

Ethical involvement of people living with Dementia in research



Ethical practice in public involvement is about respecting people's rights and dignity, including those living with dementia.

Because dementia is progressive and varies from person to person, people's abilities and preferences may change over time. Ethical involvement means staying flexible, listening, and adapting so the person can lead wherever possible. Uncertainty is natural; what matters is how we navigate it together.

Click on the topics above to explore how these principles translate to public involvement with people living with dementia

Rights & legislation

Everyone has the right to express themselves, access information, and make their own choices. Legal frameworks like the **Human Rights Act (1998)** and the **UN Convention on the Rights of Persons with Disabilities (CRPD)** remind us of our responsibility to support people with dementia to be heard, make decisions, and stay in control of their lives. As researchers, we have a responsibility to ensure these rights are upheld in meaningful ways.

Start with ethical foundations

- ✓ Use the UK Standards for Public Involvement to shape your approach.
- ✓ Check your organisation's policies on payment, safeguarding, and accessibility.
- ✓ Focus on welcoming, supporting, and recognising people as equal partners.
- ✓ Talk about roles clearly from the outset and explore options together.
- ✓ Clarify expectations and co-create role descriptions and timelines.

Understand and apply capacity principles

While formal consent is not required for public involvement (unlike research participation), the principles of the **Mental Capacity Act (2005)** offer helpful guidance:

- Presume capacity unless it's clearly shown otherwise.
- Respect people's choices, even when others may disagree.
- Support people to understand and decide. Give time, space, and practical aids.

Make involvement flexible

Dementia affects people differently and abilities may change over time. Involve early, learn together and be prepared to adapt .

- Focus on current strengths, not fixed expectations.
- Allow people to step in, step out, or change roles.
- Clarify that involvement is voluntary. There is no contract or obligation.
- Avoid rigid processes or burdensome requirements.

Independence & respect

People living with dementia bring valuable experience to research. Involvement should support their independence, identity, and dignity.

Each person experiences dementia in their own way, and those experiences may change over time. Because experiences of dementia vary and can change over time, this guide is designed to prompt reflection and help start open conversations.

Recognise people as experts in their own lives

- Keep involvement active, with roles that have purpose and impact
- Ask how people prefer to be involved.
- Use clear, respectful language .
- Work towards mutual respect and shared benefit.

Build trust through relationships

- Involvement grows over time, as you are getting to know people.
- Make time for conversation and shared learning.
- Long-term relationships help you understand what matters and how people want to be supported as dementia progresses.

Create opportunities, not limits

Well-meaning caution can restrict autonomy and opportunity.

- Avoid assumptions about ability.
- Balance safety with choice.
- Involve people in understanding and managing risk.

Enable people to stay in control

- Provide clear, manageable information.
- Use visual or written supports if useful.
- Let people choose how to contribute; e.g. speaking, writing, or creative approaches.
- Allow time for reflection.

Inclusion & accessibility

People living with dementia can and do contribute meaningfully to research. Inclusive involvement means looking at what gets in the way, respecting differences, and creating supportive conditions. This takes listening, curiosity and developing the approach over time.

Challenge barriers and foster equity

Inclusive involvement comes from paying attention to what helps people take part and our learning together.

- Start with individual preferences and strengths.
- Involve early and keep people involved over time.
- Check assumptions and biases. Notice how they may influence experience.
- Shadowing, mentoring and training can build confidence and new skills, for public partners and researchers.
- Be curious and culturally humble when working with underrepresented communities.

Be clear, creative and adaptive

Involvement may look different at different stages of dementia and contexts.

- Involve people in shaping their role and the support they want.
- Ensure understanding using accessible, dementia-friendly formats.
- Adjust settings, materials, and timing to suit different abilities and preferences.
- Offer breaks, smaller tasks, or shorter sessions when needed.
- Use inclusive language. Avoid jargon or distressing terms.
- Use creative approaches and tools like visual aids, storytelling, or art where helpful.

Make involvement fair and rewarding

People should never be worse off for taking part in research. Payments should be prompt, clear, and made in ways that suit the individual.

Allow for accessibility needs such as support tools or carer payments. Wherever possible, expenses should be covered up front. Keep things simple by avoiding financial or bureaucratic hurdles.

Follow national [NIHR guidance on payment and recognition](#).



Wellbeing & support



People living with dementia generously share their time, energy, and lived experience to shape better research. This often comes alongside personal challenges, changing health, and daily life. Apart from being inclusive, involvement must be caring. Supporting wellbeing means taking proactive steps to promote physical and emotional health.

Start with emotional safety

Showing care and reliability builds confidence.

- Build trust through introductions and informal conversation, for all involved.
- Allow time for reflection and joy, especially if topics are emotional.
- Create a calm and kind atmosphere. Small things like room layout, tone, and breaks make a big difference.

Make roles flexible and responsive


People's needs and circumstances change. Involvement can evolve with them.

- Reinforce that people can pause, step back, or stop at any time.
- Let individuals lead on what works for them and make it easy to adjust their involvement.
- For example trial shorter sessions or smaller tasks to test if it works for them.

If you're unsure, check in with someone who knows the person well, and with their agreement, involve them for support if helpful. You can also work with established groups that have trained support workers.

Watch for signs of overload

Be alert to changes that may signal stress, fatigue, or overwhelm. Respond kindly. Offer adjustments or a break if needed.

- Drop in energy, confidence, or engagement.
 - Signs of withdrawal, frustration, or confusion during/after sessions.
 - Missed meetings or changes in communication.
 - Concerns raised by carers or family
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With thanks

This guide has been produced by Keith Oliver, Jenny Richards, Elizabeth Abbot, Alicia Bewick and Naomi Morley. We are a group of people living with Dementia, carers and researchers, working together to explore and enhance public involvement in research with people living with Dementia.

We would like to thank all those who have contributed to this project and so generously given their time to participate in many conversations and inspiring this work.

We would also like to acknowledge the kind support from the Department of Health and Social Care and National Institute for Health and Care Research (NIHR) Applied Research Collaboration South West Peninsula (PenARC). We are grateful for the resources and platform provided for learning and growth.

This guide is independent work supported by the National Institute for Health Research. The views expressed in this publication are those of the author(s) and not necessarily those of the National Institute for Health and Care Research or the Department of Health and Social Care