Parkinson’s Research Outreach Network at the University of Hertfordshire

Report on the ‘Experiences of taking part in Parkinson’s Research’ event, 22 March 2025, Hampson Park Community Centre, Stevenage.

PRONET

The Parkinson’s Research Outreach Network at the University of Hertfordshire (PRONET at UH) was set up in 2024 with the aim of bringing together people interested in research into Parkinson’s, including people living with the condition, their family members and carers, professionals working with people with Parkinson’s including clinicians, and researchers based at the university undertaking research to better understand and improve treatments for Parkinson’s.

Our first PRONET event ‘Meet the Researcher’ held at the University of Hertfordshire in October 2024 focused on research undertaken at the university, with researchers talking informally about their research on a variety of topics relevant to Parkinson’s.

This second PRONET event, ‘Experiences of taking part in Parkinson’s research’ heard from people with Parkinson’s about research studies they had taken part in and discussed things to think about when considering volunteering to take part in research. The idea for this event came from suggestions made at workshops with the local Parkinson’s community in 2024 exploring ideas for PRONET events.

The event opened with a brief overview of PRONET from Lucy Annett, and then Vivienne Levy introduced the panellists. Lucy and Vivienne are members of the PRONET steering group. Each of the three panellists, Lee, Trevor and Rosie, first described two research studies they had taken part in. The panel then discussed general points about research participation, including motivations for taking part and practical points to consider. Questions and points raised by the audience followed. The event concluded with a few words from Claire Shearer, Regional Lead – East of England, Parkinson’s UK, about opportunities to shape research planning and take part in research studies through the Parkinson’s UK website.

Keen interest in the topic of research participation was evident from the 60 people who attended the event, filling the main hall at Hampson Park Community Centre, Stevenage.

The Panel

The panel chair Vivienne Levy lives in St Albans and is now retired. Vivienne used to work for drug companies including managing clinical trials. Vivienne was diagnosed with Parkinson's about 4 years ago and is a member of the PRONET steering group.

Lee Price lives in Bishops Stortford and works in IT. Lee was diagnosed with Parkinson's 7 years ago and volunteers as a lay reviewer of grant applications for Parkinson's UK

Trevor Elliott lives in Norfolk and was diagnosed with Parkinson's about 5 years ago. Trevor used to work as a Programme Manger manager specialising in organisational change management and is now retired. Trevor is passionate about the benefits of exercise and last summer completed a sponsored walk along the entire length of Hadrian's wall, with his dog Sam. The walk took 5 days and featured on BBC Look East.

Rosie Brewis lives in Welwyn Garden City. Rosie is a retired doctor who used to work as a paediatrician and then a GP. Rosie was diagnosed with Parkinson's about 8 years ago. Rosie's volunteer roles with Parkinson's UK include Project Engagement volunteer which involved visiting a research project funded by Parkinson's UK at the University of Hertfordshire. Roise is also a member of the Research Interest Group East at Parkinson's UK and the PRONET steering group.

Panel chair Vivienne, and panellists Lee, Trevor and Rosie

The Research Studies

1. Rapsodi GBA gene study

Lee spoke first about taking part in a research study at the Royal Free Hospital, London (with Professor Anthony Schapira at University College London) that is investigating links between alterations in the GBA1 gene and an increased risk of Parkinson's. The GBA1 gene encodes the enzyme glucocerebrosidase which clears waste from cells. Lee's involvement in this longitudinal research study includes visiting a neurologist at the Royal Free Hospital each year to give blood and saliva samples, and an update on his symptoms.

https://www.rapsodistudy.com/en

Toffoli et al (2023) Phenotypic effect of GBA1 variants in individuals with and without Parkinson's disease: The RAPSODI study, *Neurobiology of Disease,*188, 106343, https://doi.org/10.1016/j.nbd.2023.106343

2. Matching mental health support to the needs of people affected by Parkinson’s

The second research study Lee talked about is assessing the benefits (and costs) of providing group-based psychological therapy to help people with Parkinson’s adjust to the diagnosis and cope with any anxiety or depression. The study funded by Parkinson’s UK is led by Dr Jennifer Foley at the National Hospital for Neurology and Neurosurgery, Queen Square, London. Lee took part in 8 weekly therapy sessions, followed by a focus group to give feedback on how he found the sessions. The study aims to produce a manual that will be freely available to health professionals seeking to run these groups in Parkinson’s services across the UK. Lee commented that he met lots of great people with Parkinson’s while taking part in this study, some of whom he is still in contact with.

3. Gut transit in Parkinson’s – the Blue Poop Challenge

Trevor spoke about a research study that involved taking a teaspoon of blue food dye as used for cake icing and recording the time it took for his poo to turn blue! This study, led by Dr Marta Camacho at the Cambridge Centre for Brain Repair, University of Cambridge, is investigating gut dysfunction in people with Parkinson’s. The Blue Poop challenge is an objective and convenient way of measuring the time it takes for food to pass through the gut. The recently reported study results showed considerable variability in gut transit time, suggesting bowel problems may affect a subset of people with Parkinson’s rather than everyone with the condition.

https://www.clinical-neuroscience.cam.ac.uk/news/new-paper-explores-gut-dysfunction-parkinsons

Camacho et al (2025) The profile of gastrointestinal dysfunction in prodromal to late-stage Parkinson’s Disease, *npj parkinson’s disease,* 11,123, https://doi.org/10.1038/s41531-025-00900-9

4. Exercise for Parkinson’s toolkit - Knowledge, Exercise Efficacy and Participation (KEEP) intervention

The second study Trevor spoke about involved taking part in an 8-week education programme about exercise, including live online group discussions with a specialist physiotherapist and other people living with Parkinson’s. The purpose of this research, led by Dr Ledia Agley at the Department of Public Health and Primary Care at the University of Cambridge, is to evaluate an exercise education programme that has been developed collaboratively by people with Parkinson’s, health care professionals and researchers. The research study showed the education programme was well-received and participants said they had a better understanding of the benefits of exercise for Parkinson’s.

Agley et al (2024) Digital Intervention Promoting Physical Activity in People Newly Diagnosed with Parkinson’s Disease: Feasibility and Acceptability of the Knowledge, Exercise-Efficacy and Participation (KEEP) Intervention, *Journal of Parkinson’s Disease*, 14(6):1193-1210, https://doi.org/10.3233/JPD-240071

5. Vision and Cognitive Changes in Parkinson’s

Rosie spoke about a research study she has been involved with over several years that measured visual function (similar to tests at the opticians) and the retina and compared these with changes over time in cognitive functions such as thinking and memory. The research, led by Professor Rimona Weil at University College London and The National Hospital for Neurology and Neurosurgery, Queen Square, London, found that the eye tests predicted which people with Parkinson’s were more likely to develop cognitive problems. More recently, Rosie has volunteered to take part in an extension of this research that is using blood tests and brain scans from different types of scanners, including a very powerful MRI scanner that collects detailed images of the brain. The aim is to see which measures best predict the progression of Parkinson's symptoms in the longer term.

Zarkali et al (2024) Neuroimaging and plasma evidence of early white matter loss in Parkinson's disease with poor outcomes, *Brain Communications*, 6(3), fcae130, https://doi.org/10.1093/braincomms/fcae130

6. Patterns of Perception in Parkinson's disease: Understanding the taboo of talking about dementia in Parkinson's

The focus of the second study Rosie spoke about was to develop better tools for discussing fears and concerns around the increased risk of dementia in Parkinson's. This research took a novel approach by inviting people with Parkinson's to take part in artistic activities, including creating artwork, Pilates, and a "Moving with Parkinson's" workshop with the English National Ballet, using the art as a means of sharing experiences of living with Parkinson's. Participants then took part in focus groups reviewing drafts of the booklets being complied as part of the toolkit. The project led by Professor Rimona Weil and Dr Ivelina Dobreva, with a team of researchers and public engagement experts at University College London, received an Outstanding Public Engagement project award. Copies of the booklets produced by this research study are available on the Parkinson's UK website. There is also a video about the project on YouTube.

https://www.parkinsons.org.uk/information-and-support/thinking-and-memory-changes

https://www.youtube.com/watch?v=SesG1EkBztQ

Panel discussion

These are the questions discussed by the panel and a summary of key points made in response to the questions.

What motivated you to volunteer to take part in research studies?

- Wanting to help other people with Parkinson's and make a contribution
- Having a particular interest in the research topic
- Wanting to stay abreast of what is happening in the area
- For research studies testing a new therapy, access to the next potential treatment

How did you find out about the research studies?

- From the Parkinson's UK website or the Clinicaltrials.gov website
- From my neurologist or a member of their team
- From local Parkinson's group meetings

What are the important things to think about when deciding whether to take part in a research study?

- The time commitment
- Ease of travel to the research centre
- If the study is to run over several years, the practicalities of making the required visits if you are no longer able to drive or if travelling on public transport becomes problematic
- If there is a monetary cost to taking part in the study, will your expenses be covered?
- Are there specific parts of the study you don't want to do?

- Is there a requirement to stop taking your current medication?

For all research studies, participants are provided with an information sheet before deciding whether to take part. What key points should you look for on the information sheets?

- Do not be put off by the length of the information sheet! The information is provided to protect you.
- The information will have been reviewed and approved by an ethics committee.

The information should include:

- a synopsis of the study
- any disadvantages/ advantages of taking part in the study including any possible adverse effect of a procedure or treatment
- who is responsible for the study
- where the research will take place
- the inclusion and exclusion criteria for the study
- that you can withdraw from the study at any time
- that if the study is a double-blind study, you may not find out which group you were in until after the study has finished which may be months or even years after you took part
- that you will not receive your individual data
- you should be given sufficient time to consider all the information provided and ask questions before being asked to sign the document
- you will be asked to sign that you have read and fully understand what is involved in taking part in the study and that you have had an opportunity to ask questions and had those questions answered

Are there any additional issues that should be considered when taking part in a drug study?

- If the study has a placebo control condition, you might not be allocated to receive the active drug
- When you have completed the study, you may not be able to continue taking the test drug unless there is a follow-on protocol or a compassionate use protocol
- The drug you were on during the study may have been beneficial for you, but the drug may not be progressed and licensed for use if the study results overall show that the drug lacks sufficient efficacy or has an unacceptable safety profile

What did you get out of participating in research?

- The feeling of belonging to a team
- Meeting other people with Parkinson’s taking part in the study
- You may find out more information about your Parkinson’s
- You may get more time with a neurologist and members of their team than usual
- You may get the option to try a new improved treatment
- A feeling of helping to provide more information on Parkinson’s in general

Were there any negative or bad experiences of taking part?

- Difficulty reaching the study site due to issues with public transport
- The time involved in waiting to be seen in a busy hospital

Have you ever been turned down for a research study and what did you think about this?

- Yes, I did not meet the eligibility criteria for a particular study

- While disappointed, I understood that particular research study needed participants who were newly diagnosed, which was no longer the case for me

What have you been told about the results of the study and how were you told about the results of the study?

There was a lot of variation in the way participants were told about the study results, some not receiving any information about the study outcome at all. How and when study results are shared may depend on:

- the size of the study
- budget availability
- who was running the study and if they are still employed by the research centre
- for large and/or long-term studies, the time taken to collect the results
- the time taken to get an article written and accepted by a journal for publication
- the time taken to produce the study output (e.g. app/ booklet/website)
- the outcomes shared are typically group averages rather than individual results

What would be your 'take home' message for people thinking of taking part in a research study?

- To move research forward and try to find a cure for Parkinson's we need people to take part in research studies.
- There will be a study somewhere/sometime that will be suitable for you. Please take part.

Feedback

Those of you who kindly completed the feedback form after attending the 'Experiences of taking part in Parkinson's research' event rated the event as 'Very good' and 'Very Informative'.

Comments in response to the question 'What did you like about the event?' included:

- The friendly, welcoming atmosphere, and the positivity within the group
- Meeting so many friendly people!
- I appreciated that there was an open environment where folks felt comfortable asking/answering questions, no hesitation in reaching for the mic.
- The panellists were excellent, and I learned a lot about the different kinds of Parkinson's studies there are.

Thank yous

Thank you to all who attended and contributed to the 'Experiences of taking part in Parkinson's research' event!

We would like to thank Christine Caine, Jonathan Garnett, Robert Garnett, Jon Gillard and Paul Moran for helping at the event.

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Future events

The PRONET team is currently planning future events for autumn 2025 and spring 2026. Details of these events will be circulated to everyone on the PRONET mailing list. If you are not already on the PRONET mailing list and would like to receive information about future events, please contact pronet@herts.ac.uk to ask to join the mailing list.

If you are interested in a particular research topic relevant to Parkinson's and would like PRONET to focus on that topic at a future event, please contact the PRONET team by email at pronet@herts.ac.uk. We look forward to hearing from you.

This report was written by Vivienne Levy and Lucy Annett, on behalf of the PRONET steering group: Lucy Annett, Rosie Brewis, Becki Hadley, Ruth Herman, Mahmoud Iravani, Vivienne Levy, Paul Williams and Nada Yousif.

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