgery, back pain, hip pain and mental illness. It has been endorsed by the UK Chief Medical Officer (Physical Activity guidelines, 2019).

In 2014, a British woman with Parkinson's disease attended an international conference and encountered Nordic Walking for Parkinson's disease for the first time. She asked her local branch for some funding and started the first NW group for PwP. The INWA instructor Brad Blake has been taking this regular class for the past seven years and published his findings through a conference presentation (Blake, 2015). He trains NW instructors due to his passion for Parkinson's. His study, of 10 participants, indicated that NW improved walking ability and might have a positive impact on mental health. It also hypothesized that Nordic Walking could be disease modifying, as it might slow down the progression of the disease. However, this study was very small and did not collect any standardised outcomes.

In addition to this small but inspirational study, there have been larger studies to support an evidence base for the benefits of NW in PwP. Reuter et al (2011) studied 90 participants and randomised them to three different forms of exercise: flexibility exercises and relaxation, NW, 'just walking'. NW was superior to the alternatives in improving stride length, gait and balance. In a Dutch study by Van Eijkeren et al; where subjects were tested at baseline, after six weeks of bi-weekly intervention and followed up at five months, there were significant improvements in the 10-metre walk test, Timed Up and Go test (Podsiadlo and Richardson, 1991) and in quality of life (PDQ-39). These persisted up to the five-month follow-up assessment.

An Italian study (Cugusi, 2015) had similar findings: with improvements from baseline on the Timed Up and Go test, Non-Motor Symptom Questionnaire (Chaudhuri, 2007) scores and a 6-metre walk test.

Nordic Walking has been endorsed by Parkinson's UK and British Nordic Walking and training of instructors for PwP is on-going but there is little research to guide implementation of this novel intervention in a UK setting.  The East Midlands is an early pilot site, and one Parkinson's disease nurse specialist has been trained as an accredited Nordic Walking Instructor (NWI). However, we do not know whether PwP will join NW groups and continue to NW after the intervention. We also do not know the motor and non-motor impact of NW at the end of an eight-week programme, or the longer-term benefits at six months.

Lockdown has had a huge impact upon the physical and psychological health of PwP. People have deconditioned due to lack of physical exercise, and this has negatively impacted upon their mental health. We know that exercise has a positive impact on well-being, resilience and coping strategies.

We chose to use the validated outcome measures from previous randomised controlled trials, cohort studies and the small feasibility study (McCracken et al, 2020) to inform this cohort study. Could this become the blueprint for a wider uptake of NW for PwP across the country?

Many PwP are keen to take part in research and this is a non-drug innovation study that is accessible and empowering. It builds on a model of self-care, rather than attending a rehab unit or expensive gym. It is a flexible model that can reach diverse groups and is ideal for people who struggle to exercise alone or who do not enjoy traditional fitness settings.

### Aims of the study

The primary aim of the study is to determine the impact of NW by PwP on their physical health and mental well-being, especially after the Covid-19 lockdown.

The secondary aim is to increase the accessibility, availability and uptake of NW by PwP by better understanding the diversity and accessibility of those engaging in an eight-week programme. This will develop our knowledge on how to better meet the needs of 'hard to reach' groups within this population and inform the set-up of new NW services.

### Research questions

The primary research question is.

1. Does an eight-week Nordic Walking programme improve mobility, posture, balance, mental health and well-being in people with Parkinson's disease?

The secondary research questions are.

2. What is the long-term impact after six months, of an eight-week NW programme on PwP? Do people join a regular group and continue to Nordic walk after the initial programme?
3. What is the diversity of PwP who are engaged in a NW programme?
4. How do PwP access a community-based NW programme?

## Method

A quasi-experimental pre-post study will be conducted collecting qualitative and quantitative data.

A sample of 40-60 PwP will be recruited and consented to participate in the project by the researcher. The participants will be recruited from the local PUK branches and relevant websites and social media, including the BNW and social prescribers. The lead researcher (SM) will liaise with the local PUK branch chairs and BNW website contacts to request the distribution of the study materials to their members. The study materials (advert) will include the contact details of the researcher (SM) and anyone who is interested in taking part will then contact the research team directly. The researcher (SM) will also use social media to advertise and distribute the study materials to other relevant groups, including local social prescribers, charities or other professionals working with PwP. Once a potential participant has been in contact with the researcher (via phone or email), a Participant Information Sheet (PIS), including all details of the study, will be sent to them (via email or post, depending upon preference) and a repeat contact arranged to gain informed consent.

Once consent has been obtained, the participant will meet the researcher to complete the health screening questionnaire (Physical activity readiness questionnaire/ PARQ), descriptive information (e.g., name, age, time since diagnosis, gender, ethnicity, contact details) and baseline measures before starting the NW. This will be conducted within one month before the start of their NW programme and within two weeks of them finishing.

Participants will complete eight (one hour) sessions of NW at The University of Nottingham main campus. They will be signposted to existing NW groups afterwards with the intention of encouraging their continued uptake of NW following the initial eight-week programme. New groups will also be established by the project team as the longer-term vision is to set up a new NW service for people with PD. All outcome measures and questionnaires will be repeated at eight weeks and again, six months after the intervention.

The costs of delivering the NW programme will be recorded and will include the instructors' time and travel, the provision of new poles, infection control measures and equipment, telephone calls, leaflets, refreshments and training. There will be additional costs to improve the safety of the intervention. A trained Nordic walk leader will be available to support the instructor, and to supervise slower walkers, or if participants feel unwell. A second, experienced NW Instructor (AC) from the research project team will be available to cover for holiday/sickness and to attend some group sessions. There will be small costs associated with expenses for three patient and public involvement representatives; two of whom have Parkinson's disease.

Qualitative data will be collected in the form of field notes and informal comments. These will be informally noted by the NW instructor during the classes and formally documented immediately after every class. They will not be audio recorded.

### Outcomes

Participant characteristics will be recorded to enable a description of the sample, including age, gender, ethnicity, socio-economic characteristics, medical history, and route into the NW class (e.g., from PUK, BNW, social media, etc.)

Participants will complete the following standardised quantitative measurements at baseline, at the end of the eight sessions and again after six months, with the NW instructor. It has been calculated that it will take 20 to 30 minutes to collect this information. The outcomes include:

- Time taken to walk 10 metres without a walking aid (Watson, 2002)
- Number of steps taken to walk 10 metres (Watson, 2002)
- Time taken to walk 20 metres without a walking aid (Motyl et al, 2013)
- Number of steps taken to walk 20 metres.
- Well-being will be assessed using the Non-Motor Scale questionnaire (Chaudhuri et al, 2007). This questionnaire has 30 questions, answered with a scale of 0-5. It asks questions about mood, falling, sleep, leg pain, weight etc. It has been used successfully in numerous PD trials.
- Tragus to wall test (Shipe, 2013) for measuring posture.
- Timed up and go test (Podsiadlo et al, 1991)

Participants can wear an optional fitness tracker or use the Strava/ Garmin App on their mobile phones. This is a growing area of research in Parkinson's and may be a useful adjunct to the other outcome measures that may aid motivation and give the individual positive feedback (Lamont et al, 2018). In the feasibility study, 2020, McCracken used video as a feedback mechanism for teaching and correcting technique. Participants found this extremely helpful for their personal use.

A small sample of participants (n=5-10) will be asked to complete an optional, enhanced outcome measure: The Berg balance test (Berg, 1989). This takes 20 minutes longer to complete but is a validated tool for measuring balance. This will be recorded by the research team at the University campus and participants can opt to have the lengthier outcome measures. It will be offered to all participants, but difficult to implement in the timescales allocated. A shorter balance score is the Uni-pedal stance test (Springer et al, 2005), but this is not advisable for people with complex Parkinson's as it carries an increased risk of falls.

## Lay Summary

Nordic Walking has been proposed as an effective, enjoyable outdoor activity for people with Parkinson's disease, which may have mental health benefits. It is growing in popularity, but the research evidence is patchy, with researchers using different outcome measures, different durations of Nordic Walking and a wide variation in physical ability between participants. Nordic Walking poles improve stability, are not walking aids, are sporty in appearance and do not look clinical, but some people are reluctant to use two walking poles in public.

As Nordic Walking is relatively easy to learn, not expensive and available to anyone who can walk unaided for 20 minutes or longer; we now need good quality published research to encourage uptake in clinical and non-clinical settings. This study will focus on increasing the accessibility, availability, and uptake of NW for people with Parkinson's Disease; and to look for any indications of physical or psychological benefit. We hope to recruit people from diverse backgrounds and to help people to get fit after the Covid-19 lockdown.

This study will recruit around 40 to 60 people with Parkinson's; offering them an eight-week programme of outdoor Nordic Walking (one hour per session, with breaks as required for technique teaching and rest) at University of Nottingham's campus. Measurements will be taken before, and after, the Nordic Walking programme. We will record walking speed and stride length, quality of life, timed up and go from a chair, the Tragus test (a simple measurement of posture), non-motor symptoms and ask the participants about their experiences during the programme. The cost of delivering the Nordic Walking programme will be calculated. The before and after results will be compared looking for any evidence of change. We will signpost people to established groups or offer follow on NW classes. Measurements and questionnaires will be repeated at eight weeks, and again at six months after the initial Nordic Walking intervention.

The results will be fed back to the participants, to Parkinson's UK and to British Nordic Walking as well as shared at conferences and through a published paper or poster.

## Ethics approval

Ethics approval has been sought from the School of Medicine, University of Nottingham. REC ref FMHS 331-0821 Nordic Walking and Parkinson's.

## Safety and monitoring adverse events.

Nordic Walking is already undertaken by thousands of people in the UK alone and therefore is described as a low-risk intervention. Specific risks, untoward incidents or adverse events are not expected; however adverse events will be collected in this study if they occur. An environmental risk assessment has been carried out for the venues and these will be updated frequently, according to fluctuating weather and terrain. There will be local access to a defibrillator if needed at the venue (at David Ross; University Sports Centre). The Nordic Walking instructors and walk leader hold current first aid certificates and the lead researcher SM is an experienced Parkinson's Nurse Specialist.

The project will follow Covid-19 guidance around safety and infection prevention and control (www.gov.uk). As it is an outdoor sport the risks are lower and social distancing will be maintained. New poles will be provided for each participant, as well as hand gel, wipes and masks (if required).

Individual health /physical activity risk assessment questionnaires (PARQ) will be completed prior to commencing Nordic Walking classes. This includes emergency contact details. A weekly verbal update will be carried out to check whether there are any new health problems.

An obvious risk for anyone with Parkinson's, who undertakes physical activity, is the risk of falls. The PARQa includes a modified falls risk assessment, and the participant is responsible for being honest about their falls risk history. This questionnaire is tailored to PwP.

For the purposes of this study, an adverse event is an event that occurs during the research protocol that causes, or increases, the risk of physical or psychological harm to the research volunteer, or results in a loss of privacy and/or confidentiality to the research volunteer or others.

## Eligibility

Inclusion criteria

- Adults over 18 with Parkinson's disease who can walk for up to an hour without a walking aid as reported by the participant. (This is stage 3 or below on the Hoehn & Yahr, 1967 scale)
- Able to participate in a one-hour training session every week (with frequent breaks for technique revision) as reported by the participant.
- Can give informed and written consent.

Exclusion criteria

- Severe dementia (unable to take on new skills/ follow instructions).
- Complex comorbidities including frequent falls and significant postural hypotension with, or without, mild cognitive impairment.

## Data collection, storage and management

See attached Data Management Plan (DMP).

Each participant will be assigned a study number, for use on study documents and the electronic database. Study documents will be held securely in accordance with regulations. The investigator will make a separate confidential record of the participant's name, study number and contact details, to permit identification of all participants enrolled in the study, in case additional follow-up is required. Most documents will be electronic and will be stored according to the DMP. All paper forms and questionnaires will be filled in using black ballpoint pen. Source documents will be filed at the investigator's site and may include consent forms, health risk assessments, environmental risk assessments, emergency contact details, pole length details, study records, field notes, paper and electronic questionnaires. Only study staff shall have access to study documentation.

In compliance with the Good Clinical Practice (GCP) guidelines, regulations and in accordance with the University of Nottingham Code of Research Conduct and Research Ethics, the Chief Investigator, Dr Vicky Booth, will maintain all records and documents regarding the conduct of the study. These will be retained for at least seven years or for longer if required. If the responsible investigator is no longer able to maintain the study records, a second person from the research team will be nominated to take over this responsibility. The study documents held by the Chief Investigator shall be archived at secure archive facilities at the University of Nottingham. This archive shall include all field notes, study databases and associated meta-data encryption codes.

## Analysis methods

The sample will be described as a group using their personal non-identifiable characteristics (e.g., age, gender, and ethnicity). Data from the outcome measures will be stored on an Excel-type/ SPSS database and analysed using descriptive statistics (means, median, ranges and standard deviation). Qualitative data from the field notes and questionnaires will be transcribed and analysed using thematic analysis (Braun and Clarke, 2006). The non-motor scale questionnaire will give scope for detailed statistical analysis; as compared to the simple non motor questionnaire (Chaudhuri, 2007). Statistical methods will be refined following the statistics taught module and are likely to be descriptive statistics. Data will be checked by a second researcher (VB, FA and PL).

## Publication and dissemination policy

The study results will be presented first to the collaborators in the project, including public and patient involvement representatives. The findings will be written up and presented to the funders and to CityCare clinical and board members after the dissertation and viva have been completed. Research findings will be presented in a poster and PowerPoint format for clinical and academic meetings. It will be presented to BNW and PUK via their respective websites and social media platforms as appropriate. An article will be written for publication with open access rights.

## Strengths and limitations of the study

This research project builds upon previous work by the research team (McCracken, Logan, Anthony and Parr, 2021) and will contribute to the body of evidence looking at the physical health benefits of Nordic Walking as regular outdoor exercise for people with Parkinson's disease. It also highlights the non-motor benefits of Nordic Walking, particularly after a national lockdown. This is still a novel area of research, and the aim is to broaden the evidence base. An additional strength is that we hope to involve 'hard to reach' groups from a diverse population in research.

A limitation of the proposed study is the heterogeneity of the sample population, particularly considering this is a clinical group where no two individuals are the same. A limitation is that the lead researcher (SM) runs a busy Parkinson's caseload in the community and will need to prioritise clinical commitments. Further limitations include: the outcome measures and field notes will be collected by the NW instructor who will also provide the intervention; this holds the potential for positive bias reporting. However, this risk can be mitigated using quantitative and standardised outcome measures which will be collected by the lead researcher and a research assistant with the use of published guidelines. Future research could use a blinded researcher. However, a significant study strength is the recruitment pathway: routine PD groups, British Nordic Walking, social prescribing and social media. Provided that the instructor is INWA trained, this should improve the results' generalisability to other NHS settings and appropriate patient groups.

Despite these limitations, two Nordic Walking instructors are available to deliver and support the project, as well as a qualified Nordic walk leader, which strengthens the practical delivery of the study. The project team are experienced, including experts in the field of research and neuro physiotherapy (Prof Logan, Dr Booth, Dr Allen and Dr Anthony). There is also PPI representation on the research team which will ensure all study procedures are acceptable before recruitment starts.

## Declarations

Ethical approval has been sought and approved to conduct this study. Consent procedures are detailed in the methods section. Availability of the data and material, if appropriate, will be provided on request from the Chief Investigator, Dr Vicky Booth. Funding was provided by Nottingham CityCare partnership in collaboration with The University of Nottingham and NIHR funding. The initial funding, for instructor training was provided by The Fore in collaboration with British Nordic Walking.

## Public and Patient Involvement

Mr John Parr has kindly agreed to be part of the project team. He is a gentleman with Parkinson's who is very active. He is of working age and is a keen sailor, enjoying outdoor sporting activities. The management of his medical condition is not conducted by any of the research team.  As well as Mr Parr, Mr Steve Johns is a gentleman with Parkinson's who, with his wife Jennifer, is chair of the Nottingham branch of Parkinson's UK. Both Mr and Mrs Johns are also contributing to the PPI of this study and there is no known conflict of interest. John, Steve and Jennifer will be helping with writing all documents, lay summaries, attending project meetings and disseminating the results. Steve has offered to participate in the eight-week Nordic walking programme.

## Acknowledgements

University of Nottingham. Prof Pip Logan. Dr Vicky Booth. Dr Frances Allen.
Nottingham CityCare: Dr Kevin Anthony, Julia Webster (manager), Community neurology team. Helen Elvidge. Tracy Tyrell. Louise Bainbridge. Gale Cockayne.
British Nordic walking CEO: Dr Catherine Hughes. Alison Clark. Maggie Bates.
Parkinson's UK: Katie Smith.

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**Appendix 66. PARQa (adapted) for PwP.**

## Physical Activity Readiness Questionnaire

Name: Height: Year of birth:

Address:

Email: Phone number: Date:

Circle yes or no to each of the questions below. If you circle 'yes,' you may need your doctor's consent before you participate in Nordic Walking.

1 Has a doctor ever said that you have a heart condition or high blood pressure? Yes/No

2 Do you have chest pain at rest or brought on by physical activity? Yes/No

3 Do you lose balance because of dizziness, or have you lost consciousness in the last 12 months? Yes/ No

4 Do you have a bone or joint problem that could be made worse by physical activity? Yes/No

5 Are you currently taking medication for a condition that you need to carry with you on a walk? Please state here: Yes/ No

6 Has your doctor ever said that you should only do medically supervised activity? Yes/ No

7 Have you been diagnosed with a long-term medical condition or allergy that might affect your ability to exercise? Please state below: Yes/ No

I realise that my body's reaction to exercise is not totally predictable. Should I develop a condition that affects my ability to exercise, I will inform my instructor immediately and stop exercising if necessary. I take full responsibility for always monitoring my own physical condition.

Signed: Date:

In case of emergency, please contact. Name:
Phone number:

Photographs: I give permission to my instructor and British Nordic Walking to use photographs taken of me in publications, advertisements, exhibitions, and the internet to illustrate their work and to promote Nordic Walking. This includes use on social media. Due to the nature of the internet, photographs may be shared across numerous channels. The photographs may also be loaned to approved third parties e.g., charitable partners, funders, and the media.
I agree to these conditions: Yes /No

Data Protection: This information will be stored securely by the instructor and uploaded to an encrypted, secure database at the University of Nottingham for research purposes. You must notify your instructor of any changes in your personal data. Your email address will be used to notify you about Nordic Walking activities.
I agree to these conditions: Yes /No

How did you hear about Nordic Walking?

How far does the participant say they can currently walk/duration/rest periods needed?

Impact of medication and timing?

| **Expressed difficulties** | Yes | No |
|---|---|---|
| Use of walking aid………………………………………………………………… | | |
| Uneven surfaces ……………………………………………………………… | | |
| Balance/co-ordination ……………………………………………………… | | |
| Falls ……………………………………………………………………………… | | |
| Fatigue…………………………………………………………………………… | | |
| Pain on walking ……………………………………………………………… | | |
| Memory/cognition…………………………………………………………… | | |
| Other impairment/ illness? ……………………………………………… | | |
| Covid symptoms?……………………………………………………………… | | |
| Other …………………………………………………………………………… | | |

Instructor’s observations from taster sessions /training/walks

Any other comments (e.g., fitness routine during lockdown).

## Appendix 77. Consent form repeated measures study

# Participants Consent Form

**Final version 4.0: 16.10.2021**

Title of Study: 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. REC ref: FMHS 331-0821

**Name of Researchers**: Lead investigator: Sarah McCracken, Parkinson's Nurse Specialist
Chief Investigator/Supervisor: Prof Logan and Dr Vicky Booth

**Please initial box**

**Name of Participant:** ______________________________________________

1. I confirm that I have read and understand the participant information sheet for the above study which is attached and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
3. I understand that should I withdraw, more than 7 days after the questionnaire and Nordic walking teaching sessions have taken place then the information collected so far cannot be erased and that this information may still be used in the study analysis. ☐
4. I understand that relevant sections of my data collected in the study may be looked at by the research group and by other responsible individuals for monitoring and audit purposes. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
5. I understand that the questionnaires will be completed before and after the 8-week period of Nordic walking intervention; and there will be a follow up questionnaire after six and nine months. Anonymous comments/ field notes during and after the classes may be used in the study reports. ☐
6. I understand that what I say in the questionnaires and during the Nordic walking group sessions will be kept confidential unless I reveal something of concern that may put me or someone else at any risk. It will then be necessary to report this to the appropriate persons. ☐
7. I understand that information about me obtained during the study will be made anonymous before it is stored. It will be uploaded into a secure database on a computer kept in a secure place. Data will be kept for 7 years after the study has ended and then destroyed. ☐
8. **Optional:** I agree that my research data may be stored and used in possible future research during and after 7 years and shared with other researchers including those working outside the University. Yes/No ☐
9. I agree to take part in the above study.

| | | |
|---|---|---|
| Name of Participant | Date | Signature |
| Name of Person taking consent | Date | Signature |

**Appendix 8. PARQ standard**

## Physical Activity Readiness Questionnaire

Name: Height: Year of birth:

Address:

Email: Phone number:

Circle yes or no to each of the questions below. If you circle 'yes,' you may need your doctor's consent before you participate in Nordic Walking.

| | | |
|---|---|---|
| 1 | Has a doctor ever said that you have a heart condition or high blood pressure? | Yes/No |
| 2 | Do you have chest pain at rest or brought on by physical activity? | Yes/No |
| 3 | Do you lose balance because of dizziness, or have you lost consciousness in the last 12 months? | Yes/ No |
| 4 | Do you have a bone or joint problem that could be made worse by physical activity? | Yes/No |
| 5 | Are you currently taking medication for a condition that you need to carry with you on a walk? Please state here: | Yes/ No |
| 6 | Has your doctor ever said that you should only do medically supervised activity? | Yes/ No |
| 7 | Have you been diagnosed with a long-term medical condition or allergy that might affect your ability to exercise? Please state below: | Yes/ No |

I realise that my body's reaction to exercise is not totally predictable. Should I develop a condition that affects my ability to exercise, I will inform my instructor immediately and stop exercising if necessary. I take full responsibility for always monitoring my own physical condition.

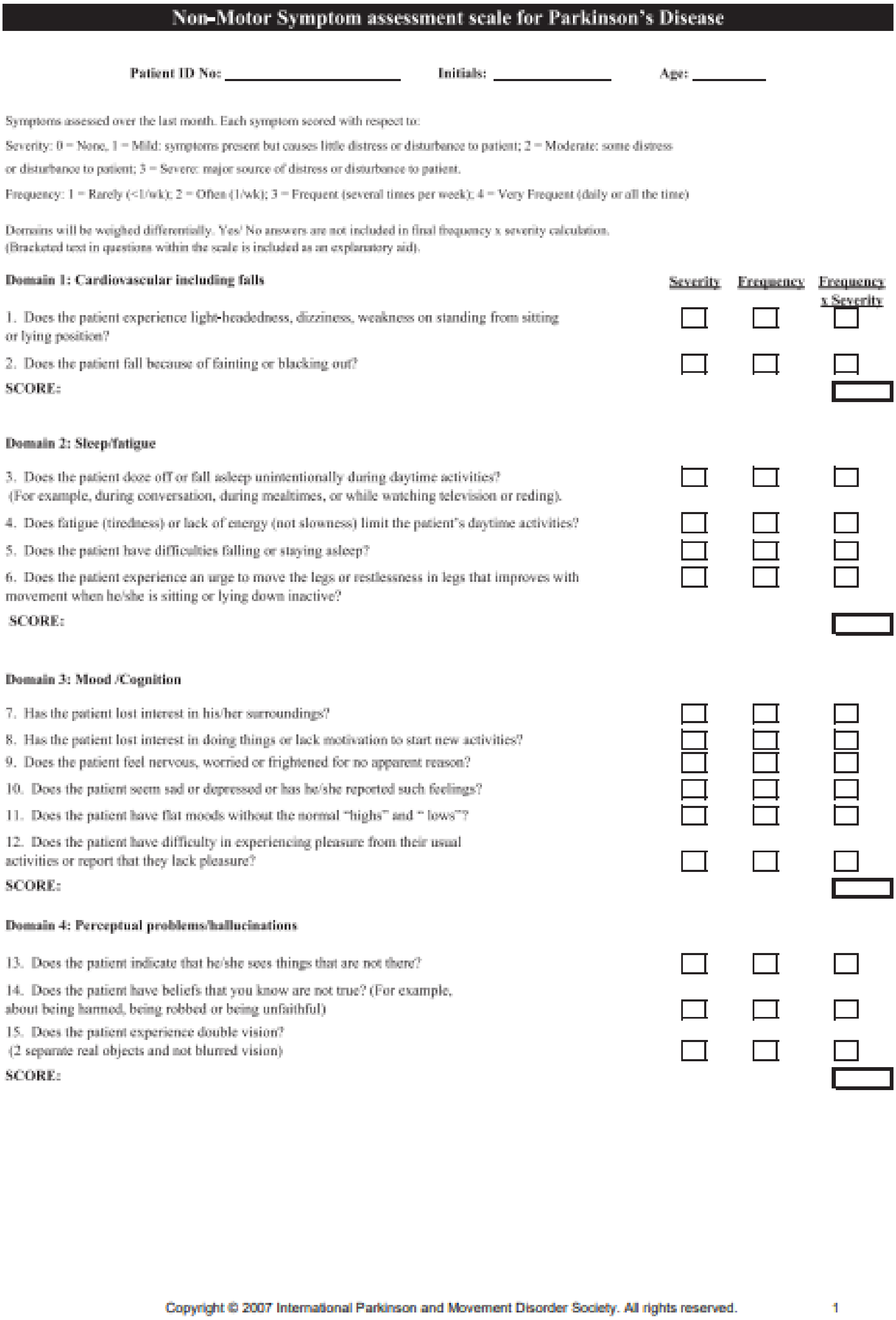
Signed: Date:

In case of emergency, please contact. Name:
Phone number:

Photographs: I give permission to my instructor and British Nordic Walking to use photographs taken of me in publications, advertisements, exhibitions, and the internet to illustrate their work and to promote Nordic Walking. This includes use on social media. Due to the nature of the internet, photographs may be shared across numerous channels. The photographs may also be loaned to approved third parties e.g., charitable partners, funders, and the media.
I agree to these conditions: Yes /No

Data Protection: This information will be stored securely by the instructor and will not be given to anyone else. You must notify your instructor of any changes in your personal data. Your email address will be used to notify you about Nordic Walking activities.
I agree to these conditions: Yes /No

## Appendix 9. NMSS Questionnaire.



### Non-Motor Symptom assessment scale for Parkinson's Disease

**Patient ID No:** ____________ **Initials:** ________ **Age:** _____

Symptoms assessed over the last month. Each symptom scored with respect to:

Severity: 0 = None, 1 = Mild: symptoms present but causes little distress or disturbance to patient; 2 = Moderate: some distress or disturbance to patient; 3 = Severe: major source of distress or disturbance to patient.

Frequency: 1 = Rarely (<1/wk); 2 = Often (1/wk); 3 = Frequent (several times per week); 4 = Very Frequent (daily or all the time)

Domains will be weighed differentially. Yes/ No answers are not included in final frequency x severity calculation.
(Bracketed text in questions within the scale is included as an explanatory aid).

| **Domain 1: Cardiovascular including falls** | Severity | Frequency | Frequency x Severity |
|---|---|---|---|
| 1. Does the patient experience light-headedness, dizziness, weakness on standing from sitting or lying position? | ☐ | ☐ | ☐ |
| 2. Does the patient fall because of fainting or blacking out? | ☐ | ☐ | ☐ |
| **SCORE:** | | | ☐ |
| **Domain 2: Sleep/fatigue** | | | |
| 3. Does the patient doze off or fall asleep unintentionally during daytime activities? (For example, during conversation, during mealtimes, or while watching television or reding). | ☐ | ☐ | ☐ |
| 4. Does fatigue (tiredness) or lack of energy (not slowness) limit the patient's daytime activities? | ☐ | ☐ | ☐ |
| 5. Does the patient have difficulties falling or staying asleep? | ☐ | ☐ | ☐ |
| 6. Does the patient experience an urge to move the legs or restlessness in legs that improves with movement when he/she is sitting or lying down inactive? | ☐ | ☐ | ☐ |
| **SCORE:** | | | ☐ |
| **Domain 3: Mood /Cognition** | | | |
| 7. Has the patient lost interest in his/her surroundings? | ☐ | ☐ | ☐ |
| 8. Has the patient lost interest in doing things or lack motivation to start new activities? | ☐ | ☐ | ☐ |
| 9. Does the patient feel nervous, worried or frightened for no apparent reason? | ☐ | ☐ | ☐ |
| 10. Does the patient seem sad or depressed or has he/she reported such feelings? | ☐ | ☐ | ☐ |
| 11. Does the patient have flat moods without the normal "highs" and " lows"? | ☐ | ☐ | ☐ |
| 12. Does the patient have difficulty in experiencing pleasure from their usual activities or report that they lack pleasure? | ☐ | ☐ | ☐ |
| **SCORE:** | | | ☐ |
| **Domain 4: Perceptual problems/hallucinations** | | | |
| 13. Does the patient indicate that he/she sees things that are not there? | ☐ | ☐ | ☐ |
| 14. Does the patient have beliefs that you know are not true? (For example, about being harmed, being robbed or being unfaithful) | ☐ | ☐ | ☐ |
| 15. Does the patient experience double vision? (2 separate real objects and not blurred vision) | ☐ | ☐ | ☐ |
| **SCORE:** | | | ☐ |

1

| | Severity | Frequency | Frequency x Severity |
|---|---|---|---|
| **Domain 5: Attention/ Memory** | | | |
| 16. Does the patient have problems sustaining concentration during activities? (For example, reading or having a conversation) | ☐ | ☐ | ☐ |
| 17. Does the patient forget things that he/she has been told a short time ago or events that happened in the last few days? | ☐ | ☐ | ☐ |
| 18. Does the patient forget to do things? (For example, take tablets or turn off domestic appliances?) | ☐ | ☐ | ☐ |
| **SCORE:** | | | ☐ |
| **Domain 6: Gastrointestinal tract** | | | |
| 19. Does the patient dribble saliva during the day? | ☐ | ☐ | ☐ |
| 20. Does the patient having difficulty swallowing? | ☐ | ☐ | ☐ |
| 21. Does the patient suffer from constipation? (Bowel action less than three times weekly) | ☐ | ☐ | ☐ |
| **SCORE:** | | | ☐ |
| **Domain 7: Urinary** | | | |
| 22. Does the patient have difficulty holding urine? (Urgency) | ☐ | ☐ | ☐ |
| 23. Does the patient have to void within 2 hours of last voiding? (Frequency) | ☐ | ☐ | ☐ |
| 24. Does the patient have to get up regularly at night to pass urine? (Nocturia) | ☐ | ☐ | ☐ |
| **SCORE:** | | | ☐ |
| **Domain 8: Sexual function** | | | |
| 25. Does the patient have altered interest in sex? (Very much increased or decreased, please underline) | ☐ | ☐ | ☐ |
| 26. Does the patient have problems having sex? | ☐ | ☐ | ☐ |
| **SCORE:** | | | ☐ |
| **Domain 9: Miscellaneous** | | | |
| 27. Does the patient suffer from pain not explained by other known conditions? (Is it related to intake of drugs and is it relieved by antiparkinson drugs?) | ☐ | ☐ | ☐ |
| 28. Does the patient report a change in ability to taste or smell? | ☐ | ☐ | ☐ |
| 29. Does the patient report a recent change in weight (not related to dieting)? | ☐ | ☐ | ☐ |
| 30. Does the patient experience excessive sweating? (not related to hot weather) | ☐ | ☐ | ☐ |
| **SCORE:** | | | ☐ |
| **TOTAL SCORE:** | | | ☐ |

Developed by the International Parkinson's Disease Non- Motor Group.

## Appendix 10. Written permission from Movement Disorders Society

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www.movementdisorders.org

International Parkinson and
Movement Disorder Society

July 9, 2021

Sarah McCracken
Nottingham CityCare
Community Neurology Team
The Meadows Health Centre
Nottingham, Nottinghamshire
NG2 2JG
United Kingdom
T: 0755 758 9080
E: sarah.mccracken1@nhs.net

**Re: Authorization to Use Materials Owned by the International Parkinson and Movement Disorder Society (MDS)**

Dear Ms. McCracken:

Thank you for your interest in the Non-Motor Symptoms Scale (“NMSS”). MDS grants permission for use of the NMSS in English within the study titled, “ NORDIC WALKING & PARKINSON'S DISEASE Increasing the accessibility of Nordic walking after the Covid-19 pandemic. Setting up a new Nordic walking service for people with Parkinson’s.” led by Professor Pip Logan and academic supervisor, Dr. Vicky Booth, acting as the lead Principal Investigators. This study is identified by the IRAS project ID: 302747. Since this is an academic study, there is no fee associated with this use.

By submitting your request to MDS, you agreed to the following:

I understand that the NMSS may only be used in paper format for the purposes described above. I also understand that reproduction, distribution, translation, or sale of any portion of the NMSS is strictly prohibited. Changes, modifications, adaptations, and derivative works of the NMSS are not permitted without the permission of MDS. Furthermore, the NMSS may not be incorporated into clinical trials, training materials, certification programs, software programs, electronic platforms or otherwise except through express authorization of MDS and payment of any applicable fees. Further, MDS shall have no liability related to use of the NMSS or any other MDS owned rating scale, and I hereby release, hold harmless, and indemnify MDS, its officers, directors, employees, volunteers, and agents, from any loss, damage, or claim based on such use.

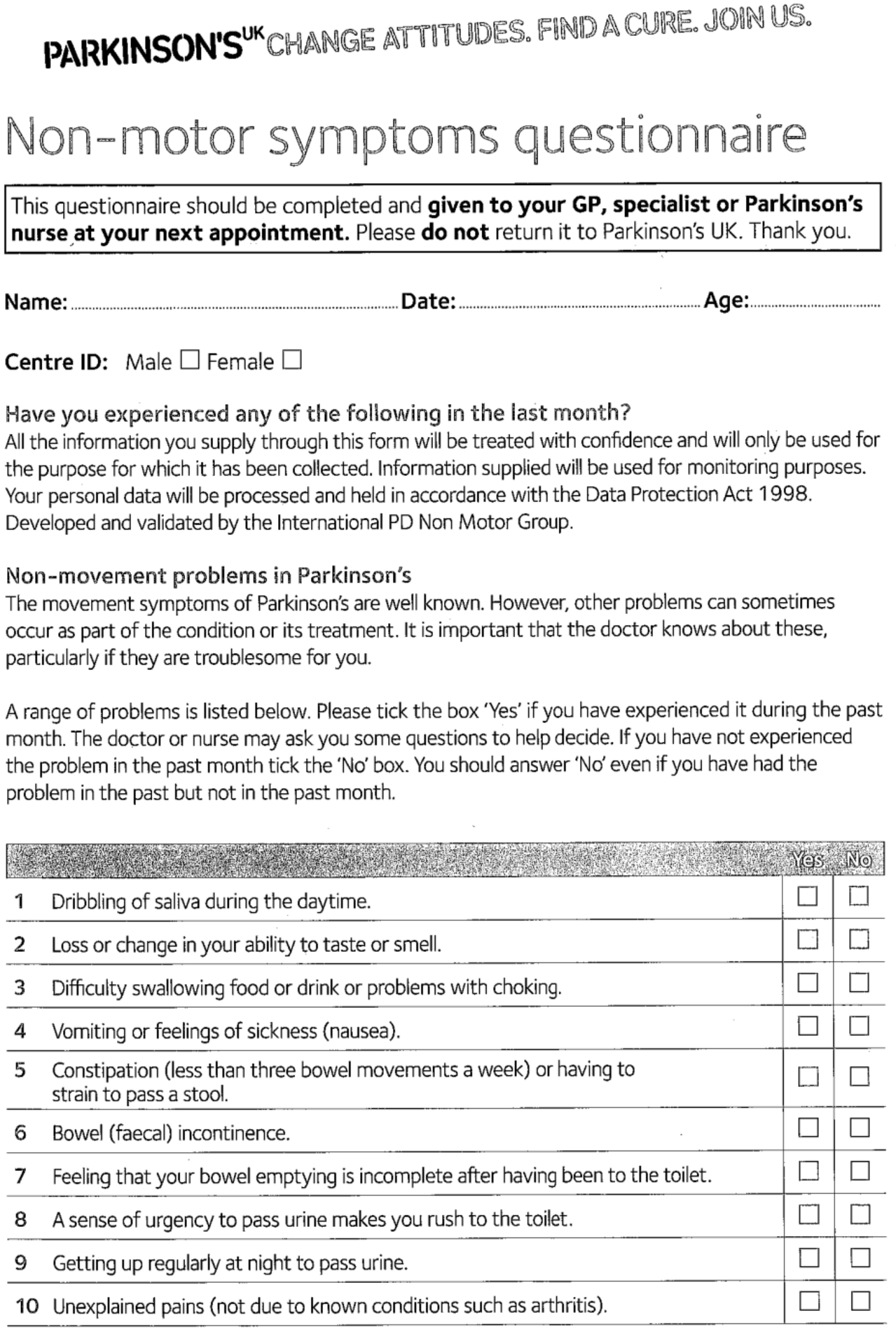
Please do not hesitate to contact me with any questions or concerns.

Sincerely,

Shazia Ali
Director of Scientific Programs
International Parkinson and Movement Disorder Society
ratingscales@movementdisorders.org

International Secretariat • 555 East Wells Street, Suite 1100 • Milwaukee, WI 53202-3823 USA • TEL: +1 414-276-2145 • FAX: +1 414-276-3349 • info@movementdisorders.org

**Appendix 11. NMQ Quest (30 NMS).**



**PARKINSON'S**UK CHANGE ATTITUDES. FIND A CURE. JOIN US.

# Non-motor symptoms questionnaire

This questionnaire should be completed and **given to your GP, specialist or Parkinson's nurse at your next appointment.** Please **do not** return it to Parkinson's UK. Thank you.

**Name:**.......................................................**Date:**...........................................**Age:**......................

**Centre ID:** Male ☐ Female ☐

## Have you experienced any of the following in the last month?

All the information you supply through this form will be treated with confidence and will only be used for the purpose for which it has been collected. Information supplied will be used for monitoring purposes. Your personal data will be processed and held in accordance with the Data Protection Act 1998. Developed and validated by the International PD Non Motor Group.

## Non-movement problems in Parkinson's

The movement symptoms of Parkinson's are well known. However, other problems can sometimes occur as part of the condition or its treatment. It is important that the doctor knows about these, particularly if they are troublesome for you.

A range of problems is listed below. Please tick the box 'Yes' if you have experienced it during the past month. The doctor or nurse may ask you some questions to help decide. If you have not experienced the problem in the past month tick the 'No' box. You should answer 'No' even if you have had the problem in the past but not in the past month.

| | | Yes | No |
|---|---|---|---|
| 1 | Dribbling of saliva during the daytime. | ☐ | ☐ |
| 2 | Loss or change in your ability to taste or smell. | ☐ | ☐ |
| 3 | Difficulty swallowing food or drink or problems with choking. | ☐ | ☐ |
| 4 | Vomiting or feelings of sickness (nausea). | ☐ | ☐ |
| 5 | Constipation (less than three bowel movements a week) or having to strain to pass a stool. | ☐ | ☐ |
| 6 | Bowel (faecal) incontinence. | ☐ | ☐ |
| 7 | Feeling that your bowel emptying is incomplete after having been to the toilet. | ☐ | ☐ |
| 8 | A sense of urgency to pass urine makes you rush to the toilet. | ☐ | ☐ |
| 9 | Getting up regularly at night to pass urine. | ☐ | ☐ |
| 10 | Unexplained pains (not due to known conditions such as arthritis). | ☐ | ☐ |

|  |  | Yes | No |
|---|---|---|---|
| 11 | Unexplained change in weight (not due to change in diet). | ☐ | ☐ |
| 12 | Problems remembering things that have happened recently or forgetting to do things. | ☐ | ☐ |
| 13 | Loss of interest in what is happening around you or in doing things. | ☐ | ☐ |
| 14 | Seeing or hearing things that you know or are told are not there. | ☐ | ☐ |
| 15 | Difficulty concentrating or staying focused. | ☐ | ☐ |
| 16 | Feeling sad, 'low' or 'blue'. | ☐ | ☐ |
| 17 | Feeling anxious, frightened or panicky. | ☐ | ☐ |
| 18 | Feeling less interested in sex or more interested in sex. | ☐ | ☐ |
| 19 | Finding it difficult to have sex when you try. | ☐ | ☐ |
| 20 | Feeling light-headed, dizzy or weak standing from sitting or lying. | ☐ | ☐ |
| 21 | Falling. | ☐ | ☐ |
| 22 | Finding it difficult to stay awake during activities such as working, driving or eating. | ☐ | ☐ |
| 23 | Difficulty getting to sleep at night or staying asleep at night. | ☐ | ☐ |
| 24 | Intense, vivid or frightening dreams. | ☐ | ☐ |
| 25 | Talking or moving about in your sleep, as if you are 'acting out' a dream. | ☐ | ☐ |
| 26 | Unpleasant sensations in your legs at night or while resting, and a feeling that you need to move. | ☐ | ☐ |
| 27 | Swelling of the legs. | ☐ | ☐ |
| 28 | Excessive sweating. | ☐ | ☐ |
| 29 | Double vision. | ☐ | ☐ |
| 30 | Believing things are happening to you that other people say are not. | ☐ | ☐ |

Chaudhuri KR, Martinez-Martin P, Schapira AHV, Stocchi F, Sethi K, Odin P et al (2006) 'An international multicentre pilot study of the the first comprehensive self-completed non motor symptoms questionnaire for Parkinson's disease: The NMSQuest study' *Mov Disord*; 21(7):916-923.

All the information you supply through this form will be treated with confidence and will only be used for the purpose for which it has been collected. Information supplied will be used for monitoring purposes. Your personal data will be processed and held in accordance with the Data Protection Act 1998. Developed and validated by the International PD Non Motor Group.

B117

**Appendix 12. FG Participant information sheet.**

**Study Title:** NORDIC WALKING & PARKINSON'S DISEASE

# What are the characteristics and core components needed to implement Nordic Walking groups for People with Parkinson's in a community rehabilitation setting?

## PARTICIPANT INFORMATION SHEET

Research Ethics Reference: FMHS 331-0821
Version 2.0 April 2022

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?

We are wanting to know more about how people participating in, and leading Nordic Walking groups, have found the experience. To do this we are conducting a series of focus group discussions with people with Parkinson's who have participated in a Nordic Walking group, instructors who have led them and the research team conducting this project.

The study aims to establish the characteristics and core components needed to implement Nordic Walking groups for People with Parkinson's in a community rehabilitation setting.

These focus groups will build upon an existing research project that is exploring the impact, accessibility, and diversity of Nordic Walking following Covid-19 lockdown, for people who have Parkinson's disease, of which you may already be a participant in.

### 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, have expressed an interest in Nordic Walking and are participating in the existing research project. You have either finished the eight-week programme of Nordic Walking classes or you are still taking part in the research project.

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 up to ten participants to the PD focus group (four to five people in each of the two groups) and three to five instructors or walk leaders.

## 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?

You will be invited to attend a single focus group in May 2022, either before or after your usual Nordic Walking class. You do not have to stay for the Nordic Walking if you are tired.

The focus group will meet at the Lakeside Arts Centre meeting room 1, University Park Campus, NG7 2RD (near the café). Refreshments will be provided. The focus group will be facilitated by an academic researcher or the research lead, Sarah McCracken.

The meeting will last for up to 90 minutes and there will be no further follow-up meetings anticipated. It will be a small group of four to six participants and two facilitators. The discussion will be audio-recorded and then transcribed.

If anything, sensitive, or of a personal nature, is disclosed during the focus group discussion, it will be kept confidential unless someone reveals something of concern that may put themself, or someone else, at any risk. It will then be necessary to report this to the appropriate persons.

Information discussed in the focus group may be sensitive and/or confidential. Participants are asked to respect other participant’s privacy and not to disclose what others have said in the focus group.

## What is Nordic Walking?

Nordic Walking is a total body workout utilising 90% of skeletal muscles. It is a version of walking that is performed with specially designed ‘sport’ walking poles like cross country ski poles. It focuses on large movements through the arms and legs and is superior to ‘just walking.’ It is 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?

No. The group discussion will be sensitively facilitated, and you will be invited to share your experience of Nordic Walking in a community rehabilitation setting.
You might be tired after a 90-minute discussion and so refreshments will be provided.

## 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.

There may be no direct benefit to taking part in the focus group, but you will be reimbursed for your travel expenses, and you will have refreshments, in a comfortable meeting room. Your contribution could help to shape Nordic Walking for Parkinson's in a community rehabilitation programme.

**Will my time/travel costs be reimbursed?**
Participants will not receive an inconvenience allowance to participate in the study, but Travel costs will be reimbursed for those who join the focus group. This will be up to £10 per participant.

**What happens to the data provided?**
The research data will be stored confidentially. Each participant will be allocated 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 seven 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 on-line 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.

Audio digital recordings and electronic data will be anonymised with a code as detailed above. Electronic storage devices will be encrypted while transferring and saving all the sensitive data generated during the research. All such data are kept on password protected databases sitting on a restricted access computer system.

Under UK Data Protection laws, the University is the Data Controller (legally responsible for the data security), and the Chief Investigator of this study (Dr Vicky Booth) 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 a 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 a nursing or medical journal and will be presented at health-related and/or Nordic Walking conferences. A report will be written for the National Rehabilitation Centre and Parkinson's UK which will be disseminated to clinical teams in the East Midlands. All participants will be anonymous within the report, and you will be sent a copy.

The research will be written up as a thesis. On successful submission of the thesis, it will be deposited both in print and on-line in the University archives, to facilitate its use in future research. The thesis will be published open access.

The research will be written up as dissertation for the degree of Master of Philosophy (MPhil).

**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 academic supervisors and the project team.

**Who is organising and funding the research?**
This study is being organised by Professor Pip Logan, Dr Vicky Booth and Dr Frances Allen through the University of Nottingham and partially funded by the National Rehabilitation Centre, National Institute for Health Research (NIHR) (through their Capacity Development Scheme), Nottingham CityCare partnership and 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. FMHS 331-0821.

**Contact Details**

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

Lead researcher: Sarah McCracken
Community Neurology Team
The Meadows health centre
1, Bridgeway Centre
The Meadows
Nottingham
NG7 2UH

Email (research): sarah.mccracken1@nottingham.ac.uk

## Appendix 13. FG Interview schedule (PwP)

**Title of Study**: What are the characteristics and core components needed to implement Nordic Walking groups for People with Parkinson's in a community rehabilitation setting?

1. Please tell us your name and why you decided to try Nordic Walking?

2. Did you have any difficulties attending the classes every week?

3. What are you enjoying about Nordic Walking?

4. Has COVID-19 been a consideration for you; before or during the Nordic Walking classes?

5. In what ways could the Nordic Walking classes be improved?

6. How do you feel about doing Nordic Walking outside, in a park?

7. What would help you to continue with Nordic Walking after you have completed eight sessions?

8. Is there anything else you want us to know about your experience of Nordic Walking?

## Appendix 14. FG Interview schedule (NWI/WL)

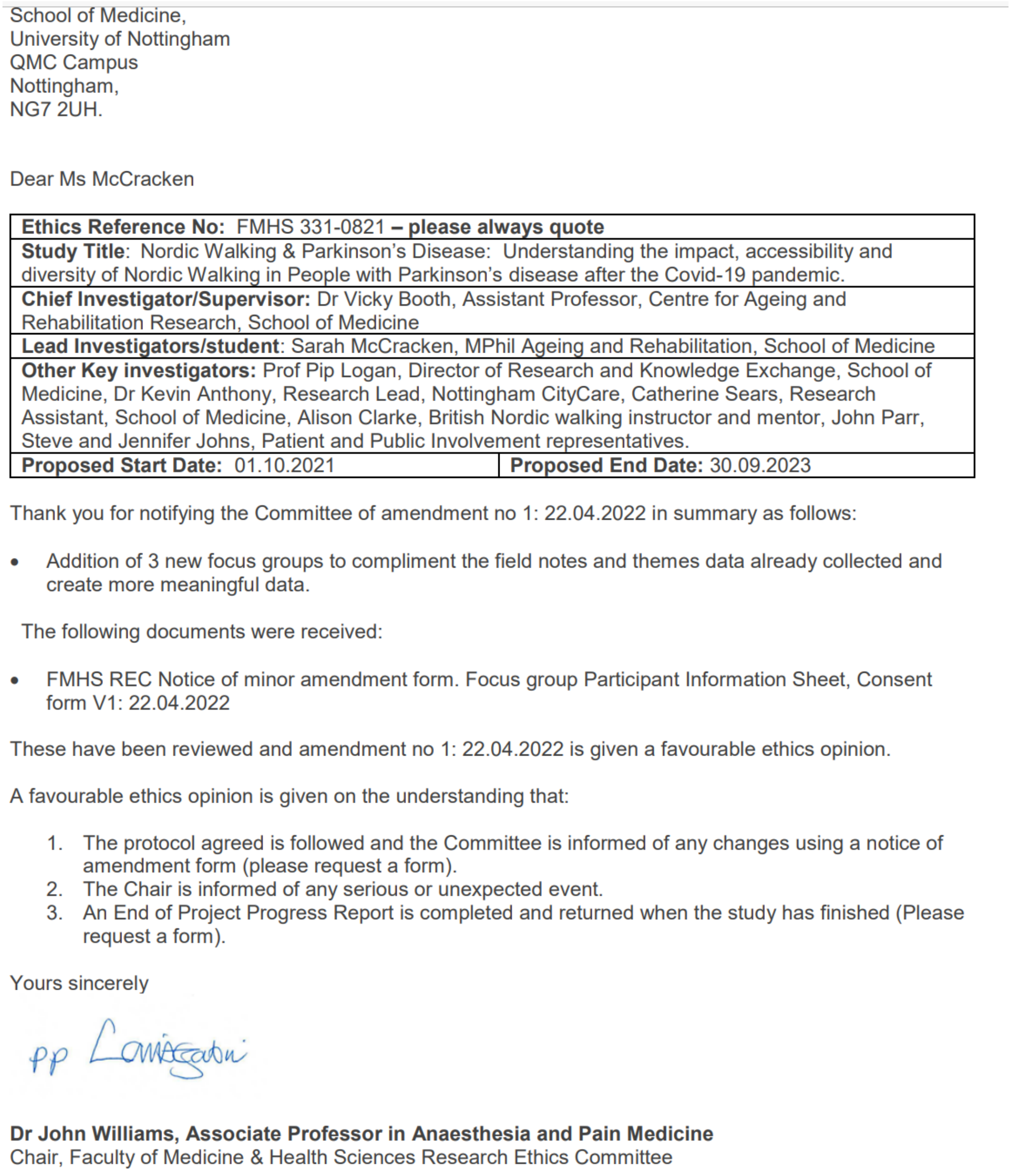
**Title of Study:** What are the characteristics and core components needed to implement Nordic Walking groups for People with Parkinson's in a community rehabilitation setting?

1. Please tell us your name and your role within the Nordic Walking research project.

How long have you been doing this?

2. What is your experience of Nordic Walking with People with Parkinson's Disease?
3. What are the challenges when working with People with PD?
4. Are there practical considerations when setting up NW classes for People with PD in a community rehab setting?
5. Do you have examples of PD classes that are mixed (non-PD or with a partner/spouse)?
6. What about different levels of fitness, or capacity, to learn a new skill?
7. Are there any specific qualities needed to be an instructor for People with Parkinson's?
8. How have you adapted your teaching or classes for People with PD?
9. Has Covid-19 been a consideration for you; before or during the Nordic Walking classes for People with PD?
10. Is there anything else you want us to know about your experience of Nordic Walking with People with Parkinson's?

## Appendix 15. Ethical approval letter (FG) May 2022



School of Medicine,
University of Nottingham
QMC Campus
Nottingham,
NG7 2UH.

Dear Ms McCracken

**Ethics Reference No:** FMHS 331-0821 **– please always quote**

**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.

**Chief Investigator/Supervisor:** Dr Vicky Booth, Assistant Professor, Centre for Ageing and Rehabilitation Research, School of Medicine

**Lead Investigators/student**: Sarah McCracken, MPhil Ageing and Rehabilitation, School of Medicine

**Other Key investigators:** Prof Pip Logan, Director of Research and Knowledge Exchange, School of Medicine, Dr Kevin Anthony, Research Lead, Nottingham CityCare, Catherine Sears, Research Assistant, School of Medicine, Alison Clarke, British Nordic walking instructor and mentor, John Parr, Steve and Jennifer Johns, Patient and Public Involvement representatives.

**Proposed Start Date:** 01.10.2021 | **Proposed End Date:** 30.09.2023

Thank you for notifying the Committee of amendment no 1: 22.04.2022 in summary as follows:

- Addition of 3 new focus groups to compliment the field notes and themes data already collected and create more meaningful data.

The following documents were received:

- FMHS REC Notice of minor amendment form. Focus group Participant Information Sheet, Consent form V1: 22.04.2022

These have been reviewed and amendment no 1: 22.04.2022 is given a favourable ethics opinion.

A favourable ethics opinion is given on the understanding that:

1. The protocol agreed is followed and the Committee is informed of any changes using a notice of amendment form (please request a form).
2. The Chair is informed of any serious or unexpected event.
3. An End of Project Progress Report is completed and returned when the study has finished (Please request a form).

Yours sincerely

pp

**Dr John Williams, Associate Professor in Anaesthesia and Pain Medicine**
Chair, Faculty of Medicine & Health Sciences Research Ethics Committee

**Appendix 16. Consent form FG study**

# Participants Consent Form

**Final version 1.0:08/04/2022 V (1)**

**Title of Study**: What are the characteristics and core components needed to implement Nordic Walking groups for People with Parkinson's in a community rehabilitation setting?
**REC ref:** FMHS 331-0821

**Name of Researchers**: Lead investigator: Sarah McCracken, Parkinson's Nurse Specialist. Chief Investigator/Supervisor: Dr Vicky Booth and Dr Frances Allen
Principal Investigator: Prof Pip Logan.

**Name of Participant:**

**Please initial box**

1. I confirm that I have read and understand the information sheet version number 1.0 dated 8/4/2022 for the above study which is attached and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without disadvantage. ☐
3. I understand that relevant sections of my data collected in the study may be looked at by the research group and by other responsible individuals for monitoring and audit purposes. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I understand that the Focus Group discussion will be audio recorded using an automated transcription service and that anonymous direct quotes from the interview may be used in the study reports. ☐
5. I understand that information about me recorded during the study will be made anonymous before it is stored in a secure database. Data will be kept for seven years after the study has ended and then deleted. ☐
6. I understand that what I say during the Focus Group discussion will be kept confidential unless I reveal something of concern that may put myself or someone else at any risk. It will then be necessary to report this to the appropriate persons. ☐
7. I understand that the information discussed in the Focus Group may be sensitive and is confidential. I agree to respect other participant's privacy and will not disclose what others have said in the Focus group. ☐
8. I agree to take part in the above study. ☐
9. Optional: I agree that my anonymous research data will be stored and used to support other research during and after seven years and shared with other researchers including those working outside the University. ☐
10. Optional: I agree to my contact details being stored for the purpose of being invited to participate in future research studies. ☐

| | | |
|---|---|---|
| ____________________ | ____________ | __________________ |
| Name of Participant | Date | Signature |
| ____________________ | ____________ | __________________ |
| Name of Person taking consent | Date | Signature |