

# The Dementia Enquirers Gold Standards for Co-Research



**deep**

The UK Network  
of Dementia Voices



Innovations  
in Dementia



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# Background

## **What are Dementia Enquirers and DEEP?**

Dementia Enquirers and DEEP<sup>1</sup> are delivered and facilitated by Innovations in Dementia<sup>2</sup>. We are very grateful for the support of the National Lottery Community Fund.

Between 2018 and 2023, people with dementia from 20 groups in the DEEP network were supported to conduct their own small-scale research projects through a programme called Dementia Enquirers. Many groups had already been involved in research studies carried out by universities. However, this programme gave people with dementia a chance to create, develop, lead, and be in control of their own research – on issues that are important to them. The aim was also to learn what it actually means—and takes—for them to be ‘in the driving seat’ of research.

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<sup>1</sup> DEEP is a network of influencing groups led by, or actively involving, people with dementia

<sup>2</sup> A not-for-profit Community Interest Company

# Involving people with dementia in research

It is not that long ago that even the idea of including people with dementia as research participants was up for debate. At the turn of the century, researchers were only just beginning to try out ways of asking the views of people with dementia in research settings.

Concerns around these approaches included ethical and practical considerations such as:

- gaining informed consent
- the risks associated with involvement
- the validity of responses from people with dementia

A number of pioneering researchers worked hard to bring the voices of people with dementia into research, testing out and learning about the best ways to do this<sup>3</sup>. They challenged not only the research system but the prevailing stigmatising narratives about people with dementia. It was people with dementia who showed them the way, by sharing their experiences and having their perspectives included in research.

Fast forward to 2023. The experiences of people with dementia are reflected in a range of research studies, with researchers needing to be explicit about the ethical approaches they adopt to make this a good and safe experience.

Additionally, there is a high expectation, particularly from research funders, that people with dementia should not just be the subjects of research, but should also have a *stake in* research and a say in what it is and how it is carried out.

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<sup>3</sup> Wilkinson, H (2001) *The Perspectives of People with Dementia*: Jessica Kingsley Publishers UK

These Gold Standards set out some principles and best practice around co-research with people with dementia including PPIE (Patient and Public Involvement and Engagement) and co-production. We describe these approaches (particularly co-production) as people with dementia and researchers 'sharing the driving seat of research'.

In Dementia Enquirers we have moved beyond PPIE and co-production to a model of people with dementia 'in the driving seat'.

## **What is Patient and Public Involvement and Engagement (PPIE)?**

Patient and Public Involvement and Engagement (PPIE) means members of the public informing and shaping research. It is different from taking part in research as a participant.

PPIE can (and should) happen even before the research starts, with academic researchers encouraged to talk with people to find out the issues that are most important to research. However, in our experience this doesn't happen very often!

PPIE makes research better. Researchers can connect with people with dementia to get advice on their research methods and project materials, to discuss findings, recommendations and dissemination. A PPIE group of people with dementia that meets regularly with researchers can really change the way the research unfolds.

For academics, their research is more efficient, effective and impactful. PPIE can help them communicate their findings more effectively, and generally make research more accessible to all.

There are positive outcomes for people with dementia as well:

- People with dementia often say they want to ‘give something back’, hoping to improve the lives of other people with dementia both now and in the future.
- There is also the opportunity to gain new knowledge and skills and to be part of a like-minded group of other people.
- A PPIE group can be an enjoyable place to be!

PPIE is a requirement of a lot of dementia research funders. The National Institute of Health Research (NIHR)<sup>4</sup> sets out its own reasons why PPIE is important:

- **Democratic principles:** people who are affected by research have a right to have a say in it. It’s a part of citizenship, public accountability, and transparency. It can also help to empower people by providing the opportunity to influence research that is relevant to them
- **Providing a different perspective:** personal knowledge and experience brings a different perspective to the research. People are not just their health condition – they bring other life experiences as well
- **Improving the quality of the research:** involving ‘patients and the public’ helps ensure that research focuses on outcomes that are important to people
- **Making the research more relevant:** by identifying a wider set of research topics than would have been generated by just academics; ensuring research is focused on what matters to people; and helping to shape and clarify the research

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4 NIHR (2021) Briefing note 3: why involve members of the public in research?

- **Interests of research funders and research organisations:** several funding bodies, as well as research ethics committees, ask grant applicants about their plans for PPIE. There are high expectations that PPIE is a consideration of funding applications (or there is a good reason why not)
- **Ethics:** research ethics committees will often ask about plans for PPIE. It may even be part of their assessment process. They too have high expectations that it is considered and planned, as it can help ensure that research is ethical, relevant and acceptable from a public perspective.

You may also be interested to read the **Dementia Enquirers Gold Standards for Ethical Research** <https://bit.ly/3XF6EwW>





## Be aware:

We should mention that people with dementia have said they don't really like the term PPIE. Firstly, it is an acronym, and people rarely know what it stands for. Secondly, it describes patients and the public. People with dementia tend not to identify as a 'patient' unless they are in a health care situation.

PPIE feels like a term created and used by researchers and research funders.

PPIE groups of people with dementia often come up with their own name that they identify with e.g. the ALWAYSs group (Action on Living Well: Asking You)<sup>5</sup> and the DEAR group (Dementia Experience in Action Research).

**From Dementia Enquirers we know that the involvement of people with dementia is not static. As people grow in confidence, their expectations about involvement increase. Involvement encourages more involvement. Good PPIE encourages co-production. Good co-production might even lead to people with dementia being more in the driving seat of research, leading their own research studies.**

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<sup>5</sup> Litherland, R, Burton, J; Cheeseman, M; Campbell, D; Hawkins, M; Hawkins, T; Oliver, K; Scott, D; Ward, J; Nelis, S; Quinn, C; Victor, C and Clare, L. (2018) 'Reflections on PPI from the 'Action on Living Well: Asking You' advisory network of people with dementia and carers as part of the IDEAL study.' *Dementia* 17 (8) pp1035-1044

# What is co-production?

Co-production means different things to different people. It is quite hard to define. It is a term that is used a lot in research, and also in health and social care, especially when new services or policies are being developed. It is about:

- Getting involved as equals
- Being recognised for the experience you bring
- Making something happen together

It is not just about participating in other people's work or ideas. But helping to shape new ideas from the beginning.

The New Economics Foundation describes co-production as:

“Where professionals and citizens share power to design, plan, assess and deliver support together. It recognises that **everyone has a vital contribution** to make in order to improve quality of life for people and communities.”

NIHR has produced its own guidance on co-producing a research project<sup>6</sup>, identifying the following key principles:

- **Sharing of power** – the research is jointly owned and people work together to achieve a joint understanding
- **Including all perspectives and skills** – make sure the research team contains all those who can make a contribution
- **Respecting and valuing** the knowledge of all those working together on the research
- **Reciprocity** – everybody benefits from working together
- **Building and maintaining relationships** – an emphasis on relationships is key to sharing power

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<sup>6</sup> NIHR (2021) Guidance on co-producing a research project

Research funders are becoming increasingly supportive of co-production, and often perceive it as a natural next step to PPIE – if it is done well.

You can read more about co-production in practice in our resource “The Right to a Grand Day Out: a story of co-production.”<sup>7</sup>

In “The Right to A Grand Day Out”, people with dementia ended up at a different point than they could ever imagined at the beginning of the project (in this case protesting with banners at a public railway station!) because of co-production. They had some recommendations for positive co-production:

- “Have a belief that keeps you focused on what you are doing. Ours was “everyone has a right to accessible transport”
- “Keep it simple! Don’t use jargon. Explain ideas”
- “It’s good to have some encouragement – to keep us on track and give us ideas”
- “Find someone you trust to help you with the practicalities but don’t let them take over”
- “Don’t feel you have to accept what others say. Keep challenging each other”
- “Payment to our group has enabled us to keep involved in this project. It acknowledges our work and contributions to the learning around co-production”

### **Be aware:**

Like PPIE, co-production is a word that is used more in research and services than in every-day life. There is a danger that ‘co-production’ and ‘PPIE’ are not really practiced in the truest sense of the words – that they are ‘tokenistic’ and people with dementia don’t feel valued.

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<sup>7</sup> The Right to a Grand Day Out: a story of co-production (2020)  
Innovations in Dementia: Exeter

# Two models of co-research

In the following section we describe two models that can be used in good co-research with people with dementia. One is the co-production model (which we describe as ‘sharing the driving seat’). The second is the driving seat model (people with dementia ‘in the driving seat’).

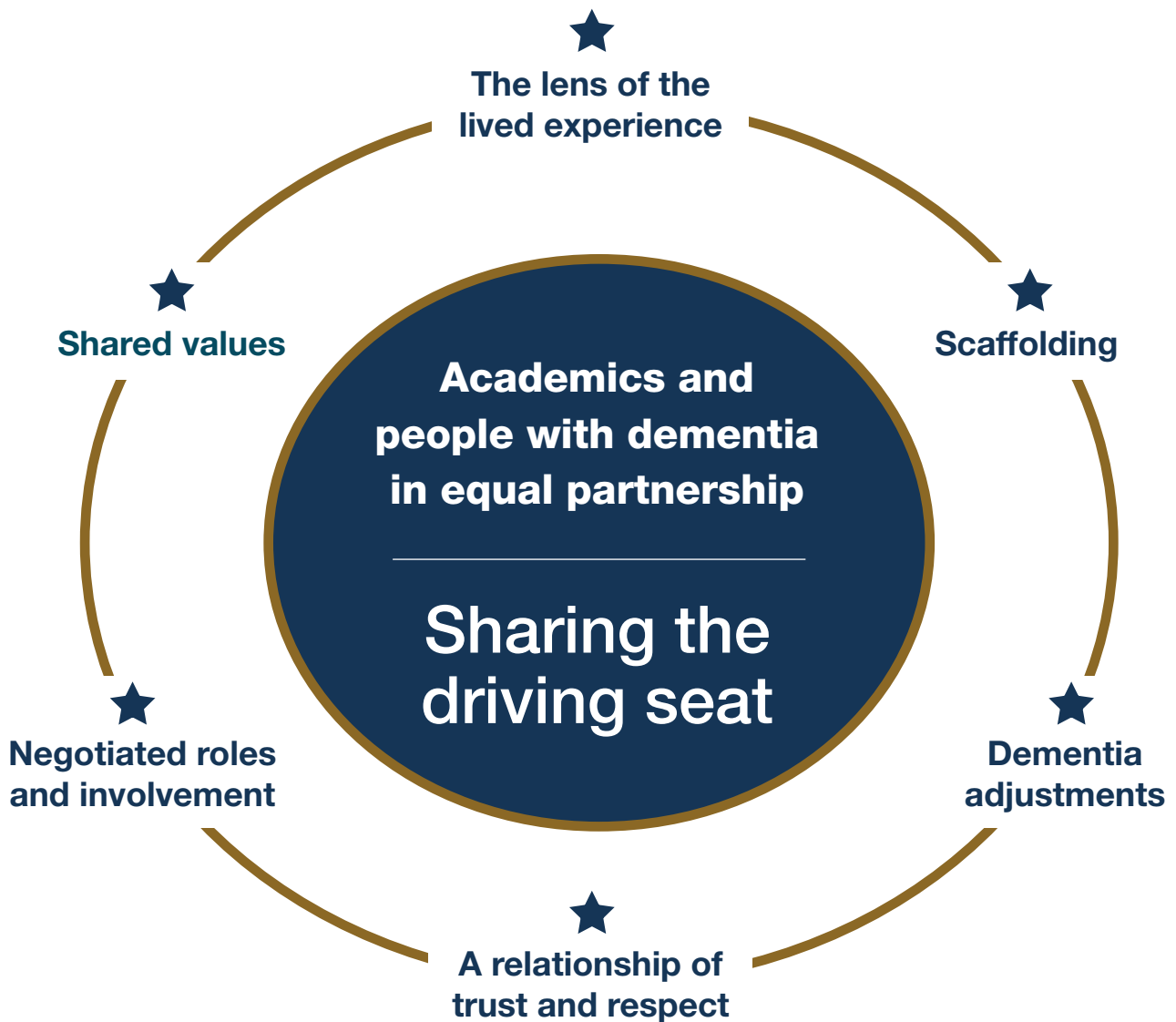
## The co-production model

High quality co-production (and PPIE) in research has got many benefits, according to people with dementia. True collaborations between people with dementia and researchers can result in:

- A range of expertise in the same place, with a balance of lived experience and researcher skills and knowledge
- Opportunities for learning and development of new skills for people with dementia
- Access to larger funding streams and therefore opportunities for more research

This model sets out the six elements that make co-production a positive experience for everyone, non-tokenistic and useful to the research.

**Remember, co-production works both ways. People with dementia may sometimes need to decide if co-production is useful to their own research – it might not always be so!**



## **The ‘driving seat’ model**

Dementia Enquirers has been about increasing the skills and knowledge of people with dementia to lead their own research. Their lived experience puts them in a very good position to say what dementia research should be about and how it should be carried out.

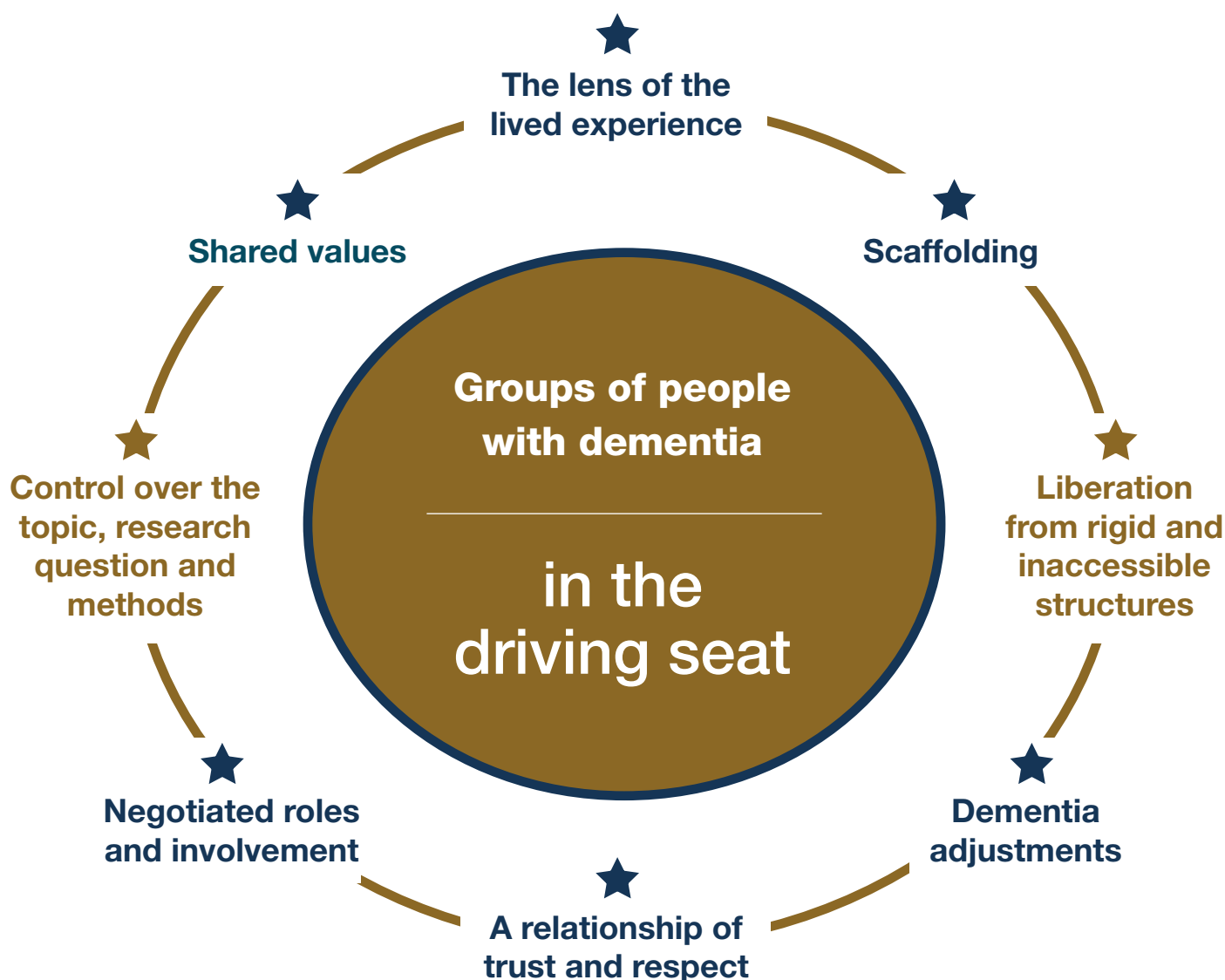
People with dementia have also adapted research methods and frameworks to be more dementia accessible, and have developed new ways of working within traditional research systems such as ethics processes. Being in the driving seat of research really helps to make dementia research better.

It is about shifting the power and democratising research. It doesn't mean that people with dementia have to do everything – but that they maintain the lead throughout.

The 'driving seat' model builds on the principles at the heart of PPIE and co-production i.e. that research is better when people who are the recipients or subjects of research findings are involved. Consequently, there are two additional Standards to our co-production model:

- a) People with dementia in control over the topic, the research question and the methods
- b) Liberation from rigid and inaccessible structures

### Dementia Enquirers Gold Standard of the 'Driving Seat' model



# What are our co-research Standards?

These Standards:

- Are defined by people with dementia
- Start from the assumption that co-research is the place you want to be and that you want to do it as well as you can
- Uses a disability rights approach, which is clear about the 'reasonable adjustments' that should be made
- Are a starting point – in your co-research with people with dementia you will generate, together, more principles and practicalities that are specific to you and your research
- Progress towards people with dementia being in the driving seat of research

## The 8 Standards are:

### Sharing the driving seat

1. Negotiated roles and involvement
2. The lens of the lived experience
3. A relationship of trust and respect
4. Dementia adjustments
5. Scaffolding
6. Shared values

### In the driving seat

## The 6 Standards above plus

7. People with dementia in control over the topic, the research question and the methods
8. Liberation from rigid and inaccessible structures

# The Dementia Enquirers Gold Standards for Co-Research checklist

This checklist is intended for researchers and people with dementia (who may also be researchers) to effectively share the driving seat in research studies, and work towards people with dementia having more opportunities to be in the driving seat. These ideas equally apply if you are working from a PPIE perspective.





## Standard 1: The lens of the lived experience

Acknowledge the importance of adding the voices of people with dementia into research processes

As researchers (with or without dementia) we will...	Yes/No/ Need to check
Publicly acknowledge the importance of a co-research approach in our research. Include this in our research websites, publicity materials and funding reports. Say it regularly to people with dementia	
Look at every aspect of our research, including anticipated work. Write a co-research plan for each part, in collaboration with people with dementia. Keep adjusting this together as the research goes on	
Don't expect people with dementia to be representative of other people with dementia, even though they will often bring with them the experiences of other people. Add numbers to our co-research activities to build a range of diverse experiences	
Create a feeling of equality within our research team, with people with dementia being as important as researchers, and others. We all bring a partial view of the world, and benefit by joining these partial views together	
Put evidence from the lived experience on the same level as other evidence	

## Standard 2: Recognise the strengths and skills of everyone

How will we negotiate and agree roles based on people's different interests, skills and knowledge?

As researchers (with or without dementia) we will...	Yes/No/ Need to check
Find out the skills and interests that people with dementia bring. There will probably be some surprises!	
Offer opportunities for people to learn about research processes. This can be through written information, a seminar or training. Think about the most appropriate ways of providing this learning – people differ in their learning styles and preferences	
Share stories around our research team. This can help inspire people about roles and opportunities they haven't yet taken up. A regular accessible newsletter is a way of doing this	
Share regular reminders about the research. As the 'jobs' stack up it can be easy to forget the focus and purpose of the research	
Keep talking about the things that people might like to get involved in. These can change as people become more confident, or their personal circumstances change	
Acknowledge what has changed because of co-research. Keep a record of the co-research activity and any action/change that has happened. If we keep adding to this list it becomes a visible, and potentially public, record of your whole approach	

## Standard 3: A relationship of trust and respect

Take steps to make sure that positive feelings arise in co-production – for everyone! Feelings about ‘trust and respect’ can be difficult to measure so think about how we will ‘know’ it’s there.

As researchers (with or without dementia) we will...	Yes/No/ Need to check
Let go of some of our learned ‘professional’ behaviour! Relax, share stories, be open and warm, listen, smile and laugh	
Do what we say we will do. Let people know we have done it. Provide feedback about what has changed	
Aim to create the best environment for co-research. Find out from people with dementia what this looks like (or take a look at Standards 4 and 5)	
Hold the co-research space, or make sure someone else is. People with dementia need to feel safe and secure that they are noticed, can speak, are being listened to and any concerns are acknowledged. We can use props to help with this such as the “I want to speak” cards	
Notice people who are quieter. Are there ways that we can draw them in? Would direct questions help? Or could we speak with them outside a main meeting?	

## Standard 4: Dementia adjustments

What adjustments can we make that ensure co-research is a good experience for people with dementia?

<b>As researchers (with or without dementia) we will...</b>	<b>Yes/No/ Need to check</b>
Write information about the project in a dementia accessible way. Where possible, try and write the same information in the same style for everyone, rather than 'special' information for people with dementia. There is more advice about writing clearly for people with dementia here <a href="https://bit.ly/3XaCNf8">https://bit.ly/3XaCNf8</a>	
When running meetings, send out reminders beforehand and on the day. Keep processes as simple as possible	
Draw on guidance from DEEP about running face-to-face meetings, online meetings and travel plans <a href="https://bit.ly/3JMYKOc">https://bit.ly/3JMYKOc</a>	
Keep meetings to an hour where possible. If a meeting is longer, make sure that breaks are factored into the agenda	
Limit agenda items at meetings to one or two main discussions	
Take it slowly. Don't speak too fast. Leave lots of space for people to speak. Notice people's body language which may show they want to speak or are trying to organise their thoughts	

## Standard 4: Dementia adjustments (continued)

What adjustments can we make that ensure co-research is a good experience for people with dementia?

<b>As researchers (with or without dementia) we will...</b>	<b>Yes/No/ Need to check</b>
<p>Translate and modify standard research systems to be as accessible as possible. Strive for clarity in every aspect, not least in language (no acronyms, jargon etc.)</p>	
<p>Write up accessible minutes of meetings straight away and send them out to people within a few days. Audio recordings of the minutes may be helpful to some people</p>	
<p>Chat to people after events and meetings to find out what the experience was like and what might need to change in the future</p>	
<p>Find out from people with dementia the personalised adjustments that will help them to participate in this role</p>	
<p>Give time, time and more time. Things will take longer. But meetings may need to be shorter. Ensure that managers and funders are conscious of the extra time needed for high quality co-research with people with dementia</p>	

## Standard 5: Scaffolding

What kind of behind the scenes, sometimes invisible support, will make people with dementia feel safe and secure in their role?

As researchers (with or without dementia) we will...	Yes/No/ Need to check
Carry the load of behind-the-scenes administrative support e.g. travel, venues, coding, appointments, arranging meetings, drafting, keeping in touch (all negotiated and agreed at the start, and ongoing). This has been described as “Looking after us, taking the strain off us”	
Mentor and provide tailored support for any individual who needs it	
Keep negotiating and making adjustments to how every member of the team works. Be prepared to be flexible	
Have high but realistic expectations of each other – encourage regular two-way communication	
Visualise the scaffolding that needs to be provided to keep co-production working well. Check the nuts and bolts and platforms regularly. Keep tightening it up	
Help to make research methods accessible and manageable by using the guide ‘How to do a Research Project’ <a href="https://bit.ly/40YYOR6">https://bit.ly/40YYOR6</a>	

## Standard 6: Shared values

Thinking about shared values provides the foundations for co-production. Making these explicit can help in the sharing of power

<b>As researchers (with or without dementia) we will...</b>	<b>Yes/No/ Need to check</b>
Talk together about what is important to people	
Create together a list of the values that connect us. It might take a while of working together to identify these values that connect you, and what this might mean for the work	
Return to our values at regular intervals; be explicit about how these values interact with our co-production work	
Pay people with dementia for their time. This acknowledges the value of the role they play in research co-production.	

## Standard 7: People with dementia in control over the topic, the research question and the methods

People have full control (or at least as much control as they want). This ensures that research is about the things that they identify as most important. Their lived experience puts them in a very good position to say what dementia research should be about and how it should be carried out.

As researchers (with or without dementia) we will...	Yes/No/ Need to check
Encourage people with dementia to think about what is important to them in their lives. What questions do they have? What would they like to know more about? What issues do they spend time discussing?	
A group discussion can help to centre people on the topics that people think are ‘most important’	
Support people with dementia to turn their research interests into a research question – by introducing a question mark	
Help people to map the kinds of roles they might like to have in the delivery of the research. What skills and interests do people have. Who would like to learn new skills?	
Scaffolding to help people take on a research role. This might be mentoring, accessible training, removing jargon and creating accessible summaries. These can go a long way to helping people to feel confident in their researcher role	



## Standard 7: People with dementia in control over the topic, the research question and the methods (continued)

People have full control (or at least as much control as they want). This ensures that research is about the things that they identify as most important. Their lived experience puts them in a very good position to say what dementia research should be about and how it should be carried out.

<b>As researchers (with or without dementia) we will...</b>	<b>Yes/No/ Need to check</b>
Enable people with dementia to ‘see’ the whole research plan – and identify the range of ways people could take over the driving seat at different points and throughout the whole research journey	
Keep returning to the concept of ‘driving seat’ – how in control of the research are people with dementia feeling? What needs to change so that people with dementia retain ownership and are leading the research?	
Remember that being in the ‘driving seat of research’ doesn’t mean that you have to do everything yourself. Team work and support (“scaffolding”) can really help.	
Be an enabler – to allow people with dementia to lead the way, calling on skills and experience as they need it, rather than the other way around	

## Standard 8: Liberation from rigid and inaccessible structures

In Dementia Enquirers, people with dementia have had the opportunity to carry out their research differently. It can be liberating to step outside ‘academic walls’. This liberation can relate to methodologies, processes, language, systems – all the ways of working which academics often adopt by default, but which are not necessarily suited to innovative and collaborative work.

As researchers (with or without dementia) we will...	Yes/No/ Need to check
Use the other resources of Dementia Enquirers to support a shift in the ways that research is carried out. Lots of researchers are referencing these resources in their funding applications and ethics applications	
Use the Dementia Enquirers Gold Standards on Ethical Research to ensure your research is ethical <i>from the perspective</i> of people with dementia (not just to jump through hoops of ethics approval)	
Take every opportunity to converse and work with people with dementia. They will teach us and help us to move outside of our ‘academic walls’	
Publish our co-research (with people with dementia of course) in peer reviewed journals and help to build a body of evidence	

# Over to you – sharing the driving seat

We hope you will use these Gold Standards in your co-research with people with dementia. The most important thing you can do though is to keep talking with people with dementia. Share your research space, and together you will continue to define and add to these Gold Standards in a way that is particular to your own research.

We all have an important part to play sharing the driving seat with people with dementia:

- People with dementia and their groups can come up with their own ideas and get going with their own research – seeking funding if they need it
- Academic researchers can promote and implement the model in their own research activities. This will require them to forge close relationships with groups or networks of people with dementia
- Funders can design specific funding streams for ‘driving seat’ projects and promote the model to those seeking funding from them
- Research Ethics Committees can make their processes much more accessible to people with dementia
- Journals can consider their publishing criteria in relation to ‘driving seat’ projects and perhaps run special editions to promote them

To find out more about  
Dementia Enquirers, visit  
**[dementiaenquirers.org.uk](http://dementiaenquirers.org.uk)** or  
contact **Rachael Litherland**  
at **[rachael@myid.org.uk](mailto:rachael@myid.org.uk)**.

**Innovations in Dementia is a not-for-profit Community Interest Company (CIC).** People with dementia are at the heart and start of all our work. We promote a positive but realistic view of dementia, demonstrating that, although it is life changing, it does not have to be life ending. We support people with dementia to live with hope and keep control of their lives.

We want to influence how others engage with people with dementia, and we provide training and consultancy. We run many innovative projects, often in partnership with universities, public bodies or charitable funders.

Please also visit our websites:

## **Innovations in Dementia**

<http://www.innovationsindementia.org.uk/>

and

## **Dementia Voices**

<https://dementivoices-id.org.uk/>

This website includes mini-sites for five of our key projects:

- DEEP (the UK Network of Dementia Voices)
- Dementia Diaries
- Dementia Tip-share
- Dementia Creatives (including Craftivists)
- Dementia Enquirers







To find out more about Dementia Enquirers, visit [dementiaenquirers.org.uk](https://dementiaenquirers.org.uk) or contact **Rachael Litherland** at [rachael@myid.org.uk](mailto:rachael@myid.org.uk).

