Advance care planning in 21st Century Australia: A systematic review and appraisal of online advance care directive templates against National Framework criteria

Running title

Review of online advance care directive templates

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Abstract

Objectives

A drive to promote advance care planning at a population level has led to a proliferation of online advance care directive (ACD) templates but little information to guide consumer choice. The current study aimed to appraise the quality of online ACD templates promoted for use in Australia.

Methods

A systematic review of online Australian ACD templates was conducted in February 2014. ACD templates were identified via Google searches, and quality was independently appraised by two reviewers against criteria from the 2011 *National Framework for Advance Care Directives*. Bias either towards or against future medical treatment was assessed using criteria designed to limit subjectivity.

Results

Fourteen online ACD templates were included, all of which were available only in English. Templates developed by Southern Cross University best met *Framework* criteria. One ACD template was found to be biased against medical treatment – the Dying with Dignity Victoria Advance Healthcare Directive.

Conclusions

More research is needed to understand how online resources can optimally elicit and record consumers' individual preferences for future care. Future iterations of the *Framework* should address online availability and provide a simple rating system to inform choice and drive quality improvement.

Key question summary

1. What is known about the topic?

Online availability of advance care directive (ACD) templates provides consumers with an opportunity for advance care planning outside of formal healthcare settings. While online availability has advantages, there is a risk that templates may be biased either for or against medical treatment and may not elicit directives that are appropriately informed by reflection on personal values and discussion with family and health professionals.

2. What does this paper add?

This is the first attempt at monitoring the quality and bias of online ACD templates designed for use in Australia.

3. What are the implications for practitioners?

The results of this review provide a description and quality index to assist consumers and clinicians in deciding which online ACD template to use or recommend.

Introduction

Advance care planning (ACP) is a process by which people reflect on and communicate their personal values and preferences for the purpose of guiding their future care in the event they become unable to speak for themselves (1). ACP often culminates in completion of an advance care directive (ACD) that formally documents the person's wishes for future care and may also involve the appointment of a substitute decision-maker. In Australia, ACP has been promoted at a population level by local, state and national initiatives with the aim of improving congruence between consumer's needs and goals of care and the healthcare provided (1-3). ACP also has important implications for the cost-effectiveness of future healthcare because of its potential to reduce unwanted treatments. Although the legal status of ACDs varies between each state and territory ('jurisdictions'), common law across Australia upholds the right of patients to refuse but not demand treatment against the advice of their medical team (1).

Whilst most research on ACP has focused on its facilitation by health professionals within formal healthcare settings (4-6), promotion at the population level has led to a proliferation of online ACD templates that consumers can complete at home (7). In this article, we use 'template' to denote a blank form that has been made available on a website for people to use when completing their advance care directive. Sometimes these templates are accompanied by guidelines that support completion of an ACD and the process of ACP more generally. These and any other resources provided to support ACP are collectively referred to as ACP materials. Online availability of ACD templates, guidelines and other materials has several advantages. The user-led nature of online materials is consistent with ACP's original philosophy of patient autonomy (8). The internet allows consumers to complete ACDs at a time and place convenient to themselves and their families, providing an opportunity for promotion and uptake of ACP for people who do not regularly access formal healthcare. It also provides an opportunity to access additional information consumers may require to inform their decision-making about various medical conditions and treatments. Finally, completion and storage of online ACDs offers promising potential for regular updating and improved accessibility to healthcare providers, especially if harmonised in the future with e-Health initiatives such as Australia's Patient Controlled Electronic Health Record (PCEHR) (9).

But whilst there are advantages to internet availability, a lack of regulation and monitoring raises concerns about the ways in which online ACDs may be promoted and used. Concerns include the potential for online materials to be biased either towards or against various medical interventions and so undermine ACP's primary purpose of promoting consumer choice based on individual values and preferences (10, 11). There is also a risk that ACDs completed online may be ill-informed because of 'quick and easy' internet functionality and the opportunity to document decisions without discussing these with family or health professionals. ACP is more properly thought of as an iterative process in which decisions and resulting directives are contextualised and revisited within each individual's changing health, beliefs and values (12). Finally, there is a concern that online templates may not be accessible to users with lower literacy and health literacy who may be in greatest need of ACP.

In 2011, the Australian Health Ministers' Advisory Council (AHMAC) published a *National Framework for Advance Care Directives* (1) to combat threats to ACD validity and barriers to implementation. The framework provides specific criteria for assessing the quality of ACD templates and guidelines but stops short of recommending specific templates. In the absence of quality control, there is a

danger that online resources may lead to a proliferation of ACDs that are of indeterminable validity and accuracy regarding patient preferences, but that nonetheless require consideration at the point of care.

The current study aimed to guide consumer choice by evaluating online ACD templates and materials for supporting completion of these promoted for use in Australia against the *Framework* criteria (1).

Methods

Eligibility criteria

ACD templates were considered eligible if they were readily available to consumers from publically-accessible Australian web-sitees, were available in English, and offered a means of documenting wishes for future care in the event of lost decision-making capacity. Supplementary information were also reviewed where these supported completion of an online ACD. ACD templates on websites of non- Australian organisations were excluded because of differences in legislative context. We also excluded forms dealing exclusively with appointment of a substitute decision-maker and ACD templates that focused on specific settings (e.g. aged care) or proxy completion so as to enable valid comparison.

Information sources

We searched the internet using the Google search engine on the 19th of February 2014. We considered Google the best approach for identifying ACD templates most likely to be used by consumers because it is the most widely used search engine internationally (13). Where templates or guidelines offered contact details, we sent emails and/or telephoned to request further information about the development process and availability of research evidence supporting each ACD template. Three attempts to contact were made at weekly intervals, after which time a non-response was assumed.

Search

Google searches used the terms ‘advance care planning’ and ‘advance care directive’ as well as the term ‘advance health directive’, which is used in some Australian jurisdictions (1).

Selection

By default, a Google search returns links to 10 web-pages on each page of results. Each web-page returned by searches was opened and appraised against set criteria Each web-page returned by searches was opened and appraised against set criteria until two consecutive results pages (i.e. 20 consecutive web-pages) yielded no new ACD templates. Links from each web-page were followed wherever they looked likely to contain information about ACP.

Data collection and items

Detailed information was extracted from each ACD template and accompanying guideline using criteria for quality provided by the *Framework* (1) (Table 1). Criteria were based not only on the *Framework* ‘Checklist for forms’ ((1)p.34) but also on a distillation of recommendations throughout the document. Information deemed relevant to each criterion was extracted verbatim independently by two reviewers (TL, PB) and inserted into an Excel spreadsheet. The reviewers met to agree on final data.

Table 1 about here

Synthesis

The degree to which each ACD template and guideline met *Framework* criteria was independently evaluated by two reviewers (TL, PB) using a three point scale of 'not met', 'partly met' and 'satisfactorily met' each of which was assigned a score of 0, ½ and 1 respectively. Inter-rater reliability for each criterion was assessed using a weighted kappa statistic because we considered disagreements of 'not met' versus 'satisfactorily met' to be of most concern (14). Wherever reviewers disagreed, a final decision was reached via discussion.

Readability of ACD templates was objectively assessed using an online program called the *Readability Test Tool* (15).

Assessment of bias focused on ACD template content rather than supporting information, unless the ACD was embedded within a guideline. Rather than devise a scale requiring subjective assessment, we used objective observation of the presence or absence of specific features where possible (Table 2). To control for the possibility that reviewers might become biased by their global impressions of a given template, instances of perceived bias were extracted verbatim and rated by the second reviewer without knowledge of which template they came from. Extracts were considered biased only where both reviewers independently identified them as such. ACD templates were reviewed for the presence of default options because these have been shown to influence decision-making in a randomised controlled trial (RCT) (16). Initial plans for linguistic analysis were abandoned because no objective method could be devised.

Table 2 about here

Finally, evidence for each resource cited in accompanying guidelines or provided by contact persons was rated using the National Health and Medical Research Council (NHMRC) grading system by the two reviewers working independently (17).

The review was conducted and reported as much as possible in accordance with the Preferred Reporting Items for Systematic reviews and Meta-analyses (PRISMA) guideline, which is primarily intended for reviews of research (18).

Results

Selection

Google searches resulted in the identification of 14 online ACD templates freely available for use in Australia (Figure 1) (19-32). All templates referenced a specific Australian state or territory in their branding and/or guideline: one for Australian Capital Territory (ACT) (19), four for New South Wales (NSW) (21-23, 29), one for Northern Territory (NT) (24), two for Queensland (25, 30), one for South Australia (SA) (28), one for Tasmania (31), two for Victoria (20, 26) and two for Western Australia (WA) (27, 32). The characteristics of each ACD template and associated materials are summarised in Table 3.

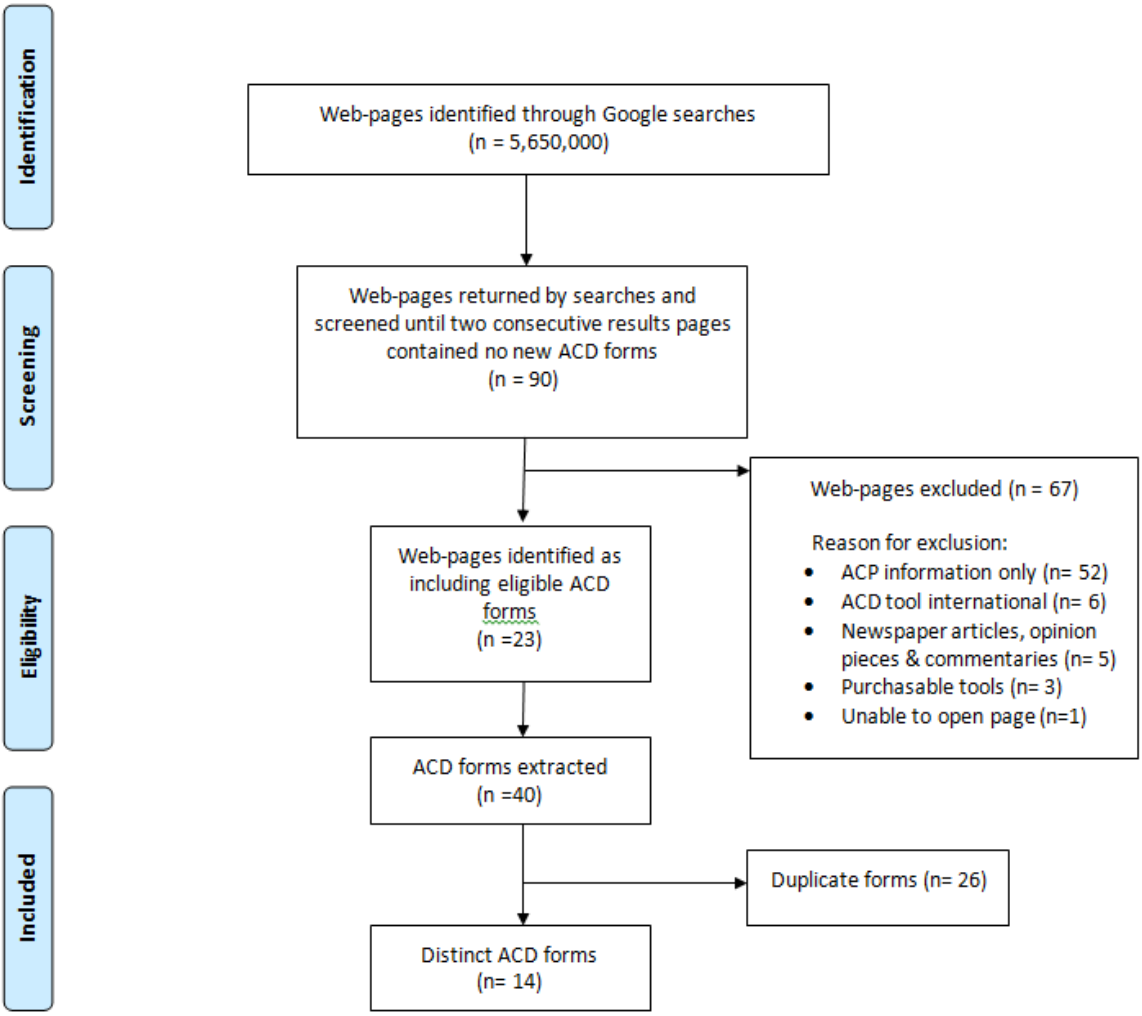

Figure 1. Flow diagram of results from Google searches, screening and eligibility assessment

Table 3

Three of the ACD templates were regional variations on the *Respecting Patient Choices*® template designed for Queensland, Victoria and WA (25-27). The Queensland and Victorian *Respecting Patient Choices*® templates were found to have similar content, while the WA template resembled two other templates from ACT and NT Health (19, 24) that were not clearly branded as *Respecting Patient Choices*® but were linked to from that website. Templates for NSW and Tasmania linked to from the *Respecting Patient Choices*® website (22, 31) were similarly branded with state/territory or local health district logos rather than being badged as *Respecting Patient Choices*® products. *Respecting Patient Choices*® information booklets and leaflets available on web-pages for each state/territory were found to be identical and were included in appraisal only for templates carrying *Respecting Patient Choices*® branding. The *Respecting Patient Choices*® team did not respond to requests for clarification. Two further templates were developed by the same University of Southern

Cross team (29, 30) and were found to be identical in content except that the original Queensland version enabled appointment of an attorney whilst the NSW version was expanded to include a residential aged care section.

Developers of seven templates responded to enquiries about development and research (20, 21, 23, 29-32).

Synthesis

Results from appraisal against *Framework* criteria for ACD templates and guidelines are reported in Supplementary Table 1 and results for ACD templates specifically in Supplementary Table 2. Inter-rater reliability was satisfactory (kappa = 0.61) (33).

Assessment of bias identified one ACD template to be produced by an organisation with a publicised pro-euthanasia agenda, Dying with Dignity Victoria (20). Rating by two reviewers identified 10 instances of bias in this and seven other ACD templates (21, 24-26, 28-30), nine being anti-treatment and the remainder pro-treatment. Two further instances were deemed ambiguous due to reviewer disagreement. Material rated as biased is reproduced verbatim in Table 6 to enable readers to form their own opinions. Default options against medical treatment were identified in only one ACD template, again that produced by Dying with Dignity Victoria (20). This template included a default that the ACD would come into effect '*at any time I have become unable to participate effectively in decisions about my medical care*', leaving it to the user to stipulate an added condition of non-recovery. The *Respecting Patient Choices*® Statement of Choices (VIC) (26) gave a semblance of choice regarding cardio-pulmonary resuscitation (CPR) but, on closer inspection, neither option presented a preference to have this treatment (see Supplementary Table 3). Six templates (19, 20, 22, 23, 25, 26) allowed for the option of refusing and/or consenting to medical treatment without specifying the circumstances under which the directive should come into force.

Assessment of research evidence found only the *Respecting Patient Choices*® ACD templates to be supported by research of any kind. An RCT (level II evidence) found ACP incorporating a *Respecting Patient Choices*® ACD template to be associated with an increased likelihood for end-of-life care to be congruent with patient wishes as well as superior family stress, anxiety, depression and satisfaction (34). Appraisal against NHMRC criteria resulted in allocation of a Grade B for evidence (17). However, the article in which this research was reported emphasised the role of one-to-one support for ACP by a trained facilitator rather than the ACD template *per se*, and clarification was not received from the authors as to which of the *Respecting Patient Choices*® ACD templates was used. Published information was found on consumer involvement by *Respecting Patient Choices*® during ACD template development (35) and was assumed to apply to all variants for the purpose of quality appraisal.

Discussion

This review found substantial variation in the degree to which online ACD templates intended for use in Australia complied with criteria set out in the *National Framework* (1). Templates developed by the Southern Cross University for use in Queensland and NSW (29, 30) were found to be most compliant with criteria, followed by those developed by Health North Coast's (NSW) (21), *Respecting Patient Choices*® (Queensland) (25) and WA Department of Health (32).

Only the ACD templates produced by the *Respecting Patient Choices*® Program were supported by high-level evidence, and even this research examined a broader program of facilitated ACP rather than ACD templates specifically. It was not possible to ascertain which version of the template was used in the RCT, and versions developed for different states varied in ways that could not be explained wholly by jurisdictional legislation. *Respecting Patient Choices*® was itself adapted from a US program called *Respecting Choices®,* further limiting clarity regarding the evolution of templates before and since the RCT (35).

With the exception of the Dying with Dignity Victoria template (20), we found little evidence for bias either for or against medical treatment at end-of-life. Furthermore, the overt nature of bias in the Dying with Dignity Victoria template means it is more likely to constitute a basis for selection by people whose preference is to refuse medical treatment than to subvert care preferences in people who are pro-treatment, ambivalent or have situationally-dependent wishes.

Another reassuring finding was that none of the ACD templates were made available without at least some information aimed at emphasising and supporting ACP as a process requiring discussion with family and health professionals. This goes some way to reducing concern that users may complete online ACDs with little knowledge or understanding of their meaning and application, although consumers may still choose to complete an ACD without referring to supporting documentation.

Of more concern is the finding that a substantial minority of ACD templates (19, 20, 22, 23, 25, 26) offered the opportunity for users to request that medical treatment be provided or refused *regardless of clinical context*. This is worrying because mitigating circumstances may arise that cannot be foreseen at time of ACD completion. Also, offering consumers the choice to request treatment under any circumstances belies the fact that clinicians are not obliged to offer treatment against their clinical judgment (1).

Further variations among ACD templates concerned their readability, language availability and whether they encouraged directives for specific treatments (e.g. CPR) and/or asked about values more generally. Readability varied from US grade 7 (36) to 18 (22), raising concerns that some forms may not be accessible for people with low literacy. Only two templates were supported by information in languages other than English (26, 37), and no templates themselves were translated. This is of concern because 3% of Australians have limited English proficiency (38). A 'combined' approach that records values and preferences as well as treatment choices contextualised within specific scenarios has been recommended as offering the most comprehensive information for decision-making, especially when accompanied by appointment of a substitute decision-maker (5).

None of the templates were in a format that enabled immediate online storage, although several could be completed electronically (24, 28-30, 32) and one offered advice on registering directives with MedicAlert (28, 39). None included information about whether the template was applicable in other jurisdictions, although some referred to local legislature. However, the *Respecting Patient Choices*® website included a page detailing differences in ACD legislation for each state and territory (40), as well as links to relevant legislation and materials produced by regional health authorities on pages dedicated to each jurisdiction.

Limitations

Our review has several limitations. Our search was designed to identify ACD templates most likely to be found by Australian consumers rather than provide an exhaustive list. Inevitably, the review is a 'snapshot' of ACD templates available online in February 2014 and will become out of date as new templates emerge to keep pace with ACD-related legislation (41). Five of the templates were not dated (19, 22, 29, 31, 32), making it difficult to assess currency. Overlap between nomenclature and uncertainty regarding authorship made it impossible to search for published research evidence via electronic databases. The scale we used to evaluate templates against the Framework criteria was not validated, and the 'partly' category included substantial variability in some cases. For this reason, we did not weight each criterion and have not emphasised overall 'scores' in case these are over-interpreted as having interval properties. Finally, while we used an online tool utilising common objective approaches for assessing readability, methods for this remain controversial (15, 42).

Future directions

A coherent public health strategy is needed to monitor the number of people completing online ACDs and to promote ACP of sufficient quality to translate into benefits at individual and population levels. ACP differs from some other behavioural changes sought by public health initiatives in that it has potential to do be counter-productive. Further research is needed to inform the design of online ACD templates so that they optimally elicit and represent personal preferences for care by people with varying literacy levels, and instil confidence in this among clinical decision-makers. Cognitive interviewing might be especially useful in elucidating the considerations people undertake when completing ACD templates, for example, when balancing the likelihood of recovery or referencing perceived normative preferences in determining their own (43). A better understanding of biases and how these can be influenced by ACD template content, examples and formatting could be used to inform quality recommendations for inclusion in future iterations of the *National Framework for Advance Care Directives* (1), which will need to keep pace with technological changes in the way that ACDs are completed and stored. Finally, it is hoped that future work will build on the current review to develop a star-rating system or similar for templates that meet *Framework* criteria to provide an incentive to developers and provide consumers with an easy-to-understand index of quality.

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Conflicts of interest

The authors have no conflicts of interest to declare.

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Table 1. Criteria used to appraise the quality of online ACD guidelines and templates based on the 2011 *National Framework for Advance Care Directives* (1)

Criteria	Rationale
Templates and guidelines	
Development should involve health professionals from different disciplines and consumers (e.g. via focus group testing)	• ACD requirements and usage may vary by discipline and setting • ACP should be consumer-led • A diversity of perspectives may help to avoid bias for or against medical treatment
Should be relevant to healthy adults as well as those with life-limiting illness	ACP should be available to anyone who wishes to undertake it
Includes definition of ACP and its implications for care and families	Informs users' decision to complete an ACD and who to consult with during ACP
Includes stories and scenarios to illustrate how ACDs can be used and applied	Supports users' understanding, especially where healthcare experience and/or literacy is limited. However, can lead to bias if not appropriately balanced (see quality assessment below)
Available in translated versions	Australia is multicultural, and healthcare professionals may especially need assistance in understanding preferences of patients from other cultures and/or where family SDMs lack proficiency in English
Provides description of roles of person completing ACD, SDM, care professionals and others	Improves ACD quality by encouraging discussion with informants: ○ affected by decisions in the ACD ○ with the patient's interests at heart ○ with expert knowledge of medical treatment ○ responsible for interpreting and implementing the ACD
Include guidance for ACD witnesses on checking the person is adult, not under undue influence, and competent	Witness needs to understand what (s)he is signing for
Promotes value of appointing and instructing an SDM	Eventualities unforeseen by ACDs may require decisions to be made by someone with detailed understanding of patient values and preferences
Where specific medical directions are to be included, recommend consulting with a healthcare professional to ensure these reflect preferences and goals and are clear, and encourage dissemination to	• Decisions regarding specific interventions depend on an understanding of clinical context, treatment factors, procedures and outcomes and evaluation of risk • Dissemination improves chances that ACD will

Criteria	Rationale
family and any professional caregivers.	be available and wishes understood when needed. SDMs should have opportunity to clarify wishes if needed. Family members may raise new issues for consideration
Describes legal status, including reference to local legislation and policy	Informs realistic expectations of how ACD will be used and any limitations that may require further action to address
<u>Templates only</u>	
Adaptable to online and hard-copy format	Accessibility and preferences for completion and storage are likely to vary
Content written in plain English, with definitions of any unfamiliar terms	Increases the likelihood that users have understood the ACD's meaning and purpose and, in turn, clinician confidence that the ACD is valid
Transferable across care settings	Preferences may need to inform care in a range of settings
Designate whether decisions are to be followed exactly or in an advisory way by SDM	Clear instructions to SDM will improve chances of wishes being followed as intended
Separate healthcare from residential and personal decisions	Different sections may need to be distributed to different SDMs
Include space for name, date of birth and signing by the person completing	Clear identification of person whose ACD it is against patient records
Include space for name and signing by a witness	Reassures clinicians that ACD is valid and therefore improves likelihood it will be acted upon
Includes date for review and makes it easy to update	Preferences for care change over time
If space for instructions for medical treatment, should allow for advance refusal and advance consent	A balance is needed between directives for and against medical treatment to avoid bias and promote individual choice
Allows separate directives for different kinds of incapacity (e.g. temporary)	Encourages consumers to understand and provides better coverage for different potential scenarios
Enables recording of values, life goals and preferred or unacceptable outcomes of care as well as directives for specific medical interventions	• Impossible to plan for all clinical scenarios • Values are more consistent over time than preference for specific treatments

ACD = advance care directive; ACP = advance care planning; SDM = substitute decision-maker

Table 2. Measures used to assess potential bias either for or against medical treatment

Potential bias	**Measurement**
Allegiance to particular ethical, political or religious perspective	• Produced and/or sponsored by an organisation with a publicised agenda • Explicit reference to doctrine
Active promotion of directives for or against medical treatment	• Instances of bias for or against medical treatment • Use of default options for or against medical treatment • Opportunities to request that medical treatment be provided versus not provided *regardless of clinical context* rather than dependent on specified conditions

Table 3. Characteristics of 14 online ACD templates identified for use in Australia

ACD template (state/territory)	URL	Guideline/ACD	Resources on website / via links	Content and features
ACT Health Advance Care Plan (ACT) (19)	http://advancecareplanning.org.au/library/uploads/documents/act/SA_Competent_cover_sheet_and_template_competent_2.pdf	None from ACT Health, but separately available on RPC website	Linked to from RPC website but ACT Health is indicated as the author and the only mention of RPC is invitation to talk to RPC consultant. ACT RPC web-page also includes version for proxy completion, separate Health Direction template, and links to ACT government resources.	Invites attachment of other documentation (e.g. organ donation); recommends completion of Health Direction for specific medical conditions; message to family and friends.
Dying with Dignity Victoria Advance Healthcare Directive (VIC) (20)	http://www.dwdv.org.au/resources/forms-download/file/13-5a-advance-heathcare-directive-general.html	Integrated and separate	EPA template, refusal of treatment template and example of completed ACD.	Organ donation; gives option of SDM being treating doctor; includes request for donations to DWD; statements requesting euthanasia if legal and absolving medical attendants from civil liability.
Healthy North Coast – Advance care or health directive (NSW) (21)	http://healthynorthcoast.org.au/wp-content/uploads/2014/02/ADVANCE-CARE-DIRECTIVE-Feb-2014-1.pdf	Separate	Information on 5 Steps of medical care decision making for families and guardians; resource to assist GPs to identify, assess and plan for patients with advanced disease; 12 minute introductory video; version of template for proxy completion.	Space for family and SDM to sign to say discussion has taken place; preferred place of death
Hunter New England Local Health District Advance Care Plan (NSW) (22)	http://www.hnehealth.nsw.gov.au/acp/documents	Separate	DVD and resources for HPs. Template is linked to from RPC website but no mention of RPC on template.	Section on how difficult consumer finds it to talk about dying with family; place of preferred care; boxes to tick for registered organ and cadaver donators.
Medicare Local Central Coast NSW - Planning what I want Advance Care Directive (NSW)	http://www.planningwhatiwant.com.au/advance-care-directive/advance-care-directive-planning-what-i-want_20130305101645.pdf	Integrated	Workbook and capacity screening tool for HPs. Workbook includes resources from HNELHD for starting conversation, selecting SDM and HNE ACD template.	Directives are based on whether current health status is acceptable; includes section on hospitalisation; special EOL requests (e.g. music, aroma therapy, food).

ACD template (state/territory)	URL	Guideline/ACD	Resources on website / via links	Content and features
(23)				
NT Health Department Statement of Choices (NT) (24)	http://health.nt.gov.au/Palliative_Care/Health_Professional/Resources/	Separate	NT Health website includes brief pamphlet. Linked to from RPC website and contents identical to RPC WA with addition of EPA appointment, and final section identical to RPC ACT, but no mention of RPC on template.	Donor information; final message to family.
RPC Statement of Choices (QLD) (25)	http://advancecareplanning.org.au/library/uploads/documents/qld/QLD_ACP-statement_of_views.pdf	Integrated and separate	Branded RPC template: detailed guidelines on ACP and completion of ACD template for consumers and HPs, video, real-life stories, FAQs, research, news and events, and opportunity for ACP support from RPC facilitator. Queensland web-page includes additional Queensland-specific ACP guide and contact sheet and links to Queensland government resources. Advises that Advance Health Directive is more legally binding document and can be obtained from newsagents. Similar to Victorian RPC template minus some content (see below).	Yes/no for 'I understand my health issues and their prognosis'; section for nominating persons to be included in discussions and decisions for specific issues (including organ or body donation); preferred place to die; message to family and friends; values and beliefs 'as previously discussed'; option to leave all decisions to SDM.
RPC Statement of Choices (VIC) (26)	http://advancecareplanning.org.au/library/uploads/documents/vic/Vic_Advance_Care_Directive_CP.pdf	Integrated and separate	Branded RPC template. Victorian web-page includes versions for proxy and aged care, ACP planning guide and MEPA template as well as various information and templates in Arabic, Greek and Italian, and links to Victorian government resources. Template (and to some extent guideline) similar to Queensland RPC but with added option of refusing CPR under any circumstances and option to defer all decisions to SDM.	Special EOL requests (e.g. music, family presence); offers RPC facilitation for ACP on template.

ACD template (state/territory)	URL	Guideline/ACD	Resources on website / via links	Content and features
RPC Statement of Choices (WA) (27)	http://advancecareplanning.org.au/library/uploads/documents/wa/WA_Statement_of_Choices.pdf	Separate	Branded RPC template. WA web-page includes links to government resources. ACD template identical to NT statement of Choices except it does not allow for appointment of EPAs.	If I am nearing my death, I want the following (list things that would be important); message to family and friends; refers to values and beliefs 'as previously discussed'; option to leave all decisions to SDM.
SA Health Anticipatory Direction (SA) (28)	http://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/health+topics/legal+matters/medical+power+of+attorney+and+anticipatory+direction	Integrated	Links to SA legal templates for EPA appointment.	Template uses only a single free text box in which to record 'wishes'; encourages inclusion of religious and cultural beliefs.
Southern Cross University and Queensland Government Advance Health Care Directive (QLD, with derivative for NSW) (29, 30)	http://www.justice.qld.gov.au/justice-services/guardianship/making-health-care-decisions/advance-health-directives and http://scu.edu.au/aslarc/index.php/8/	Integrated into ACD template	Guidance on SDM and appointment templates. SCU website includes Enduring Guardian templates, long/short versions of ACD template as well as those specific to gay and lesbian people and residential aged care; HP resources include flowchart for obtaining consent to treatment and checklist for assessing capacity.	Consent for removal of tissue and permission to switch off life-sustaining treatment to do so; space to identify people who should NOT be contacted about treatment; provision for >1 SDM and how they should contribute together; requires doctor to sign to say patient has understood medical consequences; witness must be justice of the peace, commissioner, lawyer or notary public.
Tasmanian Department of Health Advance Care Directive for Care at the End of Life (TAS) (31)	http://www.dhhs.tas.gov.au/palliativecare/advance_care_planning_for_healthy_dying	Separate	HP resource for assessing capacity, community slide show, information leaflet about ACP.	Are you a registered organ and tissue donor?; Are you a University of Tasmania body bequest donor?; provision for completion by proxy as well as self.

ACD template (state/territory)	URL	Guideline/ACD	Resources on website / via links	Content and features
WA Department of Health Advance Health Directive (WA) (32)	http://www.health.wa.gov.au/advancehealthdirective/home/	Integrated and separate	Workbook, self-directed learning module providing in-depth audio and written information and contact for support.	States 'An AHD is ineffective after death. Therefore, this is not the appropriate document on which to record your wishes with regards to organ donation'. Gives space to identifying HP who has provided info on treatment.

ACD = advance care directive; ACP = advance care planning; ACT = Australian Capital Territory; EPA = enduring power of attorney; HP = health professional; NSW = New South Wales; NT = Northern Territory; QLD = Queensland; RPC = *Respecting Patient Choices*®; SDM = substitute decision-maker; TAS = Tasmania; VIC = Victoria; WA = Western Australia

Supplementary Table 1. Results from appraisal of 14 ACD templates and guidelines against criteria from the 2011 *National Framework for Advance Care Directives* (1)

ACD template	Consultation during development	Applicable in ill and good health	ACP fully defined	Scenarios/ examples used	Translated	Roles clarified	Includes guidance for witness	Includes provision for SDM	Encourages discussion and dissemination	Provides information on legal status of ACDs	Overall score out of 10*
ACT Health Advance Care Plan (ACT) (19)	PARTLY Consumers	√ Space to list current health problems	PARTLY	√ Health conditions, treatments	X	X	X Patient testifies to soundness of own mind	√ Additional SDM template	√ Consultation with RPC consultant; dissemination to HP and family	√ Comes into effect only when not able to speak for self; law requires wishes must be taken into account when determining treatment	6
Dying with Dignity Victoria Advance Healthcare Directive (VIC) (20)	PARTLY GPs and consumers	√ Disease-specific templates (e.g. dementia) are available to DWD members.	PARTLY	√ Example of completed template	X	PARTLY HP as witness	√ HP as witness	√ Additional SDM template	PARTLY HP clarification; family dissemination; copy on medical records if in hospital	√ Right to refuse treatment and legal status of Refusal of Treatment Certificate for specific life-threatening diagnosis. Reference to work by DWD to include within statute law.	7

ACD template	Consultation during development	Applicable in ill and good health	ACP fully defined	Scenarios/ examples used	Translated	Roles clarified	Includes guidance for witness	Includes provision for SDM	Encourages discussion and dissemination	Provides information on legal status of ACDs	Overall score out of 10*
Healthy North Coast - Advance care or health directive (NSW) (21)	√ Multidisicplinary HPs and consumers	√ Includes 3 scenarios - current health, severe dementia, bedridden and unable to communicate, if admitted to hostel or nursing home; template for proxy completion also available	√	√ Potential outcomes of care (including detailed description of dementia progression) and treatments	X	√ Detailed handbook for HPs and info on roles of family	√ Patient testifies to soundness of own mind	PARTLY SDM can sign to say discussion has happened	PARTLY Dissemination to HP and family	√ Legal status of document; only comes into force when capacity lost; cannot be overruled without a court order. Website info has section on rights (includes The Laws of Consent and professional ethics to support the rights of SDM to consent or refuse treatment).	8
Hunter New England Local Health District Advance Care Plan (NSW) (22)	No information	PARTLY Broadscale applicability	PARTLY	PARTLY	X	PARTLY Website includes checklist for identifying SDM	X	PARTLY Recommends discussion with Enduring Guardian, EPA and medical team	√ Consultation with and dissemination to HP and family	X	3½

ACD template	Consultation during development	Applicable in ill and good health	ACP fully defined	Scenarios/ examples used	Translated	Roles clarified	Includes guidance for witness	Includes provision for SDM	Encourages discussion and dissemination	Provides information on legal status of ACDs	Overall score out of 10*
Medicare Local Central Coast – Planning What I Want Advance Care Directive (NSW) (23)	√ Multidisicplinary HPs and consumers	√ Asks whether have a chronic condition and bases directives on whether current health status is unacceptable or not.	PARTLY	√ Health conditions, treatments, beliefs, directives	X	PARTLY SDM role and checklist for choosing one	X	√	PARTLY Consultation with HP; dissemination to HP and family	PARTLY Reference to common law	6
NT Health Department Statement of Choices (NT) (24)	No information	PARTLY Broadscale applicability	PARTLY	PARTLY Treatments	X	PARTLY SDM	√ Patient testifies to soundness of own mind	PARTLY Attorney appointment space provided but does not promote	PARTLY ACD template encourages medical understanding and NT Health flyer supports dissemination	PARTLY Referral to the Natural Death Act; comes into effect only when not able to speak for self	4½

ACD template	Consultation during development	Applicable in ill and good health	ACP fully defined	Scenarios/ examples used	Translated	Roles clarified	Includes guidance for witness	Includes provision for SDM	Encourages discussion and dissemination	Provides information on legal status of ACDs	Overall score out of 10*
RPC Statement of Choices (QLD) (25)	PARTLY Consumers	√ Space to list current health problems	√	√ Treatments, reasons why one might wish to change directives	X	√ Consumer, witness, SDM	√ HP as witness; further attest that (s)he is not a nominated attorney to the person or a relation or a beneficiary under the person's will	√ Also advice on criteria for SDM	√ Consultation with HP; dissemination to HP and family	√ Info on legal status of statement of choices, AHD and SDM appointment; understand that doctors will only provide treatment that might be medically beneficial	8½
RPC Statement of Choices (VIC) (26)	PARTLY Consumers	√ Space to list current health problems	PARTLY	PARTLY Treatments	PARTLY Not ACD, but Refusal of Medical Treatment and EPA templates as well as informatio n booklets available in Greek, Italian and Arabic	PARTLY Consumer, HP, SDM	√ HP as witness	√ Also advice on criteria for SDM	√ Consultation with HP; dissemination to HP and family	√ Info on legal status of statement of choices, AHD and SDM appointment; understand that doctors will only provide treatment that might be medically beneficial	7½

ACD template	Consultation during development	Applicable in ill and good health	ACP fully defined	Scenarios/ examples used	Translated	Roles clarified	Includes guidance for witness	Includes provision for SDM	Encourages discussion and dissemination	Provides information on legal status of ACDs	Overall score out of 10*
RPC Statement of Choices (WA) (27)	PARTLY Consumers	PARTLY Broadscale applicability	PARTLY	PARTLY Treatments	X	PARTLY Consumer	X Patient testifies to soundness of own mind	X	PARTLY Dissemination to HP and family	PARTLY Advises that statement of wishes will be taken into account when determining my treatment	3½
SA Health Anticipatory Direction (SA) (28)	No information	√ Examples are given for both health states	√	√ Treatments, outcomes of care	X	PARTLY Requirements of consumer + duties of witness	√ Understanding of nature and effect of AD; witness must be authorised	PARTLY Not on template but reference in guideline to appointment of enduring guardian and medical agent	√ Discussion with GP, dissemination to family	PARTLY Cannot request euthanasia, comes into effect only when incompetent; refers to Palliative Care Act 1995; says carers 'bound to' follow wishes; lists criteria for consumer for ACD to be valid	6½

ACD template	Consultation during development	Applicable in ill and good health	ACP fully defined	Scenarios/ examples used	Translated	Roles clarified	Includes guidance for witness	Includes provision for SDM	Encourages discussion and dissemination	Provides information on legal status of ACDs	Overall score out of 10*
Southern Cross University and Queensland Government Advance Health Care Directive (QLD, with derivative for NSW) (29, 30)	√ Multidisicplinary HPs and consumers	√ Broadscale applicability	PARTLY	√ Health conditions, treatments, beliefs, directives	X	√ Consumer, HP, witness, SDM	√	QLD √; NSW PARTLY Attorney appointment, acceptance and revocation templates on website	PARTLY Consultation with HP; dissemination to HP and family	PARTLY QLD - Info on right to refuse but not request treatment or euthanasia; comes into effect only when not able to speak for self; criteria regarding age and capacity; attorney templates give details of powers. NSW - Advice to sign before qualified witness.	QLD 7½ NSW 7

ACD template	Consultation during development	Applicable in ill and good health	ACP fully defined	Scenarios/ examples used	Translated	Roles clarified	Includes guidance for witness	Includes provision for SDM	Encourages discussion and dissemination	Provides information on legal status of ACDs	Overall score out of 10*
Tasmanian Department of Health Advance Care Directive for Care at the End of Life (TAS) (31)	X	PARTLY Broadscale applicability	√	√ Directives detailing unacceptable outcomes	X Space for interpreter to sign	PARTLY Witness	√	√ Enduring Guardian and Person Responsible (someone not appointed as EG but who could be contacted to speak on behalf if needed)	√ Consultation with and dissemination to HP and family	√ Website link says: Under common law in Australia, it is expected that a doctor should comply with the wishes expressed in an Advance Care Directive, taking into account the clinical situation at the time. They would also talk to the 'Person Responsible' or 'Enduring Guardian' who can speak on your behalf about what they know of your wishes. Community slide show gives info about common law right to refuse not demand	7

ACD template	Consultation during development	Applicable in ill and good health	ACP fully defined	Scenarios/ examples used	Translated	Roles clarified	Includes guidance for witness	Includes provision for SDM	Encourages discussion and dissemination	Provides information on legal status of ACDs	Overall score out of 10*
WA Department of Health Advance Health Directive (WA) (32)	√ Multidisicplinary HPs and consumers	√ Workbook asks consumer to identify state of health and related concerns	PARTLY	PARTLY Health conditions and states, treatments	PARTLY Information but not template available in written and audio Arabic, Cantonese, Mandarin, Croatian, Italian, Polish, Serbian, Vietnamese	PARTLY Stipulates requirements for consumer and gives reasons why it may be advisable to confer with family and HPs.	PARTLY Designates one of witnesses must be authorised to witness statutory declarations	√ Defers to Enduring Power of Guardianship template. Indicates SDM may be alternative to ACD. Provides tick box to say template has been completed.	√ Consultation with and dissemination to HP and family	√ Details lack of right to request euthanasia; comes into effect only when not able to speak for self; circumstances under which ACD will be ruled invalid	7½

ACD = advance care directive; ACP = advance care planning; EPA = enduring power of attorney; HP = health professional; RPC = *Respecting Patient Choices*®; SDM = substitute decision-maker; * overall scores were derived by summation of scores for each criterion allocated as follows: criterion met 1, criterion partially met ½, criterion not met 0.

Supplementary Table 2. Results from appraisal of 14 ACD templates against criteria from the 2011 *National Framework for Advance Care Directives* (1)

ACD template	Adaptable to online and hard copy	Read-ability (US grade)	Unfamiliar terms explained	Transferable across care setting	Instructions exact or advisory	Separates health care vs other directives	Provides space for consumer name, DOB and signature	Includes date of review and makes it easy to update	Advance refusal and consent	Allows separate direction for different kinds of incapacity	Enables recording of values and life goals	Overall score out of 10*
ACT Health Advance Care Plan (ACT) (19)	X Pdf	11	X	PARTLY Space to enter people holding copy	√ Implies advisory	X	√	X	√	X	√ Values, acceptable outcome	4½
Dying with Dignity Victoria Advance Healthcare Directive (VIC) (20)	X Pdf	13	X	√ Reference to if entering a hospital, hospice or other healthcare facility. DWD templates available to members include aged care-specific.	√ Implies direct	PARTLY Relevant templates available to DWD members	PARTLY	X	√ But uses opt -in format.	√ Provides option to request directive should be enacted even if HPs think good chance of recovery	X Generally assumes values are against life sustaining treatment	5

ACD template	Adaptable to online and hard copy	Read-ability (US grade)	Unfamiliar terms explained	Transferable across care setting	Instructions exact or advisory	Separates health care vs other directives	Provides space for consumer name, DOB and signature	Includes date of review and makes it easy to update	Advance refusal and consent	Allows separate direction for different kinds of incapacity	Enables recording of values and life goals	Overall score out of 10*
Healthy North Coast - Advance care or health directive (NSW) (21)	X Pdf	10	√	√ Includes section for signing to say would rather be treated in hostel/nursing home than hospital	√ Implies exact	X	√	PARTLY Review, sign and date every 2-4 years	√	√ Includes scenario of level of functioning will be acceptable to me and/or the illness is reversible & I am likely to return to my former self & health.	PARTLY Unacceptable outcomes	7

ACD template	Adaptable to online and hard copy	Read-ability (US grade)	Unfamiliar terms explained	Transferable across care setting	Instructions exact or advisory	Separates health care vs other directives	Provides space for consumer name, DOB and signature	Includes date of review and makes it easy to update	Advance refusal and consent	Allows separate direction for different kinds of incapacity	Enables recording of values and life goals	Overall score out of 10*
Hunter New England Local Health District Advance Care Plan (NSW) (22)	X Pdf	18	X	PARTLY Includes item on preference for place of care	PARTLY Implies advisory	PARTLY Includes item on preferred place of care	√	X	√	X	√ Personal, religious/ spiritual, and (un)acceptable outcomes	4½
Medicare Local Central Coast NSW - Planning what I want Advance Care Directive (NSW) (23)	X Pdf	12	√ Health states, treatments	PARTLY Workbook refers to different settings; an aged care version of template will be made available shortly	X	X	√	X	Consent and refusal	√ Rules out treatment refusal for <7 days artificial feeding	PARTLY Philosophy of life, religion, values. Workbook encourages exploration of what is important, what makes	4

ACD template	Adaptable to online and hard copy	Read-ability (US grade)	Unfamiliar terms explained	Transferable across care setting	Instructions exact or advisory	Separates health care vs other directives	Provides space for consumer name, DOB and signature	Includes date of review and makes it easy to update	Advance refusal and consent	Allows separate direction for different kinds of incapacity	Enables recording of values and life goals	Overall score out of 10*
											days meaningful, worries. Uses acceptability of current health status as starting point for unacceptable outcomes	
NT Health Department Statement of Choices (NT) (24)	√ MS Word	9	PARTLY Treatments	PARTLY Most suited to acute healthcare setting	√ Implies exact	X	√	X	√	No	X General section, with reference to beliefs and values in instructions	5

ACD template	Adaptable to online and hard copy	Read-ability (US grade)	Unfamiliar terms explained	Transferable across care setting	Instructions exact or advisory	Separates health care vs other directives	Provides space for consumer name, DOB and signature	Includes date of review and makes it easy to update	Advance refusal and consent	Allows separate direction for different kinds of incapacity	Enables recording of values and life goals	Overall score out of 10*
RPC Statement of Choices (QLD) (25)	X Pdf	11	PARTLY Examples given for treatments	PARTLY No limits to transferability	√ Implies advisory	PARTLY	√	X	√	X	√ Values, spiritual / cultural preferences, acceptable /unacceptable outcomes	5½
RPC Statement of Choices (VIC) (26)	X Pdf	10	PARTLY Legal terms, examples given for treatments	PARTLY No limits to transferability	√ Implies advisory	PARTLY Distinction between Medical, General and Financial EPAs	PARTLY	X	√	X	√ Values, uncceptable outcomes	5
RPC Statement of Choices (WA) (27)	X Pdf	12	PARTLY Treatments	PARTLY No limits to transferability	√ Implies advisory	X	PARTLY	X	√	X	PARTLY Beliefs and values 'as previously discussed'	4

ACD template	Adaptable to online and hard copy	Read-ability (US grade)	Unfamiliar terms explained	Transferable across care setting	Instructions exact or advisory	Separates health care vs other directives	Provides space for consumer name, DOB and signature	Includes date of review and makes it easy to update	Advance refusal and consent	Allows separate direction for different kinds of incapacity	Enables recording of values and life goals	Overall score out of 10*
SA Health Anticipatory Direction (SA) (28)	√ Writable pdf	7	PARTLY Limited treatments; jargon avoided	√ No limits to transferability. Includes guidance on dissemination including registering on MedicAlert	√ Implies exact	X	PARTLY	X	PARTLY just one free text space for 'wishes'	PARTLY	PARTLY Just one free-text space for 'wishes'; examples include religious beliefs	5½
Southern Cross University and Queensland Government Advance Health Care Directive (QLD, with derivative for NSW) (29, 30)	√ Writable pdf	11	√ Health states, treatments	√ No limits to transferability; reference to nursing home	√ Space to specify limits on attorney powers	QLD PARTLY; NSW √ Attorney template refers to personal/ health matters. advises a separate template will be needed for SDM relating to financial matters	√	√	√	√ Gives space for if temporaril y lose capacity, terminal, permanent coma, permanent vegetative state, unlikely to recover enough to live without life-sustaining measures	PARTLY Religious beliefs and any particular wishes about health care or special health matters	QLD 9 NSW 9½

ACD template	Adaptable to online and hard copy	Read-ability (US grade)	Unfamiliar terms explained	Transferable across care setting	Instructions exact or advisory	Separates health care vs other directives	Provides space for consumer name, DOB and signature	Includes date of review and makes it easy to update	Advance refusal and consent	Allows separate direction for different kinds of incapacity	Enables recording of values and life goals	Overall score out of 10*
Tasmanian Department of Health Advance Care Directive for Care at the End of Life (TAS) (31)	X Pdf	15; large print version availabl e	PARTLY Limited health states, treatments	PARTLY no relevant info	PARTLY	PARTLY Website info distinguishes healthcare from financial decisions	√	X	PARTLY Refusal	X	√ Religious/ spiritual beliefs; unaccepta ble outcomes	4
WA Department of Health Advance Health Directive (WA) (32)	√ Writable pdf	12	√ Health conditions, treatments	√ Refers to 'if in hospital' and recommends storage options that will enable transfer, including electronic health record service.	√ Implies exact	PARTLY Gives info about appointing Enduring Guardian vs Enduring Attorney to act on their behalf on financial matters	√	X	√	X	X Recomme nds considerin g what consumer most fears in workbook but does not include on template	6½

ACD = advance care directive; EPA = enduring power of attorney; HP = health professional; RPC = *Respecting Patient Choices*®; * overall scores were derived by summation of scores for each criterion allocated as follows: criterion met 1, criterion partially met ½, criterion not met 0.

Supplementary Table 3. Contents from seven ACD templates rated as biased for or against medical treatment by two independent reviewers

ACD Template	Content	Treatment bias	
		Pro	Anti
Dying with Dignity Victoria Advance Healthcare Directive (VIC) (20)	Where the stipulation/s apply, any Distressing Symptoms are to be maximally palliated by appropriate analgesic, sedative or other palliative treatment, even though that palliative treatment may also have the additional consequence of shortening my life.		√
	If it should be legal to do so at that time, I request that my death be hastened by a doctor providing or administering a fatal dose to allow me to die with dignity.		√
	The overwhelming majority of Australians believe in the right of the terminally ill to seek and obtain medical assistance to end their life with dignity.		√
Healthy North Coast - Advance care or health directive (NSW) (21)	You would probably only say NO to cardio-pulmonary resuscitation (CPR) if you had decided that for life to be meaningful you need to have a certain level of function, or that you would be happy to die peacefully at this point in your life. If you said NO to artificial feeding, you would die within a short time, but this may be your intention as the chances of recovery are poor. Where you choose NO, you will be kept comfortable & pain-free.		√
	If you are in a nursing home with severe dementia your physical and mental condition will gradually deteriorate. After 1-3 years you would normally be dependent on 24 hour nursing care. At this stage you may be increasingly bedbound either through muscle weakness or through falls or fractured hips. Heart attacks and strokes are common causes of death in the elderly. Tablets for blood pressure, cholesterol and blood thinning prevent these and may make you live longer. If you have severe dementia you may not want to have these. However you may survive the heart attack or stroke and then become more disabled.		√
NT Health Department Statement of Choices (NT) (24)	I do not want to be kept alive by extraordinary or overly burdensome measures that might be used to prolong my life (e.g. Cardio – Pulmonary Resuscitation).		√
RPC Statement of Choices (QLD)	Good Medical Practices - Circle appropriate option(s) e.g. major operation, intravenous fluids, blood transfusion, antibiotics, other:	√	
RPC Statement of Choices (VIC) (26)	( ) It has been explained to me by Dr_____ that I would not benefit from attempted CPR and I understand and accept this OR ( ) I do NOT want CPR, even if the doctors think it could be beneficial.		√
SA Health Anticipatory Direction (SA) (28)	How would you feel about LST in the face of terminal illness? What is your bottom line? For example, under what circumstances would dying be preferable to sustaining life?		√

ACD Template	Content	Treatment bias	
		Pro	Anti
	Examples given in italics are of strong refusal.		
Southern Cross University and Queensland Government Advance Health Care Directive (QLD and NSW) (29, 30)	Record your wishes here. (For example, you may wish to write something similar to the following: 'I value life, but not under all conditions. I consider dignity and quality of life to be more important than mere existence' or 'I request that I be given sufficient medication to control my pain, even if this hastens my death'.)		√

CPR = cardio-pulmonary resuscitation; LST = life sustaining treatment