

The DEEP-Ethics Gold Standards for Dementia Research Accessible Summary

Version 1: Summer 2020

‘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

The DEEP-Ethics Gold Standards for Dementia Research

Accessible Summary

Version 1: Summer 2020

We hope Dementia Enquirers will support more people to be involved in research, not just academics. So, we are piloting these DEEP-Ethics Gold Standards.

The Standards draw together some principles which have been identified by people with dementia who are involved in research (or are wanting to be involved).

The 6 principles 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.

To find out more contact Philly Hare – philly@myid.org.uk or visit www.dementiavoices.org.uk/dementia-enquirers/