10.1071/AH14187_AC

© CSIRO 2015

Australian Health Review 2015, 39, 552–560.

Advance care planning in 21st century Australia: a systematic review and appraisal of online advance care directive templates against national framework criteria

Tim Luckett^{1,5} PhD, Senior Research Fellow

Priyanka Bhattarai¹ BN (Hons), Research Assistant

Jane Phillips¹ PhD, RN, Professor Nursing (Palliative Care) and Director Centre for Cardiovascular and Chronic Care

Meera Agar² MBBS,MPC, FRACP, FAChPM PhD, Director of Palliative Care, Braeside Hospital, HammondCare; Conjoint Associate Professor, the University of New South Wales (UNSW); Clinical Trial Director, Ingham Institute of Applied Medical Research

David Currow³ B Med MPH FRACP, Professor of Palliative and Supportive Services

Yordanka Krastev¹ MD PhD, Research Ethics Manager

Patricia M. Davidson⁴ PhD Med RN FAAN, Dean and Professor

¹Faculty of Health, University of Technology Sydney, Building 10, Level 7, 235–253 Jones Street, Ultimo, NSW 2007, Australia. Email: priyanka.bhattarai@uts.edu.au; jane.phillips@uts.edu.au; yordanka.krastev@uts.edu.au

²Department Palliative Care, Braeside Hospital, Locked Bag 82, Wetherill Park, NSW 1851, Australia. Email: meera.agar@sswahs.nsw.gov.au

³Department Palliative and Supportive Services, Flinders University, Health Sciences Building, Repatriation General Hospital, 210–216 Daws Road, Daw Park, SA 5041, Australia. Email: david.currow@health.sa.gov.au

⁴School of Nursing, Johns Hopkins University, 525 N Wolfe Street, Baltimore, MD 21205, USA. Email: pdavidson@jhu.edu

⁵Corresponding author. Email: tim.luckett@uts.edu.au

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	V Space to list current health problems	PARTLY	V Health conditions, treatments	X	X	X Patient testifies to soundness of own mind	√ Additional SDM template	V Consultation with RPC consultant; dissemination to HP and family	V Comes into effect only when not able to speak for self; law requires wishes must be taken into account when determining treatment	6

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*
Dying with Dignity Victoria Advance Healthcare Directive (VIC) (20)	PARTLY GPs and consumers	V Disease- specific templates (e.g. dementia) are available to DWD members.	PARTLY	V Example of completed template	X	PARTLY HP as witness	V HP as witness	√ Additional SDM template	PARTLY HP clarification; family dissemination; copy on medical records if in hospital	V Right to refuse treatment and legal status of Refusal of Treatment Certificate for specific lifethreatening 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) (24)	√ Multidisicplina ry HPs and consumers	V Includes 3 scenarios - current health, severe dementia, bedridden and unable to communicat e, if admitted to hostel or nursing home; template for proxy completion also available	✓	V Potential outcomes of care (including detailed description of dementia progression) and treatments	X	V Detailed handbook for HPs and info on roles of family	V Patient testifies to soundness of own mind	PARTLY SDM can sign to say discussion has happened	PARTLY Dissemination to HP and family	V 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) (21)	No information	PARTLY Broadscale applicability	PARTLY	PARTLY	X	PARTLY Website includes checklist for identifying SDM	X	PARTLY Recommend s discussion with Enduring Guardian, EPA and medical team	V 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) (22)	√ Multidisicplina ry HPs and consumers	V Asks whether have a chronic condition and bases directives on whether current health status is unacceptabl e or not.	PARTLY	V Health conditions, treatments, beliefs, directives	X	PARTLY SDM role and checklist for choosing one	X	V	PARTLY Consultation with HP; dissemination to HP and family	PARTLY Reference to common law	6
NT Health Department Statement of Choices (NT) (23)	No information	PARTLY Broadscale applicability	PARTLY	PARTLY Treatments	X	PARTLY SDM	V Patient testifies to soundness of own mind	PARTLY Attorney appointmen t 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
RPC Statement of Choices (QLD) (26)	PARTLY Consumers	V Space to list current health problems	√	V Treatments, reasons why one might wish to change directives	X	√ Consumer, witness, SDM	V HP as witness; further attest that (s)he is not a nominated attorney to the person or a relation	V Also advice on criteria for SDM	V Consultation with HP; dissemination to HP and family	V Info on legal status of statement of choices, AHD and SDM appointment; understand that doctors will only provide	8½

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*
							or a beneficiary under the person's will			treatment that might be medically beneficial	
RPC Statement of Choices (VIC) (27)	PARTLY Consumers	V 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	V HP as witness	V Also advice on criteria for SDM	V Consultation with HP; dissemination to HP and family	V 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) (25)	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) (32)	No information	V Examples are given for both health states	V	√ Treatments, outcomes of care	X	PARTLY Requireme nts of consumer + duties of witness	V Understandi ng of nature and effect of AD; witness must be authorised	PARTLY Not on template but reference in guideline to appointmen t of enduring guardian and medical agent	V 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) (28, 29)	√ Multidisicplina ry HPs and consumers	√ Broadscale applicability	PARTLY	V Health conditions, treatments, beliefs, directives	X	√ Consumer, HP, witness, SDM	√	QLD V; NSW PARTLY Attorney appointmen t, 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
Tasmanian Department of Health Advance Care Directive for Care at the End of Life (TAS) (30)	X	PARTLY Broadscale applicability	V	V Directives detailing unacceptabl e outcomes	X Space for interpreter to sign	PARTLY Witness	V	V Enduring Guardian and Person Responsible (someone not appointed as EG but who could be contacted to speak on behalf if	V Consultation with and dissemination to HP and family	V 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	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*
								needed)		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	

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) (31)	√ Multidisicplina ry HPs and consumers	V Workbook asks consumer to identify state of health and related concerns	PARTLY	PARTLY Health conditions and states, treatments	PARTLY Informatio n but not template available in written and audio Arabic, Cantonese, Mandarin, Croatian, Italian, Polish, Serbian, Vietnames e	PARTLY Stipulates requireme nts 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	V Defers to Enduring Power of Guardianshi p template. Indicates SDM may be alternative to ACD. Provides tick box to say template has been completed.	V Consultation with and dissemination to HP and family	V 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	V Implies advisory	X	√	X	√	X	V Values, acceptable outcome	4½
Dying with Dignity Victoria Advance Healthcare Directive (VIC) (20)	X Pdf	13	X	V Reference to if entering a hospital, hospice or other healthcare facility. DWD templates available to members include aged care-specific.	V Implies direct	PARTLY Relevant templates available to DWD members	PARTLY	X	V 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) (24)	X Pdf	10	V	V Includes section for signing to say would rather be treated in hostel/nursing home than hospital	V Implies exact	X	V	PARTLY Review, sign and date every 2-4 years	▼	V Includes scenario of level of functionin g will be acceptable to me and/or the illness is reversible & I am likely to return to my former self & health.	PARTLY Unaccepta ble 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) (21)	X Pdf	18	X	PARTLY Includes item on preference for place of care	PARTLY Implies advisory	PARTLY Includes item on preferred place of care	V	X	√	X	V Personal, religious/ spiritual, and (un)accept able outcomes	4½
Medicare Local Central Coast NSW - Planning what I want Advance Care Directive (NSW) (22)	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	V	X	Consent and refusal	V Rules out treatment refusal for <7 days artificial feeding	PARTLY Philosophy of life, religion, values. Workbook encourage s exploratio n of what is important, what	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*
											makes days meaningful , worries. Uses acceptabili ty of current health status as starting point for unaccepta ble outcomes	
NT Health Department Statement of Choices (NT) (23)	√ MS Word	9	PARTLY Treatments	PARTLY Most suited to acute healthcare setting	V Implies exact	X	√	X	V	No	X General section, with reference to beliefs and values in instruction s	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) (26)	X Pdf	11	PARTLY Examples given for treatments	PARTLY No limits to transferability	V Implies advisory	PARTLY	√	X	٧	X	V Values, spiritual / cultural preference s, acceptable /unaccept able outcomes	5½
RPC Statement of Choices (VIC) (27)	X Pdf	10	PARTLY Legal terms, examples given for treatments	PARTLY No limits to transferability	V Implies advisory	PARTLY Distinction between Medical, General and Financial EPAs	PARTLY	X	٧	X	V Values, uncceptabl e outcomes	5
RPC Statement of Choices (WA) (25)	X Pdf	12	PARTLY Treatments	PARTLY No limits to transferability	V Implies advisory	X	PARTLY	X	٧	X	PARTLY Beliefs and values 'as previously	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) (32)	V Writable pdf	7	PARTLY Limited treatments; jargon avoided	V No limits to transferability. Includes guidance on dissemination including registering on MedicAlert	V 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) (28, 29)	√ Writable pdf	11	V Health states, treatments	V No limits to transferability; reference to nursing home	V Space to specify limits on attorney powers	QLD PARTLY; NSW V Attorney template refers to personal/ health matters. advises a separate template will be needed for	V	V	٧	V Gives space for if temporaril y lose capacity, terminal, permanent coma, permanent vegetative state, unlikely to	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*
						SDM relating to financial matters				recover enough to live without life- sustaining measures		
Tasmanian Department of Health Advance Care Directive for Care at the End of Life (TAS) (30)	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) (31)	√ Writable pdf	12	V Health conditions, treatments	V Refers to 'if in hospital' and recommends storage options that will enable transfer, including electronic	V Implies exact	PARTLY Gives info about appointing Enduring Guardian vs Enduring Attorney to act on their behalf on financial	√	X	٧	X	X Recomme nds considerin g what consumer most fears in workbook but does	6½

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*
				health record service.		matters					not include on template	

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		tment ias
		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.		٧
	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.		٧
	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.		٧
Healthy North Coast - Advance care or health directive (NSW) (24)	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.		٧
	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.		٧
NT Health Department Statement of Choices (NT) (23)	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).		٧
RPC Statement of	Good Medical Practices - Circle appropriate option(s) e.g. major operation, intravenous fluids, blood transfusion, antibiotics,	٧	

ACD Template	Content	Treatment bias		
		Pro	Anti	
Choices (QLD) (26)	other:			
RPC Statement of Choices (VIC) (27)	() 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.		٧	
SA Health Anticipatory Direction (SA) (32)	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? Examples given in italics are of strong refusal.		٧	
Southern Cross University and Queensland Government Advance Health Care Directive (QLD and NSW) (28, 29)	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'.)		٧	

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