BMJ Open

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

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2017-018024
Article Type:	Protocol
Date Submitted by the Author:	01-Jun-2017
Complete List of Authors:	Ruseckaite, Rasa; Monash University, Epidemiology and Preventive Medicine Detering, Karen; Austin Health, Advance care planning Program; University of Melbourne, Faculty of Medicine, Dentistry and Health Science Evans, Sue; Department of Epidemiology and Preventive Me, Monash University Perera, Veronika; Austin Health, Advance Care Planning Australia Walker, Lynne; Austin Health, Advance Care Planning Australia Sinclair, Craig; University of Western Australia, Rural Clinical School of Western Australia Clayton, Josephine; Greenwich Hospital, HammondCare Palliative and Supportive Care Service Nolte, Linda; Austin Health, Advance care planning Program
Primary Subject Heading:	Health services research
Secondary Subject Heading:	Epidemiology, General practice / Family practice, Palliative care, Patient-centred medicine
Keywords:	advance care planning, prevalence, AUDIT, general practice, residential aged care, hospital

Title: Protocol for a national prevalence study of advance care planning documentation and self-reported uptake in Australia

Corresponding author:

Rasa Ruseckaite
Department of Epidemiology and Preventive Medicine
School of Public Health and Preventive Medicine, Monash University
553 St Kilda Rd, Melbourne, Victoria, Australia 3004
Email: rasa.ruseckaite@monash.edu
Telephone: +61 3 9903 0437

Authors:

Karen Detering, Advance Care Planning Australia, Austin Health, Melbourne, Victoria, Australia; Faculty of Medicine, Dentistry and Health Sciences, Melbourne University, Melbourne, Victoria, Australia

Sue Evans, Department of Epidemiology and Preventive Medicine, School of Public Health and Preventive Medicine, Monash University, Melbourne, Victoria, Australia

Veronica Perera, Advance Care Planning Australia, Austin Health, Melbourne, Victoria, Australia

Lynne Walker, Advance Care Planning Australia, Austin Health, Melbourne, Victoria, Australia

Craig Sinclair, Rural Clinical School of Western Australia, University of Western Australia, Albany, Western Australia, Australia

Josephine Clayton, Hammond Care Palliative & Supportive Care Service, Greenwich Hospital, Sydney, New South Wales, Australia; Australia and Sydney Medical School, The University of Sydney, Sydney, New South Wales, Australia

Linda Nolte, Advance Care Planning Australia, Austin Health, Melbourne, VIC, Australia

Word count: text 2,906; abstract 299

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 regarding 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 over 65 years in three sectors. Fifty records from 48 participating Australian organisations will be audited (total of 2400 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 (ACD) or informal ACP documentation that can be located in records within 15 minutes. 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: ACTRN12617000743369

Strengths and limitations of this study

- This is the first national multicentre cross-sectional prevalence study consisting of records audit and surveys of persons >65 years aiming to determine the prevalence of advance care planning documentation in Australian hospitals, residential aged care facilities and general practices.
- The results of this study will inform future steps toward improved advance care planning data collection methodology, advance care planning 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 advance care planning documentation in Australia.

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 and sharing their personal values, life goals, and preferences regarding future medical care (1, 2). 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 (3).

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 health care and personal life management (2). Documentation of a person's preferences helps family members and services make informed decisions about care when a person is unable to express their choices. 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 (4). 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 (5). Informal approaches to ACP documentation are also used, including non-statutory forms, personally written letters, a plan outlining the person's values, beliefs, and specific goals for care, or notes in a 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 (6). 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 (7-12). 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 audits of health records; interviews; and surveys of service providers, service users and families (13-21).

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 prevalence study assessing ACP practice was undertaken in 2015 in the USA with the sample of 24,291 people over five years. It found ACP prevalence of 12.7% (22). A large Australian sample size (2,764 people) in a prevalence study was described by Nair (17) in 2000 in the Hunter region of New South Wales, with very low levels (0.2%) of formal ACDs found. Another study of 3,055 participants in South Australia found that nearly half of the study participants had not completed any ACD (20). The first attempt to conduct a national prevalence study in Australia was made by White et al (21). This self-report study included 2,405 community participants across all jurisdictions of whom only 14% had their ACDs completed.

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 Advance Care Planning Australia in partnership with Monash University, will be the first 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. The results will inform future steps toward 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 and accessibility of ACP documentation in paper and/or electronic health records of people over the age of 65 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 (21), 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 addition, we hypothesise that there will be discrepancies between peoples’ self-reported completion of ACP documentation, and their presence in the audited records.

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 minutes. 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 cross-sectional prevalence pilot study consists of two parts: 1) an audit of a person's records and 2) a survey of those people whose files were audited. It will be conducted among people admitted to hospital, attending general practices, or residing at residential aged care facilities in Australia. This pilot study will trial methodology and data collection tools for national ACP prevalence studies.

Fifty records will be audited in each of 48 Australian organisations (expected sample of 2400 records). Participating organisations will be recruited through an expressions of interest process. It is expected that 48 organisations (two hospitals, two residential aged care facilities and two general practices) in each of the eight Australian jurisdictions 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 (Table 1).

[Table 1 here please]

Successful organisations will receive funding to cover staff costs required to participate in the study. Data collectors will receive a training manual with jurisdictional specific information, and will undertake training (two webinar sessions of 90 minutes duration conducted over two weeks) on conducting the record audit and surveys. A couple of sample health records will be provided for the extraction of the data prior the study to ensure the concordance amongst the data collectors.

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 over the age of 65 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 2.

[Table 2 here please]

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 2). The list will only contain the person's unique record number. All other identifiable details will be removed.

Randomization

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 50 records in each centre for review.

Following simple randomization procedures each record number will be randomly assigned to two groups: group one ("to include to the audit") or group two ("not to include to the audit"). The "Research Randomizer" (www.randomizer.org) software solution will be used to undertake this task. The research team will provide data collectors with a list containing record numbers of the 50 people assigned to group. Data collectors will start auditing once they receive audit and supplementary lists. In the situation when a person's paper or electronic record cannot be located, this will be noted, and additional record numbers will be drawn.

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 (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 (4, 23, 24). 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 minutes, 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. It is anticipated that the total time for the audit will take between 30 and 45 minutes 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.

Recruitment

People from participating organisations whose files have been audited are suitable for inclusion in Part 2 of this project, providing they meet the eligibility criteria outlined in Table 2.

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 (25).

Data collection

Those who consent will be provided with a paper or electronic survey presented on a tablet or laptop (Supplementary 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 minutes 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.

Variables

The list of variables to be collected during the study is detailed in Table 3.

[Table 3 here please]

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 EQ-5D five dimensions questionnaire (chosen because it has been extensively validated and shown to be sensitive, internally consistent, and reliable (26)), 3) knowledge and experience regarding ACP, and 4) self-reported use of ACP documentation (i.e. 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 (27). Based on assumptions and findings from previous research, we have chosen a sample 50 people from each organisation, with an expected total sample size of 2400 records (28). This will yield a comparison of data from

800 people's records according to sector. Estimated precision and confidence intervals of the chosen sample are shown in Table 4.

[Table 4 here please]

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 customized data security control for each organization and is suitable for distributed collection environments. The database will have in-built validation and range checks to reduce data collection errors.

Participants and research staff 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. Presence of ACP documentation, such as ACDs and advance care plans will be described using the mode, frequency, and distribution of the respective categories. Comparisons will be made using *t-tests* for the continuous type variables and *chi-square* 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, validity of the document, 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 every three months for the initial 12-month period. Members of the Advisory Group will include representatives from Advance Care Planning 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 has been approved by Austin Health Human Research Ethics Committee (reference number: HREC/17/Austin/83).

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 Advance Care Planning 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.

Supplementary documents

1. Supplementary Table 1 – Records audit tool
2. Supplementary Table 2 – Survey

Funding

This program is supported by funding from the Australian Government as a part of a Specialist Palliative Care and Advance Care Planning Advisory Service Program.

Authors' contributions

RR acted as a principal investigator and contributed to the concept, drafting, design and revising of the protocol. KD contributed to the concept, drafting, design and critically revising of the protocol. SE 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. JC contributed to the concept and design of the protocol. LN conceived the study and contributed to the concept and critically revising of the protocol.

Competing interests

None

REFERENCES

1. Sudore RL, Lum HD, You JJ, Hanson LC, Meier DE, Pantilat SZ, et al. Defining Advance Care Planning for Adults: A Consensus Definition from a Multidisciplinary Delphi Panel. Journal of pain and symptom management. 2017.

2. The Australian Commission of Quality and Safety in Health Care. The National Consensus Statement: Essential elements for safe and high-quality end-of-life care [cited 2016 (accessed Nov 2016)].

3. Detering K. Accessibility of Advance Care Plans in Victoria – A Summary Options Paper. Melbourne: Advance Care Planning Australia, 2017.

4. Carter RZ, Detering KM, Silvester W, Sutton E. Advance care planning in Australia: what does the law say? Australian health review : a publication of the Australian Hospital Association. 2016.

5. Australian Health Ministers' Advisory Council. Clinical, Technical and Ethical Principal Committee (issuing body). A national framework for advance care directives. Canberra Australian Health Ministers' Advisory Council, 2011.

6. Victorian Government. Advance care planning: have the conversation. A strategy for Victoian health services 2014-2018. State of Victoria, Department of Health 2014.

7. Ashby MA, Thornton RN, Thomas RL. Advance care planning: lessons from a study of Tasmanian enduring guardianship forms. The Medical journal of Australia. 2013;198(4):188-9.

8. Bischoff KE, Sudore R, Miao Y, Boscardin WJ, Smith AK. Advance care planning and the quality of end-of-life care in older adults. Journal of the American Geriatrics Society. 2013;61(2):209-14.

9. Brunner-La Rocca HP, Rickenbacher P, Muzzarelli S, Schindler R, Maeder MT, Jeker U, et al. End-of-life preferences of elderly patients with chronic heart failure. European Heart Journal. 2012;33(6):752-9.

10. Carr D. "I don't want to die like that ...": the impact of significant others' death quality on advance care planning. The Gerontologist. 2012;52(6):770-81.

11. Laakkonen ML, Pitkala KH, Strandberg TE, Berglind S, Tilvis RS. Living will, resuscitation preferences, and attitudes towards life in an aged population. Gerontology. 2004;50(4):247-54.

12. Volker DL, Divin-Cosgrove C, Harrison T. Advance directives, control, and quality of life for persons with disabilities. Journal of palliative medicine. 2013;16(8):971-4.

13. Bezzina AJ. Prevalence of advance care directives in aged care facilities of the Northern Illawarra. Emergency medicine Australasia : EMA. 2009;21(5):379-85.

14. Cheang F, Finnegan T, Stewart C, Hession A, Clayton JM. Single-centre cross-sectional analysis of advance care planning among elderly inpatients. Internal medicine journal. 2014;44(10):967-74.

15. Kirkpatrick JN, Guger CJ, Arnsdorf MF, Fedson SE. Advance directives in the cardiac care unit. American Heart Journal. 2007;154(3):477-81.

16. Milnes S, Orford NR, Berkeley L, Lambert N, Simpson N, Elderkin T, et al. A prospective observational study of prevalence and outcomes of patients with Gold Standard Framework criteria in a tertiary regional Australian Hospital. BMJ supportive & palliative care. 2015.

17. Nair B, Kerridge I, Dobson A, McPhee J, Saul P. Advance care planning in residential care. Australian and New Zealand journal of medicine. 2000;30(3):339-43.

18. Street M, Ottmann G, Johnstone MJ, Considine J, Livingston PM. Advance care planning for older people in Australia presenting to the emergency department from the community or residential aged care facilities. Health & social care in the community. 2015;23(5):513-22.

19. Wheatley E, Huntington MK. Advanced directives and code status documentation in an academic practice. Family medicine. 2012;44(8):574-8.

20. Bradley SL, Woodman RJ, Tieman JJ, Phillips PA. Use of advance directives by South Australians: results from the Health Omnibus Survey Spring 2012. The Medical journal of Australia. 2014;201(8):467-9.

21. White B, Tilse C, Wilson J, Rosenman L, Strub T, Feeney R, et al. Prevalence and predictors of advance directives in Australia. Internal medicine journal. 2014;44(10):975-80.

22. Butler J, Binney Z, Kalogeropoulos A, Owen M, Clevenger C, Gunter D, et al. Advance directives among hospitalized patients with heart failure. JACC Heart failure. 2015;3(2):112-21.

23. Haysom G. Review of the National Registration and Accreditation Scheme for health practitioners. Aus Health Law Bulletin. 2015;23(1):12-5.

24. White B, Wilmott L, Trowse P, Parker M, Cartwright C. The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment : Part 1 (New South Wales). J Law Med. 2011;18(3):498-522.

25. Australian Government. National Health and Medical Reserach Council. National Statement on Ethical Conduct in Human Research (2007) (Updated May 2015). https://www.nhmrc.gov.au/book/national-statement-ethical-conduct-human-research.

26. Rabin R, de Charro F. EQ-5D: a measure of health status from the EuroQoL Group. Ann Med. 2001;33:337-3423.

27. Billingham SA, Whitehead AL, Julious SA. An audit of sample sizes for pilot and feasibility trials being undertaken in the United Kingdom registered in the United Kingdom Clinical Research Network database. BMC medical research methodology. 2013;13:104.

28. Sim J, Lewis M. The size of a pilot study for a clinical trial should be calculated in relation to considerations of precision and efficiency. Journal of clinical epidemiology. 2012;65(3):301-8.

TABLES

Table 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 (i.e. computer, laptop or tablet)
- Must have Internet, e-mail 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 three 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 four to six weeks of notification of successful application.

ACP – advance care planning; IT – information technology

Table 2 Overview of inclusion and exclusion criteria for the study participants

Inclusion criteria	
Part 1. Records audit	**Part 2. Survey**
Males and females	Everybody included in Part 1
≥65 years of age (≥55 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	
Part 1. Records audit	**Part 2. Survey**
<65 years of age (<55 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

Table 3 Data variables collected during the study

Part1. 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 minutes		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

ECOG - Eastern Cooperative Oncology Group

Table 4 Precision of positive predictive value of ACP/ACD documentation estimates

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

ACD – advance care direction; ACP – advance care planning

GENERIC HEALTH RECORD REVIEW FORM

Study ID number
Study site

Date form completed ___ /___/___ Time started______ Time completed_____

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, go to Section 2)	Date of most recent documentation __/__/__
2. How long did it take you to find the ACP documentation?	☐ Less than 5 minutes ☐ 5-10 minutes ☐ 10-15 minutes	
3. Where did you find the ACP documentation?	☐ Paper record ☐ Electronic record	
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)	
5. What type of documentation did you find?	☐ Statutory advance care directive documentation (if YES please go to Question 6) ☐ Legally appointed substitute decision maker (If YES, please go to Question 7) ☐ Non-statutory advance care directive documentation (If YES please go to Question 8) ☐ Other documentation (If YES please go to Question 9) (please specify)	

6. Details of the person's statutory advance care directive documentation	☐ Yes, there is a copy ☐ No – I did not find a copy of the advance care directive but documentation in notes indicates that person has a statutory advance care directive (please go to Question 7) ☐ No document or notes located
	If YES, please specify the name of the document
	Was the document signed ☐ Yes ☐ No (If NO please go to Question 7)
	Who signed the document? (please tick all that apply) ☐ Person ☐ Doctor ☐ Legal practitioner ☐ Justice of Peace ☐ Appointed decision maker ☐ Unable to determine ☐ Signatures were not found ☐ Other (please specify)
	☐ Not Applicable
	Is the document signed in accordance with legislation? ☐ Yes ☐ No ☐ I don't know
7. Details of the person's legally appointed substitute decision maker	☐ Yes, there is a copy ☐ No - did not find a copy of the advance care directive but documentation in notes indicates that person has a legally appointed substitute decision maker (Please go to Question 8) ☐ No document or notes located
	If YES, please specify the name of the document

	What is the relationship of the substitute decision maker to the person? (Please tick all that apply) ☐ Spouse/partner ☐ Child ☐ Sibling ☐ Other family ☐ Friend ☐ Other (please specify)
	Was the document signed? ☐ Yes ☐ No (If NO , please go to Question 8)
	Who signed the document? (please tick all that apply) ☐ Person ☐ Doctor ☐ Legal practitioner ☐ Justice of Peace ☐ Appointed decision maker ☐ Unable to determine ☐ Signatures were not found ☐ Other (please specify)
	☐ Not Applicable
	Is the document signed in accordance with legislation? ☐ Yes ☐ No ☐ I don't know
8. Details of the person's non-statutory advance care directive documentation	☐Yes, there is a copy ☐No - did not find a copy of the advanced care directive but documentation in notes indicates that person has non-statutory advance care directive documentation (please go to Question 9)

	If YES, please specify the name of the document
	Was the document signed? ☐ Yes ☐ No (if NO , please go to Question 9)
	Who signed the document? (Please tick all that apply) ☐ Person ☐ Doctor ☐ Legal practitioner ☐ Justice of Peace ☐ Appointed decision maker ☐ Unable to determine ☐ Signatures were not found ☐ Other (please specify)
	☐ Not Applicable
	Is the document signed in accordance with legislation? ☐ Yes ☐ No ☐ I don't know
9. Details of the person's other type of advance care planning documentation (please tick all that apply)	☐ Yes, there are other type(s) of ACP documentation ☐ No did not find copy(ies) of other type(s) of ACP documentation, but documentation in notes indicates that person has a substitute decision maker (please go to Question 10)
	If YES, please specify the name(s) of the document(s)
	The document(s) are in the form of (please tick all that apply): ☐ Notes ☐ Charts ☐ Letters ☐ Goals of Care with person's wishes clearly stated

	☐ Evidence or statement of family awareness of person’s advance care plan ☐ Interstate advance care directive ☐ Other correspondence (please specify)
	Who completed the document? ☐ Person ☐ Doctor ☐ Nurse ☐ Other (please specify)
PERSON’S PREFERENCES	
10. Can you locate the person’s preferences regarding their care?	☐ Yes ☐ No (If NO go to SECTION 2)
	If YES, does it include: ☐ Life prolonging treatment ☐ Life prolonging treatment with specific outcomes / or some limitations of treatment ☐ No life prolonging treatment ☐ Person does not want to make the decision ☐ I cannot locate
11. Other preferences (pleas tick all that apply)	☐ Preferred place of care/location ☐ Preferred place of death/location ☐ Other preferences and values (please specify) ☐ None
SECTION 2. MEDICAL ORDERS	
12. Is there a medical order limiting treatment?	☐ Yes ☐ No (go to SECTION 3)
13. What are the limitations on the order?	☐ No limitation of treatment
	☐ Limitation of treatment
	If there is a limitation on treatment (please tick all that apply): ☐ Not for cardiopulmonary resuscitation (CPR)

	☐ Not for intubation ☐ Not for intensive care unit (ICU) ☐ Not for hospitalisation ☐ Not for antibiotics ☐ Other (please specify)
	☐ Comfort care/palliative care (i.e. no life prolonging treatment)
	☐ Symptom management is primary goal (palliative care)
	☐ Other orders (please specify)
14. Does the medical order acknowledge the person's advance care directive/advance care plan?	☐ Yes ☐ No ☐ Not applicable ☐ Unclear
15. Does the medical order acknowledge discussion with patient/family?	☐ Yes ☐ No ☐ Unclear
16. If there is an advance care directive/advance care plan, are the medical orders consistent with the person's wishes?	☐ Yes ☐ No ☐ Not applicable ☐ Unclear

SECTION 3. PERSON'S DETAILS	
17. Age	

18. Sex	☐ Male ☐ Female ☐ Other (please specify)
19. Postcode	
20. Country of birth	☐ Australia ☐ Other (please specify) ☐ Unknown – information not available in record
21. Indigenous status	☐ Aboriginal ☐ Torres Strait Islander ☐ Both Aboriginal and Torres Strait Islander ☐ Not stated (information not available in record)
22. Ethnicity	☐ Available (please specify) ☐ Unknown – information not available in record
23. Religion	☐ Available (please specify) ☐ Unknown – information not available in record
24. Language status	☐ Speaks English ☐ Interpreter required (please specify the language) ☐ Unknown – information not available in record
25. Date of person's admission/visit	
26. Person came from	☐ Aged care facility ☐ Hospital ☐ Home ☐ Other (please specify)
27. Medical condition (please tick all that apply)	☐ Circulatory system ☐ Respiratory system ☐ Neurological system

	☐ Gastrointestinal system ☐ Musculoskeletal and connective tissue ☐ Endocrine, nutritional and metabolic disorders ☐ Urinary/excretory and reproductive ☐ Cancer ☐ Mental Illness ☐ Dementia ☐ Other (please specify)	
28. Is this person receiving palliative care?	☐ Yes ☐ No ☐ Unknown	If Yes, is the palliative care from the specialist palliative care service? ☐ Yes ☐ No
29. Eastern Cooperative Oncology group (ECOG) performance status – this is a scale used to assess how a person's disease is progressing and how the disease impacts the daily living abilities of the person. This information can help to determine appropriate treatment and prognosis	☐ Fully active, able to carry on all pre-disease performance without restriction ☐ Restricted in physically strenuous activity, but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work ☐ Ambulatory and capable of all selfcare but unable to carry out any work activities; up and about more than 50% of waking hours ☐ Capable of only limited selfcare; confined to bed or chair more than 50% of waking hours ☐ Completely disabled; cannot carry on any selfcare; totally confined to bed or chair ☐ Information not available	

PERSON SURVEY

Study ID number
Study site

Date form completed ___ /___ /___

Section 1: About you	
1. I am completing this survey:	☐ On my own without help from someone else ☐ With help from someone else (e.g. friend/relative, staff member)
2. I am:	☐ Male ☐ Female ☐ Other (please specify)
3. My age is:	
4. I was born in:	☐ Australia ☐ Other country (please specify)
5. I am:	☐ Aboriginal ☐ Torres Strait Islander ☐ Both Aboriginal and Torres Strait Islander ☐ Neither ☐ Prefer not to say
6. The language I speak at home is:	
7. Are you religious?	☐ Yes (please go to Q.8) ☐ No ☐ Prefer not to answer (please go to Question 9)

8. How important is your religion to you?	☐ Very important ☐ Important ☐ Somewhat important ☐ Not important
9. What is your current relationship status?	☐ Married/de facto/in a relationship ☐ Single ☐ Divorced or separated ☐ Widowed
10. What is your highest level of education?	☐ No formal schooling ☐ Primary school (Highest year completed) ☐ Secondary or High school (Highest year completed) ☐ Trade school or Apprenticeship ☐ Diploma ☐ University degree
11. Who do you live with?	☐ Husband/wife/partner ☐ Children ☐ Brother/sister ☐ Other family ☐ Friends ☐ I live alone

Section 2: About your health

Under each heading, please tick the ONE box that best describes your health TODAY.

12. Mobility	☐ I have no problems in walking about ☐ I have slight problems in walking about ☐ I have moderate problems in walking about ☐ I have severe problems in walking about

	☐ I am unable to walk about
13. Usual Activities *(e.g. work, study, housework, family or leisure activities)*	☐ I have no problems doing my usual activities ☐ I have slight problems doing my usual activities ☐ I have moderate problems doing my usual activities ☐ I have severe problems doing my usual activities ☐ I am unable to do my usual activities
14. Self-Care	☐ I have no problems washing or dressing myself ☐ I have slight problems washing or dressing myself ☐ I have moderate problems washing or dressing myself ☐ I have severe problems washing or dressing myself ☐ I am unable to wash or dress myself
15. Pain/discomfort	☐ I have no pain or discomfort ☐ I have slight pain or discomfort ☐ I have moderate pain or discomfort ☐ I have severe pain or discomfort ☐ I have extreme pain or discomfort
16. Anxiety/depression	☐ I am not anxious or depressed ☐ I am slightly anxious or depressed ☐ I am moderately anxious or depressed ☐ I am severely anxious or depressed ☐ I am extremely anxious or depressed

Section 3: Your understanding and experience of advance care planning

ADVANCE CARE PLANNING is the opportunity for people to tell their family, friends and doctors ahead of time, what they would want if they became seriously ill and could no longer speak for themselves. Ideally they would talk to their family, friends and doctors. It is also a good idea to write it down.

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 review my advance care plan from time to time
19. Who would you trust to make medical decisions for you if you were too unwell to do so yourself? (please tick all that apply)	☐ Husband/wife/ partner ☐ Children ☐ Brother/sister ☐ Other family ☐ Friend ☐ Doctor ☐ Other (please specify) ☐ I can't decide ☐ I have not thought about that yet
20. What things would **worry you most** about your future? (please tick all that apply)	☐ Not being able to look after myself ☐ Being in pain/distressed ☐ Not being able to get out of bed

	☐ Not being able to make choices for myself ☐ Relying on others ☐ Being a burden on my family/ friends/carers ☐ Not being able to talk to my family/ friends/carers ☐ Not wanting to go to hospital ☐ Wanting to live as long as possible ☐ Wanting to get well ☐ Other (please specify)
21. Thinking about your future, if you became really unwell or unconscious, and couldn't tell the doctors what you want, which sentence reflects best how you feel?	☐ I want to live for as long as possible ☐ I want to live as long as possible but only if my acceptable outcomes and preferences for care are likely ☐ I would not want any treatment that was to prolong my life, I would want to receive comfort care ☐ I would not want to make this decision myself. The person I would want to make this decision for me is my____

Section 4: Telling others about your advance care plans

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 (If NO, go to Question 24) ☐ I cannot remember (If you cannot remember, go to Question 24) If YES, who did you talk to? ☐ Husband/wife/partner ☐ Children ☐ Brother/sister ☐ Other family ☐ Friend

	☐ Doctor ☐ Other (please specify) ☐ I can't decide ☐ I have not thought about that yet
23. Have you ever written down your goals, values, and beliefs or your preferences about specific medical treatment in case you become seriously ill or unable to make your own decisions?	☐ Yes ☐ No (If NO go to Question 25) ☐ I cannot remember (If you cannot remember go to Question 25)
	If YES, how long ago did you do this? In what type of document did you write this? Where is this document kept?
24. Have you ever signed a legal document to appoint someone to make healthcare decisions on your behalf if you were unable to make your own decisions?	☐ Yes ☐ No (If NO go to Question26) ☐ I cannot remember (If you cannot remember go to Question 26)
	If YES how long ago did you sign this document? What type of document did you sign? Where is this document kept?
25. Any other comments regarding your experiences with advance care planning	

STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation	
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	YES, p.1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	YES, p.3
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	YES, p.5-7
Objectives	3	State specific objectives, including any prespecified hypotheses	YES, p.7
Methods			
Study design	4	Present key elements of study design early in the paper	YES, p.8
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	YES, p.8-9
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	YES, p.9
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case	NA
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	YES, p.12
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	YES, p.12
Bias	9	Describe any efforts to address potential sources of bias	NA (pilot study)
Study size	10	Explain how the study size was arrived at	YES, p.12
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	YES, p.13-14
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	YES, p.13-14
		(*b*) Describe any methods used to examine subgroups and interactions	YES, p.13-14
		(*c*) Explain how missing data were addressed	NA
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking	NA

		account of sampling strategy
		(*e*) Describe any sensitivity analyses
Results [NOT APPLICABLE, STUDY PROTOCOL]		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed
		(b) Give reasons for non-participation at each stage
		(c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders
		(b) Indicate number of participants with missing data for each variable of interest
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time
		Case-control study—Report numbers in each exposure category, or summary measures of exposure
		Cross-sectional study—Report numbers of outcome events or summary measures
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included
		(*b*) Report category boundaries when continuous variables were categorized
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses
Discussion		
Key results	18	Summarise key results with reference to study objectives
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	Discuss the generalisability (external validity) of the study results
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

BMJ Open

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

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2017-018024.R1
Article Type:	Protocol
Date Submitted by the Author:	25-Jul-2017
Complete List of Authors:	Ruseckaite, Rasa; Monash University, Epidemiology and Preventive Medicine Detering, Karen; Austin Health, Advance care planning Program; University of Melbourne, Faculty of Medicine, Dentistry and Health Science Evans, Sue; Department of Epidemiology and Preventive Me, Monash University Perera, Veronika; Austin Health, Advance Care Planning Australia Walker, Lynne; Austin Health, Advance Care Planning Australia Sinclair, Craig; University of Western Australia, Rural Clinical School of Western Australia Clayton, Josephine; Greenwich Hospital, HammondCare Palliative and Supportive Care Service Nolte, Linda; Austin Health, Advance care planning Program
Primary Subject Heading:	Health services research
Secondary Subject Heading:	Epidemiology, General practice / Family practice, Palliative care, Patient-centred medicine
Keywords:	advance care planning, prevalence, AUDIT, general practice, residential aged care, hospital

Title: Protocol for a national prevalence study of advance care planning documentation and self-reported uptake in Australia

Corresponding author:

Dr Karen Detering, Austin Health, 145 Studley Road Heidelberg, Vic 3084, Australia

karen.detering@austin.org.au

Authors:

Rasa Ruseckaite, Department of Epidemiology and Preventive Medicine, School of Public Health and Preventive Medicine, Monash University, Melbourne, Victoria, Australia

Karen M Detering, Advance Care Planning Australia, Austin Health, Melbourne, Victoria, Australia; Faculty of Medicine, Dentistry and Health Sciences, Melbourne University, Melbourne, Victoria, Australia

Sue Evans, Department of Epidemiology and Preventive Medicine, School of Public Health and Preventive Medicine, Monash University, Melbourne, Victoria, Australia

Veronica Perera, Advance Care Planning Australia, Austin Health, Melbourne, Victoria, Australia

Lynne Walker, Advance Care Planning Australia, Austin Health, Melbourne, Victoria, Australia

Craig Sinclair, Rural Clinical School of Western Australia, University of Western Australia, Albany, Western Australia, Australia

Josephine M Clayton, Hammond Care Palliative & Supportive Care Service, Greenwich Hospital, Sydney, New South Wales, Australia; Australia and Sydney Medical School, The University of Sydney, Sydney, New South Wales, Australia

Linda Nolte, Advance Care Planning Australia, Austin Health, Melbourne, VIC, Australia

Word count: text 3,579; abstract 300

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 regarding 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. Fifty records from 49 participating Australian organisations 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 minutes. 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: ACTRN12617000743369

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 years aiming to determine the prevalence of advance care planning documentation in Australian hospitals, residential aged care facilities and general practices.
- The results of this study will inform future steps toward improved advance care planning data collection methodology, advance care planning 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 advance care planning documentation in Australia.

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 and sharing their personal values, life goals, and preferences regarding future medical care (1, 2). 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 (3).

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 health care and personal life management (2). 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 (4). 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 (5). 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 (6). 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 (7-12). 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 (13-21).

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 five years. It found ACP prevalence of 12.7% (22). A large Australian sample size (2,764 people) in a prospective prevalence study was described by Nair (17) in 2000 in the Hunter region of New South Wales, with very low levels (0.2%) of formal ACDs found. A prospective survey of 3,055 participants in South Australia found that 46% of the study participants had completed an ACD (20). The first attempt to conduct a national prevalence study in Australia was made by White et al (21). This self-report study included 2,405 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 Advance Care Planning 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 toward 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 (21), 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 (23). In regards to aim 3 we hypothesize 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 hypothesize 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 minutes 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 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.

Fifty records will be audited in each of 49 Australian organisations (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 (Table 1).

[Table 1 here please]

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 health care 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-minutes 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 amongst 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 fifteen 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 2.

[Table 2 here please]

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 (24).

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 2). The list will only contain the person's unique record number. All other identifiable details will be removed.

Randomization

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 randomization procedures each record number will be randomly assigned to two groups: group one ("to include to the audit") or group two ("not to include to the audit"). Only those randomised to group one will be included in the study. The "Research Randomizer" (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 utilised for the purposes of the study, and the final 10 (supplementary list) to be utilised on an as needed basis if any of the first 50 records are not able to be accessed for any reason (e.g. 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.

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 (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 (4, 25, 26). 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 minutes, 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 timeframe of 15 minutes 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 minutes 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 (27). 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 hypothesize 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 2. 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 (28). 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 (Supplementary 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 minutes 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.

Variables

The list of variables to be collected during the study is detailed in Table 3.

[Table 3 here please]

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 EQ-5D five dimensions questionnaire (chosen because it has been extensively validated and shown to be sensitive, internally consistent, and reliable (29)), 3) knowledge and experience regarding ACP, and 4) self-reported use of ACP documentation (i.e. 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 (30). Based on assumptions and findings from previous research, we have chosen a sample 50 people from each organisation, with an expected total sample size of 2450 records (31). This will yield a comparison of data of at least 800 people's records per sector. Estimated precision and confidence intervals of the chosen sample are shown in Table 4. Based on the previous knowledge of 14% of the Australian population having an ACP/ACD (21), the 95% confidence limits for the sample of 50 people would range from 3 to 22%.

[Table 4 here please]

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 customized data security control for each organization 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 minutes. 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-square* 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 Advance Care Planning 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 the 2nd May 2017 by Austin Health Human Research Ethics Committee (reference number: HREC/17/Austin/83). The anticipated date for completion of the study is the 31st 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 Advance Care Planning 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.

Supplementary documents

1. Supplementary Table 1 – Records audit tool
2. Supplementary Table 2 – Survey

Funding

This program is supported by funding from the Australian Government as a part of a Specialist Palliative Care and Advance Care Planning Advisory Service Program.

Authors' contributions

RR acted as a principal investigator and contributed to the concept, drafting, design and revising of the protocol. KD contributed to the concept, drafting, design and critically revising of the protocol. SE 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. JC contributed to the concept and design of the protocol. LN conceived the study and contributed to the concept and critically revising of the protocol.

Competing interests

None

REFERENCES

1. Sudore RL, Lum HD, You JJ, Hanson LC, Meier DE, Pantilat SZ, et al. Defining Advance Care Planning for Adults: A Consensus Definition from a Multidisciplinary Delphi Panel. Journal of pain and symptom management. 2017.

2. The Australian Commission of Quality and Safety in Health Care. The National Consensus Statement: Essential elements for safe and high-quality end-of-life care [cited 2016 (accessed Nov 2016)].

3. Detering K. Accessibility of Advance Care Plans in Victoria – A Summary Options Paper. Melbourne: Advance Care Planning Australia, 2017.

4. Carter RZ, Detering KM, Silvester W, Sutton E. Advance care planning in Australia: what does the law say? Australian health review : a publication of the Australian Hospital Association. 2016.

5. Australian Health Ministers' Advisory Council. Clinical, Technical and Ethical Principal Committee (issuing body). A national framework for advance care directives. Canberra Australian Health Ministers' Advisory Council, 2011.

6. Victorian Government. Advance care planning: have the conversation. A strategy for Victoian health services 2014-2018. State of Victoria, Department of Health 2014.

7. Ashby MA, Thornton RN, Thomas RL. Advance care planning: lessons from a study of Tasmanian enduring guardianship forms. The Medical journal of Australia. 2013;198(4):188-9.

8. Bischoff KE, Sudore R, Miao Y, Boscardin WJ, Smith AK. Advance care planning and the quality of end-of-life care in older adults. Journal of the American Geriatrics Society. 2013;61(2):209-14.

9. Brunner-La Rocca HP, Rickenbacher P, Muzzarelli S, Schindler R, Maeder MT, Jeker U, et al. End-of-life preferences of elderly patients with chronic heart failure. European Heart Journal. 2012;33(6):752-9.

10. Carr D. "I don't want to die like that ...": the impact of significant others' death quality on advance care planning. The Gerontologist. 2012;52(6):770-81.

11. Laakkonen ML, Pitkala KH, Strandberg TE, Berglind S, Tilvis RS. Living will, resuscitation preferences, and attitudes towards life in an aged population. Gerontology. 2004;50(4):247-54.

12. Volker DL, Divin-Cosgrove C, Harrison T. Advance directives, control, and quality of life for persons with disabilities. Journal of palliative medicine. 2013;16(8):971-4.

13. Bezzina AJ. Prevalence of advance care directives in aged care facilities of the Northern Illawarra. Emergency medicine Australasia : EMA. 2009;21(5):379-85.

14. Cheang F, Finnegan T, Stewart C, Hession A, Clayton JM. Single-centre cross-sectional analysis of advance care planning among elderly inpatients. Internal medicine journal. 2014;44(10):967-74.

15. Kirkpatrick JN, Guger CJ, Arnsdorf MF, Fedson SE. Advance directives in the cardiac care unit. American Heart Journal. 2007;154(3):477-81.

16. Milnes S, Orford NR, Berkeley L, Lambert N, Simpson N, Elderkin T, et al. A prospective observational study of prevalence and outcomes of patients with Gold Standard Framework criteria in a tertiary regional Australian Hospital. BMJ supportive & palliative care. 2015.

17. Nair B, Kerridge I, Dobson A, McPhee J, Saul P. Advance care planning in residential care. Australian and New Zealand journal of medicine. 2000;30(3):339-43.

18. Street M, Ottmann G, Johnstone MJ, Considine J, Livingston PM. Advance care planning for older people in Australia presenting to the emergency department from the

community or residential aged care facilities. Health & social care in the community. 2015;23(5):513-22.

19. Wheatley E, Huntington MK. Advanced directives and code status documentation in an academic practice. Family medicine. 2012;44(8):574-8.

20. Bradley SL, Woodman RJ, Tieman JJ, Phillips PA. Use of advance directives by South Australians: results from the Health Omnibus Survey Spring 2012. The Medical journal of Australia. 2014;201(8):467-9.

21. White B, Tilse C, Wilson J, Rosenman L, Strub T, Feeney R, et al. Prevalence and predictors of advance directives in Australia. Internal medicine journal. 2014;44(10):975-80.

22. Butler J, Binney Z, Kalogeropoulos A, Owen M, Clevenger C, Gunter D, et al. Advance directives among hospitalized patients with heart failure. JACC Heart failure. 2015;3(2):112-21.

23. Detering K, Carter R, Sellars M, Lewis E, Sutton E. A prospective comparative effectiveness cohort study, comparing two models of advance care planning provision for Australian community aged care clients. BMJ supportive & palliative care. 2017;in press.

24. Grove A. Research paper series, 206-17. Aged Care: a quick guide. Parliament of Australia. Department of Parliamentary Services; 2016.

25. Haysom G. Review of the National Registration and Accreditation Scheme for health practitioners. Aus Health Law Bulletin. 2015;23(1):12-5.

26. White B, Wilmott L, Trowse P, Parker M, Cartwright C. The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment : Part 1 (New South Wales). J Law Med. 2011;18(3):498-522.

27. Krosnick JA. Survey research. Annual review of psychology. 1999;50:537-67.

28. Australian Government. National Health and Medical Research Council. National Statement on Ethical Conduct in Human Research (2007) (Updated May 2015). www.nhmrc.gov.au/book/national-statement-ethical-conduct-human-research.

29. Rabin R, de Charro F. EQ-5D: a measure of health status from the EuroQoL Group. Ann Med. 2001;33:337-3423.

30. Billingham SA, Whitehead AL, Julious SA. An audit of sample sizes for pilot and feasibility trials being undertaken in the United Kingdom registered in the United Kingdom Clinical Research Network database. BMC medical research methodology. 2013;13:104.

31. Sim J, Lewis M. The size of a pilot study for a clinical trial should be calculated in relation to considerations of precision and efficiency. Journal of clinical epidemiology. 2012;65(3):301-8.

TABLES

Table 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 (i.e. computer, laptop or tablet)
- Must have Internet, e-mail 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 three 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 four to six weeks of notification of successful application.

ACP – advance care planning; IT – information technology

Table 2 Overview of inclusion and exclusion criteria for the study participants

Inclusion criteria	
Part 1. Records audit	**Part 2. Survey**
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	
Part 1. Records audit	**Part 2. Survey**
<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

Table 3 Data variables collected during the study

Part1. 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 minutes		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

ECOG - Eastern Cooperative Oncology Group

Table 4 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	0.83-0.99	800	0.93-0.96
0.9	50	0.78-0.97	800	0.87-0.92
0.8	50	0.66-0.90	800	0.77-0.83
0.7	50	0.55-0.82	800	0.67-0.73
0.6	50	0.45-0.74	800	0.56-0.63
0.5	50	0.36-0.64	800	0.46-0.54
0.4	50	0.26-0.55	800	0.37-0.43
0.3	50	0.18-0.45	800	0.27-0.33
0.2	50	0.10-0.34	800	0.17-0.23
0.1	50	0.03-0.22	800	0.08-0.12
0.05	50	0.01-0.17	800	0.04-0.07
0.02	50	0.00-0.11	800	0.00-0.03

ACD – advance care directive; ACP – advance care planning

GENERIC HEALTH RECORD REVIEW FORM

Study ID number
Study site
Date form completed ___ /___ /___

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, go to Section 2)	Date of most recent documentation __/__/__
2. How long did it take you to find the ACP documentation?	☐ Less than 5 minutes ☐ 5-10 minutes ☐ 10-15 minutes	
3. Where did you find the ACP documentation? (please tick all that apply)	☐ Paper record ☐ Electronic record	
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)________________	
5. What type of documentation did you find? (please tick all that apply)	☐ Statutory ACD - preferences for care (if YES please go to Question 6) ☐ Statutory ACD - SDM appointed by the person (If YES, please go to Question 7)	

	☐ Interstate statutory ACD - preferences for care ☐ *ACT: Health Direction* ☐ *NT: Direction Under Natural Death Act (prior to 17/03/2014)* ☐ *NT: Advance Personal Plan (from 18/13/2014)* ☐ *QLD: Advance Health Directive* ☐ *SA: Anticipatory Direction (prior to 01/07/2014)* ☐ *SA: Advance Care Directive (from 02/07/2014)* ☐ *TAS: Enduring Guardian (a statutory document that contains information about preferences for care)* ☐ *VIC: A Refusal of Treatment Certificate (competent)* ☐ *VIC: A Refusal of Treatment Certificate (incompetent)* ☐ *WA: Advance Health Directive* ☐ Interstate statutory ACD - SDM appointed by the person ☐ *ACT: Enduring Power of Attorney (HealthCare Matters)* ☐ *NSW: Enduring Guardian* ☐ *NT: Enduring Power of Attorney (prior to 17/03/2014)* ☐ *NT: Decision Maker (Healthcare Matters) (from 18/13/2014)* ☐ *QLD: Enduring Power of Attorney (Personal Matters)* ☐ *SA: Medical Power of Attorney (prior to 01/07/2014)* ☐ *SA: Advance Care Directive – Substitute Decision Maker Appointment (from 02/07/2014)* ☐ *TAS: Enduring Guardian* ☐ *VIC: Enduring Power of Attorney Medical Treatment* ☐ *VIC: Enduring Power of Guardianship (prior to 31/08/15)*

	☐ *VIC: Enduring Power of Attorney (Personal Matters) (from 01/09/2015)* ☐ *WA: Enduring Guardian* ☐ Non-statutory or common law ACD documentation (If YES please go to Question 8) ☐ Other documentation (If YES please go to Question 9) (please specify)
6. Details of the person's statutory ACD documentation (preferences for care)	☐ Yes, there is a copy in the record ☐ No – I did not find a copy of a statutory ACD (preferences for care), but the record indicates the person has completed one. ☐ No document or notes (regarding the existence of it) located in the record
	If YES, please specify the name of the document
	Was the document signed ☐ Yes ☐ No (Please proceed to the next question)
	Who signed the document? (please tick all that apply) ☐ Person ☐ Doctor ☐ Legal practitioner ☐ Justice of Peace ☐ SDM appointed by the person ☐ Unable to determine ☐ Signatures were not found ☐ Other (please specify)
	☐ Not Applicable
	Is the document signed in accordance with legislation? ☐ Yes

	☐ No ☐ I don’t know
7. Details of the person’s statutory ACD – SDM appointed by the person	☐ Yes, there is a copy in the record ☐ No - did not find a copy of the statutory ACD (SDM appointed by the person), but the record indicates the person has completed one. ☐ No document or notes (regarding the existence of it) located in the record
	If YES, please specify the name of the document
	What is the relationship of the substitute decision maker to the person? (Please tick all that apply) ☐ Spouse/partner ☐ Child ☐ Sibling ☐ Other family ☐ Friend ☐ Other (please specify) ☐ Not stated
	Was the document signed? ☐ Yes ☐ No (Please proceed to the next question)
	Who signed the document? (please tick all that apply) ☐ Person ☐ Doctor ☐ Legal practitioner ☐ Justice of Peace

	☐ Appointed decision maker ☐ Unable to determine ☐ Signatures were not found ☐ Other (please specify)
	☐ Not Applicable
	Is the document signed in accordance with legislation? ☐ Yes ☐ No ☐ I don't know
8. Details of the person's non-statutory ACD documentation	☐ Yes, there is a copy ☐ No – I did not find a copy of a non-statutory ACD but the record indicates the person has completed one. ☐ No document or notes (regarding the existence of it) located in the record
	If YES, please specify the name of the document
	Was the document signed? ☐ Yes ☐ No (Please proceed to the next question)
	Who signed the document? (Please tick all that apply) ☐ Person ☐ Doctor ☐ Legal practitioner ☐ Justice of Peace ☐ Appointed decision-maker ☐ Unable to determine

	☐ Signatures were not found ☐ Other (please specify)
9. Details of the person’s other type of ACP documentation (please tick all that apply)	Please specify the name(s) of the document(s)____
	The document(s) are in the form of (please tick all that apply): ☐ Notes ☐ Charts ☐ Letters ☐ Goals of Care with person’s wishes clearly stated ☐ Evidence or statement of family awareness of person’s advance care plan (please specify)____________________________________ ☐ Other correspondence (please specify)____________________________________
	Who completed the documentation? ☐ Person ☐ Doctor ☐ Nurse ☐ Other (please specify)
PERSON’S PREFERENCES	
10. In the person’s ACP documentation did it include documentation of their preferences for care?	☐ Yes ☐ No (If NO go to SECTION 2)
	If YES, what is selected? ☐ Life prolonging treatment ☐ Life prolonging treatment with specific outcomes / or some limitations of treatment ☐ No life prolonging treatment ☐ Person wants to delegate decisions to another person (e.g. SDM)

11. Other preferences (please tick all that apply)	☐ Preferred place of care/location (please specify) ☐ Preferred place of death/location (please specify) ☐ Other preferences and values (please specify) ☐ None
SECTION 2. MEDICAL ORDERS	
12. Is there a medical order?	☐Yes ☐ No (go to SECTION 3)
13. Does the medical order limit treatment?	☐ Yes ☐ No (Please go to **Question 15**)
14. What are the limitations on the order?	**If there is a limitation on treatment (please tick all that apply):** ☐ Not for cardiopulmonary resuscitation (CPR) ☐ Not for intubation ☐ Not for intensive care unit (ICU) ☐ Not for hospitalisation ☐ Not for antibiotics ☐ Other limitations (please specify)____________________
15. Does the medical order acknowledge the person's ACD/advance care plan?	☐ Yes ☐ No ☐ Not applicable (no ACD or advance care plan) ☐ Unclear
16. If there is an ACD/advance care plan, are the medical orders consistent with the person's wishes?	☐ Yes ☐ No ☐ Unclear ☐ Not applicable (no ACD or advance care plan)

17. Does the medical order acknowledge discussion with the person?	☐ Yes ☐ No, not documented ☐ No, reason for not discussing with person is documented (e.g. person not competent)
18. Does the medical order acknowledge discussion with person's family?	☐ Yes ☐ No, not documented ☐ No, reason for not discussing with family is documented (e.g. discussed with person, no family available)
SECTION 3. PERSON'S DETAILS	
19. Age	
20. Sex	☐ Male ☐ Female ☐ Indeterminate/Intersex/Unspecified
21. Postcode	
22. Country of birth	☐ Australia ☐ Other (please specify)__________________ ☐ Unknown – information not available in record
23. Indigenous status	☐ Aboriginal ☐ Torres Strait Islander ☐ Both Aboriginal and Torres Strait Islander ☐ Neither ☐ Not stated (information not available in record)
24. Ethnicity	☐ Available (please specify) ☐ Unknown – information not available in record

25. Religion	☐ Available (please specify) ☐ Unknown – information not available in record	
26. Language status	☐ Speaks English ☐ Interpreter required (please specify the language) ☐ Unknown – information not available in record	
27. Date of person's admission/visit		
28. Person came from	☐ Aged care facility ☐ Hospital ☐ Home ☐ Other (please specify)____________________ ☐ Unknown	
29. Medical condition (please tick all that apply)	☐ Circulatory system ☐ Respiratory system ☐ Neurological system ☐ Gastrointestinal system ☐ Musculoskeletal and connective tissue ☐ Endocrine, nutritional and metabolic disorders ☐ Urinary/excretory and reproductive ☐ Cancer ☐ Mental Illness ☐ Dementia ☐ Other (please specify) ___________________________________	
30. Is this person receiving palliative care?	☐ Yes	If Yes, is the palliative care from the specialist palliative care service?

	☐ No ☐ Unknown	☐ Yes ☐ No ☐ Unknown
31. Eastern Cooperative Oncology group (ECOG) performance status – this is a scale used to assess how a person's disease is progressing and how the disease impacts the daily living abilities of the person. This information can help to determine appropriate treatment and prognosis	☐ Fully active, able to carry on all pre-disease performance without restriction ☐ Restricted in physically strenuous activity, but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work ☐ Ambulatory and capable of all selfcare but unable to carry out any work activities; up and about more than 50% of waking hours ☐ Capable of only limited selfcare; confined to bed or chair more than 50% of waking hours ☐ Completely disabled; cannot carry on any selfcare; totally confined to bed or chair ☐ Information not available	

Staff member to complete	
Person's ability to participate in this survey (please choose one option)	☐ Person is able to participate ☐ Person does not want to take part in the study ☐ Person is unable to consent ☐ Person does not speak English ☐ Other (please specify) ________________________

PERSON SURVEY

Study ID number
Study site
Date form completed ___ /___ /___

Section 1: About you

1. I am completing this survey:	☐ On my own without help from someone else ☐ With help from someone else (e.g. friend/relative, staff member). Please specify who__________________
2. I am:	☐ Male ☐ Female ☐ Other (please specify)__________________
3. My age is:	
4. I was born in:	☐ Australia ☐ Other country (please specify) __________________
5. I am:	☐ Aboriginal ☐ Torres Strait Islander ☐ Both Aboriginal and Torres Strait Islander ☐ Neither ☐ Prefer not to answer
6. The language I speak at home is:	
7. My ethnicity is:	

8. How important is your religion to you?	☐ Very important ☐ Important ☐ Somewhat important ☐ Not important ☐ Prefer not to answer
9. What is your current relationship status?	☐ Married/de facto/in a relationship ☐ Single ☐ Divorced or separated ☐ Widowed
10. What is your highest level of education?	☐ No formal schooling ☐ Primary school (Highest year completed) ☐ Secondary or High school (Highest year completed) ☐ Trade school or Apprenticeship ☐ Diploma ☐ University degree
11. Who do you live with?	☐ Husband/wife/partner ☐ Children ☐ Brother/sister ☐ Other family ☐ Friends ☐ I live alone

Section 2: About your health

Under each heading, please tick the ONE box that best describes your health TODAY.

12. Mobility	☐ I have no problems in walking about

	☐ I have slight problems in walking about ☐ I have moderate problems in walking about ☐ I have severe problems in walking about ☐ I am unable to walk about
13. Usual Activities *(e.g. work, study, housework, family or leisure activities)*	☐ I have no problems doing my usual activities ☐ I have slight problems doing my usual activities ☐ I have moderate problems doing my usual activities ☐ I have severe problems doing my usual activities ☐ I am unable to do my usual activities
14. Self-Care	☐ I have no problems washing or dressing myself ☐ I have slight problems washing or dressing myself ☐ I have moderate problems washing or dressing myself ☐ I have severe problems washing or dressing myself ☐ I am unable to wash or dress myself
15. Pain/discomfort	☐ I have no pain or discomfort ☐ I have slight pain or discomfort ☐ I have moderate pain or discomfort ☐ I have severe pain or discomfort ☐ I have extreme pain or discomfort
16. Anxiety/depression	☐ I am not anxious or depressed ☐ I am slightly anxious or depressed ☐ I am moderately anxious or depressed ☐ I am severely anxious or depressed ☐ I am extremely anxious or depressed

Section 3: Your understanding and experience of advance care planning

ADVANCE CARE PLANNING is the opportunity for people to tell their family, friends and doctors ahead of time, what they would want if they became seriously ill and could no longer speak for themselves. Ideally they would talk to their family, friends and doctors. It is also a good idea to write it down.

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 document and I review my advance care plan from time to time
19. Who would you trust to make medical decisions for you if you were too unwell to do so for yourself? (please tick all that apply)	☐ Husband/wife/ partner ☐ Children ☐ Brother/sister ☐ Other family ☐ Friend ☐ Doctor ☐ Other (please specify) ☐ I can't decide ☐ No-one

	☐ I have not thought about that yet
20. What things would **worry you most** about your future? (please tick all that apply)	☐ Not being able to look after myself ☐ Being in pain/distressed ☐ Not being able to get out of bed ☐ Not being able to make decisions for myself ☐ Relying on others ☐ Being a burden on my family/ friends/carers ☐ Not being able to talk to my family/ friends/carers ☐ Being admitted to hospital ☐ Wanting to live as long as possible ☐ Wanting to get well ☐ Other (please specify) ___________________
21. Thinking about your future, if you became really unwell or unconscious, and couldn't tell the doctors what you want, which sentence reflects best how you feel?	☐ I want to live for as long as possible ☐ I want to live as long as possible but only if my acceptable outcomes and preferences for care are likely ☐ I would not want any treatment that was to prolong my life, I would want to receive comfort care ☐ I would not want to make this decision myself. The person I would want to make this decision for me is my___________________

Section 4: Telling others about your advance care plans

22. Have you ever talked to anyone about your goals, values, beliefs or your preferences about specific	☐ Yes ☐ No (If No, go to **Question 24**) ☐ I cannot remember (If you cannot remember, go to **Question 24**)

medical treatment in case you become seriously ill or unable to make your own decisions?	If YES, who did you talk to? ☐ Husband/wife/partner ☐ Children ☐ Brother/sister ☐ Other family ☐ Friend ☐ Doctor ☐ Other (please specify) ___________________ ☐ I have not thought about that yet
23. Have you ever written down your goals, values, and beliefs or your preferences about specific medical treatment in case you become seriously ill or unable to make your own decisions?	☐ Yes ☐ No (If No go to **Question 25**) ☐ I cannot remember (If you cannot remember go to **Question 25**)
	If YES, how long ago did you do this? ___________________ In what type of document did you write this? ___________________ Where is this document kept? ___________________
24. Have you ever signed a legal document to appoint someone to make healthcare decisions on your behalf if you were unable to make your own decisions?	☐ Yes ☐ No (If No go to **Question26**) ☐ I cannot remember (If you cannot remember go to **Question 26**)
	If YES how long ago did you sign this document? ___________________ What type of document did you sign? ___________________ Where is this document kept? ___________________
25. Any other comments regarding your experiences with advance care planning	

STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation	
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	YES, p.1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	YES, p.3
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	YES, p.5-7
Objectives	3	State specific objectives, including any prespecified hypotheses	YES, p.7
Methods			
Study design	4	Present key elements of study design early in the paper	YES, p.8
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	YES, p.8-9
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	YES, p.9
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case	NA
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	YES, p.12
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	YES, p.12
Bias	9	Describe any efforts to address potential sources of bias	NA (pilot study)
Study size	10	Explain how the study size was arrived at	YES, p.12
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	YES, p.13-14
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	YES, p.13-14
		(*b*) Describe any methods used to examine subgroups and interactions	YES, p.13-14
		(*c*) Explain how missing data were addressed	NA
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking	NA

		account of sampling strategy
		(*e*) Describe any sensitivity analyses

Results [NOT APPLICABLE, STUDY PROTOCOL]		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed
		(b) Give reasons for non-participation at each stage
		(c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders
		(b) Indicate number of participants with missing data for each variable of interest
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time
		Case-control study—Report numbers in each exposure category, or summary measures of exposure
		Cross-sectional study—Report numbers of outcome events or summary measures
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included
		(*b*) Report category boundaries when continuous variables were categorized
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses
Discussion		
Key results	18	Summarise key results with reference to study objectives
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	Discuss the generalisability (external validity) of the study results
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.