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INVOLVING PEOPLE LIVING WITH DEMENTIA IN RESEARCH: WHAT ARE THE ETHICAL ISSUES AND HOW IS IT COVERED IN ADVANCE CARE PLANNING?

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Background While we strive to involve people living with dementia (PWD) in their own health care decision making to the extent that their capacity permits, guidelines for their involvement in research which may not have an immediate personal benefit are less evident. Dementia is a national health priority in Australia, but significant gaps remain in our understanding of how best to involve PWD in research and how to address the issue in advance care planning.

Aim This paper summarises research into the questions of what are the ethical issues about involving PWD in research?

Methods A narrative literature review was conducted and analysed with reference to the Australian National Statement on Ethical Conduct in Human Research.

Results The review can be summarised under the following themes: substitute judgement; how capacity can vary due to risks; barriers to recruiting people with dementia; how to determine capacity to give consent; and gaining assent rather than consent from participants. The results of the review were further analysed in relation to the current guidelines for research and existing guides for developing advance care plans.

Discussion Gaps in the National Statement included: how capacity should be determined; what defines best interests; how assent and dissent by someone with dementia should be determined and respected; and whether or not people with dementia should be included in high-risk research.

Conclusion Researchers, ethics committees, health care professionals, PWD and their carers need better guidance about how to address this issue in advance care plans.