Dementia Enquirers

Bringing people with dementia into the heart of research

Our learning about research ethics

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 in research led by people with dementia themselves. So, what does Dementia Enquirers mean to you in your work on Research Ethics Committees (RECs)?

The 6 Standards are:

1. Working in real partnership ('co-production')
2. Respect and acknowledgment
3. Safety and wellbeing
4. Informed consent and capacity
5. Confidentiality and anonymity
6. Information that is simple, accessible and open

Recognising the problems

It goes without saying that research must be ethical... but many people find current processes inaccessible and unfit for purpose. When REC approval is required, the process can often feel very daunting (not only to people who aren't familiar with it, but also to people who are!). It is often hard to know which REC(s) you would go to, what kind of approval you need, and what happens during the approval process. There are seemingly different (and inconsistent) processes between many of the different RECs. The systems can often feel complicated, jargon-ridden, time-consuming, resource-draining and de-skilling. And not only that, but some of the processes themselves seem actually *unethical* – or at least not central to what is, or should be, ethical about a project.

Approaching ethics from the perspective of people with dementia

The work on the '**Dementia Enquirers Gold Standards for Ethical Research**' **https://bit.ly/3XF6EwW** has highlighted that ethics permeate every aspect of research – it's so much more than just getting a proposal through a committee. We have shown how, once we make the language, systems and concepts more accessible, people with dementia (and many others) can engage with ethics processes with enthusiasm. Not only that, but involving people with dementia in ethics processes can actually broaden the scope and impact of research.

What can RECs do?

RECs can encourage researchers to be guided by the Gold Standards right from the start of drafting their proposals; before submitting to a funder; before submitting to a REC; and throughout the whole process of fieldwork, analysis, reporting and dissemination.

RECs also have a key role to play in:

- accepting that people with dementia can be in the driving seat of research
- making their own processes and language simpler and more accessible (though still in line with regulatory requirements)
- expecting that research involving, or carried out, by people with dementia, must also use simpler and more accessible methods – and that these are not unethical
- accepting that, if a project follows the Gold Standards, this is evidence that it is ethical (though this will not always mean that REC approval is not needed).

What difference will this make?

We believe that the outcomes from these actions will be significant because:

- standards of research involving people with dementia will rise, and the skills and confidence of researchers to involve people with dementia will increase
- research will reflect much more closely the priorities of people with dementia (for example in relation to research design and conduct) and make the most of all they can contribute
- research teams will have more thorough discussions about research ethics when working co-productively
- many more people with dementia will feel confident to be involved in research, in whatever capacity

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

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COMMUNITY FUND

Innovations in Dementia

Dementia Enquirers

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