

# Addressing Inequities in Research: Advance planning for participation

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**Creating Connections Palliative Care Conference**  
*Palliative Care Research: Achieving change in practice and policy*

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# Inequity Problem

- Under-representation in research for people unable to give their own consent
- Inclusive research is necessary to build evidence for quality care and supports

Review Article : *Gerontologist*, 2022, Vol. 62, No. 2, e112–e122

## Older Persons' and Their Caregivers' Perspectives and Experiences of Research Participation With Impaired Decision-Making Capacity: A Scoping Review

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## Advance planning for research participation: Time to translate this innovation into practice

*Australian J Ageing*, 2023;42:225–233.

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### COMMENTARY

Protection by exclusion? The (lack of) inclusion of adults who lack capacity to consent to research in clinical trials in the UK  
Shepherd et al. *Trials* (2019) 20:474

Victoria Shepherd<sup>1,2\*</sup>, Fiona Wood<sup>1</sup>, Richard Griffith<sup>3</sup>, Mark Sheehan<sup>4</sup> and Kerenza Hood<sup>2</sup>

# Advance Planning for Research Participation

Consider values and wishes  
in relation to research

Document preferences in an  
Advance Research Directive

Select trusted supporter /  
decision-maker

# Ethical and Legal Context

## International

- US National Bioethics Advisory Commission (1998)
- World Psychiatric Association, Old Age Psychiatry Section (2009)
- International Ethical Guidelines for Health-Related Research Involving Humans (2016)
- Alzheimer Europe, Report on involvement of people with dementia in research (2019)

## Australia

- National Statement on Ethical Conduct in Human Research, Chapter 4.5
- ACT Medical Research Power of Attorney (2016)
- Victoria Medical Treatment Planning and Decisions Act 2016 (in force 2018)
- WA Guardianship and Administration Act 1990 (2020)
- TAS Guardianship and Administration Amendment (Advance Care Directives) Act 2021 (2022)

# Australian research on stakeholder views

People 60+ *survey*  
(n=174)

- >90% agreeable to wide range of research activities
- 79% expressed interest in making an ARD

Dementia  
researchers *survey*  
(n=63)

- >80% supported ARDs to promote autonomy and research participation
- 57-89% would offer ARDs for various research activities

Dementia  
researchers  
*interviews*  
(n=11)

- feedback on a prototype ARD form
- views on implementation of advance research planning

Consumers 50+  
*interviews*  
(n=25)

- feedback on a developed ARD form and a guidance document
- views on implementation of advance research planning

Research supported with funding from the Australian Association of Gerontology

# UK Research

Planning ahead for research participation: survey of public and professional stakeholders' views about the acceptability and feasibility of advance research planning

Shepherd et al. *BMC Medical Ethics* (2023) 24:70  
<https://doi.org/10.1186/s12910-023-00948-3>


Healthcare professionals' understanding of the legislation governing research involving adults lacking mental capacity in England and Wales: a national survey

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To cite: Shepherd V, Griffith R, Sheehan M, et al. *J Med Ethics* 2018;44:632–637.

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**‘There’s more to life than money and health’: Family caregivers’ views on the role of Power of Attorney in proxy decisions about research participation for people living with dementia**

Victoria Shepherd <sup>1</sup>, Richard Griffith<sup>2</sup>, Kerenza Hood<sup>3</sup>, Mark Sheehan<sup>4</sup>, and Fiona Wood<sup>5</sup>

*Dementia*

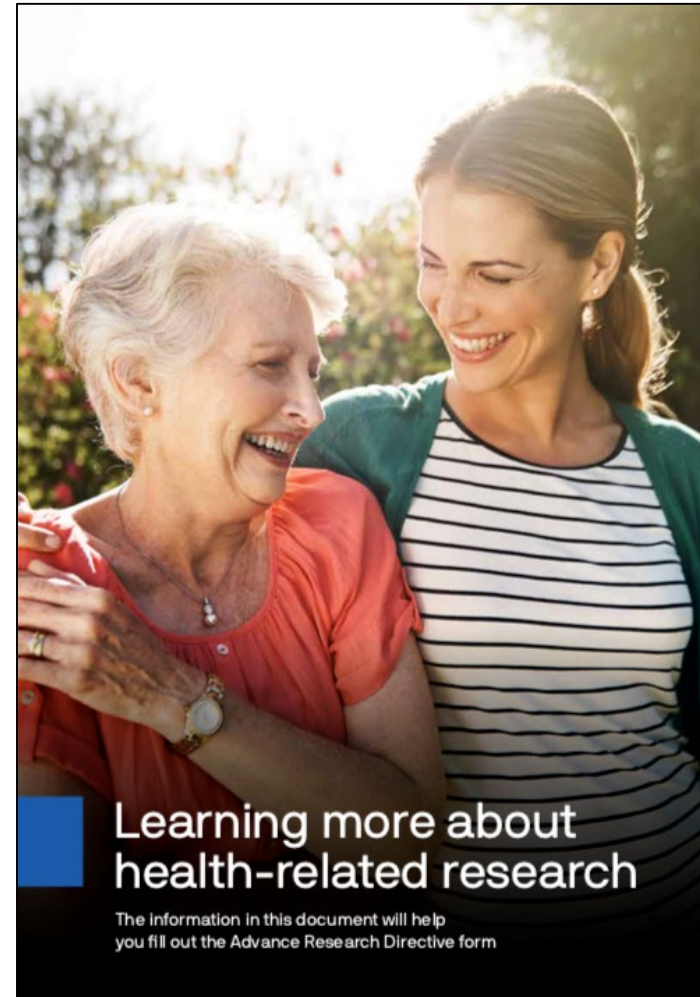
Volume 20, Issue 1, January 2021, Pages 308-325

Development of a decision support intervention for family members of adults who lack capacity to consent to trials



Shepherd et al. *BMC Med Inform Decis Mak* (2021) 21:30  
<https://doi.org/10.1186/s12911-021-01390-4>

# ARD form and Guidance Booklet



<https://www.stepupfordementiaresearch.org.au/useful-resources-2/>



# Advance Research Directive Form

Part 1: Let's Start to Think about Research

Part 2: My Wishes about Taking Part in Research

Part 3: Choosing a Support and Decision-Maker

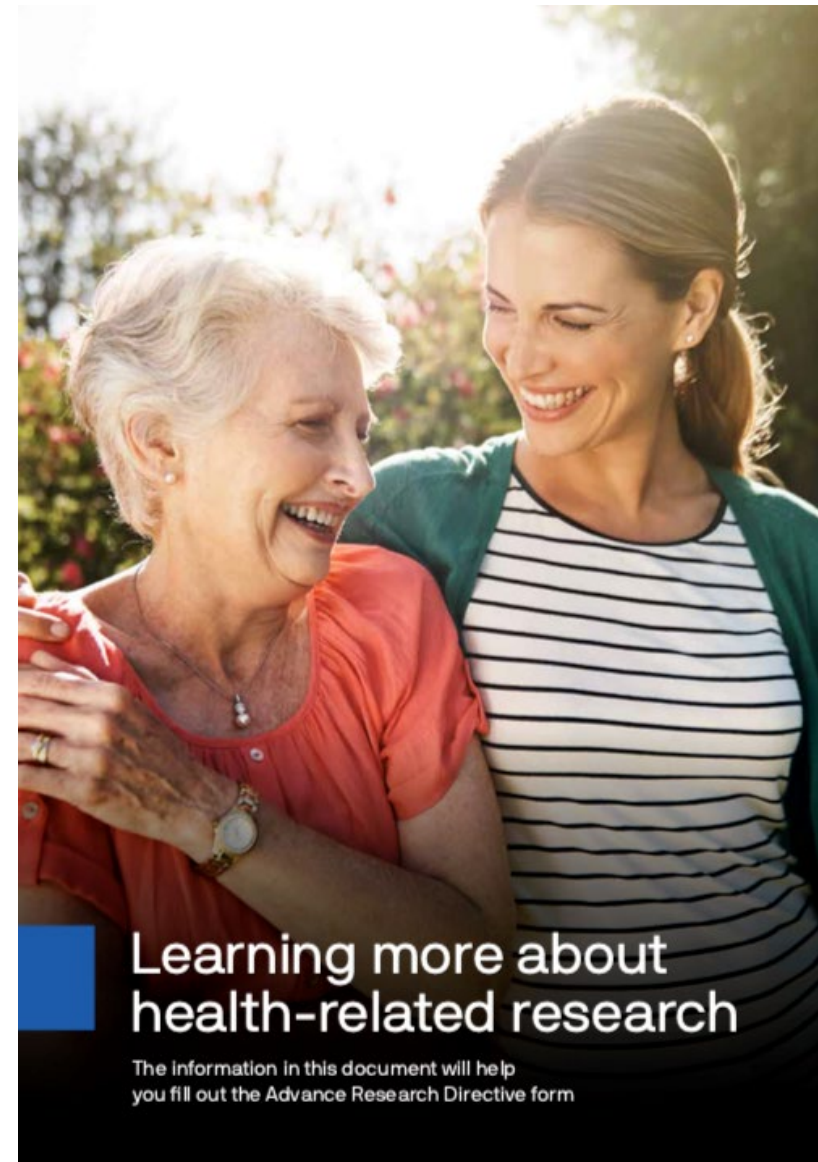
Part 4: Signatures





# Guidance Booklet

- Section 1: Health-related Research
- Section 2: Examples of Research Studies
- Section 3: Making and Using an Advance Research Directive, with example scenario
- Self-Quiz



# Overall Assessment

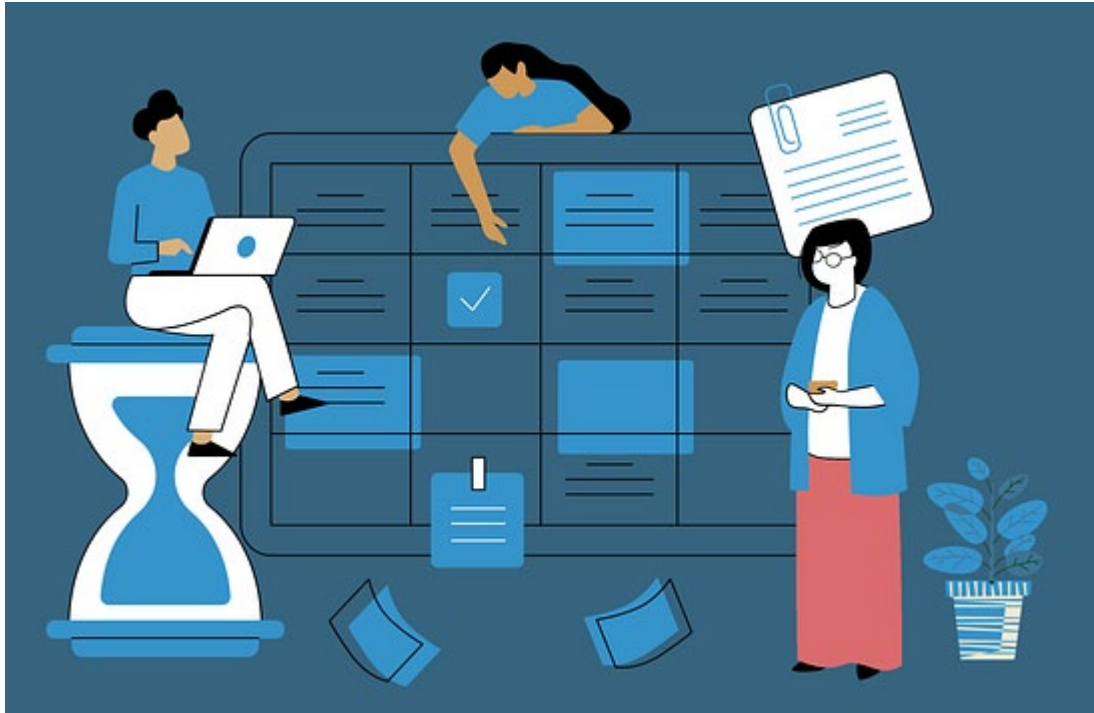
- All participants described ARD materials as straightforward and easy to understand
- Right amount of information and level of detail both for people with good research literacy and for people who had not participated in a research study before
- ***“It was very clear, easy to understand. It didn't feel like I was trying to make sense of a medical document, or a legal document, which can just turn you off.” (P13, female, 55)***
- ***“I think there's a lot of information there that will put people's minds at rest ... it's presented in a way that's easy to understand.” (P22, male, 56)***
- ***“when it comes to explanation [about research] ... it's addressed all the likely questions.” (P1, male, 83)*** who had taken part in over 20 research studies
- All would use the Directive to document their willingness to take part in future research

# Opportunities to Encourage Research Planning

- Making research decisions - eg, to join a study, sign up to a registry, donate for post-mortem research
- Advance care planning
- Legal planning
- Receiving a new diagnosis
- Making care or living transitions



# Research on Advance Research Planning



# References

- Ries N, Johnston B. Making an Advance Research Directive: An Interview Study with Adults Aged 55 and Older with Interests in Dementia Research. *Ethics in Health Research*. 2023;45(3): 2-17.
- Ries N, Mansfield E. Advance Research Directives: A Qualitative Study of Dementia Researchers' Views on a Prototype Directive and Implementation Strategies. *Ethics in Health Research*. 2021;43(3):10-25.
- Ries N, 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.
- Ries N, 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.
- 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):415-429.