

Advance Care Planning: national prevalence in general practice, residential aged care facilities and hospitals

Protocol and interim findings

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Advance Care Planning Australia

Advance Care Planning Australia (ACPA) is a national program to improve community awareness of advance care planning, build workforce capability through education initiatives, produce information resources and translate the evidence into practice

ACPA is the lead agency for the national Specialist Palliative Care and Advance Care Planning Advisory Service program known as **Decision Assist**.

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Acknowledgements



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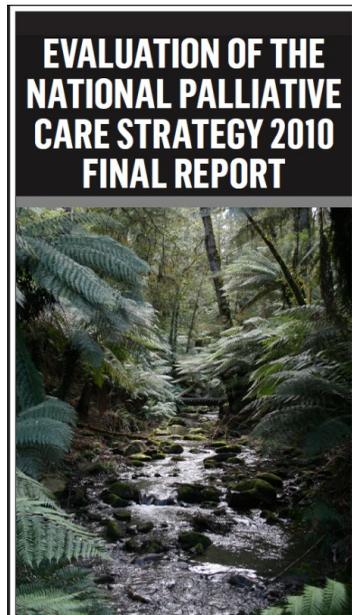
Decision Assist: an Australian Government initiative.



Policy context

Identified the lack of advance care planning data to measure and track the uptake and the use of ACPs by patients and health professionals

Identified the need to improve data and data collection for the purpose of monitoring the strategy's effectiveness



Purpose of the study

To determine the Australian national prevalence of advance care planning and completion of Advance Care Directives (ACDs) in general practice, residential aged care facilities and hospitals.

To explore people's self-reported use of ACP and views about the process.



Aims of the study

1. Determine the prevalence of ACP documentation in paper and/or electronic health records of people aged 65 years or more in general practice, residential aged care facilities and hospitals
2. Assess the quality, validity and variation of the ACP documentation across different sectors and jurisdictions
3. Explore peoples' views on ACP, and self-reported ACP uptake
4. Explore whether clinical care plans and medical orders developed for the person are consistent with their documented preferences for care.



Components of the study

Literature review

National governance – advisory committee and national collaborators

National consultation and investigation of terminology, legislation and forms

Protocol development including tools and ethics approval

Piloting testing across sectors

Study coordinator education program and jurisdictional manuals

Application process, panel assessment, contracting and funding

Database development, data collection, analyses and reporting

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Study protocol – file audit

- 50 records audited in 49 Australian organisations (expected sample of 2450 records)
- ACP documentation that can be located in records within 15 minutes of opening the record
- Data collectors receive approved data collection tools, training manual with jurisdictional specific information, and will undertake 90-minutes of online training on conducting the record audit and surveys
- Take between 30 to 45 minutes to complete the audit

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Study protocol – file audit

Inclusion criteria	
Part 1. Records audit	Part 2. Survey
Males and females ≥65 years of age (≥50 years for ATSI people) For hospitals and residential aged care facilities: admitted for >48 hours For general practices: visiting general practice on the nominated day/(s) of the study	Everybody included in Part 1 English-speaking Able to consent
Exclusion criteria	
Part 1. Records audit	Part 2. Survey
<65 years of age (<50 years for ATSI people) People admitted to the ICU People in maternal/obstetric wards People in mental health units For hospitals and residential aged care facilities: admitted for <48 hours	Non-English speaking People who do not have decision-making capacity People unable to or electing not to provide consent People expected to die within 24 hours

ATSI – Aboriginal and Torres Strait Islander peoples; ICU – intensive care unit

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Study protocol – file audit

- Obtain a list of current inpatients or residential clients who meet the study eligibility
- Eligible participant list is randomised by Monash University; random sampling will not be performed in general practices
- A total of 60 records will be provided; the first 50 to be utilised for the purposes of the study
- Data collectors will start auditing once they receive the audit lists
- Data collection will use either a paper-based or electronic data collection tool specifically designed for this study and jurisdiction
- Auditing requires 3 coordinators over 3 days

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Study protocol – manual example

Statutory preferences	Statutory decision-maker	Non-statutory documents	Other documentation
Refusal of Treatment Certificate (Competent)	Enduring Power of Attorney Medical Treatment	Advance Care Directive	Resuscitation Plan (if there is documented evidence reflecting the person's preference)
Refusal of Treatment Certificate (Non-Competent)	Enduring Power of Guardianship (prior to 31/08/2015)	Advance Care Plan	Goals of Care Form (if
	Enduring Power of Attorney (Personal Matters) (from 01/09/2015)	Statement of Choices	

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SECTION 1. TYPE AND PLACE OF DOCUMENTATION

1. Can you find any advance care planning (ACP) documentation regarding health and personal care and preferred health outcomes within 15 minutes? Yes (If YES, please complete the date of most recent documentation) No (If NO, please go to Section 2)

4. In which section of the record did you find the ACP documentation? (please tick all that apply)

- Specified area for ACP documentation
- Legal section
- Notes section
- My Health Record
- Other (please specify)



Study protocol – the survey

- Those whose files are audited are suitable for inclusion in the survey providing they meet the eligibility criteria
- Individuals lacking decision-making capacity will be excluded from the survey
- Participants provided with the Explanatory Statement and Consent Form
- The person's capacity to give consent will be judged on the day(s) of the study by a nurse or other clinician
- Take between 20 and 30 minutes to complete the survey



Study protocol – survey

17. Have you ever heard about advance care planning?

- Yes, I have heard of advance care planning
- Yes, I have an advance care plan or advance care directive
- No, I haven't heard of advance care planning before

18. Thinking about advance care planning in general terms, which of the following statements most closely applies to you?

- I am not interested in advance care planning
- I am thinking about advance care planning
- I am planning on doing advance care planning
- I have spoken to someone (e.g. my family/friends/carer/doctor) about advance care planning
- I have written my preferences in an advance care plan/advance care directive/other document
- I have written my preferences in an advance care plan / advance care directive / other

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22. Have you ever talked to anyone about your goals, values, beliefs or your preferences about specific medical treatment in case you become seriously ill or unable to make your own decisions?

- Yes
- No
- I cannot remember

Study variables

File audit

- demographic characteristics, clinical information, information on the ACP documentation, person's preferences regarding their care, and medically driven orders.

The survey

- demographic characteristics, generic quality of life and health status using EQ-5D five dimensions questionnaire, knowledge and experience regarding ACP, and self-reported use of ACP documentation

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Study limitations

- Differences in terminology, legislation and forms
- Differences in uptake of jurisdictions and sectors
- Documented medical orders vary – SA, NSW and QLD have a state-wide approach and others states do not
- Varying understanding by study coordinators

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State	Statutory preferences	Statutory decision-maker
Australian Capital Territory (ACT)	Health Direction	Enduring Power of Attorney
New South Wales (NSW)		Enduring Guardian
Northern Territory (NT)	Advance Personal Plan	Advance Personal Plan-Substitute Decision Maker Appointment
	Direction under Natural Death Act (if made before 17 March 2014)	
Queensland	Advance Health Directive	Enduring Power of Attorney for personal matters
South Australia (SA)	Advance Care Directive	Advance Care Directive-Substitute Decision Maker Appointment
	Anticipatory Direction (if made before 30 June 2014)	Medical Power of Attorney (if made before 30 June 2014)
		Enduring Power of Guardianship (if made before 1 July 2014)
Tasmania		Enduring Guardian
Victoria	Refusal of Treatment Certificate (Competent)	Enduring Power of Attorney (Medical Treatment)
	Refusal of Treatment Certificate (Non-Competent)	Enduring Power of Guardianship (if made before 31 August 2015)
		Enduring Power of Attorney (Personal Matters) from 1 September 2015
Western Australia (WA)	Advance Health Directive	Enduring Guardian

Summary

- This study addresses an important policy issue and gap in the published literature; it will provide important information to inform evaluation of strategy and programs.
- The development and implementation of a national advance care planning prevalence study and protocol is complex; it requires significant leadership, consultation, resourcing, coordination and time.
- There are important learnings to be shared.
- ACPA will be implementing this study over the coming three years.

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National Advance Care Planning Prevalence Study

Advance Care Planning Australia in partnership with Monash University will be conducting a world first National Advance Care Planning Prevalence Study.



APPLICATIONS NOW OPEN

National Advance Care Planning Prevalence Study

Applications to participate in the National Advance Care Planning Prevalence Study are now open to all accredited public and private hospitals, residential aged care facilities and general practices.

[Apply now](#)

Thank you

Advance Care Planning Australia: *building the foundation for a national collaborative approach to advance care planning*

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