2025

ActivPARK – Physical activity in persons with Parkinson's disease

DOCUMENT APPROVED BY THE ETHICS AUTHORITY IN SWEDEN 2025-02-05, DNR 2024-07526-01

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Introduction and aims

The long-term goal of this multicenter clinical cohort study (ActivPARK) is to maintain and enhance functioning, health, and wellbeing in persons with Parkinson's disease (PwPD) by tailored and personalized physical activity (PA) interventions. A prerequisite for designing a potent intervention is that we understand how PA is perceived and influenced. There is a critical need to develop a comprehensive understanding of predictive factors of PA in PwPD.

To achieve this goal, we need to enhance knowledge of the evolution of PA behavior with the diversity of patient profiles (characteristics, clinical and functioning outcomes) in different regions of Sweden. This will be achieved by establishing a longitudinal and multicenter cohort study.

The research idea for the multicenter cohort study is founded on the knowledge that remaining and engaging in health-enhancing activities while living with PD is crucial for maintaining and improving functioning, health, and wellbeing. The longitudinal nature of the study will further enable the identification of different target groups and phenotypes, as well as deriving interventions / targets to facilitate more contextually relevant care pathways and treatments.

The development and preparation phase are ongoing (see figure below for a methodological overview of all phases). We hereby apply for ethical approval for the **pilot phase**, to conduct a multi-center feasibility cohort study in Sweden, i.e., to inform and refine processes and scientific criteria for the definitive national longitudinal cohort study and for **the national study phase**, performing the full-scale clinical cohort study with a **qualitative sub study** using semi-structured interviews.

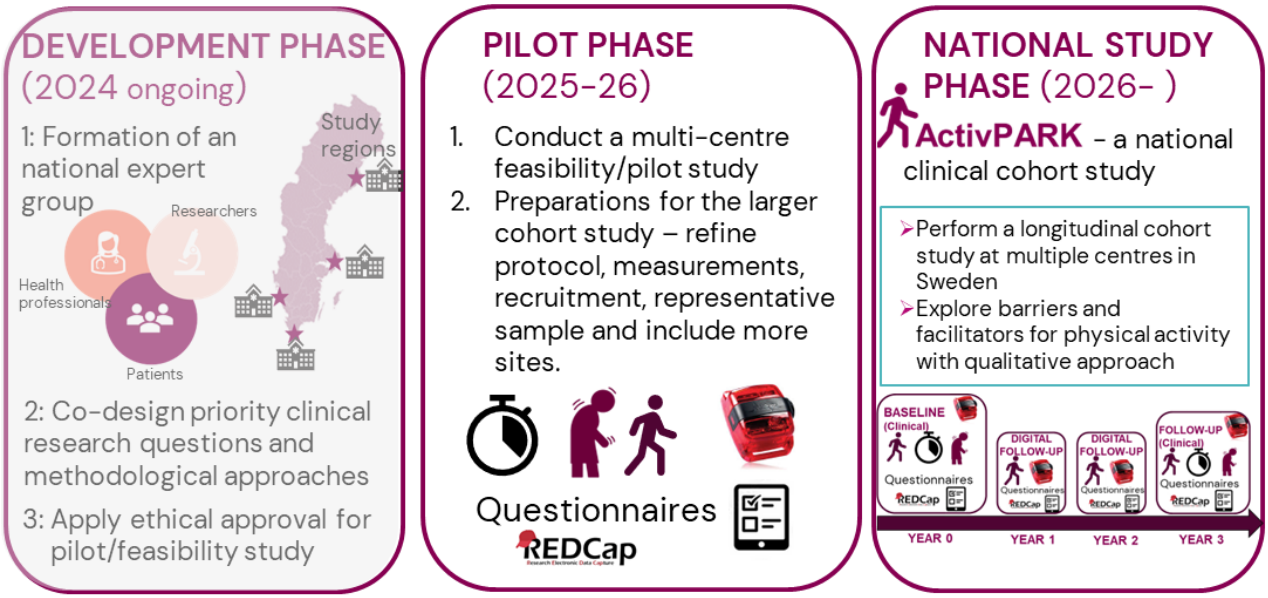


Figure 1. Phases and process of the project. Here we apply for the Pilot phase and the National study phase.

Specific aims

Pilot phase

- To explore process feasibility (i.e., determining recruitment rates, retention rates, representative sample, eligibility criteria, viability of assessment battery in multiple modes, coordination between multiple sites) and scientific feasibility (i.e., safety and sample diversity and representativity).

National cohort phase

- To describe physical activity levels and sedentary behavior in people with Parkinsons disease.
- To identify risk factors of physical inactivity and sedentary behavior in PwPD.
- To explore changes and identify predictors of changes in PA and sedentary behavior in PwPD across Sweden.
- To describe and explore experiences of physical activity and every day activities as well as perceptions of facilitators and barriers for being physically active with PD (qualitative sub study).

Research questions

- How feasible is the ActivPARK study regarding assessments and study procedure/design, as well as sample diversity and representativity.
- How physically active are PwPD in different stages of the disease, or with different phenotypes.
- What factors are associated with physical activity level (including different intensity levels), inactivity, and sedentary behavior (cross-sectional and longitudinal) in people with Parkinson's disease?
- What factors influence inactivity and sedentary behavior in people with Parkinson's disease?
- How does the level of physical activity and sedentary behavior change over time in PwPD? Does this differ in relation to different PD-subtypes?
- What factors can predict that people with Parkinson's disease will become inactive and more sedentary?
- How do people with Parkinson's disease describe and experience physical activity in daily life?
- What do people with Parkinson's perceive as facilitators and barriers for being physically active?

Background

Parkinson's disease (PD) is globally one of the leading neurodegenerative health conditions, where a doubled prevalence is projected [1]. PD is a neurodegenerative disease characterized by both motor (slowness of movement, tremor, rigidity, and impaired balance) and non-motor symptoms (cognition, sleep, depression, and anxiety), that influence engagement in PA. The benefits of exercise and PA for PwPD are strongly supported in the literature [2]. PwPD have much to gain from engaging in a physically active lifestyle in terms of managing and potentially modifying symptom progression [3]. Despite the proven benefits of PA, PwPD are generally less physically active than healthy people of similar age [4]. Physical inactivity is seen early in the disease course and likely declines prior to clinically visible motor symptoms [5]. Early detection of reduced PA might be critical for preventing physical decline and secondary diseases/symptoms such as cardiovascular disease, falls or pain in PwPD [6].

Another critical reason why we still lack a good understanding of PD and effective treatment lies in the heterogeneity and complexity of the disease. Even though the evidence of individual clinical heterogeneity increases, different subtypes of PD remain insufficiently investigated in relation to PA. Our group recently provided novel insights into three distinct PA profiles (Sedentary, Light Movers, and Steady Movers) in PwPD [7, 8], se figure 2. "Sedentary" included PwPD with greater time spent in sedentary behavior, little time in light intensity physical activity (LIPA), and negligible time in moderate-to-vigorous physical activity (MVPA). "Light Movers" were PwPD with values close to the mean for all activity variables. "Steady Movers" spent less time in sedentary behavior during midday, and more time in LIPA and MVPA throughout the day, compared to the other profiles. "Sedentary" people were characterized by poorer balance and functional mobility and were more likely to have fallen

previously. However, the robustness of these subtypes over time with disease progression is unknown. We also lack knowledge of predictive factors for developing a sedentary lifestyle.

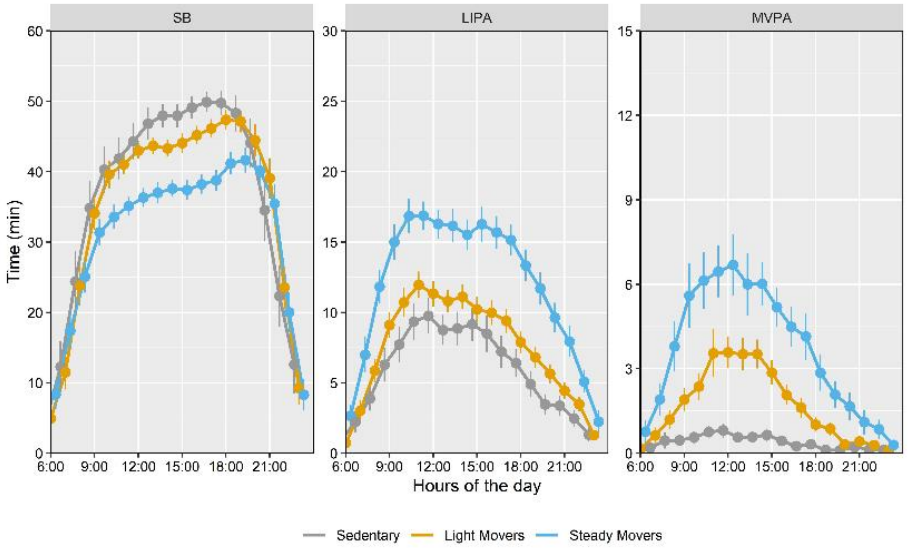


Figure 2. Illustration of PA-subtypes in PwPD.

PA and exercise interventions have been found to be effective as symptomatic treatment and potentially slowing the progression of the disease [6, 9, 10]. Despite this, high-quality clinical PD-cohort databases that includes PA is lacking, and PA-data is unavailable in any existing health registry in Sweden (including the National PD Patient Registry, PARKreg).

Activity sensors (accelerometers) have revolutionized the measurement of PA in everyday life and proved valid in PwPD [11, 12]. However, international health registers still rely on self-reported PA data [13], which has limited validity due to re-call bias and conceptual or cultural differences in PA related definitions. In relation to prediction of PA behavior, most prior studies used limited explanatory models, often restricted to disease-characteristics and clinically derived physical functioning data. Few efforts have been made to explore multi-domain measurements longitudinally including contextual factors [14, 15] (e.g., personal factors such as preferences, habits, motivation, and environmental factors) to better understand how PA should be targeted to enhance health and wellbeing in PwPD. Furthermore, knowledge of the interplay between health care utilization (including pharmacological and non-pharmacological interventions) and PA status among PwPD is limited. This “black box” concerning conceptual understanding of PA in PwPD hinders the development of tailored and person-centered interventions to be the primary impetus for enhancing functioning. It is therefore necessary to deepen the contextual knowledge and fill this knowledge gap about PA using a **multicenter clinical cohort study.** This, to examine the burden, determine influential factors on PA, categorize the modifiability of factors, and determine intervention targets for future clinical trials and implementation.

Preliminary and previous results

During the last 10 years, our group has extensively explored PA and exercise in PwPD, including using neuroimaging methods to relate behavioral changes to brain structure and function. We have described PA levels and patterns as well as identified different subtypes of PA patterns in PwPD [4, 8]. Further, we have proposed and validated cut-offs for different

levels of PA and investigated immediate and long-term responses to exercise interventions in rigorous clinical trials [11, 16-18]. Recently, we described and compared PA and health in PwPD during the pandemic [19]. This brought us insights into the need to contribute to the literature gap on longitudinal studies measuring objective PA patterns and influential factors in PwPD.

During 2024, we have worked with planning and developing the ActivPARK project in a development phase (see figure 1) with consensus iterations for final recommendations. A national, multistakeholder expert / steering group was formed. The group identified key initial recommendations on “what” should be evaluated in reference to PA, “how” it should be measured, as well as “where” and “when”. This was done by using the nominal group techniques as underlying methodology. The nominal group technique utilizes both qualitative and quantitative methodologies, and its highly structured discussions helps to generate views and experiences from a wide range of participants [20]. The feasibility of the key decisions will subsequently be tested in the pilot phase.

Methods

Study design

The ActivPARK study is a large multicenter study with open cohort design with several sites across Sweden (e.g., Lund/Malmö, Umeå, Göteborg, Stockholm). This project is designed in a resource effective way with follow-ups on distance and by using digital questionnaires/assessments. We will initiate with a pilot study investigating feasibility components for the larger multicenter study evaluating such as recruitment rates, the diversity of the population, outcome measures and coordination of sites. The larger cohort study will also include a cross-sectional qualitative sub study using individual semi-structured interviews to gain deeper understanding of the barriers and facilitators to physical activity in PwPD.

Participants and recruitment

PwPD will be recruited through advertisement, other research studies, patient organizations and our established collaboration with clinical sites (hospitals, rehabilitation clinics and primary care facilities). We will include participants diagnosed with PD with mild to severe severity (Hoehn & Yahr 1-4). However, we will screen for people with speech or cognitive difficulties that affect the ability to understand and follow verbal/written instructions to highlight this specific subset which would otherwise require more intense health and social care services. We anticipate that they will be a small part of the cohort and will adapt the core set to be able to include them as well.

Testing procedure

- Baseline measurements will consist of a clinical visit and questionnaires sent out via REDCap.
- Follow-up measurements will be performed in years 1 and 2 through telephone interviews, questionnaires via REDCap and an accelerometer will be sent to each participant and returned using pre-stamped envelopes.
- In year 3, the participants will be invited for a clinical visit, be asked to wear an accelerometer for a week as well as questionnaires via REDCap.

Main outcome

PA as a multidimensional behavior can inform about health and well-being of PwPD. The ActiGraph accelerometer (GT3X+, ActiGraph, Pensacola, FL, US) will be used to measure absolute and relative time spent in sedentary behavior, LIPA, and MVPA, by total time in bouts or through variation over a day. We will assess PA with accelerometers both at the baseline visit and all of the follow-up assessments. The participants will be instructed to wear

the accelerometer on the hip for seven consecutive days, which provides ecologically valid measured PA. Our research group has previously developed disease-sensitive cut-off points for intensity classification of PA in PwPD [11] as well as a used a similar a protocol for remote assessment in the home environment [19].

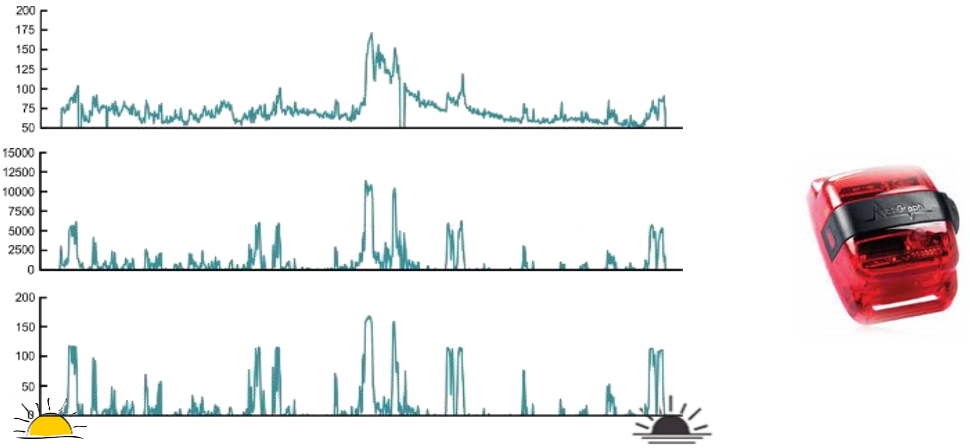


Figure 3. Example of the ActiGraph accelerometer and its output.

Explanatory variables
The findings from the national steering group's initial recommendations on explanatory models / factors to consider for PA will be included. Apart from disease-related variables (including motor symptoms), the national study group prioritized the following: psychological factors (e.g., preferences and motivation for PA and exercise, previous activity habits, apathy), as well as contextual factors, (i.e., the physical built, social, and attitudinal environment), and resources in the evaluation of exposures across the various settings across Sweden. For some of these explanatory factors, no standardized measures were available and therefore new proposed items and questions were developed; these will be further tested in the pilot study. More traditional PD-measures will also be included, which for example cover disease- and symptom severity and the presence of nonmotor symptoms, PD medications and other treatments. Moreover, gait velocity, balance and walking ability will also be assessed.

Specifically, standardized questions will be used to collect information on personal factors (e.g. sex, age, length, weight, other diseases/comorbidities, educational level, socioeconomic status/income medical history, and fall history) and environmental factors (e.g. living situation, education, employment status, support resource in daily life and use of assistive devices). Questions on PD medications, health care utilization (rehab/hospital visits, health care contacts), other PD treatments as well as questions of PA history and current PA-level will be asked either through REDCap, over phone or at the clinical visit.

The **clinical visit** will take approximately 1 to 1.5 hour and constitutes the Movement Disorders Society - Unified Parkinson's Disease Rating scale (MDS-UPDRS [21] including the Hoeh & Yahr stages [22]), assessment of balance (Mini-BESTest including the Timed up and Go test [23, 24]), gait (10 meter walking test or gait analysis) and cognitive function (Montreal Cognitive Assessment, MoCA [25]). At the clinical visit, they will also be instructed how to wear an accelerometer for seven days in their home environment.

Some of the clinical assessments are prioritized lower and will only be assessed if equipment is available at the sites and if the PwPD has time and energy. The assessment with lower priority are, assessment of cognitive function with the Ray Auditory Verbal Learning test (RAVLT [26]), and pain with Kings Parkinsons Pain Scale (KPPS [27]). Optional and where equipment is available are measurement of body composition with Bioelectrical Impedance Analysis (BIA) as well as the addition of gait analysis (assessing cadence, velocity and step time) to the gait assessment using either a pressure sensitive walkway (GAITRite, CIR Systems, Inc) or wireless inertial sensors (Opal, APDM Inc) positioned on trunk, low back, wrists and ankles. These sensors are light-weighted; similar to a regular watch. Some sites will also use these sensors while assessing mobility (i.e., Timed Up & Go test).

Clinical visit

Area of assessment	Measurement
Motor symptoms	MDS- UPDRS part 3-4
Non-motor symptoms	MDS- UPDRS part 1a
Physical activity	Accelerometer to wear for next seven days
Gait	10-meter walk test or *gait analysis*
Balance	Mini-BESTest, Timed Up and Go
Cognition	Montreal Cognitive Assessment (MoCA), *Rey-Auditory Verbal Learning Test (RAVLT)*
Pain	*Kings Parkinsons Pain Scale (KPPS)*
Body composition	*Bioelectrical Impedance Analysis (BIA)*

Italic denotes lower prioritized measurements

Questionnaires will be administered digitally via REDCap and cover physical activity level (Frändin Grimby scale[28]), non-motor symptoms (Non-Motor Symptoms Questionnaire items, NMSQ[29, 30]), depression and anxiety (Hospital Anxiety and Depression Scale, HADS [31]), Walking ability (WALK-12G [32] and Freezing of gait questionnaire, FOGQsa [33]), balance confidence (Activities specific balance confidence, ABC scale[34]), motivation (Behavioural Regulation In Exercise Questionnaire, BREQ 4), disability (World health organization (WHO) disability assessment schedule, Whodas 2.0 [35]), executive functioning (Executive function questionnaire, DEX[36]), fatigue (Parkinson's Fatigue Scale, PFS[37, 38]), self-efficacy (Self-efficacy of exercise/PA, ESES[39]), nutrition (parts of Mini Nutritional Assessment (MNA[40]) score and questions about protein intake, changes in weight, dysphagia), sleep (Scales for Outcomes in Parkinson's disease – Sleep, SCOPA-SLEEP[41]), Wellbeing (The WHO- Five Well-Being Index (WHO-5)[42])and Quality of life (Parkinson's Disease Questionnaire, PDQ-39 [43]).

We estimate that all the questionnaires take approximately 1.5 h fill in therefore they will be administered at two or three different occasions/emails (approx. 30 min each) adjacent to the clinical visit to reduce fatigue filling in the forms. We will also evaluate the feasibility of all these questionnaires during the pilot phase and most likely reduce the battery for the larger cohort study.

Questionnaires via REDCap

Area of assessment	Measurement
Physical activity	Frändin Grimby Scale
Non-motor symptoms	Non-Motor Symptoms Questionnaire (NMSQ), MDS-UPDRS part 1b
Anxiety and depression	Hospital Anxiety and Depression Scale (HADS)
Gait	WALK-12G questionnaire, Freezing of gait questionnaire (FOGQsa)
Balance	Activities specific balance confidence (ABC scale)
Motivation	Behavioural Regulation in Exercise Questionnaire (BREQ 4)
ADL	MDS-UPDRS part 2
Disability	*World health organization (WHO) disability assessment schedule (Whodas 2.0)*
Cognition, executive function	Executive function questionnaire (DEX)
Fatigue	Parkinson's Fatigue Scale (PFS-16)

Self-efficacy	Self-efficacy of exercise/PA (ESES)
Nutrition	Mini Nutritional Assessment, questions on protein intake, weight and dysphagia
Sleep	Scales for Outcomes in Parkinson's disease – Sleep (SCOPA-SLEEP)
Pain	Visal analog scale VAS (0-100)
Wellbeing	*The WHO- Five Well-Being Index (WHO-5)*
Quality of life	*Parkinson's Disease Questionnaire (PDQ39)*

Italic denotes lower prioritized questionnaires

Pilot (feasibility) phase
The pilot/feasibility study aims to evaluate recruitment rates and whether a diverse and representative population can reasonably be enrolled, as a success factor in the larger cohort study. To ensure that the proposed multicenter cohort study can be scaled to four regions of Sweden, this pilot phase aims to conduct feasibility study in at least two of the sites to specifically evaluate and achieve process and scientific feasibility for the definitive longitudinal cohort study. We will here specifically address process feasibility (i.e., determining recruitment rates, retention rates, viability of assessment battery in multiple modes, coordination between multiple sites) and scientific feasibility (i.e., safety and population diversity and representation as well as explore associations that might be worth following up in the larger study).

As stated under participants, we will include PwPD diagnosed with mild to severe severity (H&Y1-4). The pilot study will also inform if we need additional exclusion criteria such as cognitive difficulties that affect the ability to understand and follow verbal/written instructions or adaptations in the core set to be able to include a diverse group of people with PD.

Sample size: We plan to include approx. 50 PwPD (10% of the total cohort) recruited from at least 2 sites, preferably more to test coordination and feasibility aspects in the different sites. We estimate this to be representative of the target study population and also large enough to provide useful information about the aspects that are being assessed for feasibility [44].

Analysis: Descriptive statistics will be used to determine feasibility criteria such as recruitment rates, retention rates, eligibility criteria, sample PA means as well as characteristics of the study samples.

National cohort phase
This phase consists of the main study, a large multicenter study with open cohort design across Sweden. Participants diagnosed with PD with mild to severe disease severity (H&Y1-4) will be recruited from four different geographical sites in Sweden (i.e., Lund/Malmö, Umeå, Göteborg, Stockholm), which differ in terms of population density, rurality (urban vs. rural), physical, social, and attitudinal features of the environment.

We propose four data collection points in the future national cohort study, specifically at baseline (in-person clinical evaluation + digital questionnaires + accelerometers in home), one-year follow-up (digital questionnaires + accelerometers in home), 2-years follow-up (digital questionnaires + accelerometers in home), and, finally, 3-years follow-up (in-person clinical evaluation + digital questionnaires + accelerometers in home), see time plan below. We are anticipating that we will only make minor changes to the design and test battery after the pilot phase and therefore plan for an internal pilot incorporating the pilot subjects into the larger cohort study at the one-year follow-up.

Sample size: A study conducted in Sweden involving patients with Parkinson's disease reported that the prevalence of decline in physical activity after one year of follow-up is approximately 16% (reference [45]). This study was conducted during the COVID-19 pandemic (first and third waves). Therefore, we estimate that the prevalence of decline in this cohort may be slightly lower, as the pandemic did not significantly affect the Swedish

population's physical activity levels. We expect the proportion of decline in physical activity in this cohort to be 10% per year, as it includes people with Parkinson's disease at various disease stages and ages.
Sample size calculations were performed using a one-sample proportion test, two-sided, in STATA 18. We assume a decline rate of 20% after two years follow-up and an alternative proportion of 26% (16% + 10%), with a power of 80% and a significance level (alpha) of 0.05. With an estimated 20% drop-off that would result in 478 participants. Hence, we anticipate including 500 patients of different disease stages and ages.

Analysis: Baseline assessments of PA and exposures will be used to identify potential risk factors for PA behavior, i.e. volume and intensity. Following on, all risk factors - more specifically those “unexposed” for some participants at baseline - will be analyzed to observe if their (exposures) emergence impacted the outcome of interest. Using multivariate/multi-level modelling/ or LASSO regressions will allow for the identification of clusters of predictors as these were prospectively and longitudinally identified. The Biostatistics Core Facility at KI has been involved in the power analysis and will be involved in analysis of data.

Qualitative interviews (sub study)
To more deeply describe physical activity and everyday activities and explore the barriers and facilitators of physical activity among PwPD, we will perform semi-structured interviews which are the most widely used interviewing format for qualitative research. The interviews will be organized around a set of predetermined open-ended questions, with additional questions and discussion points emerging from the dialogue [46]. We will strive for diversity and recruit participants from all sites and hold interviews digitally (Zoom/Teams) or at a preferred location (home or clinic) if possible and expect that each session will take approximately 1 to 1.5 hours. The sessions will be audio recorded. The interviewer will be prepared to tailor the interview questions and communication style to the patients’ capabilities, and in case of cognitive impairment, to adopt strategies suggested to optimize communication with patients with cognitive deficits [47].
Sample size: For the qualitative sub study, study participants will be consecutively included using a varied sampling method until data saturation is reached. We here anticipate a sample of 15-20 PwPD to reach saturation in accordance with previous literature [48].
Analysis: The interview transcripts will be systematically analyzed using standard procedures for qualitative content analysis according to published guidelines. More specifically, we will use thematic qualitative content analysis - a replicable and valid method for text data analysis. During data analysis the research team will mainly strive for an inductive approach to category development, by allowing categories to emerge from the data [49, 50].

National study group

The already established national expert group consists of **Academics and health care professionals** with diverse experience in clinical therapy service delivery and research of the PD population from several regions in Sweden. This group covers different ages, experiences, four regions as well as several disciplines and professions. Most have joint positions between health care and academia facilitating implementation.

The sites responsible are professor **Erika Franzén** (PI) from Karolinska Institute (KI) and Karolinska University Hospital (K), Stockholm, associate professor **Maria H Nilsson**, at Lund University and the Memory Clinic, Department of Neurology, Rehabilitation Medicine, Skåne University Hospital, Skåne County Council, professor **Filip Bergquist** University of Gothenburg and University Hospital Senior Consultant at the Neurology clinic at Sahlgrenska Academy, Västra Götaland County Council and postdoc **Gudrun Johansson** Department of Community Medicine and Rehabilitation at Umeå University and

physiotherapist at the Neuro- and Stroke rehabilitation clinic at University Hospital of Umeå, County Council of Västerbotten.

The group also includes **Conran Joseph**, associate professor at Stellenbosch University, South Africa; expert in epidemiologic designs in neurological disorders**, Susanne Guidetti**, professor/ occupational therapist, **Peter Hagell**, professor/nurse, **David Moulaee Conradsson** associate professor/physiotherapist, **Maria Hagströmer** professor/ physiotherapist, **Urban Ekman**, associate professor/psychologist, **Franziska Albrecht** assistant professor/neurobiologist and **Gerd Faxén-Irving**, PhD/Docent and dietician as well as other clinicians at the four sites and not least **people with PD** and representative from the **Swedish Parkinson Association** (Parkinsonförbundet).

Ethical considerations

The testing procedure will not include any additional risks compared to regular clinical assessments as most of the clinical tests and questionnaires included in this proposal are part of regular clinical assessments of PwPD. However, there might be a risk of responder burden due to the extensive questionnaires and therefore this will be an important feasibility factor in the pilot phase.

While testing gait and balance in populations with impaired balance (e.g. PD) or older adults there is always a risk of instability and falls. Therefore, participants will not be asked to walk faster than they are comfortable with, and the test leader will be positioned close to the participants during all testing to prevent them from falling in case of a trip or slip. If needed, participants with more severe balance impairments will be equipped with a safety belt to ensure further safety. Consideration for fatigue during testing has been made and breaks in the protocol have been set up.

The instruments used to measure physical activity (accelerometer) are non-invasive methods without any documented associated risks for the individual. Furthermore, the size of the accelerometer is similar to a normal wristwatch and will not interfere with the ability of the participant to perform daily activities.

All data will be analyzed on a group level, and all data will be pseudonymized; the code key to connect individual with data will be kept secured and encrypted. Data will be stored as paper and digitally in accordance with regulations of public authority archives and the General Data Protection Regulation.

Significance and clinical relevance

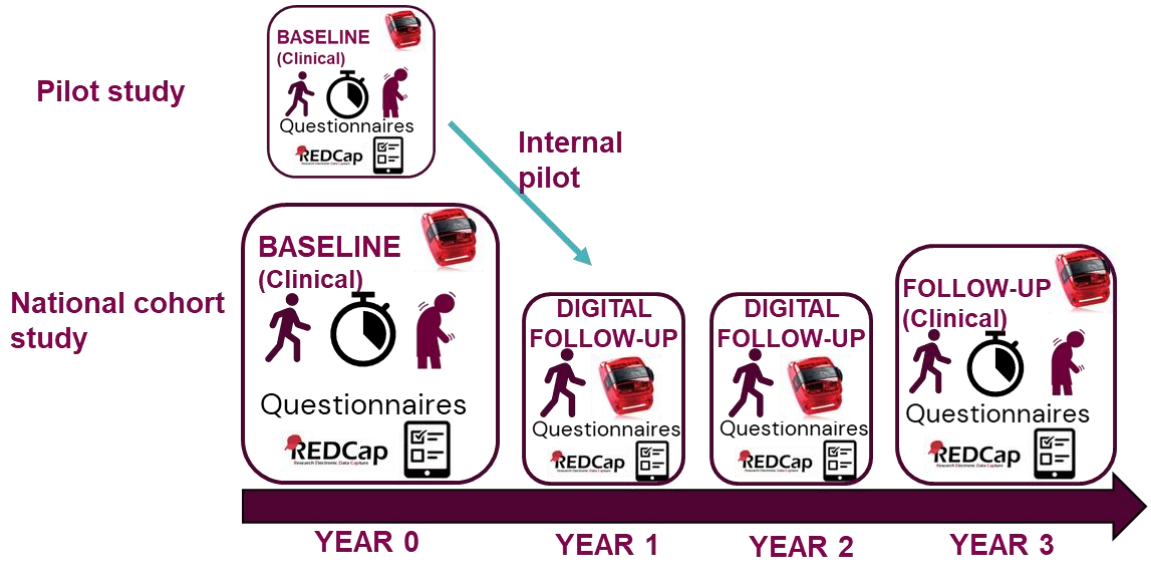
This project includes people with PD and non-profit organisations in the design, development, and implementation of the pilot/feasibility and future national cohort study. Importantly, end users and PD organisations are active members of the already established national steering committee for this project; they have engaged in several workshops and decision-making processes (voting) since the inception. End users are seen as equal partners with experiential knowledge and lived experiences, which is invaluable in ensuring that societal questions of high priority are pursued.
The clinical relevance of this project is in understanding how PA evolve and how it is influenced, in a diverse and representative group of PwPD across Sweden. This includes the role of contextual factors which is difficult to capture comprehensively. Developing a more holistic explanatory framework for PA in Sweden can help unravel unique intervention components to be targeted in future clinical therapy trials.

This project has the potential of improving our understanding of PA and subtypes in PwPD, enabling more person-centered interventions and prevention strategies, and thereby using the health care system more effectively. This work could also inform the importance of PA as

an essential factor in screening and support in the diagnosis of PD, especially early onset PD and further strengthen the multidisciplinary management of PD.

Time plan

The pilot study will start during spring 2025 with setting up the sites, educating the data assessors/physical therapists as well as setting up routines for measurements, data management, storing and communication. Thereafter the data collection will begin, and sites will join in when ready for collecting data. The pilot will run during 2025 and 2026, and we will continuously follow the feasibility and adapt minor changes to the protocol, design and coordination. If there are no major changes, we will conduct an internal pilot and integrate the pilot subjects into the follow-up assessments of the larger study. The national cohort study will most likely go on until 2032 depending on the sample size and recruiting rates. The qualitative sub study will be performed during 2026 and 2027.



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