

# Embracing Patient and Public Involvement

The Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) has introduced innovative training sessions on how to best to assess mental capacity and gain informed consent from potential study participants.

Informed consent can only be given when an individual has adequate reasoning abilities and a full understanding of the implications of their decisions. Impairments to reasoning and judgment include mental illness and conditions such as Alzheimer's disease. Consequently DeNDRoN research staff spend a great deal of time conducting interviews which serve to assess mental capacity before gaining informed consent for an individual to take part in research.

Thames Valley DeNDRoN tackled this issue by running managed workshops, led by patients and carers, to offer staff and research colleagues guidance in this critical area of work. Olivier Bazin, Data and Communications Manager for Thames Valley DeNDRoN, explains how the workshop evolved,

"The problem we faced was a lack of informed consent training available nationally. We had many staff starting near the same time, and needed to offer a quick solution to their essential training needs. Obviously, the sooner our research staff could start to work independently to meet our research commitments, the better."

To meet this need Olivier delivered a workshop that focused on the main principles of the Mental Capacity Act 2005, while using role play to address the practical requirements and challenges that research staff face when obtaining consent. Crucially, Olivier asked public representatives to lead the role plays, giving Patient and Public Involvement (PPI) a meaningful role in the development of practice within the Network. He continues,

"Professional actors often play the role of patients or carers in such scenarios, but we saw a fantastic opportunity to integrate PPI into our Network in a substantive way. So we asked our PPI Members' Advisory Panel to lead the role playing section of the session. We gave them research case study scenarios, based on active studies within the NIHR Clinical Research Network Portfolio of research and asked them to play the role of potential study participants."

The Thames Valley PPI Members' Advisory Panel is made up of local people with an active interest in DeNDRoN. Primarily, these are people who have been affected by dementia or neurodegenerative diseases (mostly carers) in some way. Olivier felt their input could be invaluable,

"We believed people with such expertise

could make the training experience more relevant, so our researchers could learn about more than just process. We wanted them to understand what people were going through during the interview."

The first session provided training for twenty people and proved popular enough to be repeated in March this year. One of the research assistants who took part in the latest session was Malika Pavey,

"I joined the Network in October 2009 and took part in training in March 2010. We'd been shadowing more experienced members of staff up until that point. You do get a good understanding of how informed consent works by doing this, but it takes some time and it's not the right environment to question how the patients feel about the process."

For Malika, taking part in the role plays added a new dimension to her understanding of assessing mental capacity and gaining informed consent,

"As a researcher we have a tendency to think about the process in a legislative way, but conducting the role plays with volunteers from the Members' Panel helped to humanise the process. I'm not suggesting researchers wander around like robots, but the feedback from role playing helped me understand how I can most effectively communicate with patients and assess consent when talking to a patient or carer in DeNDRoN."

**"This is PPI at its best because it links patients and carers directly with clinical staff."**

The training session helped DeNDRoN staff to build the confidence and skills they needed to take consent and assess mental capacity in the "real world". Importantly, it achieved this in a way that gave them a valuable insight of the unique needs of the people in their Network. Because patients and carers experience the consent process, it stands to reason that they are best placed to offer guidance on how aspects of staff communication can be improved.

Joyce Ruiz joined the members' advisory panel alongside her husband when he developed dementia. She found taking part in the workshop a worthwhile, rewarding process,

"I was able to point out to young researchers areas that they needed to develop, which is not something we often get the chance to do. We've played a role in written and printed communications, but this is the first time I've had the opportunity to advise research staff how to best communicate with patients."

The role play also gave Joyce an opportunity to recommend some key issues for researchers to think about when talking to DeNDRoN

patients and their carers,

"I highlighted the importance of using language that lay people can understand. From my experience I've found that researchers have a tendency to use clinical language too much. They don't try and alienate patients on purpose; it's just the language they're used to. It's also really important for researchers to understand how important time is. My husband often responded to questions by saying yes, but he didn't necessarily understand what was being said. You have to take time to interact with people to gauge their level of understanding and this is something that inexperienced researchers don't necessarily appreciate."

Terry McGrath, PPI lead for DeNDRoN was delighted with the course and sees it as a great example of how PPI can make a real impact on Network performance:

"This is PPI at its best because it links patients and carers directly with clinical staff. They are not one step removed from the clinician. They're not part of a focus group influencing a report, or providing feedback on a publication. They are telling the clinician what he/she needs to do and as a result it has a much bigger impact. It validates the message, for both the public representative and the clinician. Ultimately, it is giving clinicians the skills they need to recruit patients and it is saying to public representatives that your voice is important and you can influence our work."

More info about this article:  
[daniel.spiers@nih.ac.uk](mailto:daniel.spiers@nih.ac.uk)

[www.dendron.org.uk](http://www.dendron.org.uk)