Dementia Enquirers

Bringing people with dementia into the heart of research

Our learning for dementia research funders

This resource has been produced as part of the Dementia Enquirers programme. Dementia Enquirers puts people in the driving seat of research – planning and leading their own research enquiries. Dementia Enquirers has produced a range of resources to support the involvement of people with dementia in research.

We have learnt so much in this programme about what is different about research led by people with dementia themselves. So, what does Dementia Enquirers mean to you as a dementia research funder?

Shifting the power and democratising research

Dementia Enquirers has been about increasing the skills and knowledge of people with dementia; putting ownership, control and power into their hands; and supporting them to lead their own research. As a research funder you can set out your expectations of how involved people with dementia should be in research proposals and their subsequent role in any funded research project. You can encourage applicants to move beyond PPIE (patient and public involvement and engagement) – and even co-production and towards a driving seat model. You can encourage researchers to draw on the resources available through the Dementia Enquirers programme.

Moving beyond PPIE and co-production

PPIE is a solid expectation for most dementia research funders. The quality of a lot of PPIE is still debatable however, with many people with dementia being critical of the more tokenistic efforts of some research projects. As part of Dementia Enquirers we have set out **'Gold Standards on Co-Research'** **https://bit.ly/3YQ7sj6**. These can both be delivered to a very high quality, and people with dementia are very favourable about these approaches when they are done well.

However, the involvement of people with dementia is not static. As people grow in confidence, their expectations about involvement increase. Involvement encourages more involvement. People with dementia leading research becomes a logical next step.

What does ‘being in the driving seat’ mean?

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. They 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. All these approaches are of benefit to academic researchers as well as other people with dementia.

We believe that people with dementia should be leading research from the beginning, with the necessary support to make this possible. Research funders have a role in encouraging researchers to shift power and democratise research.

The impact of being in the driving seat

Dementia Enquirers has built the confidence of people with dementia to lead their own research. It has made the most of people’s skills and developed new skills. It has generated a range of projects based on the things that people with dementia find important.

One of our principles is that experiential knowledge needs to be taken as worthy of influencing research. This kind of knowledge is by no means lesser than the knowledge of other stakeholders. But it is the case that all knowledge, including the knowledge of academics, is *partial* – we are trying to find the whole picture. Dementia Enquirers has put new questions on the research agenda, and piloted new ways of answering those questions.

Many people with dementia have gone on to partner with academic researchers in a more equitable way, and as true co-investigators.

Of course, the biggest outcome is that dementia research is better when people with dementia are properly involved.

Building on the legacy of Dementia Enquirers

How can you, as a research funder, carry forward the learning from this programme? You are perfectly placed to set higher funding expectations about the involvement of people with dementia in research, promoting a 'driving seat' model as well as PPIE and co-production.

You can encourage dementia researchers to use the Dementia Enquirers resources to plan and deliver their research, involving people with dementia from the very beginning.

With most research funding being directed through academic institutions, there is a major barrier to people with dementia leading their own research. You could develop research funding streams that would enable people with dementia to take the lead in funding applications.

Finally, you could ask applicants to show that they have applied the **'Dementia Enquirers Gold Standards for Ethical Research'** **https://bit.ly/3XF6EwW**.

For more ideas from Dementia Enquirers visit **www.dementiaenquirers.org.uk**

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Innovations in Dementia

Dementia Enquirers

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