

# BMJ Open Protocol for a national prevalence study of advance care planning documentation and self-reported uptake in Australia

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## ABSTRACT

**Introduction** Advance care planning (ACP) is a process between a person, their family/carer(s) and healthcare providers that supports adults at any age or stage of health in understanding and sharing their personal values, life goals and preferences regarding future medical care. The Australian government funds a number of national initiatives aimed at increasing ACP uptake; however, there is currently no standardised Australian data on formal ACP documentation or self-reported uptake. This makes it difficult to evaluate the impact of ACP initiatives. This study aims to determine the Australian national prevalence of ACP and completion of Advance Care Directives (ACDs) in hospitals, aged care facilities and general practices. It will also explore people's self-reported use of ACP and views about the process.

**Methods and analysis** Researchers will conduct a national multicentre cross-sectional prevalence study, consisting of a record audit and surveys of people aged 65 years or more in three sectors. From 49 participating Australian organisations, 50 records will be audited (total of 2450 records). People whose records were audited, who speak English and have a decision-making capacity will also be invited to complete a survey. The primary outcome measure will be the number of people who have formal or informal ACP documentation that can be located in records within 15 min. Other outcomes will include demographics, measure of illness and functional capacity, details of ACP documentation (including type of document), location of documentation in the person's records and whether current clinical care plans are consistent with ACP documentation. People will be surveyed, to measure self-reported interest, uptake and use of ACP/ACDs, and self-reported quality of life.

**Ethics and dissemination** This protocol has been approved by the Austin Health Human Research Ethics Committee (reference HREC/17/Austin/83). Results will be submitted to international peer-reviewed journals and presented at international conferences.

**Trial registration number** ACTRN12617000743369

## INTRODUCTION

### Background

Advance care planning (ACP) is a process between a person, their family/carer(s) and healthcare providers that supports adults at any age or stage of health in understanding

## Strengths and limitations of this study

- This is the first national multicentre cross-sectional prevalence study consisting of records audit and surveys of persons aged 65 years or more aiming to determine the prevalence of advance care planning (ACP) documentation in Australian hospitals, residential aged care facilities and general practices.
- The results of this study will inform future steps towards improved ACP data collection methodology, ACP implementation strategies and evaluation processes.
- This pilot study is principally aimed at establishing feasibility, and may lack statistical power to determine the actual prevalence of ACP documentation in Australia.

and sharing their personal values, life goals and preferences regarding future medical care.<sup>1 2</sup> ACP is an ongoing process wherein people have the opportunity to discuss and plan for future decision making, particularly for a time when they may not be able to make decisions for themselves. The ultimate goal of ACP is to align the care the person actually receives with their preferences. In order for this to occur, ACP information needs to be accessible when required, and treatment plans need to be developed in accordance with the person's values, goals, beliefs and specific preferences.<sup>3</sup>

A person may choose to document their preferences for care in formal or informal documents. An Advance Care Directive (ACD) is a type of formal document, recognised by common law or specific legislation that is completed and signed by a competent adult. It can record the person's preferences for future care, and appoint a substitute decision-maker to make decisions about healthcare and personal life management.<sup>2</sup> Documentation of a person's preferences helps substitute decision-makers and services make informed decisions about care when a

person is unable to express their preferences. Missing, ambiguous or inaccurate documentation can mean that preferences discussed or outlined in plans may not be followed. While ACP documents are used in all Australian states and territories, they take different forms, have different names and, while recognised under common law, many are also prescribed by legislation.<sup>4</sup> Examples of formal ACP documentation could include a written appointment of one or more substitute decision-makers, or completion of ACDs specifying instructions for future treatments.<sup>5</sup> Informal approaches to ACP documentation are also used, including non-statutory forms, personally written letters, a written plan outlining the person's values, beliefs and specific goals for care, and letters or documentation in a person's record by a professional outlining the person's preferences. In some cases, this statutory and non-statutory documentation may be completed by a person's substitute decision-maker; however, such plans may not have the same legal weighting as statutory documentation in some circumstances.

Australia's population is ageing and the incidence of chronic and complex healthcare conditions will rise accordingly. It is important to maintain an approach that meets personal preferences for quality and end-of-life care as care needs change over time.<sup>6</sup> Numerous Australian and international studies have been conducted to understand issues related to end-of-life care and how ACP may influence the care that people receive.<sup>7-12</sup> These studies have been conducted in a range of sectors, including hospitals, residential aged care facilities, general practices and the community. Various research methodologies have been used to understand ACP prevalence, including retrospective audits of health records, interviews, and surveys of service providers, service users and families.<sup>13-21</sup>

The lack of standardised, national data relating to ACP prevalence in Australia means that there is a lack of evidence to assist organisations and government to understand the impact of ACP initiatives. A search of literature between 2010 and 2016 has identified that the largest international sample size in a retrospective prevalence study assessing ACP practice was undertaken in 2015 in the USA with the sample of 24 291 people over 5 years. It found ACP prevalence of 12.7%.<sup>22</sup> A large Australian sample size (2764 people) in a prospective prevalence study was described by Nair *et al*<sup>17</sup> in the Hunter region of New South Wales, with very low levels (0.2%) of formal ACDs found. A prospective survey of 3055 participants in South Australia found that 46% of the study participants had completed an ACD.<sup>20</sup> The first attempt to conduct a national prevalence study in Australia was made by White *et al*.<sup>21</sup> This self-report study included 2405 community participants across all jurisdictions of whom only 14% had completed ACDs.

The majority of the Australian studies were self-reports, limited to single-settings, and did not examine patterns of ACP across multiple sectors and jurisdictions. There is a gap in evidence regarding ACP documentation and self-reported uptake nationally. This research undertaken

by ACP Australia in partnership with Monash University, will be the first prospective study to undertake a coordinated assessment of the national prevalence of ACP uptake, and documentation in hospitals, residential aged care facilities and general practices using a standardised approach to data collection.

This will be a pilot study aiming to examine the feasibility of an approach that is intended to ultimately be used in a large scale prevalence study in future. The results will inform future steps towards improved ACP data collection methodology, ACP implementation strategies and evaluation processes. We anticipate that the results from this study will act as a baseline for future national ACP prevalence studies.

### Aims and hypotheses

The specific aims of this study are to (1) determine the prevalence of ACP documentation in paper and/or electronic health records of people aged 65 years or more in hospitals, residential aged care facilities and general practices; (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 and (4) explore whether clinical care plans and medical orders developed for the person are consistent with their documented preferences for care.

We hypothesise that the prevalence of ACP documentation will be low and consistent with that identified by White *et al*,<sup>21</sup> and that more people will have an ACD appointing a substitute decision-maker than an ACD (or similar document) outlining their preferences for care. In regards to aim 2, we hypothesise that the ACP documentation will be signed by the person making the document, and witnessed according to the legislative requirements in each of the jurisdictions for formal ACDs, but there will be issues with validity of the documents based on failure to meet the witnessing requirements.<sup>23</sup> In regards to aim 3, we hypothesise that there will be discrepancies between peoples' self-reported completion of ACP documentation, and their presence in the audited records. In regards to aim 4, we hypothesise that there will be discrepancies between a person's ACD and their clinical care plans and medical orders.

### Outcomes

The primary outcome of this study will be ACP prevalence, and this is measured by the number of people who have ACP documentation that can be located in their records within 15 min of opening the record. Secondary outcomes include the type, quality and validity of ACP documentation, peoples' self-reported views on ACP and ACP uptake and consistency between ACP documentation and clinical care plans and medical orders.

## METHODS AND ANALYSIS

### Study design and population

This national multicentre prospective cross-sectional prevalence pilot study consists of two parts: (1) an audit of

**Box 1 Assessment criteria for organisations expressing their interest in the study**

- ▶ Have the approval and endorsement of their executive team
- ▶ Be an accredited organisation according to the sector requirements
- ▶ Must have access to IT and devices for online data collection (ie, computer, laptop or tablet)
- ▶ Must have Internet, email and telephone access
- ▶ Have a patient/client information management system with the ability to extract the list of all admissions of persons aged 65 years or more admitted to hospital or residential aged care facility for more than 48 hours at the time of the study
- ▶ Have the capacity to review a minimum of 30 files/records and administer a minimum of 30 surveys in the nominated time period
- ▶ Have staff with the capacity to undertake up to 3 hours online training prior to study
- ▶ Have appropriately skilled staff to assess a person's decision-making capacity
- ▶ Have appropriately skilled staff who are available to answer questions about ACP
- ▶ Have policies in place about privacy and confidentiality
- ▶ Be willing to accept retrospective payment for involvement in this study
- ▶ Be willing to sign a service agreement
- ▶ Gain site-specific approval within 4–6 weeks of notification of successful application

ACP, advance care planning; IT, information technology.

person's records and (2) a survey of those people whose records were audited. It will be conducted among people admitted to hospital, residing in residential aged care facilities or attending general practices in Australia.

In each of 49 Australian organisations, 50 records will be audited (expected sample of 2450 records). Participating organisations (hospitals, residential aged care facilities and general practices) will be recruited through an expressions of interest process. It is expected that at least 49 organisations distributed across the eight Australian jurisdictions and the three settings, will participate

in this study. Expression of interest applications will be assessed on each organisation's commitment to the project deliverables and ability to audit the required 50 records (box 1).

Successful organisations will receive funding to cover staff costs required to participate in the study. Organisations responding to the expression of interest will be required to nominate three staff members who have experience in retrieving information from health records, can assist participants to complete the survey where necessary, and are available to answer questions from participants about ACP, or refer them to their healthcare team. It is expected that data collectors may be quality managers, nurses or allied health professionals such as social workers.

Data collectors will receive a training manual with jurisdictional-specific information, and will undertake 90 min of online training on conducting the record audit and surveys. A sample of two health records will be provided for the extraction of the data prior the study to ensure the concordance among the data collectors. A short questionnaire will be provided to assess staff's knowledge and skills. Prior to actually undertaking the study, data collectors will be provided with the training manual and a list of frequently asked questions about the data collection tools. On the day(s) of the study, investigators will be available to answer the questions and queries from data collectors. To test the processes and feasibility of the study design, and data collection tools, and to identify potential problems that might arise we will conduct a trial of the audit with three staff and approximately 15 participants at the lead site. Each organisation will use their information management system or database to provide the research team with a list of patient/client records that meet eligibility criteria. The study sample will comprise people aged 65 years or more admitted to hospitals, residential aged care facilities or visiting general practice. Inclusion and exclusion criteria for part 1 (audit) and 2 (survey) are listed in (table 1).

**Table 1** Overview of inclusion and exclusion criteria for the study participants

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

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

A lower age cut-off (50 years or more) has been applied for Aboriginal and Torres Strait Islander people to reflect planning for aged care services in this population.<sup>24</sup>

## Part 1. records audit

### Recruitment

At hospitals and residential aged care facilities, data collector/(s) will contact the organisation's Health Information Management team (or similar) to obtain a list of current inpatients or residential clients who meet the study eligibility criteria (table 1). The list will only contain the person's unique record number. All other identifiable details will be removed.

### Randomisation

Each hospital and residential aged care facility will transmit their eligible inpatient/client list through a secure file transfer protocol to Monash University where a random number generator will select records in each centre for review.

Following simple randomisation procedures, each record number will be randomly assigned to two groups: group 1 ('to include to the audit') or group 2 ('not to include to the audit'). Only those randomised to group 1 will be included in the study. The 'Research Randomiser' (<https://www.randomizer.org>) software solution will be used to undertake this task. A total of 60 records will be provided; the first 50 to be used for the purposes of the study, and the final 10 (supplementary lists 1 and 2) to be used on an as needed basis if any of the first 50 records are not able to be accessed for any reason (eg, patient discharge occurring in the period between producing the list and accessing the record).

Data collectors will start auditing once they receive audit and supplementary lists 1 and 2.

For practicality purposes random sampling will not be performed in general practices. Records of the first 50 eligible people visiting the practice on the specified day(s) and meeting the selection criteria will be included in the audit.

### Data collection

Data collectors will obtain selected paper and/or electronic records. Data collection will be carried out using either a paper-based or electronic data collection tool specifically designed for this study (online supplementary table 1). Although advance care plans and ACDs are used in all Australian jurisdictions, the terminology, format, documentation requirements, how the ACD applies and the hierarchy of decision-makers differ from state to state.<sup>4 25 26</sup> Data collectors will be given training material with information, terminology and definitions relevant to their jurisdictions.

Data collectors will attempt to locate ACP documentation within 15 min, and if the ACP documentation is not found, they will stop searching for ACP documentation and move on to answering other audit items, such as demographic information. The time frame of 15 min

will commence when the paper and/or electronic record becomes available. It is anticipated that the total time for the audit will take between 30 and 45 min to extract data from each record.

### Data de-identification

A study number will be assigned to each person on the audit list. This study number will be entered onto the data collection form. Identifiable information such as name or date of birth will not be recorded. Data collectors will generate a separate list containing the study number and person's name. This list will be used to identify potential participants for the second component of the study (the survey). The list with identifying information will remain at the participating organisation and will not be disclosed to the research team.

## Part 2: the survey

The survey will be undertaken to explore the person's understanding and experience of ACP and identify their preferences for care. The questions for the survey were based on examples from other ACP prevalence surveys found during the literature review. Despite limitations surveys have in collecting sensitive data on person's experiences, they are widely used in medical research and are suitable for gathering data about abstract ideas or concepts that are otherwise difficult to quantify, such as opinions, attitudes and beliefs.<sup>27</sup> Administration of the survey requires minimal resources, and the results arising from analysis of closed-ended responses can be easily compared with the findings from the records audit. We hypothesise that there will be differences between the record audit and the survey responses regarding the existence of ACDs.

### Recruitment

All people from participating organisations whose files are audited are suitable for inclusion in part 2 of this project, providing they meet the eligibility criteria outlined in (table 1). Individuals lacking decision-making capacity will be excluded from the survey.

### Informed consent

Data collectors will explain the study and provide participants 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 in hospitals/residential aged care facilities, or by a nurse/doctor/other clinician in general practice, based on established principles of informed consent.<sup>28</sup> As some of the questions will ask about the end-of-life issues and death, there is a small chance that participants might experience distress or concern during the survey. To address this respondents are offered telephone numbers of relevant support services in the explanatory statement.

### Data collection

Those who consent will be provided with a paper or electronic survey presented on a tablet or laptop (online supplementary

**Table 2** Data variables collected during the study

Part 1: Records audit		Part 2: Survey	
Category	Variable	Category	Variable
Organisation		Demographics	
	Name		Age
	Type		Sex
	State		Country of birth
	Size		Aboriginal status
Demographics			Ethnicity
	Age		Religion
	Sex		Language spoken
	Postcode		Relationship status
	Country of birth		Education
	Aboriginal status		Level of support
	Ethnicity	Health status/EQ-5D	
	Religion		Mobility
	Language spoken		Usual activities
	Date of admission/visit		Self-care
	Came from		Pain-discomfort
	Medical condition		Anxiety/depression
	ECOG status	Knowledge	
Documentation			Knowledge of ACP
			Previous discussions
			Barriers and enablers
			Personal preferences
	Ability to find in 15 min		Readiness for ACP
	Date of the document		Future worries/wishes
			Legal appointment of substitute decision-maker
	Time taken to find	Evidence	
	Location of the document		Evidence of ACP documentation
	Name, type and other details		
Person's preferences			
	Life prolonging treatment type		
	Treatment to extend life		
	Comfort/palliative care		
	Other preferences		
	Place of care and/or death		
Medical orders			
	Limitations of medical treatment		
	Palliative/comfort care		
	Other orders		
	Consistency with person's wishes		

ACP, advance care planning; ECOG, Eastern Cooperative Oncology Group; EQ-5D, EuroQol-5 Dimension.

table 2). Participants can complete this survey themselves or ask for help from the data collector. It is anticipated that a person will take between 20 and 30 min to complete the survey. If participants complete a paper-based survey, data collectors will enter the data electronically at a later time.

#### Data de-identification

Identifiable information will not be collected. Each participant will be assigned a study number which will be entered and stored electronically. This will be the same number which was generated during the record audit.

**Table 3** Precision of positive predictive value of ACP/ACD documentation estimates

Proportion of records with ACP/ACD (%)	Records reviewed at site level (N)	95% CI	Records reviewed at sector level (N)	95% CI
0.95	50	0.83 to 0.99	800	0.93 to 0.96
0.9	50	0.78 to 0.97	800	0.87 to 0.92
0.8	50	0.66 to 0.90	800	0.77 to 0.83
0.7	50	0.55 to 0.82	800	0.67 to 0.73
0.6	50	0.45 to 0.74	800	0.56 to 0.63
0.5	50	0.36 to 0.64	800	0.46 to 0.54
0.4	50	0.26 to 0.55	800	0.37 to 0.43
0.3	50	0.18 to 0.45	800	0.27 to 0.33
0.2	50	0.10 to 0.34	800	0.17 to 0.23
0.1	50	0.03 to 0.22	800	0.08 to 0.12
0.05	50	0.01 to 0.17	800	0.04 to 0.07
0.02	50	0.00 to 0.11	800	0.00 to 0.03

ACD, advance care directive; ACP, advance care planning.

## Variables

The list of variables to be collected during the study is detailed in (table 2).

### Part 1: Records audit

Data extracted from the person's record will include: (1) demographic characteristics, (2) clinical information, (3) information on the ACP documentation, (4) person's preferences regarding their care and (5) medically driven orders.

### Part 2: The survey

The following information will be collected during the surveys: (1) demographic characteristics, (2) generic quality of life and health status using EuroQol-5 Dimension questionnaire (chosen because it has been extensively validated and shown to be sensitive, internally consistent and reliable<sup>29</sup>), (3) knowledge and experience regarding ACP and (4) self-reported use of ACP documentation (ie, participants will be asked whether they have documented their values and beliefs or preferences for future care, how this documentation is stored, and whether they have legally appointed a substitute decision-maker).

## Population size

While a sample size justification is important for pilot and feasibility trials, a formal sample size calculation may not be appropriate.<sup>30</sup> On the basis of assumptions and findings from previous research, we have chosen a sample of 50 people from each organisation, with an expected total sample size of 2450 records.<sup>31</sup> This will yield a comparison of data of at least 800 people's records per sector. Estimated precision and CIs of the chosen sample are shown in table 3. On the basis of the previous knowledge of 14% of the Australian population having an ACP/ACD,<sup>21</sup> the 95% CIs for the sample of 50 people would range from 3% to 22%.

## Data processing

### Data management

All data collected during this study will be stored on a cloud-based database specifically designed for this project. Cloud-based storage will ensure customised data security control for each organisation and is suitable for distributed collection environments. The database will have in-built validation and range checks to reduce data collection errors.

Participants completing the survey and data collectors completing the audit may access the web-based record audit tool and survey on a personal computer, laptop or tablet. Organisations will need internet access in order to access the cloud-based database and data collection forms. The research team will also make paper-based forms available for people (organisations and those completing the survey) who have limited computer access, or are not comfortable with using digital technologies.

### Statistical analysis

Descriptive statistics will be calculated for the total sample of the study and will be stratified by major grouping variables: organisation type, state, location, age, sex, ethnicity, diagnosis, functional status and outcomes.

Data collectors will judge ACP documentation to be present if they find evidence of any ACP documentation of the person's preferences (either formal or informal), or legal appointment of a substitute decision-maker by the person within 15 min. Presence of ACP documentation, such as ACDs and advance care plans will be described using the mode, frequency and distribution of the respective categories. There is no standard measure for quality and validity of ACP documentation in Australia. Statutory documents need to be signed by the person and witnessed by specific authorities such as a doctor, a legal practitioner, a Justice of the Peace and in some jurisdictions also by the

appointed decision-maker. Unsigned documents are not legally valid, and therefore presence or absence of such signatures will be used to determine the validity of the ACP documentation. Comparisons will be made using t-tests for the continuous type variables and  $\chi^2$  contingency table analysis for the categorical type variables.

Data collectors will also look for other evidence of ACP discussions, such as a note in the person's record, recording on a limitation of treatment form which clearly states the decision is based on the person's preferences, or other documentation of a person's preferences, but where a statutory or non-statutory ACD has not been completed. These will be reported as descriptive data.

Multivariate logistic regression will be performed, predicting the presence of ACP documentation while controlling for the type of organisation, jurisdictions, location, age, sex and ethnicity. In instances where data are missing, analysis will be performed using list-wise deletion. The level of significance will be set at 0.05.

### Project governance

The ACP prevalence study will be overseen by a project Advisory Group. This group will meet bimonthly for the initial 12-month period. Members of the Advisory Group will include representatives from ACP Australia, Monash University, Australian Institute of Health and Welfare, jurisdictions and members of the hospital, aged care and general practice sectors. The Advisory Group will be responsible for reviewing and endorsing the project methodology, advertising the expression of interest to the settings, advising on barriers or enablers to conducting this research within their relevant sector and/or jurisdictions including risk management and reviewing prevalence study findings and reports.

### ETHICS AND DISSEMINATION

This research protocol for this study was approved on 2 May 2017 by Austin Health Human Research Ethics Committee (reference number: HREC/17/Austin/83). The anticipated date for completion of the study is 31 December 2017.

Results of this study will be provided to the participating organisations and the Australian Government. No reports will identify any specific organisation but jurisdictional comparisons will be possible. Findings will be presented at relevant conferences and published in peer-reviewed journals, on the ACP Australia website and in lay and social media where appropriate. The investigators will review drafts of the manuscripts, abstracts, press releases and any other publications arising from the study. Authorship will be determined in accordance with the International Committee of Medical Journal Editors guidelines, and other contributors will be acknowledged.

The results will be highly relevant to clinical practice and policy nationally and internationally; therefore, the findings of this study will also be disseminated through relevant government departments, as well as through

various national and international professional bodies, societies and peer review networks.

**Contributors** RR acted as a principal investigator and contributed to the concept, drafting, design and revising of the protocol. KMD contributed to the concept, drafting, design and critically revising of the protocol. SME contributed to the design and critically revising the protocol. VP contributed to the design and critically revising the protocol. CS contributed to the concept, design and critically revising the protocol. JMC contributed to the concept and design of the protocol. LN conceived the study and contributed to the concept and critically revising of the protocol.

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**Competing interests** None declared.

**Patient consent** Obtained.

**Ethics approval** Austin Health Human Research Ethics Committee (reference number: HREC/17/Austin/83).

**Provenance and peer review** Not commissioned; externally peer reviewed.

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