

Empowering people living with dementia to guide future research involvement

Advanced Research Directives (ARDs) are designed to allow individuals in the early stages of dementia to outline their preferences for participating in research as their symptoms evolve.

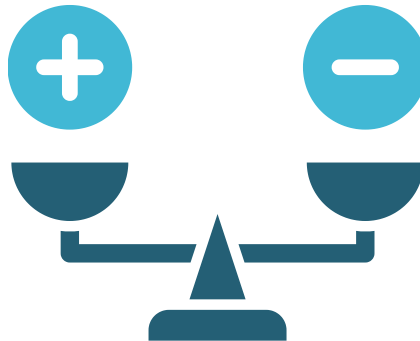


Most dementia researchers agree ARDs would enable autonomy in decision-making and increase opportunities for people with dementia to be included in research.

ADVANTAGES

Help other decision makers know the wishes of the person with impaired capacity

Help to include people with impaired capacity in research

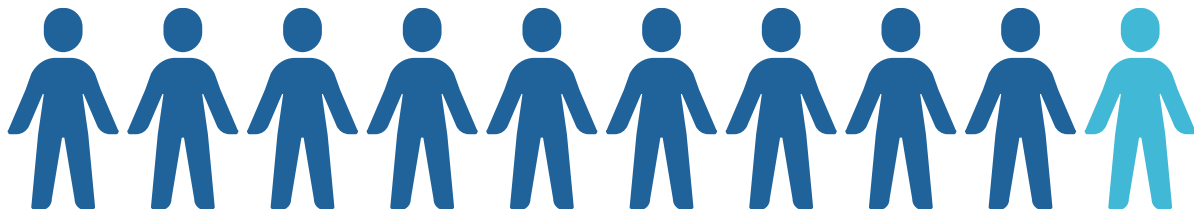


DISADVANTAGES

Time lag - documents may be mislaid

May not be accepted as evidence by ethics committees

May not adequately protect the person's interests



Most older people would be willing to be included in future research activities such as cognitive testing, behavioural observations, physical measurements and therapies, imaging procedures, access to medical records data, use of previous biological samples and future blood draws (including for genetic research).

Fewer people were agreeable to being included in drug studies.

INFORMATION SOURCES

Ries N, Mansfield E. Advance Research Directives: Dementia Researchers' Views on a Prototype Directive and Implementation Strategies. *Ethics & human research*. 2021;43(3):10-25. <https://doi.org/10.1002/eahr.500091>

Ries NM, Mansfield E, Sanson-Fisher R. Advance Research Directives: Legal and Ethical Issues and Insights from a National Survey of Dementia Researchers in Australia. *Medical law review*. 2020;28(2):375-400.

DOI: [10.1093/medlaw/fwaa003](https://doi.org/10.1093/medlaw/fwaa003)

Ries NM, Mansfield E, Sanson-Fisher R. Ethical and legal aspects of research involving older people with cognitive impairment: A survey of dementia researchers in Australia. *International journal of law and psychiatry*. 2020;68:101534-. DOI: [10.1016/j.ijlps.2019.101534](https://doi.org/10.1016/j.ijlps.2019.101534)

Ries N, Mansfield E, Sanson-Fisher R. Planning Ahead for Dementia Research Participation: Insights from a Survey of Older Australians and Implications for Ethics, Law and Practice. *Journal of bioethical inquiry*. 2019;16(3):415-29. DOI: [10.1007/s11673-019-09929-x](https://doi.org/10.1007/s11673-019-09929-x)



The National Dementia Helpline

Free call 1800 100 500

Email helpline@dementia.org.au

Useful links from the Dementia Australia website:

<https://www.dementia.org.au/>

<https://www.dementia.org.au/research/participate-dementia-research>



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