Received: 13 June 2022 | Revised: 30 October 2022 | Accepted: 14 November 2022

DOI: 10.1111/ajag.13161

Australasian Journal on Ageing WILEY

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

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Funding information
Australian Association of Gerontology Research Trust, Grant/Award Number: Strategic Research Grant

Abstract

Objectives: Advance planning for research is a process that involves thinking about, discussing and expressing preferences for taking part in research during future periods of incapacity. The process may include making an advance research directive and naming trusted people to be involved in decisions about research participation. Advance research planning could help to overcome barriers to including people with dementia in research. To encourage innovation in this area, this article presents recommendations informed by a stakeholder workshop that brought together consumer representatives and representatives active in dementia, ageing and health-related research, policy-making, advocacy and service delivery in health and aged care.

Methods: An online workshop where 15 stakeholders shared perspectives and suggestions for implementing advance research planning, with a focus on research involving people with dementia.

Results: Raising awareness of advance research planning requires multi-faceted strategies. Training and resources are needed for researchers, ethics committees and organisations regarding this form of advance planning and the use of research directives. Like any form of advance planning, planning ahead for research must be a voluntary, informed and person-centred process. There is a lack of uniform legal rules on research involving people who lack the capacity to consent; however, advance research directives could, in principle, inform decisions about research participation.

Conclusions: As a matter of law, policy and practice, people are encouraged to plan ahead in many areas of their life. Research planning has been relatively neglected, and the recommendations offered here aim to encourage innovation in research and implementation in this area.

KEYWORDS
advance directives, dementia, research, ethics

1 | INTRODUCTION

The denial of opportunities to participate in research is a human rights issue for people living with dementia. Research inclusion at all stages of dementia is necessary to build the evidence for care and support,[1] yet there are longstanding problems with the under-representation of people with dementia in research, and in particular those with more advanced cognitive impairment.[2] In circumstances where potential participants are unable to give their own consent to research, other people are involved in decisions in formal and informal ways. Legislation may set out who has the power to authorise research participation, such as a decision-maker appointed by the person or a statutory tribunal.[3] Informal gatekeepers, such as clinicians and facility managers, often mediate research access to people with dementia.[4] Yet, people who exercise formal and informal authority may not be well-positioned to make a decision about research participation, especially if they do not know the person's views and preferences in relation to taking part in research studies.[5] Could advance planning for research help to overcome some of these barriers to the inclusion in research for people with dementia?

1.1 | Advance research planning

Advance planning for research is a voluntary process that involves thinking about, discussing and documenting preferences for taking part in research in the future. This process may include making an advance research directive and naming trusted people to be involved in decisions about research participation. Through this process, people have an opportunity to consider their wishes at a time when they have the capacity to do so. Having conversations with family members and other key people in the person's life can prepare those who are often '*a vital component to support participation*'[1(p311)] to know and advocate for the person's wishes. An advance research directive can strengthen authentic decision-making by those exercising legal authority, where authenticity '*is informed by knowledge of the person's values and is motivated by respect for the person*'.[6(p6)] This knowledge can also guide the actions of others involved in research access and activities.

First proposed over 30 years ago, the concepts of research planning and advance research directives have gained some ethical and legal recognition internationally, but reported use remains nascent.[7] In Australia, there is ethical and legal support for the principle that people may express their values and preferences about future research participation in advance directives or in legal documents that appoint substitute decision-makers.[7] The known wishes of a person have weight and should inform future decisions. Table 1 gives an overview of relevant domestic law and international guidelines and position statements.

Practice Impact

Advance research planning is a process that involves thinking about, discussing and expressing preferences for taking part in research during future periods of incapacity. It may include making an advance research directive. Informed by a stakeholder workshop, this article presents recommendations to encourage the translation of this innovative process into practice, with a focus on dementia.

Advance research planning may be tailored to a specific research project where it is anticipated that participants may experience cognitive changes during the term of the study. Their preferences for involvement in study activities during periods of incapacity can be considered and documented in a process sometimes described as *'advance consent'*.[8] Research planning may also be undertaken outside the context of a specific study, where individuals express their general views on taking part in research during future periods of incapacity and consider and document the kinds of research activities or procedures in which they would be willing or unwilling to be involved. In this article, an advance research directive refers to this latter process.

Studies in Australia demonstrate that researchers and older people are interested in making and using advance research directives. In a survey study, Australian dementia researchers supported adopting research directives into practice, with over 80% citing benefits, such as enabling people to make their own choices about future research participation; helping others (e.g. researchers and substitute decision-makers) to make decisions with regard to a person's known wishes; and supporting inclusion in research for adults with cognitive impairment.[7] Another survey sought the views of people aged 60 years and over on taking part in health research if they had dementia and were unable to give their own consent.[9] Over 90% said they would agree to participate in a range of research activities (e.g. observations, blood draws and scans) during future periods of incapacity and over three-quarters (79%) expressed interest in making an advance research directive if given the opportunity to do so.

However, there is scant reported testing or use of research directives in Australia[7] and little attention to practical steps needed to support awareness and implementation of research planning.

TABLE 1 Advance directives and research—domestic and international landscape

Australia

All states and territories have legal rules that enable people with capacity to: (1) record their preferences to guide future decisions about various aspects of their lives, including health-care, financial and lifestyle matters; and (2) appoint substitute decision-makers. The status of advance research directives varies within this legal context. In some states and territories, specific statutory rules apply (see below). Otherwise, general principles apply: if people express their preferences about what happens to them in the event of future incapacity, those wishes should be respected to the extent possible. Legislative definitions of medical research vary and may limit substitute decision-making for certain types of medical research; these definitions and limitations are not summarised here.

National Principles

Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws* (2014)

Sets out four national principles to guide legal frameworks for decision-making:

- All adults have a right to make decisions that affect their lives and to have those decisions respected.
- People must have access to support necessary for them to make, communicate and participate in decisions that affect their lives.
- A person's will and preferences must direct decisions that affect their lives.
- Effective safeguards are needed to prevent abuse and undue influence in decision-making.

Advance research planning is consistent with these principles; for example, a research directive enables a person to document their preferences for research participation, which should then guide future decisions.

National Statement on Ethical Conduct in Human Research (updated 2018)

'People with a cognitive impairment … are entitled to participate in research…' (Guideline 4.5.3)

'The process of seeking the person's consent should include discussion of any possibility that his or her capacity to consent or to participate in the research may vary or be lost altogether. The participant's wishes about what should happen in that circumstance should be followed unless changed circumstances mean that acting in accordance with those wishes would be contrary to the participant's best interests'. (4.5.7)

Australian Capital Territory

Powers of Attorney Act 2006

A person may appoint a medical research power of attorney. The attorney must follow decision-making principles, including giving effect to the person's wishes *'as far as they can be worked out … unless making the decision in accordance with the wishes is likely to significantly adversely affect the principal's interests' [s 41B(2)(a)]. The enduring power of attorney appointment form prompts the person to 'specify directions, limitations or conditions on the attorney's power'*.

New South Wales

Guardianship Act 1987; NSW Law Reform Commission, *Report 145: Review of the Guardianship Act* (2018)

Legislation does not cover advance directives for health care or for research. The NSW Law Reform Commission has recommended statutory recognition of both types of advance directives, stating that *'A patient may consent to health care or a medical research procedure in a valid advance care directive'*. (Recommendation 10.5)

Northern Territory

Advance Personal Planning Act 2013; Guardianship of Adults Act 2016

The *Advance Personal Planning Act* enables people to prepare an advance personal plan to set out their *'views, wishes and beliefs'* to guide future decisions *'about all or any aspect of the adult's care and welfare (including health care) and property and financial affairs'*. [s 8(1), (2)]

Queensland

Powers of Attorney Act 1998; Guardianship and Administration Act 2000

In an advance health directive made under the *Powers of Attorney Act*, a person may give directions about *'health matters'* and provide information related to those directions. [s 35(1)]

South Australia

Advance Care Directives Act 2013; Consent to Medical Treatment and Palliative Care Act 1995

The *Advance Care Directives Act* enables people to *'give directions about their future health care, residential and accommodation arrangements and personal affairs'* including *'specifying outcomes or interventions that they wish to avoid'*. [s 9(a), (b)]

Tasmania

Guardianship and Administration Amendment (Advance Care Directives) Act 2021

A person may make an advance directive to convey *'directions, values and preferences'* with regard to medical research procedures [s 35G(1)].

(Continues)

TABLE 1 (Continued)

Victoria	
Medical Treatment Planning and Decisions Act 2016	
A person may make an advance directive that sets out their *'binding instructions or preferences and values'* with regard to medical research procedures [s 12].	
Western Australia	
Guardianship and Administration Act 1990	
A person may make an advance health directive that *'includes a decision to consent or refuse consent to the commencement or continuation of the person's participation in medical research'*. [s 110P, s 3]	
International examples	
Global	
Council for International Organizations of Medical Sciences (CIOMS), International Ethical Guidelines for Health-related Research Involving Humans (2016)	*'If participants have made advance directives for participation in research while fully capable of giving informed consent, the directives should be respected'*. (p 61)
World Psychiatric Association, Section on Old Age Psychiatry, Consensus Statement on Ethics and Capacity in Older People with Mental Disorders (2009)	As part of advance care planning, older people *'should be encouraged to include a statement addressing their wishes concerning participation in research'* (p 1323)
Europe	
Alzheimer Europe, Overcoming ethical challenges affecting the involvement of people with dementia in research: recognising diversity and promoting inclusive research (2019)	*'Accept preferences expressed in an advance directive as a valid expression of interest in participating in the research'*. Involve *'people who are authorised to do so in determining whether proposed research is in line with the wishes expressed in the advance directive'*. (p 73)
United Kingdom	
Medical Research Council Ethics Guide, Medical research involving adults who cannot consent (2007)	Where a person with impaired capacity is included in research, *'[n]othing should be done which would be contrary to an advance directive or any other statement by the participant. … Researchers should find out from relatives and carers what the participant's views were on relevant issues prior to loss of capacity. They should specifically ask whether any relevant advance directives or expressions of wish are available and, if so, keep a record of them'*. (p 28)
Mental Capacity Act Code of Practice, Chapter 11 (Research involving a person who lacks capacity)	*'Researchers … must not do anything to go against any advance decision to refuse treatment or other statement the person has previously made expressing preferences about their care or treatment'*. (para 11.30)
USA	
United States National Bioethics Advisory Commission, Research Involving Persons with Mental Disorders that May Affect Decisionmaking Capacity (1998).	People should have an *'opportunity to express their preferences (where they have them) regarding future research participation…'* An advance research directive *'should be given considerable weight by whoever has authority to authorize research participation, but it cannot by itself be considered sufficient for enrollment in a particular study'*.
Canada	
Canadian Institutes of Health Research, Tri-Council Policy Statement, Ethical Conduct for Research Involving Humans (2018)	Article 3.11: *'Where individuals have signed a research directive indicating their preferences about future participation in research in the event they lose capacity or upon death, researchers and authorized third parties should be guided by these directives during the consent process'*. Using research directives *'respects the right of individuals to express their preference regarding participation in research and respects privacy by allowing individuals to control information about themselves and materials from their bodies'*.

TABLE 2 Workshop participants and affiliations[a]

Participant	Affiliation
Kate Harding	Consumer Engagement Coordinator Dementia Australia
Yun-Hee Jeon	Director, StepUp for Dementia Research Professor of Healthy Ageing, Faculty of Medicine and Health, University of Sydney
Briony Johnston	PhD Candidate and Research Assistant, Faculty of Law University of Technology Sydney
Elise Mansfield	Postdoctoral Research Fellow, Health Behaviour Research Collaborative School of Medicine & Public Health, University of Newcastle
Kylie Miskovski	General Manager, Policy and Advocacy Dementia Australia
Rhonda Nay	Emeritus Professor, Office of Nursing & Midwifery La Trobe University
Deborah Parker	Professor of Nursing Aged Care (Dementia), Faculty of Health University of Technology Sydney
Ann Peitsch	Dementia Advocate with Dementia Australia Person Living with Dementia
Nola Ries	Professor, Faculty of Law University of Technology Sydney
Val Schache	Dementia Advocate with Dementia Australia Person Living with Dementia
Linda Schnitker	Conjoint Research Fellow Bolton Clarke Research Institute, Bolton Clarke School of Nursing, Queensland University of Technology
Craig Sinclair	Postdoctoral Research Fellow, School of Psychology University of New South Wales
Judith Webster	Consumer Representative StepUp for Dementia Research
Chris White	Consumer Representative StepUp for Dementia Research

[a]Based on consent to be publicly acknowledged. Two participants preferred not to be identified by name.

To provide practical strategies to encourage innovation and adoption of advance research planning into practice, this article presents recommendations informed by a workshop that brought together consumer representatives and representatives active in dementia, ageing and health-related research, policy-making, advocacy and service delivery in health and aged care.

2 | METHODS

An online workshop was designed as a forum for stakeholders to exchange views and suggestions on processes to support advance planning for research. Targeted invitations were sent to individuals and/or organisations to elicit relevant expertise, and consumer representatives were identified through Dementia Australia and StepUp for Dementia Research.[10] All participants voluntarily agreed to participate. Table 2 lists participants and their affiliation.

Prior to the workshop, participants received the following materials as preparatory reading: a workshop agenda; brief participant biographies; a sample advance research directive form and an accompanying guidance booklet (see Appendix S1). The latter documents were developed as part of earlier work (led by authors NR, EM and BJ) with input from dementia researchers[11] and consumers aged 50 and older with interests in dementia research. (The consumer interview study is reported in a separate research article that is under review).

The workshop was held on 29 October 2021 and was conducted over 2.5 hours using the World Café method (www.theworldcafe.com) of small group conversation rounds adapted for an online format. The lead author (NR) facilitated the workshop with 15 participants. Breakout groups consisted of five participants who took part in three rounds of conversation, each 20 minutes in duration. Each group included: consumer representatives; university-based researchers with experience in dementia

research; and individuals with subject matter or sector expertise in research ethics, dementia, aged care and/or advance care planning.

Groups discussed three topics: (1) raising awareness of advance planning for research; (2) ethical and legal aspects of advance research directives; and (3) documents to support advance research planning, including preparing, storing and using research directives. Appendix S2 provides the workshop agenda and discussion prompts for the three topic areas.

During each conversation round, participants recorded their ideas on a shared online document. After the small group conversation rounds, participants had a full group discussion on key points. This discussion was audio-recorded with participant consent and then transcribed. Participants were also invited to contribute comments in writing using a 'chat' function in the online workshop platform. Data were saved in de-identified format.

Following the workshop, a writing group was formed to develop recommendations on advance research planning and its translation to practice informed by the stakeholder discussion. Two authors (NR and BJ) used a qualitative descriptive approach to review and synthesise key points from the written comments recorded on the shared online document, the saved 'chat' comments and the final discussion transcript. The lead author prepared a first draft of the manuscript, and all authors contributed revisions for a second draft, which was then shared with all workshop participants for comment. Illustrative quotations from the workshop document appear in italicised text in the next section. The workshop and associated data collection were approved by the University of Technology Sydney Human Research Ethics Committee (ETH21-6367).

3 | RESULTS

3.1 | RECOMMENDATIONS: Raising awareness of advance research planning

3.1.1 | A phased approach

Workshop participants recommended a phased approach to raise awareness of advance research planning, starting first with those for whom the process is most likely to be relevant, including people interested in research and *'anybody with a health condition that is likely to impact on their decision-making ability*'. The opportunity to prepare an advance research directive may be of interest for individuals who sign up to a research registry (e.g. StepUp for Dementia Research), participants in longitudinal research studies (e.g. in areas such as ageing and dementia) and people who choose to make a posthumous body donation for research.

Australia's Clinical Practice Guidelines and Principles of Care for People with Dementia[12] state that health and aged care professionals should discuss advance planning with people with dementia, including making advance care directives and appointing substitute decision-makers for health and financial matters. For people with dementia, information on research planning can be introduced when appropriate and meaningful, taking care not to overwhelm people with information at the time of diagnosis.[13] As an example, workshop participants noted that research planning could be discussed alongside other planning activities in postdiagnosis support programs provided by Dementia Australia.

As a next phase, awareness of research planning could be promoted more broadly. Peak bodies such as Dementia Australia, Advance Care Planning Australia and Cancer Councils have key roles in public education and would be trusted sources to disseminate information and resources on planning ahead for research. Information could be promoted through health services, including memory clinics and geriatricians.

Consumer advocacy groups involved in health research initiatives were highlighted as important partners in communicating information to relevant audiences and collaborating in projects to implement research planning: *'Consumer … involvement in research creates a community who are potentially very helpful messengers to the broader community'*.

3.1.2 | Training and resources

Workshop participants considered that training and resources on advance research planning are required for researchers, human research ethics committees and organisations seeking to enhance their readiness to undertake research with participants with dementia. Workshop discussion recognised varying knowledge and practices in research communities on the ethical aspects of consent and inclusion in research for people with cognitive impairment. It was noted that training is needed for *'some researchers around keeping up their skills in consent'* and practices such as supported decision-making.

Workshop participants agreed that advance research planning aligns with changing perspectives on 'vulnerable' participants in research, with a focus on ethically appropriate opportunities for inclusion rather than over-protective exclusion.[14] Aged care organisations may implement advance research planning as part of improving research readiness among staff and clients.[15]

The Royal Commission into Aged Care Quality and Safety observed that '*[t]here have been many missed opportunities in research and innovation in the aged care sector*'.[16(p77)] Through research planning initiatives, aged care clients, and those in their support networks, can learn about research participation, consider their preferences for involvement in research activities in the event of incapacity and prepare research directives if they wish.

Guidance on research planning should also be developed for medical and health professionals, especially those involved as clinician-researchers in fields such as geriatrics, neurology and dementia. Workshop participants noted it is *'also worth targeting lawyers [since they advise] about other forms of planning, such as making a will'* and can prompt people to consider research planning. Dissemination of advance research planning information through a range of sources will, over time, raise broader community awareness of this form of planning ahead.

3.2 | Ethical and legal aspects of advance research directives

3.2.1 | Voluntary and well-informed processes

Like any other kind of advance planning, workshop attendees agreed that making a research directive must be a voluntary and informed process, and not influenced by factors such as dependence on care. A concern expressed in the workshop was that in *'pushing for research to be integrated in clinical care, there may be a perceived moral obligation to contribute to research being conducted at a particular institution'*. In addition, if people undertake a comprehensive approach to planning ahead, they will prepare various documents, such as appointments for substitute decision-makers and advance directives for health care and for research. It is important that people engaged in these processes, and those who support them, understand the function and legal status of each document and avoid creating conflicting documents and confusion about the authority of different appointed decision-makers.

Advance research planning may be incorporated into advance care planning initiatives, but the differences between making choices about future care and future research must be clear. Research on motivations for involvement in dementia research indicates the importance of distinguishing '*the goals of research (to generate generalizable knowledge) from clinical care (to benefit an individual person)*'.[17(p94)] This point was echoed in our workshop: *'it is important to separate consent to clinical care and consent for research. Need to ensure there is no confusion or blanket approach to consent. There must be a distinction between the two'*.

3.2.2 | Core values and person-centred approaches

An advance research directive (ARD) addresses the problem of not knowing a person's preferences about taking part in research during periods of incapacity. However, the person's wishes are just one ethico-legal consideration in the context of research that seeks to involve people who may be unable to give their own consent. Other key aspects include the core values and principles that the proposed research has merit, is well-designed—including effective co-design where appropriate—and risks to participants are minimised.[18] As stated in the workshop:

> *Must be careful that the ARD is not seen as one document that rules/applies to everything. Need to look at the area of research, is it justifiable to include this person? Must go through the process of making sure the key principles of ethical research are adhered to, and one document alone is unlikely to give all the answers we need.*

Workshop participants underscored that research processes must be continuously person-centred and engage a person who has cognitive impairment in decisions about themselves. When a person who expressed willingness for research participation in a directive has an opportunity to take part in a particular research activity, it is essential to elicit their current perspectives.[1] As the National Statement provides '*[r]efusal or reluctance to participate in a research project by a person with a cognitive impairment … should be respected*'.[18(4.5.11)] Consistent with the ethical principle of justice, people should not be excluded from opportunities to take part in research because they do not have a research directive. That is, advance research planning should augment existing processes for enabling participation of people with dementia in research, rather than replacing them.

If people choose to prepare a research directive, they should be aware they can amend or revoke it, as long as they have the capacity to do so. As with any advance planning document, like a will or power of attorney, it is important to periodically review and update a research directive to ensure it conveys a person's current preferences.

3.3 | Advance research directive documentation

3.3.1 | User-friendly documents

Workshop participants agreed it is important to have well-designed documents to support advance research planning. They found the sample research directive form and guidance booklet (see Appendix S1) to be *'very easy to read and understand'* and *'clearly written and straightforward to complete'*. The workshop discussion noted that an advance research directive should not be *'just another form to fill out'* and it is important to *'highlight points of difference'* with other types of advance planning, especially planning for care in end-of-life circumstances. Efforts to promote advance care planning may be hindered by *'a reluctance to talk about death and end of life'*. By contrast, *'people may be more willing to talk about advance research planning with a focus on benefiting others'* and contributing to the advancement of knowledge.

Australian research has found that the uptake of advance planning activities is higher among people of Anglo-Celtic background.[19] Workshop participants recognised the need for further work to develop tailored research planning resources and directive documents that are accessible and meaningful to a range of groups, including Indigenous people and people from culturally and linguistically diverse backgrounds. Co-design practices have recently proven successful in a large-scale advance care planning co-design education program for Chinese-speaking people in Australia.[20]

3.3.2 | Status and use of documents

Workshop discussion also considered the absence of uniform legal rules on advance research directives and the inclusion in research of people who lack the capacity to consent. In this context, research directives are best framed as an expression of a person's preferences that, while not necessarily legally binding, can serve to inform decisions about research participation. However, advance planning documents will fail to meet this purpose if they are not available when needed. Workshop participants agreed it is essential to encourage people who make research directives to share copies with key people, especially those who may be involved in decision-making and providing support for research participation. If research registries, institutes or programs facilitate advance research planning with prospective participants, appropriate systems for secure storage and access will be required. People who participate in the national e-health system, *'My Health Record'*, are able to upload their advance directive documents to this platform.

4 | CONCLUSIONS

As a matter of law, policy and practice, people are encouraged to plan ahead in many areas of their life. Research planning has been relatively neglected, and the recommendations we offer here aim to encourage implementation and evaluation of this concept in practice. We have proposed strategies to raise awareness, situated research planning and research directives in a broader ethico-legal context and considered the status and use of advance research directive documentation. We have focused on dementia, but our recommendations are relevant to research planning for people with other conditions that may affect decision-making capacity.

A number of topics are ripe for investigation, including: the effectiveness of strategies for implementing research planning for relevant audiences; introducing research planning into advance care planning initiatives; responses to and use of research directives by those involved in research processes, including researchers, human research ethics committees and substitute decision-makers; and the impact of advance research planning on research participation for different populations and in different settings.

Research in this area will also generate evidence to inform changes to ethical guidelines and legislation. Modernised frameworks should seek to reduce unnecessary barriers to research inclusion and support practices that give a voice to people who wish to plan ahead for research participation.

ACKNOWLEDGEMENTS

We acknowledge the contributions of all participants who took part in a stakeholder workshop. Open access publishing facilitated by University of Technology Sydney, as part of the Wiley - University of Technology Sydney agreement via the Council of Australian University Librarians.

CONFLICTS OF INTEREST

No conflicts of interest declared.

DATA AVAILABILITY STATEMENT

De-identified data from the workshop referenced in this article are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Ries N, Johnston B, Jeon Y-H, et al. Advance planning for research participation: Time to translate this innovation into practice. *Australas J Ageing*. 2022;00:1-9. doi:10.1111/ajag.13161