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Development and evaluation of an aged care specific Advance Care Plan

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ABSTRACT

Objectives To report on the quality of advance care planning (ACP) documents in use in residential aged care facilities (RACF) in areas of Victoria Australia prior to a systematic intervention; to report on the development and performance of an aged care specific Advance Care Plan template used during the intervention.

Design An audit of the quality of pre-existing documentation used to record resident treatment preferences and end-of-life wishes at participating RACFs; development and pilot of an aged care specific Advance Care Plan template; an audit of the completeness and quality of Advance Care Plans completed on the new template during a systematic ACP intervention.

Participants and setting 19 selected RACFs (managed by 12 aged care organisations) in metropolitan and regional areas of Victoria.

Results Documentation in use at facilities prior to the ACP intervention most commonly recorded preferences regarding hospital transfer, life prolonging treatment and personal/cultural/religious wishes. However, 7 of 12 document sets failed to adequately and clearly specify the resident's preferences as regards life prolonging medical treatment. The newly developed aged care specific Advance Care Plan template was met with approval by participating RACFs.
Of 203 Advance Care Plans completed on the template throughout the project period, 49% included the appointment of a Medical Enduring Power of Attorney. Requests concerning medical treatment were specified in almost all completed documents (97%), with 73% nominating the option of refusal of life-prolonging treatment. Over 90% of plans included information concerning residents' values and beliefs, and future health situations that the resident would find to be unacceptable were specified in 78% of completed plans.

Conclusions Standardised procedures and documentation are needed to improve the quality of processes, documents and outcomes of ACP in the residential aged care sector.

It is well recognised that having a documented and accessible Advance Care Plan developed as part of a systematic approach to advance care planning (ACP) offers individuals some level of control over their end-of-life healthcare options, and can potentially provide improved quality of life during this final stage.[1–6] However, ACP documentation in use across different healthcare settings and jurisdictions often varies in format and content, resulting in recommendations for national document standardisation.[7–9] In addition, there are a range of barriers that can hamper the completion and availability of Advance Care Plans, thus limiting the likelihood that an individual's wishes will be followed at end-of-life.

These barriers can occur at any stage of the Advance Care Plan, from its development through to the moment that end-of-life medical treatment decisions are being made. Individuals and/or family members may be unwilling to discuss options for future treatment and receive no direction about the appropriateness and importance of such discussions from healthcare providers.[10 11] In crucial periods, when an individual's deteriorating health may require life-prolonging treatments, medical practitioners may not have access to details of the individual's Advance Care Plan[12] or may choose to make medical decisions based on their own views or on standard protocols.[13 14] There are also various procedures that need to operate effectively to ensure that the individual's preferences are expressed accurately and clearly, are up-to-date, can be located easily and quickly, and are likely to be interpreted appropriately and consistently by key staff within and across the health spectrum.[5 15–22]

The importance of having Advance Care Plans that are easily accessible and interpretable by staff not involved in

their original preparation is crucial whether in the hospital or in a residential aged care facility. These issues have received some attention in Australia and elsewhere.[23] For example, some researchers have noted that medical practitioners and other health professionals outside the original setting may find the preferences or advance directives difficult to interpret.[24] Documentation may be inconsistently worded and can be located in different sets of records, for example, patient medical records or separate ACP-specific forms stored with administrative files.[7 25 26]

In Victoria, Australia in 2009, under the umbrella of the federally funded Respecting Patient Choices (RPC) programme, a working party was established to develop an Advance Care Plan template for use in residential aged care facilities (RACFs) that were participating in the Making Health Choices (MHC) project. The goal of the MHC project was to develop, trial and evaluate a sustainable system for implementing effective ACP in RACFs throughout Australia. The preimplementation state of ACP in these trial sites has been described previously.[27]

This paper reports on the principles used to guide the development of the aged care specific Advance Care Plan template, the preimplementation quality of ACP documents and the performance of the newly developed Advance Care Plan template.

METHODS

Membership of the Working Party comprised industry experts in aged and palliative care, academics and RPC staff involved in the MHC project. An important outcome of this working party's deliberations was a set of guiding principles for conducting ACP in the aged care setting (see table 1).

Details of the MHC project and the RACFs involved in this project have been described.[27] A total of 19 RACFs, representing 12 aged care organisations, participated in the project. This number included facilities based in rural or metropolitan locations with bed numbers ranging from under 50 to over 100, all of which provided high-level care (care for residents who may have complex healthcare needs and/or who may require increased support for activities of daily living and/or behavioural management), either as the majority of care provided (high-care only facilities), in a separate unit alongside a low care unit (low and high care) or as part of an aging-in-place facility (high care provided in situ as residents' needs increase).[27]

Preimplementation ACP documentation

Participating RACFs provided copies of existing documentation used to record resident treatment preferences and end-of-life wishes prior to the MHC project. This documentation was then assessed by two raters for the presence and quality of information according to the nine key domains referred to in table 1, item 17. Since the small sample size precluded statistical examination of inter-rater reliability, differences between raters in their assessments of these documents were resolved by reviewing items against these criteria until concordance was reached.

Development of recommended aged care specific Advance Care Plan template

The recommended template was developed by the working party based on the guidelines (table 1) and piloted at two RACFs that were not participating in the MHC project. Those testing the form (lifestyle coordinators, registered nurses and relatives, and one general practitioner) answered six questions regarding the clarity and usability of the form (see online supplementary table S1 for questions and responses).

Audit of Advance Care Plans completed on the recommended template

After commencement of the MHC programme, participating RACFs were also asked to provide de-identified actual examples of Advance Care Plans they had completed at their facility using the recommended template. These plans were completed by participating staff during ACP discussions with RACF residents and/or their family members (if the resident was not competent) over the course of the MHC project. ACP discussions would assist the resident to consider their current health state, their current goals, values and beliefs and their future preferences regarding health care if they should become seriously unwell. The staff would assist the resident/family to complete the plan in their own words. It would then be signed by the competent resident or the nominated family member of the resident who had lost capacity, and witnessed by the staff member, the general practitioner or a family member. If appropriate, the staff member would also assist the resident to appoint a substitute decision maker. The completeness and quality of all sections of submitted Advance Care Plans was assessed by a single rater. The reliability of ratings was assessed by applying κ statistics to assessments made on 30 cases by an independent second rater. Inter-rater agreement was acceptable for all relevant items, ranging from κ 0.73–0.79.

RESULTS

Pre-existing ACP documentation

All 12 aged care organisations provided preimplementation documents (representing documents in use at all 19 participating RACFs), with the use of 14 different titles. Some RACFs used two separate documents, however, the purpose of each document was not always clear from the title given (see table 2). Table 3 provides details of the number of organisations with documentation adequately covering each of the nine key domains identified in table 1, item 17. None of the organisations used document sets that covered all of these key domains. Only a third of the

Table 1 Principles for Advance Care Planning

Overarching statement:
The purpose of advance care planning (ACP) is to aid decision-making if the older person loses capacity. Where the older person has capacity for decision-making their current views take precedence over the ACP document. The ACP is used only when the older person is unable to communicate their wishes regarding medical treatments.
1 *Policies*. Written policies about ACP should be readily accessible in every residential aged care service (RACS). Policies should include the systems needed to establish ACP as a routine component of care, all aspects of documentation, including where the ACP is to be kept, how many copies, when to be reviewed, etc.
2 *Education*. Education about ACP should be regularly provided to all RAC staff and GPs.
3 *Information in RACS*. Information about ACP is best provided to residents and families before admission (eg, included in information brochure); followed by well planned individual discussions as soon as practicable after admission—normally within 28 days unless there are unforeseen circumstances.
4 *Routinely administered and reviewed*: ACP should be incorporated into routine clinical decision making and care planning, regularly reviewed, particularly when circumstances change (eg, exacerbation of illness, health deterioration or hospital admission), or at least annually.
5 *Voluntariness*. While the aim of ACP is to involve every older person in the discussion, no one should be coerced and everyone is free to change their ACP at any time.
6 *Communication is the key*. ACP should be accompanied by full discussion with the older person and/or family, in private, and initiated by a health professional with relevant skills in this area. ACP forms should not be sent via mail without the corresponding personal discussion.
7 *Older persons' best interests*. The older person's treatment should be directed towards their best interests, informed by (a), the competent person's current wishes, (b) the non-competent person's previously expressed wishes, or (c) family's views regarding the older persons' wishes. In every case, decisions should be fully supported by appropriate information.
8 *The older person with dementia*. Every person with dementia should be deemed competent unless deemed incompetent by the relevant medical officer. People with dementia may be able to take part in some aspects of ACP even if they lack competence to complete a legal document.
9 *Inevitability of death*. Most people requiring aged care services have at least one and, in many cases, several life-threatening, incurable illnesses leading to inevitable death. ACP discussions should therefore promote frank discussion of death and dying.
10 *End of life*. Older persons and their families should be informed about the principles of end-of-life care, namely that this (a) does not mean 'no treatment'; (b) is offered well before death is imminent; (c) neither hastens death nor unduly prolongs life; and (d) is delivered by all doctors and nurses with assistance from specialist services as required.
11 *Treatment options*. The focus of the conversation is on reasonable outcomes and 'living well'—it should raise the issues of life-prolonging treatment generally and not focus on any specific treatment.
12 *Family's role*. Families are encouraged to participate in all aspects of the older person's care planning. The family should comply with what is in the older person's best interest even if this is not congruent with their own views.
13 *GP involvement*. Best practice is for the GP to be included in ACP discussions. A copy of the (current) ACP should be forwarded to the older person's GP.
14 *Confidentiality*. The older person and/or family should be informed about confidentiality and safekeeping of their documented wishes. Information will only be provided to health professionals as required.
15 *ACP and enduring power of attorney*. ACP complements any legally binding power of attorney document.
16 *Information transfer*: Effective systems to support transfer of information (ie, copies of completed ACP-related documents) to the older persons' medical records, GP, family and local health services are paramount.
17 *Documentation*: ACP documents should clearly specify (at a minimum) (a) nominated substitute decision maker (and contact details) where applicable, (b) resident competency at the time of completion (c) current state of health, (c) values and beliefs (things that matter most in life), (d) future unacceptable health conditions, (e) specification of resident preferences in relation to life-prolonging treatment and hospital transfer, (f) specific wanted/unwanted treatments—where applicable, (g) goals for end-of-life care, (h) appropriate signatures (clear, complete, dated, witnessed) and include evidence of GP review.

organisations had developed documentation that clearly provided details of an individual who had been given Medical Enduring Power of Attorney (MEPOA), and specification of the resident's competency status was included in only a quarter of the document sets. Documentation most commonly recorded preferences regarding hospital transfer, life prolonging treatment and personal/cultural/religious wishes. However, the recording of preferences around life-prolonging treatment was judged inadequate in the majority of document sets. Reasons for a rating of inadequate included: (1) cases where documents referred to CPR preferences only (four documentation sets); (2) where documents did not ask for specific treatment preferences but had questions that were phrased in a way that may elicit non-specific responses for example, 'do you or your family have any concerns regarding the prolonging of life by artificial means?' (two document sets); (3) where documents asked for confirmation that resuscitation and palliative care issues had been 'explained to the resident/family', and do not elicit specific treatment preferences (one document set). In the case of preferences around hospital transfer, one set was rated inadequate because residents were only asked to indicate a yes/no response to the statement 'only to be transferred to hospital if absolutely necessary' (the term 'absolutely necessary' gives no practical guidance to the nurse who must make the decision about what to do). Items recording information regarding personal/cultural/religious wishes were assessed as inadequate in three of the documentation sets for the following reasons: (1) Residents were only

Table 2 Names of advance care planning related document sets reported by aged care organisations

Aged care organisation	Document name
1	Advance Care Plan; Palliative Care assessment
2	End of Life Choices
3	End of Life Choices
4	Terminal Care Wishes; Palliative Care Wishes
5	Funeral Arrangements and Terminal Care Wishes
6	Advanced Care Wishes Assessment; Palliative Care Assessment
7	End of Life Wishes Statement; Serious Illness/ Palliative Care, Death Instructions and/or Wishes
8	Advanced Care Directive
9	Terminal Care Wishes Sheet; Palliative Care Assessment
10	Terminal Care Wishes; Palliative Care Assessment
11	Palliative Care Plan
12	Terminal Wishes Consultation

asked if they would like a minister to be contacted; (2) Residents were only asked if they had any cultural wishes relating to death and if they would require the notification of a religious minister in specified situations; (3) Residents were only asked if they had any religious/spiritual wishes.

Testing of the draft recommended Advance Care Plan template

Staff who trialled the draft recommended Advance Care Plan template provided positive responses to all six assessment questions, noting that it was much simpler to use than their existing documentation, and suitable for use with competent and non-competent residents. Furthermore, testers noted that the template provided a clear guide during ACP discussions. As a result of the positive feedback, the draft template format was used for the MHC project.

Table 3 Completeness and quality of existing documentation sets used by participant aged care organisations to record resident treatment preferences/wishes for end of life care

	Number of document sets from a total of 12 where item is:		
	Present	Present but inadequate	Absent
Specification of:			
Medical Enduring Power of Attorney (MEPOA) status/details	4	1	7
Resident competency at time of completion	3	0	9
Resident preferences concerning hospital transfer	8	1	3
Resident preferences concerning life prolonging medical treatment	5	7	0
Personal/cultural/religious wishes	9	3	0
End of life values/important issues	4	0	8
Resident signature section	6	0	6
Witness/family/MEPOA signature section	8	0	4
GP signature section	4	0	8

Completed Advance Care Plans using the recommended template

A total of 244 completed care plans were provided by 16 separate facilities (representing 10/12 participating aged care organisations) with a total of 1074 beds. Forty-one of these plans were excluded from the audit because they were provided by facilities that were part of the same umbrella organisation that chose to continue to use their preimplementation ACP documentation (reports from this organisation indicated that recent Board ratification of existing documentation precluded the use of the newly developed Advance Care Plan template in these facilities). This left 203 Advance Care Plans completed on the recommended template that were provided by 13 different RACFs to be included in this audit.

Of 203 plans, 49% included the appointment of a MEPOA with completed contact details, while 40% of plans indicated that no MEPOA had been appointed for the resident in question. Overall requests concerning medical treatment were specified in almost all completed documents (97%), with 73% nominating the option of refusal of life-prolonging treatment. Twelve per cent preferred the doctors to make medical treatment decisions in keeping with the resident's expressed preferences, while only 6% selected transfer to hospital for treatment and assessment as their preferred choice.

Nearly all plans (99%[i]) also had information listed in the 'wanted/not wanted treatments' section of the form. Treatments listed as wanted and those listed as not wanted were judged to be consistent in 96% of submitted plans where this rating was possible. Of the seven plans receiving an inconsistency rating for this item; five made inconsistent requests around CPR for example, 'wanted-CPR, not wanted—ventilation'; and two made inconsistent requests relating to surgery for example, 'wanted—surgery to clear bowel obstruction, not wanted—IVs'. The information in this section was assessed to be consistent with selections made in the overall medical treatment request section of the form in 98% of cases. All four plans that received an inconsistency rating indicated tick box 1 (refusal of life prolonging treatment selected) and yet requested CPR in the wanted treatment list (in two

[i]Percentage calculated excluding plans (n=4) where a rating was not possible due to incomplete copies of the plan.

Box 1 Examples of values and belief statements given in completed Aged Care Plans

- My children, grandchildren and great-grandchildren
- Strong family ties, independence is highly important
- Maintain independence and social interactions. No specific religion
- Family and friends. Soft music playing during the day. Sitting in the garden on nice warm days. Church (catholic) communion, blessing of the sick
- Family. Independence, going visiting places, being among people
- Family, religious beliefs, independence and privacy. Favourite football club
- Family, reading, knitting, keeping her mind active. Has her own spiritual beliefs and does not wish to be visited by clerics. Independence important but is seriously decreasing
- Family very important. To be treated with dignity by being kept clean and comfortable. Also having adequate pain management. Music especially opera CDs
- Likes limited company, likes own space. Family
- Strong family affiliation. Practising Roman Catholic. Enjoys bingo, pokies, magazines, jigsaws and pets, particularly the family dog
- Independence.

Box 2 Examples of resident/family statements regarding unacceptable future health situations

- Can't walk, can't talk, can't eat
- Feeding/breathing tubes, needing assistance to go to the toilet, loss of any more independence
- Poor quality of life, unable to get around, unable to communicate
- Current health status is unacceptable
- Unable to communicate, would find pain that was not managed unacceptable
- Having to live a poor quality of life, not able to eat/drink, loss of dignity
- Unable to communicate, feed myself, comprehend surroundings
- Being kept alive when there is no hope of recovery
- Bed bound, unable to move or communicate or lead any sort of meaningful existence
- Prolonging my life no matter what, machines keeping me alive
- If I can't swallow on my own, to receive percutaneous endoscopic gastronomy feeding
- Current condition unacceptable
- Unable to tell my family that I love them all

cases the request for CPR was specifically in the context of a witnessed arrest only).

Over 90% of plans included information concerning residents' values and beliefs (see box 1). Major themes drawn from these values included: family, independence, faith and spiritual beliefs. Future health situations that the resident would find to be unacceptable were specified in 78% of completed plans, examples of which are given in box 2. The resident's current health status was completed in 93% of plans although the information provided frequently appeared to be the staff's knowledge of the resident's health status (71%) rather than residents' or families interpretation of their current health. Finally, 93% of plans had been signed by a competent resident or on behalf of a non-competent resident with 86% of these plans assessed as having all sections signed and witnessed correctly.

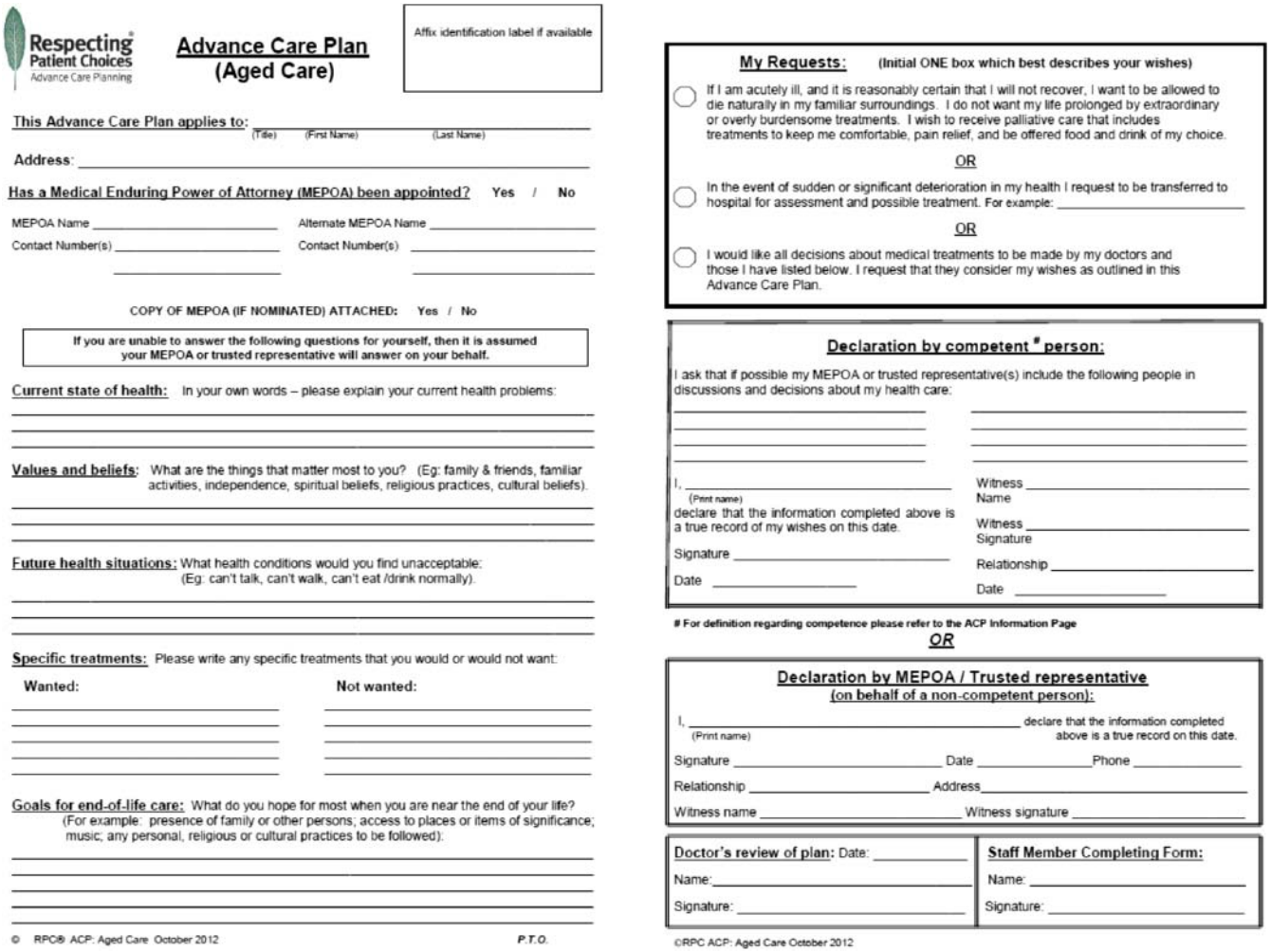
Following further feedback from participants using the template during the project period, a final version of the RPC Advance Care Plan template was developed. This template is provided in figure 1.

DISCUSSION

This paper describes the process of developing, piloting and wider testing of an effective Advance Care Plan template for use in RACFs. It details the limitations with documentation used in participating RACFs prior to implementation. It identifies key principles for ACP, major domains of information that should be covered in an effective Advance Care Plan and reports on the results of 203 Advance Care Plans completed using the recommended template in 13 separate facilities.

In line with previous research in this area,[7] the existing document sets used by the participating organisations had a number of serious limitations, beginning with the variability in their titles and structures. Given the mobility of the aged care workforce,[28] it would be important to have consistency in the naming and layout of these ACP documents to ensure new staff can identify and work with them easily. It is also notable that a majority of document sets used by these organisations failed to include key components of a workable Advance Care Plan. These included: MEPOA status and details; whether the resident was competent at the time of completion; and information concerning the resident's end-of-life values and important wishes. Without this information it is difficult to see how the resident's wishes could be effectively enacted. Seven of the 12 documents also failed to adequately and clearly specify the resident's preferences as regards life-prolonging medical treatment. It was also disappointing how frequently the most common questions in the pre-existing documents were regarding funeral arrangements and the resident's desire to be transferred to hospital.

The development of the guiding principles for ACP by the expert working group served to ensure that the new Advance Care Plan template contained all the



Respecting Patient Choices
Advance Care Planning

Advance Care Plan (Aged Care)

Affix identification label if available

This Advance Care Plan applies to: _____ (Title) (First Name) (Last Name)

Address: _____

Has a Medical Enduring Power of Attorney (MEPOA) been appointed? Yes / No

MEPOA Name _____ Alternate MEPOA Name _____

Contact Number(s) _____ Contact Number(s) _____

COPY OF MEPOA (IF NOMINATED) ATTACHED: Yes / No

If you are unable to answer the following questions for yourself, then it is assumed your MEPOA or trusted representative will answer on your behalf.

Current state of health: In your own words – please explain your current health problems:

Values and beliefs: What are the things that matter most to you? (Eg: family & friends, familiar activities, independence, spiritual beliefs, religious practices, cultural beliefs).

Future health situations: What health conditions would you find unacceptable: (Eg: can't talk, can't walk, can't eat /drink normally).

Specific treatments: Please write any specific treatments that you would or would not want:

Wanted: Not wanted:

Goals for end-of-life care: What do you hope for most when you are near the end of your life? (For example: presence of family or other persons; access to places or items of significance; music; any personal, religious or cultural practices to be followed):

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My Requests: (Initial ONE box which best describes your wishes)

- If I am acutely ill, and it is reasonably certain that I will not recover, I want to be allowed to die naturally in my familiar surroundings. I do not want my life prolonged by extraordinary or overly burdensome treatments. I wish to receive palliative care that includes treatments to keep me comfortable, pain relief, and be offered food and drink of my choice.

OR

- In the event of sudden or significant deterioration in my health I request to be transferred to hospital for assessment and possible treatment. For example: _____

OR

- I would like all decisions about medical treatments to be made by my doctors and those I have listed below. I request that they consider my wishes as outlined in this Advance Care Plan.

Declaration by competent # person:

I ask that if possible my MEPOA or trusted representative(s) include the following people in discussions and decisions about my health care:

_____ _____
_____ _____
_____ _____
_____ _____

I, _____ (Print name) declare that the information completed above is a true record of my wishes on this date.

Signature _____

Date _____

Witness Name _____

Witness Signature _____

Relationship _____

Date _____

For definition regarding competence please refer to the ACP Information Page

OR

Declaration by MEPOA / Trusted representative (on behalf of a non-competent person):

I, _____ (Print name) declare that the information completed above is a true record on this date.

Signature _____ Date _____ Phone _____

Relationship _____ Address _____

Witness name _____ Witness signature _____

Doctor's review of plan: Date: _____	**Staff Member Completing Form:**
Name: _____	Name: _____
Signature: _____	Signature: _____

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Figure 1 Aged care specific Advance Care Plan.

essential elements and guided the objective assessment of old and new documents. The new document template was met with broad approval and its ease-of-use was confirmed by the high standard of completion. Completion of Advance Care Plans, by RACF staff using the recommended template as part of the MHC project, was clearer and more thorough with the inclusion of fields such as personal values and unacceptable future health situations. It is notable that fewer than half of these completed Advance Care Plans specified a MEPOA including complete contact details. Many residents, however, may have lacked the capacity to appoint a MEPOA by the time ACP was conducted. The addition of information on residents' values and priorities, and unacceptable health situations is in line with recent studies regarding effective ACP[29 30] and makes it more likely that attention, care and resources that are given to residents in their last stage of life will be comforting and acceptable.

The main limitation of this study is the relatively small number of RACFs from which this data was gathered. This limitation is offset by the consistency of the findings regarding the inadequacy of preimplementation documents and the high performance of the Advance Care Plan template.

A major conclusion to draw from this assessment is that standardisation of ACP processes and documentation is likely to improve the quality and ultimately the outcomes of ACP in the residential aged care sector. The guiding principles for ACP in aged care and the use of the template presented in this paper, should assist RACFs and their staff to increase the frequency and quality of completion of Advance Care Plans in the residential aged care setting. Completion and revision of clear comprehensive ACP documents are essential components of this process.

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