

Gordon Kennedy

I am a retired civil engineer, My introduction to PPI began under another name. My wife Phyllis was diagnosed with Alzheimer's disease over 20 years ago. This led to Phyllis being invited to participate in the clinical trial of a drug called Aricept, the first possible drug treatment for the disease, which was being carried out by Prof Passmore's team at Queen's. This led a few years later to Phyllis participating in further research projects into the illness. One such project was being funded by the Alzheimer's Society and it involved their newly formed Volunteer Research Network. The

Network is made up of people either with dementia, or who have direct experience of caring for people with dementia. As Network members, we prioritise the aspects of the disease which the Society should be funding, score the four page lay summaries which all grant applicants are required to submit and sit on appointment panels. In addition, three Network members are appointed to all successful research proposals as monitors. Because of this requirement, Prof Passmore invited me to be one of the Society's monitors for his new project, which was rather back to front, as it was because I was asked to be a monitor that I joined the Network, rather than the other way round!

That invitation was the beginning of a 15 year journey as a lay participant in dementia research, a journey which I have found to be both enlightening and personally rewarding. It has also led me into a broader PPI journey. As the work which the Alzheimer's Society's Volunteer Research Network had been doing, was in effect PPI in action, I was invited to participate in the steering group. That too has been a privilege, in sharing and learning how properly implemented PPI can be of real benefit not only to the users, but also to the researchers, as they seek to find cures and at the same time, improve the care and treatment of all users of the Health Service.

One recent, very positive development of the PPI role, has been in meeting with researchers at the formative stage of their research proposals. There is a real risk that involving service users in research can simply be seen as putting a contact name in the PPI section of the grant application form! People with the specific illness being studied, and those caring for them, have unique insights and experiences which, if tapped into, can enable researchers to better focus and develop their projects. Early involvement with PPI representatives can allow this to happen, thus leading to better research and better outcomes. That, in my opinion, is what PPI is seeking to achieve.

Most recently I have participated in the public announcement of the Join Dementia Research register, which has been set up in Northern Ireland to enable more people to participate in clinical trials. Research is an exciting journey with new technologies enabling new discoveries and insights to be made across a broad range of disciplines on an ongoing basis. As a lay person, it has been my privilege over the last 15 years to participate in some small way in that journey.