



## WELCOME TO OUR SPRING 2024 NEWSLETTER

THE START OF 2023 HAS BEEN REALLY BUSY AND WE WANTED TO SHARE OUR PLANS. WE ARE RECEIVING MORE REQUESTS FROM RESEARCHERS FOR PARTNERS IN RESEARCH INVOLVEMENT IN THEIR RESEARCH WHICH IS FANTASTIC. WE ARE ALSO ATTENDING A NUMBER OF EVENTS AS WELL AS WORKING ON OUR PROJECTS. KEEP READING FOR MORE DETAILS...



### OUR BOOK

As seen in our last newsletter- we wrote a book. We have had some great feedback so far, please do keep sharing your thoughts. The group really appreciate knowing the impact it has had.

We are delighted to have had over 10000 downloads and to have been able to donate hard copies of books to various organisations.



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

### PROJECT PLANS FOR 2024

1. Co-create clinical trial support for people with Parkinson's
  - a. If you are living with or supporting someone with Parkinson's disease and would like to help us develop this work please get in touch.
2. Looking a post-diagnostic information provided to people affected by neuroprogressive conditions.
  - a. If you are living with or supporting someone with a neuroprogressive condition e.g. dementia, MS, MND, Parkinson's, Huntingtons and would like to know more, please get in touch.
3. Collaborating with other organisations to look at risk factors of dementia and other neuroprogressive diseases
4. Looking at Capacity to care in collaboration with ENRICH Scotland

### WEBINARS

Our Partners In Research webinars have been really successful so far. The speakers that we invite are based on areas of interest to our Partners in Research, RiCH Voices and staff. This year we have had sessions with the following organisations:

Brain Health Scotland - click [here](#) to watch

Dr Victoria Shepherd from Cardiff University on Advanced Research Planning - click [here](#) to watch

Our co-authors are doing a Q&A session on Thursday 28th March at 1pm. To sign up click [here](#)



# PARTNERS IN RESEARCH



## HEAR FROM OUR PARTNERS IN RESEARCH



### WINNIE HENRY

Like many people of a certain age I am not always sure my speech is politically correct. I grew up in a different working environment than people usually encounter in today's world. In that world of thirty, forty, fifty and sixty years ago very rarely did people seem to take offence at, for example, some of the stereotyping that occurred. Add to this the fact that I am Glaswegian. Glasgow is known as a place where its citizens are renowned for their love of banter and one line quips. I know realise how much was wrong with both the attitudes and also some of the situations people encountered in those days .

It was with all this in mind I decided to take a course on offer , online ,at King's College. London. The course was called , Research Methods: A Practical Guide to peer and Community Research. Personally, I found it a good refresher course. As often happens to me on this type of course, I am reminded of stuff I was taught many years ago and I am glad it is all so applicable in today's world.

But how I despaired at times over the question, was I getting it correct in this world of political correctness? I really found it very difficult . I constantly questioned myself. Could anything in the way I phased this or that particular question offend anyone?

**I made it through the course successfully and I hope it made me a better researcher and definitely a more aware one when it comes to political awareness.**

### DAVID ROSS

in terms of Partners in Research I have been classed, loosely, as an expert with or of," Lived Experience". Being an ex-carer for my wife this is an experience I could have done without. We all have lived experience in some form or other, some good some not so good, but it's down to the individual what they do with that experience.

I am retired engineer with world wide experience of many different countries and cultures sometimes in hostile areas, desert locations, jungles and rarely, more exotic places. From a very basic start in life to being involved from the ground up to quite senior levels within industry and politics it gives you that, what some may call, "the old wise man of the village," tag.

What it doesn't do is prepare you for the mostly unknown signs and symptoms of a hugely debilitating form of neurological condition or dementia that strikes a loved one, out of the darkness like a Ninja warrior. It leaves you confused, angry, stressed and any other form of stress or grief you can imagine. When you realize that something is definitely wrong with your life partner you seek professional help, which in my case didn't agree with my fears for almost two years. Once my fears were accepted then tested and a diagnosis given I was left in limbo; what could I have done sooner, why did it happen, what caused this and why didn't I, with all my worldly experience see it?

The answer to that is simple, lack of awareness; no previous direct involvement, or any medical or psychological training. You hear about these things and carry on with your life: with an, It'll never happen to me attitude, but it can!

"We don't know and everyone is different", plus being handed an information pack with scary bits like expected lifespan and social services details, didn't help me to understand why my wife contracted Frontotemporal Dementia (FTD) with overlapping Amyotrophic Lateral sclerosis (ALS). Being practical and inquisitive I had to find out WHY! As no one could help me I conducted my own research, retrospectively, quite in-depth through academic papers (that weren't always easy to understand), and using the internet on a world-wide basis. This threw up more questions, due to the variety of theories and the agenda of those producing the information. Eventually I did come to conclusions as to the probable cause/s and documented them all. But, as one professor told me, "I agree with everything you have written, but you can't prove it!" This is when I realised I wasn't in the loop, not part of the system, a system I believe needs to change and expand its horizons letting others with "lived experience" enter.

I didn't have a voice or a platform to take my research further, I am still looking for answers, there so many unknowns out there that need to be explored and there are many people like me willing to help, given the chance.

**THAT'S WHY I JOINED PARTNER'S IN RESEARCH! TO GAIN ACCEPTANCE.**





SCOTLAND

NHS RESEARCH SCOTLAND

NEUROPROGRESSIVE AND DEMENTIA

# PARTNERS IN RESEARCH



## CONFERENCES

We are fortunate enough to be involved in several conferences over the next few months, with our Partners in Research sharing their experiences alongside Rosie:

Our NDN/SDRC conference is taking place on 13/14th June and we will be talking at it.

We have also received confirmation that our abstract (work summary) has been accepted for the British Gerontology Society Conference in Newcastle on 3-5th July

## CONTACT US

If you are interested in joining our Partners in Research or finding out more, please contact us on  
TAY.ppipartners@nhs.scot  
or 01382 423086



NRS AND CHIEF SCIENTIST OFFICE- PATIENT AND PUBLIC INVOLVEMENT EVENT TOOK PLACE ON 12TH MARCH AT THE V&A DUNDEE. AS PART OF THE EVENT AWARDS, ROSIE RECEIVED THE 'PPI IMPACT AWARD' -

"I WANT TO SAY A MASSIVE THANK YOU TO ALL OF THE PARTNERS IN RESEARCH. WITHOUT YOUR WILLINGNESS TO GET INVOLVED AND TRY NEW THINGS, WE WOULD NOT HAVE GOT TO WHERE WE ARE TODAY. THANK YOU SO MUCH FOR EVERYTHING."

## WELCOME TO OUR NEW PARTNERS IN RESEARCH

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.

When you join Partners in Research you are asked which activities you would like to be part of or hear more about. We are also always open to new ideas/suggestions of what you would like to see.

Please don't hesitate to let us know.

Welcome

