

# The Dementia Enquirers Gold Standards for Ethical Research Accessible Summary

Version 2: Spring 2023

‘Research ethics’ can sound mysterious and rather scary. But ‘being ethical’ in research is really just about being honest, respectful and careful towards anyone involved in a research project.

## **An ethical research project:**

- is honest and clear
- is respectful of everyone taking part, their dignity and rights
- looks after the health, safety and wellbeing of everyone taking part
- has a clear plan to complete the research – but stays flexible
- has a clear purpose/reason to be done
- abides by the law and any regulations

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Dementia Enquirers aimed to support more people to be involved in research, not just academics and practitioner researchers. So, we piloted a new set of Standards which have been identified by people with dementia who are involved in research (or are wanting to be involved).

### 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

We hope that these Standards will help to ensure that all dementia-related research is ethical from the perspective of people with dementia.

You can access the full Dementia Enquirers Gold Standards for Ethical Research at <https://bit.ly/3XF6EwW>

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).