

PARTICIPANT INFORMATION SHEET

Version 1.5. Completed 21/08/2024.

Before seeking consent, the researcher should read through the information sheet with the participant to ensure they have understood all points.

1. Research Project Title

Investigating Differences in Biomechanics and Muscular Activity During Activities of Daily Living In People With Parkinson's Disease (With and Without Freezing of Gait).

2. Why have I been chosen?

Freezing of gait typically occurs in advanced Parkinson's Disease, however, our knowledge is limited. You have volunteered to participate in this research project to aid in gaining stronger understanding of this common symptom of Parkinson's Disease, freezing of gait.

3. Purposes of the research

This study will look at how you walk, and we will make a comparison between people with Parkinson's Disease, with and without freezing of gait. You will be asked to perform everyday tasks, such as walking, turning and sitting, so that we can understand how your everyday lives are affected.

4. Expected duration of the subject's participation

Parkinson's cohort: 2-visits (2 hours per visit, approx. 4-hours total). Healthy cohort: 1-visit (approx. 90 minutes).

5. Can I participate?

- If you have Parkinson's Disease (Hoehn and Yahr Stage II/III) then you are eligible to participate in this study.
- If you are an adult without Parkinson's Disease (over 40), then you are eligible to participate in this study.
- If you have any injuries that may affect your ability to walk and move normally, for example, injuries in the hips, knees, ankles, spine, and neck, please contact lead researcher Lewis Ball (lrb33@kent.ac.uk).
- If you have any neurological or physical dysfunctions (other than those associated with Parkinson's Disease). Examples of conditions that may exclude you from this study are strokes, osteoporosis, arthritis, etc. Please contact lead researcher Lewis Ball (lrb33@kent.ac.uk) to check eligibility.
- If you have any questions regarding your eligibility, please contact Lewis Ball (PhD Researcher) lrb33@kent.ac.uk.

6. What do I have to do?

Pre-visit

- Let us know if you have any injuries or dysfunctions (not related to Parkinson's Disease)
- Email us at lrb33@kent.ac.uk.

Testing

- You can consume water normally.
- You not eaten for two hours prior to arrival to the lab (Parkinson's patients ONLY)
- Free from illness, infection, or injury for the two weeks prior to testing.
- **Please wear skin-tight shorts and a tight-fitting t-shirt with no reflective features.** If you do not have the above, we can provide you with the appropriate clothing when you visit the lab.
- Parkinson's participants will be asked to withdraw from their medication for 12h before testing, and after one trial we will then ask you to take your medication before conducting the same protocols.

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Symptoms that MAY be experienced from short-term dopaminergic medication withdrawal:

- Tremor, walking/balance impairment, slowness of movement, urinary urgency, anxiety, dribbling, pain, low mood, limb numbness, sleep dysfunction, constipation.
- Researchers will provide information to best manage these symptoms SHOULD they occur. You should speak to your GP or healthcare provider to understand potential symptoms that could occur during overnight medication withdrawal.
- Lead researcher Lewis Ball will place markers across the lower body, pelvis, arms and shoulders.
- Non-invasive electrodes will be placed on important muscles of the lower limb, including the calf muscle and the shin, to assess muscle activity level. Researchers will shave, abrade and sterilise the appropriate areas.
- You will provide us with informed consent once you are happy with the procedure.
- Participants will be asked to complete questionnaires (pre-test re-test, general health questionnaires, freezing of gait questionnaire) whilst markers are being positioned. These questionnaires will be used to assess readiness to exercise.
- Participants will then complete a variety of everyday walking tasks, including:
 - (3 trials @ each amplitude) Standing turns (45, 90, 180 degrees) [11, 45, 46].
 - (3 trials @ each amplitude) Walking turns (90 degrees) [11, 45, 46].
 - (3 trials) Timed up and go (TUG) (turning to the participants most-affected side).
 - (6 trials) 7m normal-paced walk.
 - (6 trials) 7m dual task intervention walk.
 - 30-second quiet stance

7. Voluntary Participation

Participation in this study is completely voluntary. Before participation we do ask you to evaluate carefully whether you are happy to be involved in this study, i.e. do you have time to spare? Are you comfortable with the procedures, including temporarily withdrawal from dopaminergic medication? If not, you **have the right to withdraw** up to a week after testing is complete.

8. Study funding and ethical approval.

This PhD is funded as a student scholarship by the University of Kent, School of Sport and Exercise Sciences (University of Kent, School of Sport and Exercise Sciences, Chipperfield Building, Room G05, Giles Lane, Canterbury, CT2 7PE).

All equipment is owned by the School of Sport and Exercise Sciences.

This research has been ethically approved by the University of Kent Natural Sciences (NATS) School of Sport and Exercise Science (SSES) Research Ethics Committee.

9. Am I at any risk?

This study involves gait tasks that induce a risk of falling. A research assistant will be at hand to reduce the risk of falling and injury, and a first-aid officer will always be present in the building throughout testing. A partner/carer/family member is welcome to be present during testing.

10. How is my data protected, and privacy ensured? Where does my data go?

Data will be managed, processed, and stored in accordance with the Information Commissioner's Office requirements, the Data Protection Act 2018, and local guidelines and standards.

<https://www.kent.ac.uk/about/assurance-and-data-protection>

Privacy will be ensured following the University of Kent's research privacy guidelines and notices.

<https://research.kent.ac.uk/ris-research-policy-support/wp-content/uploads/sites/2326/2021/06/GDPR-Privacy-Notice-Research.pdf>

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11. I have a question...

For answers to questions about the research, please contact Lewis Ball (PhD Researcher) at lrb33@kent.ac.uk.

In the event of a complaint, please contact Dr. Jake Bowd (Lecturer and Supervisor) at j.bowd@kent.ac.uk, And/or Prof. John Dickinson (Research Graduate Studies Lead) at j.w.dickinson@kent.ac.uk.

12. What happens to my results? Can I find out my results?

The results of this research will form part of Lewis Ball's PhD thesis. We also aim to publish findings in a discipline specific scientific journal. Participants will remain anonymous.

I would like a copy of my findings: Yes ☐ No ☐

If you ticked yes, please provide an email address below:

Your personal results will be provided as soon as possible after data analysis has occurred. Full anonymity will be provided in accordance with the University of Kent's data protection policy.

Thank-you for taking your time to read this information sheet and choosing to participate in this research. Your contribution to research in Parkinson's Disease is so important and together we can keep aiming to improve quality of lives of all those affected. If you have any questions do not hesitate to ask (lrb33@kent.ac.uk).