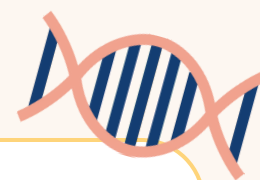


## Research and Innovation: Top tips for engagement and co-design with people living with dementia

Involving people with lived experience in research is essential if we are to find answers and solutions that meet their needs, and it reaps other benefits too. Kath Sykes, Applied Research Collaboration Kent Surrey and Sussex (ARC KSS) Living Well with Dementia Implementation Lead, shares some top tips on best practice.



### 1 Build and maintain trusted relationships

Build and maintain trusted relationships with the services providing community support to people living with dementia. They are more likely to support dissemination of information and support engagement for researchers if they: 1) trust you will understand and respond to people's living with dementia needs, and 2) think what you are doing will be of benefit to the people they support.

### 2 Go to where people with dementia feel comfortable

By going to the people you want to engage with, you will increase the participation of people who may otherwise be excluded, unable or worried about travelling/attending somewhere new.

### 3 Ensure information is designed for them

At the very least, this means writing in plain language and thinking about presentation. Avoid medical and academic language and jargon in all communication. Consider how this is presented too. People with dementia can have visual and auditory changes that affect how they will experience written and verbal communication.

### 4 Be prepared to adapt to individual needs

Including online, some people will prefer one to one, some people will be happy to engage in small friendly groups.

### 5 Invest time in building a connection

Take the time to build trust and connect with the people you are engaging with, understand what matters to them, even if it is not related to your research. Be personable, take time to introduce yourself, what you are doing and why.



## 6 Be dementia friendly

People experience dementia differently, but always follow recommended practices. Pace all activities, maintain a calm and friendly environment, avoid loud and/or background noises which can be distracting and distort sound. Read the room for disengagement, people with dementia are less likely to speak up if they are struggling.

## 7 Design for dementia

If you are designing for dementia refer to recommended design principles for dementia, don't assume, and do test what works in your project.

## 8 Design for inclusivity

Think about representation, accessibility, usability and acceptability from the start. Experience of dementia will differ depending on an individual's biopsychosocial circumstances, not everyone with dementia is the same and all these factors need to be considered when designing inclusively.

## 9 Follow up

This will help ensure people feel their contribution is really valued, and it will help future researchers secure engagement in the future too.

There are many benefits to involving people with dementia in research and innovation- including better quality and relevant research and outputs. It can also really benefit people living with dementia too, helping them feel valued, involved and supported. *"Doing this makes me feel like I'm making a difference, that I'm important and I matter"* was one heartfelt comment from a person living with dementia who has recently been co-designing a digital self-report tool with us.

### Below are some links you might find useful

[A practical guide to designing products and services for people affected by dementia](#)

[Creating websites for people with dementia](#)

[Designing for Dementia](#)

[The Digital Inclusion Framework \(DIF\) for Health and Care](#)

