

PARTNERS IN RESEARCH



WELCOME TO OUR AUTUMN 2024 NEWSLETTER

WHERE HAS 2024 GONE ALREADY?! OUR 'PATIENT AND PUBLIC INVOLVEMENT' GROUP - PARTNERS IN RESEARCH - HAVE BEEN VERY BUSY AND WE HAVE ALSO ATTENDED A NUMBER OF CONFERENCES TO TALK ABOUT OUR WORK
KEEP READING FOR MORE DETAILS...

PARTNER IN RESEARCH GROUPS

Our groups have been very busy so far this year with lots of researchers sharing their studies and asking for feedback on them, which is fab for our carers and people with neuroprogressive conditions to be involved in.

We have also further developed our two co-research groups, which we shared in the last newsletter. More details can be found below:

Dementia co-research

- Aim to explore the things that help and hinder involvement in 'patient and public involvement' or co-research
- Co-create a survey to explore involvement from the perspective of people with lived experience
- Speak to groups to explore findings in more detail



Parkinson's co-research

- Co-create a companion guide for clinical research studies
- Explore funding opportunities to bring people with Parkinson's disease together to further develop the prototype
- Consider the best ways to evaluate the usefulness of the companion guide resource

PARTNERS IN RESEARCH



OUR BOOK

We have now had over 16000 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

WELCOME TO OUR NEW 'PIRS'

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.

WELCOME

CONFERENCES

We recently presented at the NDN /SDRC /Brain Health Arc in June

We will be attending the Alzheimer Europe Conference in Geneva in Oct to present our work

We also recently produced a video on why our PiRs joined the group. Have a watch:

<https://youtu.be/JUr4nzwVwu0>



MEET FIONA



I am a retired physiotherapist who specialised in care of the elderly and neurological conditions. During this time I signed up for SHARE and took part in research studies into Alzheimer's Disease. I also joined the Patient and Public Involvement group. Around 2020, my mother was diagnosed with Alzheimer's Disease and as her disease progressed, my caring role increased until her passing in October 2024.

In July 2021 I was contacted by Rosie and asked if I would like to be involved in the Partners in Research group which was part of the Neuroprogressive and Dementia Network.

My wish to be involved in the group has been on many levels. Firstly, as an advocate for my mum and the issues she and my family encountered during her diagnosis, disease progression and finally her end of life care. Personally, the experience of being a carer and the barriers I faced to access information, support and self-care.

Professionally I still have an interest in research and evidence based practice not just for dementia but for all neuroprogressive conditions that I encountered in my working life.

I am enjoying the experience of working with others who have great passion for what we do, the feeling we can make a difference and facilitate change in the lives of those diagnosed with these conditions and their carers either by reviewing research proposals for academics, co-research or working on projects with researches from out with this group.

If you are thinking about joining us - do it! You won't regret it and you can participate as much or as little as you want.



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 PiR activities. We hope this will lead to a supportive familiar face for future group meetings.