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**Research Project Proposal (1000 words max.)**

**Title:** Exploring attitudes and perceived need for novel neuromodulatory approaches to address cognitive impairment in people with Parkinson's disease.

**Background and Context:** Parkinson's is the second most common neurodegenerative disease in the world affecting more than 10 million people.<sup>1</sup> Approximately 60% to 80% of people with Parkinson's disease (PD) experience cognitive impairment that impacts their quality of life.<sup>2</sup> Cognitive decline in PD can often present before the onset of motor symptoms and is characterized by a spectrum of clinical deficits including impairment in attention, working memory, executive function etc.<sup>3</sup> About 60% of patients with Parkinson's Disease with mild cognitive impairment (PD-MCI) progress to Parkinson Disease Dementia (PDD) within 5 years.<sup>4</sup> The combination of motor and cognitive symptoms presents challenges for pharmacological management, thus currently there is no approved treatment for PD-MCI. A recent Cochrane review on the subject concluded that there is an urgent need for more research in non-pharmacological interventions to address cognitive impairment in PD (2). This represents a significant gap that novel innovative neuromodulatory strategies may be able to address.<sup>5</sup> Currently, a group at Trinity is trialling new therapies involving neuromodulation for mild cognitive impairment and intend to extend this to the PD-MCI population. This approach is novel in PD-MCI. Thus, my proposed project for the Laidlaw scholarship will add to this effort by scoping attitudes and perceived need for this type of intervention among people with lived experience of PD-MCI.

**Neuromodulation for cognitive impairment:** Transcranial electrical stimulation (tES) is a non-invasive, painless neuromodulatory technique that stimulates particular areas of the brain using direct low-intensity currents.<sup>6</sup> Examples of promising novel tES interventions include Occipital Nerve Stimulation (ONS) which stimulates the occipital nerve in pulses. The ONS treatment is currently being tested in Alzheimer disease (AD) by Trinity researchers. It is thought to improve cognitive symptoms through the Locus Coeruleus Noradrenergic (LC-NA) system.<sup>7</sup> Due to the nature of cognitive impairment in Parkinson's disease (PD), which largely impacts executive functions like dopamine and noradrenergic-mediated cognitive function, ONS may represent greater therapeutic potential in Lewy body conditions like PD-MCI compared to AD.<sup>8</sup> This exciting non-pharmacological approach is being explored further by my supervisors Prof. Leroi (School of Medicine - Geriatric Psychiatry) and Prof Vanneste (School of Psychology) under the auspices of the newly funded 'HRB-CTN Dementia Trials Ireland' platform.



***Attitudes and perceived need for non-pharmacological treatments in PD-MCI:*** So far, only a few studies have been published that examine the viewpoints of patients/potential therapy recipients about emerging non-invasive neuromodulatory therapies. Therefore, I am interested in exploring what people with Parkinson's disease think about neuromodulation, particularly about ONS, as a therapeutic option for cognitive impairment. As a staunch advocate of patient-centred research, I see my study as a collaboration with participants in which I can talk *with* them about ONS and learn about *their* perspectives.

***Overall aim:*** To explore attitudes and the need for novel neuromodulatory approaches to address cognitive impairment in people with Parkinson's disease.

**Objectives:**

- ascertain attitudes, awareness and perceived needs for non-pharmacological interventions using a self-report survey of people with lived experience of PD-MCI
- explore in depth the perceptions of people with PD-MCI to neuromodulatory therapy who have and have not received the therapy, using qualitative methods.
- become part of the study team and learn more about the intervention and trial methods.
- develop skills in survey and qualitative research methods and analysis.

***Method:*** This mixed method study will consist of a cross-sectional self-reported survey study and in-depth semi-structured interviews. No contact with participants will be undertaken prior to ethical approval for the project.

***Timeline & Recruitment of Participant:***

***Pre-Week 1 Survey study:*** As the first preparatory step I will actively participate in Lewy Body Ireland's (LBI) peer support group, '*TeaTime with Lewy.*' These meetings will allow me to build rapport with members of LBI. I will conduct an online information and briefing session about neuromodulatory approaches including ONS and distribute Patient information leaflets (PIL) to members of LBI and Parkinson's Society Ireland. Subsequently, I will request their participation in the email-based *Attitudes and perceived needs survey.*

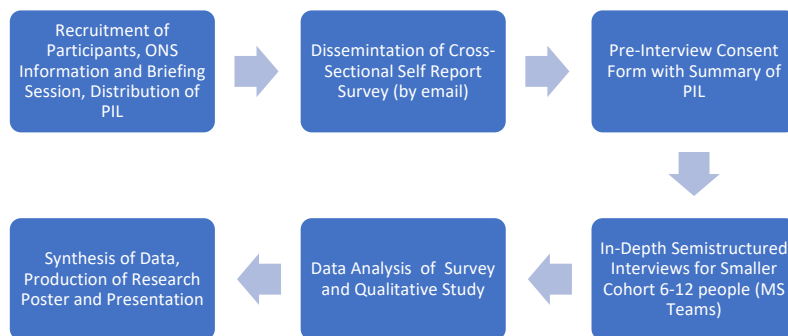
***Qualitative exploration:*** From the same cohort, I intend to recruit 6-12 interested participants with PD-MCI to undertake in-depth interviews about the topic. I will also endeavour to include additional participants from the planned POC study led by Professor Leroi and Prof Vanneste in June-Aug 2022. These participants will have received the ONS intervention (anticipated sample size, n=6).



**Participant Inclusion Criteria:**

- Adult men and women, (> 18 years) with a self-declared diagnosis of PD or Lewy Body Disease.
- Capacity to provide consent to the study.
- Access to internet and willing to undertake an email-based survey
- For the qualitative sub-study, able and willing to undertake an online MS Teams interview and having **attended an online information and briefing session about ONS**.

**Key Steps of Methodology:**



Week	Key Activity	Tasks
<b>Design of Materials</b>		
1	<i>Attitudes and perceived needs survey</i>	a. Develop a draft survey adapted from a published survey for neuromodulation <sup>9,10</sup> b. Field test the draft survey with 5 people with PD-MCI to test the level of acceptance c. Questions will be in YES/NO statements or level of agreement format.  *Surveys will include a sociodemographic section
2-3	<i>Qualitative Study</i>	Using findings from draft survey and information from published literature a. Develop an interview questionnaire with 4-5 open-ended questions b. Develop a sociodemographic questionnaire
<b>Data Collection</b>		
2-4	<i>Survey study</i>	a. Distribute surveys in two stages (1) immediately following the briefing session for participants in attendance



		<p>(2) subsequently to those who did not attend the session.</p> <p><i>*Not all survey respondents will need to have attended the session (this will be specified on the survey form).</i> <i>*Reminders to fill out the survey will be sent after two weeks followed by a final reminder for remaining outstanding responses</i></p>
3-4	<i>Qualitative Study</i>	<p>a. Will use the Dementia Research Group's Microsoft Teams (MS Teams) account to interview participants</p> <p>b. Conduct one-on-one in depth semi-structured interviews with individuals with self-reported PD - MCI about their feelings towards ONS as a potential therapeutic option</p> <p>c. Ask patients to fill in the socio-demographic questionnaire</p> <p><i>* Only participants who attended the briefing session and received the PIL will be interviewed,</i> <i>* This qualitative approach is an effective way to delve deeply into participants' attitudes and beliefs about ONS</i></p>
<b>Data Analysis</b>		
4 - 6	<i>Survey study</i>	<p>a. apply descriptive statistics to report respondent demographics and responses</p> <p>b. may perform a regression analysis depending on sample size to ascertain predictors of perceived need for the therapy (high vs low) and attitude (favourable vs unfavourable).</p>
	<i>Qualitative study</i>	<p>a. transcribe interview recordings verbatim</p> <p>b. pseudonymize the information</p> <p>c. perform thematic analysis</p> <p>d. identify suitable methods of analysis, such as grounded theory, phenomenological theory</p> <p>e. use qualitative data analysis software (e.g., nVivo).</p>
5-6	<i>Synthesis of survey and qualitative data</i>	<p>a. examine data and establish an a priori method for synthesis,</p> <p>b. prioritize the strongest data (based on sample size or richness of data) to drive the combined findings.</p> <p>c. Poster and Presentation</p>



***Ethics, Data Protection and Safety:***

- With the support of supervisors, I will apply for ethical approval, in March 2022 to ensure the project work can start in Summer 2022.
- will only use TCD data management team approved software for surveys and qualitative interviews
- will follow GDPR guidelines for data management and maintain anonymity on the survey
- **will request every participant (survey and qualitative study) to sign an informed consent digitally agreeing to recording and analysis of their data.**
- will share my contact details with the interviewees and encourage them to contact me if they have any questions

***Expected results and contribution to body of knowledge:***

My research will provide

- An opportunity for meaningful Patient and Public Involvement (PPI)
- Feasibility data that will significantly contribute to the design of future studies looking at ONS therapeutic value in people with PD,
- Support for next stage funding application for a pilot RCT of the intervention, led by my supervisors.

***Requirements for equipment, materials, field trips, and funding (if applicable):*** I would require funding for travel, incidental expenses. I would also need to procure a license for a qualitative data analysis software. In case Covid-19 restrictions are reintroduced, there will be minimal impact on the project as I will adopt/maximize online mode of interviews for data acquisition.



References (excluded from word count)

1. Lew MF, Yeung Y. Parkinson's disease [Internet]. Reference Module in Biomedical Sciences. Elsevier; 2014 [cited 2022Feb7]. Available from: <https://www.sciencedirect.com/science/article/pii/B978012801238300146X>
2. Orgeta V, McDonald KR, Poliakoff E, Hindle JV, Clare L, Leroi I. Cognitive training interventions for dementia and mild cognitive impairment in parkinson's disease. *Cochrane Database of Systematic Reviews*. 2020;2020(2).
3. Goldman JG, Aggarwal NT, Schroeder CD. Mild cognitive impairment: An update in parkinson's disease and lessons learned from alzheimer's disease. *Neurodegenerative Disease Management*. 2015;5(5):425–43.
4. Aarsland D, Batzu L, Halliday GM, Geurtsen GJ, Ballard C, Ray Chaudhuri K, et al. Parkinson disease-associated cognitive impairment. *Nature Reviews Disease Primers*. 2021;7(1).
5. Elder GJ, Taylor J-P. Transcranial magnetic stimulation and transcranial direct current stimulation: Treatments for cognitive and neuropsychiatric symptoms in the neurodegenerative dementias? *Alzheimer's Research & Therapy*. 2014;6(5-8).
6. Mennitto D. The brain stimulation program at the Johns Hopkins Hospital in Baltimore, Maryland [Internet]. The Brain Stimulation Program at The Johns Hopkins Hospital in Baltimore, Maryland. 2019 [cited 2022Feb7]. Available from: [https://www.hopkinsmedicine.org/psychiatry/specialty\\_areas/brain\\_stimulation/tcds.html](https://www.hopkinsmedicine.org/psychiatry/specialty_areas/brain_stimulation/tcds.html)
7. Luckey AM, McLeod SL, Robertson IH, To WT, Vanneste S. Greater occipital nerve stimulation boosts associative memory in older individuals: A randomized trial. *Neurorehabilitation and Neural Repair*. 2020;34(11):1020–9.
8. Mondal B, Choudhury S, Banerjee R, Roy A, Chatterjee K, Basu P, et al. Non-invasive vagus nerve stimulation improves clinical and molecular biomarkers of parkinson's disease in patients with freezing of gait. *npj Parkinson's Disease*. 2021;7(1).
9. Sperens M, Hamberg K, Hariz G-M. Are patients ready for “EARLYSTIM”? attitudes towards deep brain stimulation among female and male patients with moderately advanced parkinson's disease. *Parkinson's Disease*. 2017Mar28;2017:1–7.
10. Das S, Matias CM, Ramesh S, Velagapudi L, Barbera JP, Katz S, et al. Capturing initial understanding and impressions of surgical therapy for parkinson's disease. *Frontiers in Neurology*. 2021Mar4;12.



Leadership-in-Action experience proposal (500 words max.)	
LiA Category	Category B: Leadership Placement
<p>For my Leadership- in-action experience (LiA) during summer of 2023, I intend to work with <a href="#">Age Care Foundation (website)</a>, a Non-Governmental Organization in Visakhapatnam, Andhra Pradesh, India, established in 2012. The foundation's objectives are to “provide Geriatric care services to underprivileged elders and palliative/supportive care to persons with health-related suffering, particularly those with incurable illnesses.”<sup>1</sup></p> <p>If selected, I plan to apply the skills I would have developed over the first two years of the scholarship by designing several initiatives with the Age Care Foundation's Geriatric Care and Education Teams. I aim to approach my LiA with a human-centred design perspective. For the first week, I will be shadowing medical volunteers in the outpatient clinic and interviewing patients and their family members about their thoughts and opinions about Age Care's services, dementia care and palliative care in South India. This will be an excellent opportunity to apply the interviewing and qualitative analysis skills I would have acquired during my summer research project in 2022.</p> <p>Through this process, I hope to apply my social and cultural intelligence skills to further my understanding of the local health scenario and social environment. I intend to put my teamwork and communication skills to the test by building rapport with the Age Care Foundation staff. Furthermore, I plan to use my creative and critical thinking abilities to document the interviews and generate social media material for Age Care to aid their online fundraising campaigns. In weeks three and four, I plan to synthesize the interviews and brainstorm what types of interventions might be beneficial to my stakeholders.</p> <p>I have discussed and agreed on preliminary ideas for projects with Dr NS Raju MD Palliative and Geriatric Physician - local supervisor and managing trustee of Age Care Foundation. These project ideas include designing a volunteering guide and training program for new Age Care Foundation volunteers. This document would provide guidance on several topics including Ethics/Confidentiality, Leadership and Communication which are all essential skills for volunteers working in healthcare. I will share and disseminate the knowledge I have acquired from Trinity and Laidlaw sessions to a wider volunteering community. I will also work on designing workshops and campaigns to raise public awareness about neurodegenerative diseases like Parkinson's and Palliative care in the local language Telugu.</p> <p>I will utilize the last two to three weeks on prototyping the interventions and gathering feedback through surveys and interviews from the stakeholders involved. This part of the LiA journey will offer me the chance to practice critical leadership skills of conveying purpose and building coalitions in a culturally sensitive and meaningful way.</p> <p>In conclusion, I believe this LiA allows me to learn about palliative care, geriatric care, and neurodegenerative diseases from the perspective of patients and medical practitioners in a developing country. It will be an immersive and holistic addition to my initial research experience engaging with people with Parkinson's Disease in Ireland.</p>	



## References

1. Age care foundation [Internet]. Age Care Foundation. [cited 2022Feb7]. Available from: <https://www.agecarefoundation.in/>