



Public Involvement Impact Review

Working Together to Shape Dementia Research



Background

Camille Cousley, a PhD student within the Dementia theme at ARC KSS and a physiotherapist at University Hospitals Sussex, had the opportunity to collaborate with the University of Chichester and the Dementia Hive in Worthing to carry out a research project that truly involved people living with dementia and their families. Camille's project was shaped by the voices and experiences of people living with dementia and their families, ensuring their perspectives were at the heart of every stage.

Involving People with Lived Experience

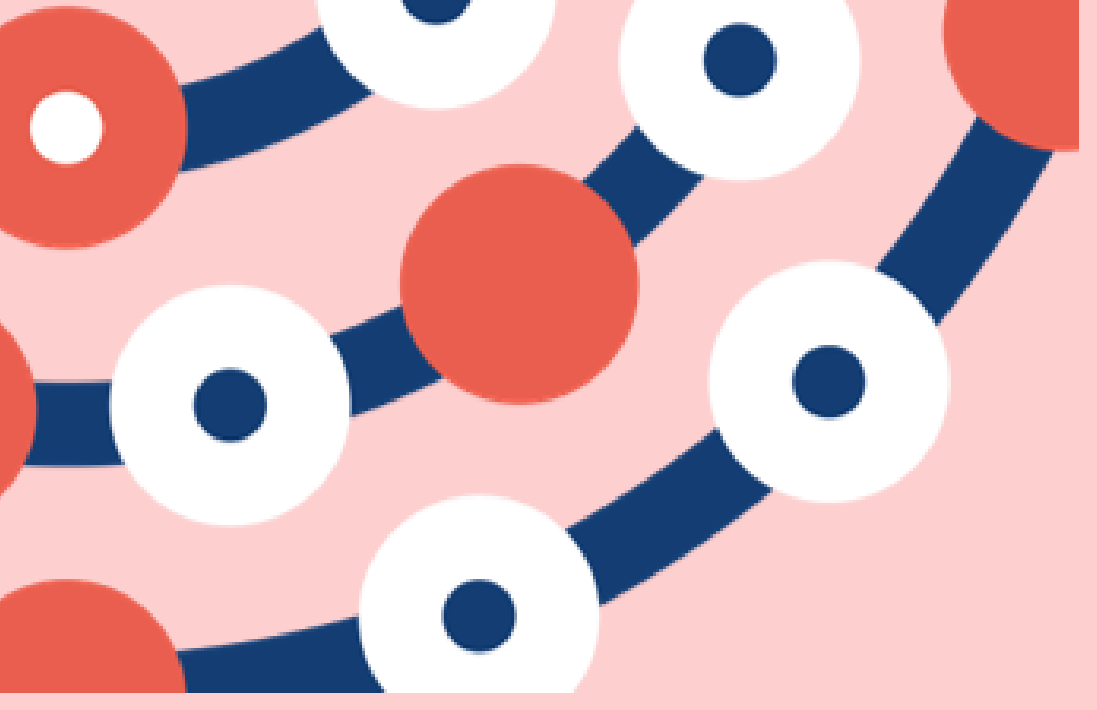
From the very start, people living with dementia, as well as their partners and caregivers played a key role in shaping the project. Their voices guided us every step of the way.

They helped decide what questions the research should ask, making sure it focused on the things that really matter to them. Their input kept the project grounded in real-life experiences.

They also gave thoughtful advice on how to involve people in the study, suggesting the best ways to invite participants, where to hold sessions, and how to collect information in ways that felt comfortable and respectful for everyone.

When it came to sharing the project more widely, they offered great ideas on how to spread the word and make sure the findings reach the people who need them most.





What I learnt

It was important to build trust first. I spent time getting to know the Dementia Hive Coordinator and the group before starting the project. Conversations, both one-to-one and in groups, helped explain the research and the process of checking mental capacity. Planning around other activities and making sure carers could attend was essential. Accessibility mattered too: for example, using audio versions of flyers for people with sight difficulties and choosing familiar venues. Extra time was needed for those new to research involvement, and not everyone could attend every session, so repetition helped.

What Changed 'IMPACT'

I really connected with everyone at the Dementia Hive, and we built a strong sense of trust and understanding. Through these conversations, a new partnership naturally formed between the research team and the group, which felt like a big step forward. They were welcoming and supportive, even offering their venue for the study, which was a huge help. Their positive feedback and openness made the whole process smoother. Having people with lived experience involved also played a key role in helping the project gain ethical approval from the university. Talking with them gave me valuable insight into how mental capacity assessments affect not just individuals, but their families too — it was a real learning experience.

Including people living with dementia and their caregivers was important to me, since research has shown they are often excluded. I wanted to show that they can contribute in meaningful ways and should be encouraged to take part in research in whatever capacity they can. I hope the work we do together can make a real difference.

