Laidlaw Report- Ananya Sanagavaram

From June 2022 to August 2022, I tried to research the views and thoughts of people with Parkinson's on neuromodulation devices like Occipital Nerve stimulation. I used the verb 'try' instead of a declarative statement as, in reality, I spent more than six weeks in the summer gaining a first-hand insight into the complexities involved in conducting health research in the age of GDPR. In my original project timeline, I was supposed to receive ethical approval in June, conduct my survey and interviews in July, and analyse data in August. Unfortunately, the reality panned out very differently. The work on my project began earlier than anticipated; I started working on my ethics application during the semester before summer. During this time, I juggled attending lectures, studying for exams and decoding the requirements for the ethics application. Luckily, I received support and guidance from my supervisor and members of the dementia research group who were kind enough to dedicate several hours from their busy schedules to address my doubts in the ethics application. However, in July, I received feedback from the Ethics committee that required further revisions before ethical approval for my project could be granted; this prevented me from collecting data for my research. Thus, currently, my project can be accurately judged as a work in progress. Every time I found myself disappointed that I could not work on my project over the summer, I reminded myself that it's not just the end product that matters; it's the journey to the endpoint that can teach you lots of things about yourself. I believe my project is 'half begun', and I am excited to work on it over the next couple of months. That being said, I completed three main tasks over the summer that were enriching personally and professionally.

Ethics Application

This process was challenging as I had to submit seven documents, a data protection impact assessment, a level II ethics application, a participant information leaflet, an explicit consent form, a study poster, draft version of my survey questionnaire. I needed to figure out the following things: (1) how was I going to collect and store data ethically and in line with GDPR. For this application section, I completed a GDPR course offered by Trinity to understand the different categories of data and the appropriate ways to collect and store them. I also created a plan for collecting, processing and storing my data. I learned about SharePoint, pseudonymisation and how to carry out a risk assessment for personal data collection (2) How was I going to inform my participants so they could understand and give their informed consent?: This involved writing two participant information leaflets (PIL) and adapting two consent forms to suit my project specifications. I struggled with this component as I could not concisely describe my project. I had to cut down superfluous scientific language and, simultaneously, ensure that I was informing my participants with enough details of what to expect when signing up for my study. I received ample support from the data protection officer who showed me how to simplify my language to make it more participant friendly.

I decided it was better to create a separate information leaflet after multiple iterations of the PIL draft. I used the PIL to satisfy the requirements of the ethics application guidelines, and I designed my own information leaflet with images about the occipital nerve stimulation device. Throughout this process, I learned four important things. Firstly, I changed my attitude towards feedback. Pre-Research project, I rarely received feedback on my assignments and always hoped to receive positive or no feedback. But as I completed the ethics application, I continuously received feedback that I had to respond to. I used to view constructive feedback as a form of personal failure that whatever I produced was not inadequate. Now however, I have learned to accept that this entire process is new to me, so I am bound to make mistakes. It's better for the participants and the overall quality of the project if I receive lots of feedback as it enables me to conduct my project in a high quality and inclusive manner. I also learned to apply project management strategies and how to digitally organise my files and emails so I can keep track of important information. This inspired me to set a goal in the PDP plan itself. I also learned about the personal and practical relevance of GDPR in research and Trinity-approved software; I learned how to scrutinise and critically assess the data storage and processing techniques I planned to use. I gained a greater appreciation for the data protection team, who advocate for the recognition of the rights of research participant's. In a way, I am grateful for the ethics process as I avoided using a paternalistic approach to health research. Lastly, I became more confident and comfortable asking for help; the entire ethics application process demanded more knowledge and expertise than I had. I relied heavily upon the guidance of others, the hesitancy and reluctance to ask for help that I had before disappeared gradually, and I found myself emailing people proactively.

Survey Development

I worked with my supervisor, who was a fantastic source of support and guidance in designing the survey and interview questionnaire. First, I used the PubMed database to find a model survey I could use as inspiration for my survey. Next, I looked at survey design and experimented with different question formats before standardising them. The survey was fun to design, but I was worried that the entire participant research experience, including the information leaflet on ONS and PIL, was too text-heavy. My supervisor was instrumental in helping me think outside the box and advised me to create an informative video about ONS and embed it in the survey. This was a dynamic way to diversify the medium I used to share information. Next, I visited the Lab for Clinical and Integrative Neuroscience (Lab CLINT) which is part of the Trinity College Institute for Neuroscience at Trinity College Dublin. I talked to four different researchers in the multidisciplinary areas related to cognition and nerve stimulation devices. It was an incredible opportunity to speak with some of the authors of the research articles I read regarding ONS. Finally, I tried on the ONS device and, in doing so, gained a first-hand experience of what getting ONS treatment would feel like. This experience helped me design relevant survey questions and create a video addressing questions potential participants would ask.

Webinar

I was grateful for the three opportunities I had over the summer to interact with people with Parkinsonian conditions. These interactions helped me understand the caregiver's irreplaceable and vital role in managing Parkinson's. I attended two meetings, ' Tea time with Lewy Body Dementia' and conducted a webinar with my supervisor in collaboration with the Parkinson's Association of Ireland. The webinar was titled 'A discussion of the cognitive and mental health challenges often faced by people living with Parkinson's, including introducing new therapies for cognitive impairment and information about a new study conducted by Trinity College Dublin.' This was the highlight of my summer break! I was nervous and felt an immense sense of impostor syndrome 'talking about my research project' in this webinar with experts. I worked on my presentation skills and rehearsed in front of family members online to see whether I was audible and understandable. I was pleasantly surprised that the audience received my research project well. Unfortunately, due to technical difficulties and time pressure, I had to cut down my presentation by half at the last minute!
Nevertheless, it was an exciting experience that made me quickly assess which parts of my research project were the most pertinent to share with audience members. During the Q&A session of the webinar, I was delighted to see many participants interested in joining my study, but I realised something profound that day. As a student, I have always viewed my research project as an incredible opportunity to hone my research skills and talk to wonderful people.

I soon discovered that the 'people' in question and their families view research calls/ trials as a rare opportunity in Ireland to do something about their disease. I noticed that many people asked whether they could immediately join a clinical trial for the 'Occipital Nerve Stimulation (ONS) device'. The ONS system is a nerve-stimulation device. I wanted to survey/ interview people with Parkinson's about this type of non-drug intervention and see whether they would be interested in potentially trying out this device. The answer to the 5-minute presentation on the device was a resounding yes. I observed that people naturally pin a lot of hope on clinical trials to reverse or slow down the insidious progressive nature of neurodegenerative diseases like Parkinson's. It was humbling to realise that this may be an 'experience' for me, but for some, the research I am doing might help support the development of clinical trials. These trials could recruit people actively looking for opportunities to try something 'new' as other interventions may have failed. The webinar experience affected me deeply in three ways; firstly, I realised that I needed to take my research more seriously as it might mean something to people beyond myself and my supervisor. Secondly, I need to keep the lovely people who attended my webinar at the centre of my research and not get lost in the paperwork of research approvals! Thirdly I realised that I needed to read and learn more about neurodegenerative diseases and caregiving. I was briefly introduced to 'caregiving' in the 'Tea Time with Lewy' Session organised by Dementia Research Network Ireland. I listened to a panel of experts, from clinicians to app developers to experienced caregivers, talk about caring for and helping loved ones with Lewy Body disease (a Parkinson's plus condition. I learned about the difficulties in communication that arise as the disease progresses. I discovered that the little things we take for granted mean a lot to some people and that researchers need to be mindful of the diversity in lived experiences of people with Parkinsonian conditions. To learn more, you need to seek out people. William Ostler once said 'Listen to your patient; he's telling you the diagnosis." This is relevant to my research as I began to recognise that to make my research accessible and inclusive, it's best to talk to the people I want to design the research for and seek them out proactively.

What did I learn about myself as a researcher?

Throughout the research process, I learned how to manage disappointment and accept and minimise the feeling of 'straying' from the path. At certain points, I did feel a bit disheartened about my project progress. Most of my fellow scholars worked on the research, collecting/gathering data and analysing. Meanwhile, I found myself brainstorming ways to remain engaged with my research, knowing I could only complete my research in September when the ethics committee reopened and approved my amendment. As the number of tasks I could achieve without ethical approval was very few, I reflected on my feelings and thoughts. This was an opportunity, in other words, to develop my confidence to walk my own path with confidence and trust that I would finish what I started. The webinar experiences helped strengthen my resolve to work on my research in small but meaningful ways.

Sometimes, I wished I was better at writing the ethical approval and blamed myself for not working harder so that I could have gotten it approved and worked on my research according to my original research. But over time I realised that to learn certain things, you need to fail at them. Accepting my failure from a stoicism perspective helped me absolve personal blame and shame. I was so scared to fail, and by failing, I mean not obtaining ethical approval on my first try. However, when I did fail I re-realised that failure is inevitable. During the action-learning set discussions, listening to my peers helped me recognise that every scholar has their own set of challenges to overcome and that our journeys are unique, so it's quite pointless to compare.

Furthermore, I realise when things don't go according to plan, it's important to reflect and develop courage and self-efficacy, which are three essential traits in leadership. You need to believe in yourself and have the courage to execute your vision. This made me question my preconceived notion about leadership development which I previously thought could only occur in group project/teamwork situations. The experience over the summer, working on designing my survey, finalising my study protocol, and doing an online course on qualitative research helped me acknowledge that I can develop leadership skills by myself. I think it's a form of personal leadership to lead by your own example and remain committed to your goals.

My next steps would be to gain ethical approval, conduct the surveys and interviews and analyse the data. Now that I have more time to secure ethical approval and based on my experience listening to people with lived experience of Parkinson', I would like to include caregivers as a potential participant pool. To conclude, this summer, I became comfortable with failing multiple times and celebrating the small wins and failing again; I take myself less seriously as I have grown comfortable dealing with 'failures' and at the same time (albeit paradoxically), I take my work more seriously as I strive to keep people at the centre of my research. No matter how long it takes, I want to do an excellent job for my personal and professional growth and for the future participants of my research. They have given their precious time and trust to me.