AMA Victoria's response to the Department of Health and Human Services (DHHS) Generic Forms for Advance Care Directives

2 June 2017

The Australian Medical Association (Victoria)

Introduction

The Department of Health and Human Services (DHHS) has developed generic forms for an *instructional* directive and a *values* directive.

AMA Victoria has provided input into the three template options presented, to guide the development of generic forms so that they may be useful to both patients and the health sector.

AMA Victoria has provided feedback in the survey template provided by DHHS.

AMA Victoria has developed "10 Minimum Standards for Medical Forms" to guide the use of standardised electronic forms (***refer Appendix 1***). The minimum standards may provide guidance on the development of forms that are accessible and useful to patients, medical treatment decision makers and health professionals.

ACP: Instructional Directive Survey

Q1. What did you like about Option 1? What did you not like?

AMA Victoria recommends including a definition section / appendix. Need to define 'consent', 'incapacitated', 'terminal phase', 'incurable illness', 'permanently unconscious', 'persistent vegetative state', 'seriously ill or injured', 'life-sustaining measures', 'inducement', 'compulsion', 'voluntary' and 'sound mind'.

In section, '*This side to be completed by the patient*', AMA Victoria recommends:

- Use plain English e.g. "this tells my family, doctors, nurses and carers what I want to happen to me and what medical care I want to receive, if I cannot make a decision at the time."
- Provide timeframe for relevance of directive.
- Include that if the person can make a decision at the time, this directive becomes irrelevant.
- Clarify what 'binding' means. Include consideration of circumstances in which medical treatment might be administered contrary to binding directive.

In section, '*You are not required to complete all of the following section*', AMA Victoria recommends:

- Simplify language to – "Please only fill in the parts you are sure on. You do not need to fill in everything."
- Where it reads:
  I, ……………… (name of patient), request that if I am incapacitated and unable to make decisions for myself, the following instructions should influence medical treatment decision making where appropriate.
  Clarify - unclear from use of the word 'influence' if the directive is a guide only, or binding.

The concept of 'life sustaining measures' needs to be clarified e.g. food is life-sustaining but so is kidney dialysis.

In section, '*To be completed by the patient*', AMA Victoria recommends:

- Where it reads:
  I, …………… (*Print Name)*, have an understanding of the health impacts of the instructions indicated in the previous section. I understand that this instructional directive remains valid until I choose to change or cancel it.
  Clarify - specify timeframe.

In section, '*Witnessing Requirements',* AMA Victoria recommends:

- Revise wording with reference to 'current conditions'. Wording fails to take account of future conditions, illness and injury.
- A witness cannot make an assessment that someone is of "sound mind."
- Not clear if this is a witness to a medical practitioner's signature (e.g. nurse), in which case the witness signature should be included *after* the doctor's signature, or witness to patient's signature?
- Replace "Doctor's signature" with "Medical practitioner's signature."
- Grey section below Witness Requirements, reads:
  If you alter or change your advance care plan, we recommend you discuss and provide copies of the changes to your medical treatment decision maker, family, GP and local hospital.
  It is unclear what the difference is between 'alter' and 'change'. A hospital may not be 'local', replace simply with "hospital". Also add "other doctors you see."

Q2. What did you like about Option 2? What did you not like?

AMA Victoria recommends including a definition section / appendix. Need to define 'consent', 'voluntary', 'incapacitated', 'terminally ill', 'persistent vegetative state', 'permanently unconscious', 'cardiopulmonary resuscitation', 'assisted ventilation', 'artificial hydration', 'artificial nutrition' and 'antibiotics'.

Option 2 provides instructional directives commencing with:
'I DO NOT want'…
AMA Victoria recommends that this sentence should be preceded with:
'I WANT'…followed by the existing 'I DO NOT want' directives.

Use plain English:

- Assisted ventilation – consider instead "put on a machine that breathes for me."
- Artificial hydration – consider instead "give water/fluid to keep me alive by a tube in my arm or a tube through my nose to my stomach." Sustagen Oral offers a form of artificial hydration but presumably reference is made here to artificial hydration via NG / IV / central line?

Need to include that if the person can make a decision at the time, this directive becomes irrelevant.

Q3. What did you like about Option 3? What did you not like?

Overall comment – Option 3 is vague. No prompts on what to consider when writing directive.

AMA Victoria recommends including a definition section / appendix. Need to define 'consent', 'voluntary' and 'incapacitated'.

AMA Victoria recommends that 'Binding Refusals of Medical Treatment' needs further clarification. Consider plain language, e.g. "if I cannot consent at the time, nobody can make a decision about my care that does not agree with the below."

Need to include that if the person can make a decision at the time, this directive becomes irrelevant.

Q5. Was there any question, format or other element that you thought would be more useful or appropriate than those found in the included instructional directives?

No comment.

Q6. Do you have any other comments, feedback, or issues you would like to raise regarding the templates included in this document?

General Feedback

- People's command of technical, legal and medical lingo varies and this presents legal difficulties for persons making advance care directives and those interpreting advance care directives.
- Use of legal jargon and medical / technical language is confusing. AMA Victoria recommends using simplified English. For example, instead of 'Instructional Directive', consider replacing with "Person's instructions if not able to provide consent", or something similar. The word 'incapacitated' could be replaced with simplified language like, "I am not well enough to make or communicate a decision."
- AMA Victoria recommends that generic forms should be accompanied by a definition section, to define complex medical and legal terms.
- Persons from culturally and linguistically diverse backgrounds may especially require greater guidance to interpret these generic forms. AMA Victoria supports the use of interpreting services.
- The language in the template options is problematic. Use of the term 'patient' is appropriate for an 'advance care *plan'* template. As the template options are marked 'advance care *directive',* reference should be made to a *person* and not a patient.

AMA Victoria questions whether these generic forms will be:

- compatible with medical software that generates each form, and / or
- available on a website that takes people through individual questions and then generates a form?

ACP: Values Directive Survey

Q1. What did you like about Option 1? What did you not like?

AMA Victoria makes the following observations:
- Option 1 is too vague and non-directive.
- The use of simplified, plain language is commendable.

Q2. What did you like about Option 2? What did you not like?

AMA Victoria makes the following observations:
- Option 2 is too vague and non-directive.
- The use of simplified, plain language is commendable.

Q3. What did you like about Option 3? What did you not like?

AMA Victoria believes that Option 3 is more direct than Options 1 and 2 – this is positive.

Drawback of Option 3 is the length of the generic form – too long.

Q5. Was there any question, or other element that you thought was missing from the included values directives?

No comment.

Q6. Do you have any other comments, feedback, or issues you would like to raise regarding the templates included in this document?

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- AMA Victoria recommends that generic forms should be accompanied by a definition section, to define complex medical and legal terms.
- Persons from culturally and linguistically diverse backgrounds may especially require greater guidance to interpret these generic forms. AMA Victoria supports the use of interpreting services.
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Option 3 has great background at the start '*What is this document for?*' etc. This adds value – AMA Victoria recommends that this should be replicated in Options 1 and 2.

Interpreter Statement and Witnessing Requirements of Option 3 are good value – AMA Victoria recommends that these should be replicated in Options 1 and 2.

Appendix 1
AMA Victoria 10 Minimum Standards for Medical Forms

Available & Accessible

1. The form is available in an electronic format that is compatible with existing electronic general practice medical records software.
2. Forms are distributed through medical software vendors. Access to forms does not require web surfing during consultations, nor form-filling online.

Value GP Time

3. The form has a clear notation that states that medical practitioners may charge a reasonable fee for their services and whether the services are rebatable by Medicare or other insurers.

Not Onerous & Respect Privacy

4. Demographic and medical data can be selected to automatically populate the electronic form with adequate space being provided for comments.
5. Only information essential for the purpose is requested and must not unnecessarily intrude upon patient privacy.
6. Forms do not require the doctor to supply information when a patient can reasonably provide this in their own right.

Easy to Administer

7. A copy is saved in the patient electronic medical file for future reference.
8. Data file storage size is kept to a minimum.
9. Prior to their release, forms are field tested under the auspices of a recognised medical representative organisation such as the AMA and the RACGP in association with the MSIA (Medical Software Industry Association).
10. Consideration should be given to future compliance with encrypted electronics transmission capability in line with new technologies being introduced into general practice.