

# PARTNERS IN RESEARCH

TIME TO  
UPDATE!



## WELCOME TO OUR SPRING 2025 NEWSLETTER

THIS IS JAM PACKED WITH LOTS OF INFORMATION SO PLEASE READ ON....

WELCOME!

Firstly, we would like to welcome Denise Munro to everyone. She has joined us as a PPI engagement officer and will be working alongside Rosie on Partners in Research work



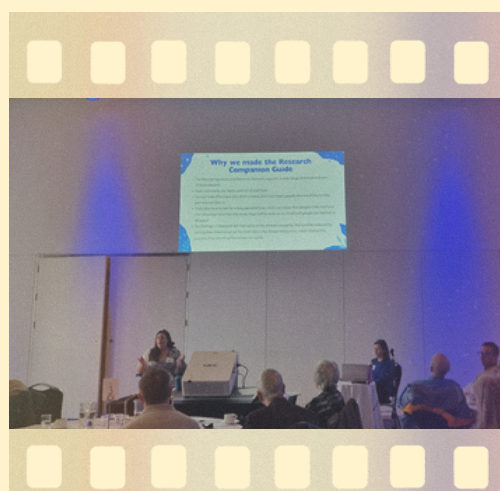
Denise WELCOME TO OUR TEAM

We are really pleased to have been able to expand our network by including Partners in Research information to our **Permission to Contact register**. We would like to give a warm welcome to those of you who are new to the team.



## Parkinson's co-research

Our co-research group, made up of people with experience of living with or supporting someone with Parkinson's disease, held an event at Dynamic Earth on 20th February. We invited people with lived experience of Parkinson's to join us. Together we looked at the draft 'Clinical Trial Companion Guide' we had been developing over the last 6 months, and discussed different ways to build on what was there, including space to record individual stories. There was a brilliant buzz around the room and the feedback on improvements to be made was fantastic - watch this space for the final version, which we hope will support people with Parkinson's disease through clinical trial research.





# PARTNERS IN RESEARCH



## Dementia co-research

As well as our Parkinson’s disease co-research group, we have a group for people with experience of dementia. Over the past few months the group have been working on a questionnaire to ask key questions that have come up during our time as Partners in Research. We are currently narrowing down the focus, but we are interested in reasons people may or may not take part in PPI or co-research; knowledge of dementia; and experiences of care. Once the group have a prototype of the questionnaire(s) we will be applying for research ethics so that we can start asking people to fill it in!



## Helping Researchers

We have already had a number of researchers submit requests to us for PPI support with their studies. The range of topics has been amazing and we are also looking to extend from Dementia to Parkinson’s and other neuroprogressive conditions.



One of the main projects we have been involved with is supporting Dr Lucy Stirland on her study ‘Dementia and Co-morbidities. We often find that if people with dementia have other health conditions, they are excluded from research. Lucy’s work has been co-produced with people who are living with multiple health conditions, including dementia, to come up with research priorities for the future.



## Quotes from Researchers

“The input from the group was interesting and informative and helped us reflect on next steps and future submissions as well”

I have received great amount of people interested in participating.

The input from the group was fantastic - it was great to have points to consider from people with lived experience and see the interest in the project I had discussed

As part of requesting support from Partners in Research, we ask researchers to provide updates on how their work has been shaped by the group, and their reflections of asking the group for help. It forms an essential part of creating clear feedback loops which our group feel is too often missing in research.



# PARTNERS IN RESEARCH



## Our Book

We have now had over 20,000 downloads of the book which is amazing!

To download a free copy please click here: <https://link.springer.com/book/9783031272226> (suitable for e-readers and audio)

Ashworth et al. (2023). Challenging Assumptions Around Dementia: User-led Research and Untold Stories. UK: Palgrave



## Events

We will be attending the NRS PPI Conference on 11th March at Stirling Court Hotel. Rosie, Denise and Partner in Research Garry, will be presenting about our work and plans for the future.

We will also be at the NHS Lothian R&D Conference on 22nd May, to share our Parkinson's work - NHS Lothian Charity funded our in person event.

## Familiar Faces

We have recently launched our new scheme to support new Partners in Research members to attend groups. All new members will have the option to chat with an existing member to hear more about getting involved in our activities. We hope this will lead to a supportive familiar face for future group meetings.

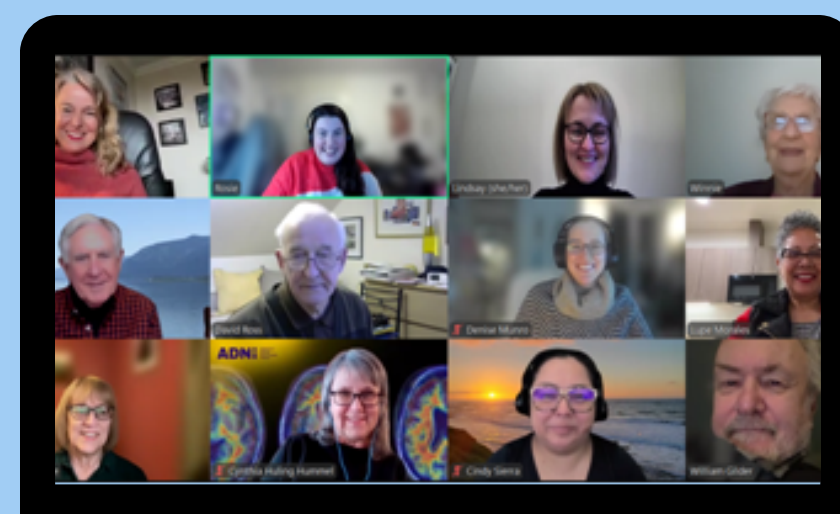


THE UNIVERSITY of EDINBURGH



## Scotland and America join forces for PPI

Partners in Research joined an online meeting with the University of Edinburgh and the Research Partnership Alliance from the Alzheimer's Clinical Trial Consortium. We got to talk with people living with dementia and carers about their experience of PPI across the US. The meeting was an excellent opportunity to get to know each other and think about possible ideas that we could work on together in the future. If you're interested in working with the group, let us know!



## Find out more

If you would like to know more about any of our ongoing work, meet with a familiar face, and/or get involved in future opportunities, get in touch. We are always keen to meet new people and develop new ideas.

[tay.ppipartners@nhs.scot](mailto:tay.ppipartners@nhs.scot)