

13 May 2021

Office of Advance Care Planning  
PO Box 2274  
Runcorn  
Qld 4113  
Via email: [acp@health.qld.gov.au](mailto:acp@health.qld.gov.au)

Dear Sir or Madam,

### **Feedback on the Statement of Choices form v5.1**

Thank you for the opportunity to contribute to the Statement of Choices Form Review 2021.

I support the Office of Advance Care Planning's commitment to encouraging Queenslanders to plan for their future health care.

While supporting this goal, I have some concerns about the implementation of the Statement of Choices Forms, the potential conflicts of interest arising from Queensland Health employing staff to assist people to complete these forms, and the risks associated with the Statement of Choices Form B that provides for the completion of the form by a third party when the subject person has lost capacity.

#### Introductory information

I support the introductory information encouraging people to think about their future health needs. However, I am concerned about the information provided under the heading 'What if my family member or someone I care for is currently unable to make health care decisions and they do not have an advance care plan?'

The document states that a Statement of Choices can still be considered for that person, explaining that the form 'should be based on that person's best interests, their expressed wishes and the views of their significant others. It should take into account the benefits and burdens of the person's illness and medical treatment' [emphasis added].

#### **The law does not recognise the authority of any person to make decisions about the care and treatment of another after they have lost capacity except under the provisions of the *Guardianship and Administration Act 2000*, or the *Powers of Attorney Act 1998*.**

In those cases the person or persons making those decisions must either be appointed as the person's guardian for personal or health matters, their attorney for personal or health matters under an Enduring Power of Attorney or an Advance Health Directive, or should be eligible to make decisions as the person's statutory health attorney under section 63 of the *Powers of Attorney Act*.

The introductory information disregards the law in this area and potentially encourages the making of the Statement of Choices document on behalf of another person by a person who does not have the requisite legal authority. While it is unlikely that a person seeking to make such a document on behalf of another would do so with bad intentions, it is nonetheless critical in terms of the human rights of people at the end of life that **these documents should only be made on behalf of another by a person recognised under the law as having that authority**.

Another serious concern in relation to the information in the introductory section is the passage quoted above recommending the person completing the Statement of Choices form on behalf of another should take into account the 'benefits and burdens of the person's illness and medical treatment'. This is an unfortunate choice of words. It is unclear whether the person

completing the document on behalf of another is expected to consider the 'benefits and burdens' of the person's illness and treatment from the point of view of the person for whom the form is being completed, the Queensland health system or some other perspective. It is also inappropriate to use terms such as 'burden' in the context of the end of life care of any person. It potentially suggests that the person and their illness are a burden to their families, the community and medical services. It is well-recognised that older members of our community are fearful of being a burden on their families and others as they age, however, that is never considered to be an appropriate consideration in any decision-making in relation to the person's care and medical treatment. Accordingly, **I would recommend that the term 'burden' be removed from the new edition of the forms.**

## Statement of Choices Form A

Part A 'My Details' seeks information about whether the person making the Statement of Choices has an Advance Health Directive, a Tribunal-appointed guardian or an Enduring Power of Attorney document.

If a person has a guardian already appointed, it is likely the Tribunal has already made a finding that the person does not have capacity to make certain personal (including health) decisions. **It is important that the form is clear that a Statement of Choices document will not override anything in a valid Advance Health Directive.** Further, a substitute decision-maker may take guidance from the content of a Statement of Choices document, however, they are not bound in any way to act on it. This is especially the case where a person may make a Statement of Choices document or have one made on their behalf after a guardian is appointed as their decision-maker.

It is also unclear from the document whether, when a person indicates that they have made an EPOA or AHD, or their listed 'Contact' has been appointed as their enduring attorney under an EPOA or AHD, Queensland Health requests a copy of those documents. Considering the Statement of Choices document acknowledges EPOAs and AHDs as 'legally-binding documents', when the Statement of Choices is not, it is unclear why the form would not direct the person completing it to provide copies of those legally-binding documents to the Office of Advance Care Planning. It is noted that the information sheet, 'How to complete an advance care plan' recommends sending a copy of a person's completed advance care planning documents (including EPOAs and AHDs) to the Office of Advance Care Planning. **It is suggested that the Statement of Choices form should encourage those completing the form to also provide copies of EPOAs and AHDs to the Office of Advance Care Planning as well as the completed Statement of Choices form.**

On page 4 of Form A under the heading 'Statement of Choices' the form states that the document remains in place until it is updated or withdrawn and suggests a time when the person making the document may want to review it. However, **there is nothing in the form to explain how a person might update their Statement of Choices document, nor does the form indicate whether the Office of Advance Care Planning follows the person up after the indicated period to remind them to review the document.** There also appears to be no information on the Advance Care Planning website for consumers about how they can update their advance care planning documents and the process for replacing or removing the documents on the electronic records system.

Under the 'My Understanding' section on page 4 of Form A, the second dot point says, '[M]y substitute decision-maker(s) and doctors may only use this document as a guide when making decisions regarding my medical treatment'. However, **a substitute decision-maker may choose not to be guided by, or rely on any information or direction contained in the Statement of Choices document. Perhaps this should be explained more fully in the form for the benefit of both the person completing the Statement of Choices document as well as treating doctors.**

The 'Usual Doctor's Statement', also raises concerns. The form does not clarify the expectations of the doctor signing the form, that is, whether the doctor should have had a consultation with

the person completing the form or have even met the person. Although the terminology used would suggest that the doctor who signs the document should be the 'usual doctor' of the person the subject of the Statement of Choices. I would appreciate some clarity about Queensland Health's views on these issues.

I have read the 'Guide for health professionals using the Statement of Choices document' prepared by the Office of Advance Care Planning. Under the section 'Doctor's Review', the guide states:

Ensure a doctor signs the document.

The doctor's signature indicates to all health professionals that the SoC is well-made, the person has been able to ask questions and adequately discuss their preferences. The doctor indicates they believe the person has capacity to make the SoC for themselves (Form A) or that (Form B) has been completed by an appropriate SDM.

Unless signed by a doctor the SoC cannot be uploaded to The Viewer.

There is nothing in the information in the guide to clarify the questions I have raised above. The focus is on ensuring that a doctor signs the document rather than on the doctor's engagement, if any, with the person making the document.

I have been informed anecdotally that doctors in the public health system have been asked to sign these forms without meeting or consulting with the patient, instead relying on second hand information from a Queensland Health employee who facilitated the discussions with the person completing the form.

**I would suggest that the form and the guide be amended to include information that clarifies the role and responsibilities of doctors completing this part of the form.**

The absence of a requirement for a formal witness to the Statement of Choices document raises a range of risks about the efficacy and reliability of the document and its content. There is no independent person who can verify that the person who has purportedly completed the Statement of Choices has done so willingly and that the information in the document reflects the person's views, wishes and preferences.

While I support the encouragement of advance care planning, I have concerns about the role of employees of Health and Hospital Services initiating advance care planning conversations with identified 'in-scope patients', that is, patients over 70 with an overnight hospital stay greater than 5 days. **There is a risk of a perception of the Health and Hospital Services being conflicted, in terms of the costs of care and the choices people may be encouraged to make, in terms of requesting or refusing care, including CPR and other life sustaining measures when completing the Statement of Choices document with support from a Hospital and Health Service employee.**

I have read the *My Care, My Choices, Metro South Health End-of-Life Strategy 2016* and the *Australian Medical Journal* article, 'Difficult but necessary conversations – the case for advance care planning',<sup>1</sup> referenced in the End-of-Life Strategy. The article notes that:

In their last year of life, Australians with advanced disease will average eight hospital admissions ...

Many patients at the end of life undergo futile (of no benefit at all) or inappropriate (harms outweigh potential benefits) interventions. Almost a quarter of intensive care beds are occupied by patients receiving potentially inappropriate care, while up to a quarter of health budgets are spent on inpatient care during the last 18 months of life without any real prospects of extending overall survival or impacting on quality of life.<sup>2</sup>

**While it is critical that limited health funding is not spent on futile treatment, the key to getting this approach right is education of doctors to ensure that decisions about clinical care are not driven**

---

<sup>1</sup> IA Scott, GK Mitchell, EJ Reymond and MP Daly, 'Difficult but necessary conversations – the case for advance care planning', *MJA* 199(10), 662, 18 November 2013.

<sup>2</sup> *Ibid*, at p 662.

**by irrelevant considerations and concerns.** It is unclear what safeguards are in place under the strategy to protect against the risk that patients are pre-emptively categorised as 'in-scope' for end-of-life conversations, thereby influencing future clinical decisions about their care, and what might amount to 'futile care', including whether to investigate the cause of symptoms that might indicate conditions that are treatable. It is also unclear what ethical input there has been to the development of the end-of-life strategy and the Statement of Choices documents.

I would be interested to meet with members of the Office of Advance Care Planning to discuss these issues and how they may be addressed going forward.

### Statement of Choices Form B

The concerns outlined above in relation to Form A also apply to the relevant sections of the Statement of Choices Form B. Further, the following outlines additional concerns relating specifically to Form B.

The Public Advocate welcomes the additional statement in Form B, stating that if a person has a legally appointed decision-maker under an AHD, an EPOA or a tribunal appointed guardian, they should be completing the form. I am of the view that, to a limited extent, Form B could be completed on behalf of another by a person who is a legally appointed decision-maker for that person.

**I am of the view that the Form B should not be completed by any person other than a legally appointed decision-maker.**

**The current content of the Form B raises the significant legal concern that it potentially encourages legally appointed decision-makers, including guardians, attorneys and Statutory Health Attorneys, to make treatment decisions on behalf of a person that they cannot lawfully make under section 66A(2) of the *Guardianship and Administration Act 2000*.**

Under section 66A(2) no legally appointed decision-maker can consent to the withdrawal or withholding of a life-sustaining measure unless it is consistent with good medical practice. Accordingly, neither a guardian, attorney, nor a Statutory Health Attorney can complete a Statement of Choices document, or make a decision on behalf of another, generally rejecting CPR or other life prolonging treatments. It would be unlawful for a legally appointed decision-maker (or for any other person) to complete the Form B and indicate '[T]he person would not wish CPR attempted under any circumstances' or '[T]he person would not wish for other life prolonging treatments under any circumstances'. In all cases, the legally appointed decision-makers are also required to request all of the medical treatments that would be 'considered to be medically beneficial'.

It is also a logical extension of this legal position that a person who is not a legally appointed decision-maker for a person cannot complete a Form B on behalf of another and reject CPR or other life prolonging treatments on behalf of that person.

It is concerning and problematic for the Statement of Choices Form B to be drafted in its current form. People using forms that are prepared by government agencies are entitled to rely on those forms as offering only lawful options for decision-making.

Aside from the consequences for people breaching the *Guardianship and Administration Act*, there is the possibility that a person who completes the Form B on behalf of another rejecting CPR or other life prolonging treatments, and those who act on those unlawful directions, may be liable under section 285 of the *Criminal Code* for failing to provide the necessities of life, or section 296, Acceleration of death. There is also the possibility of breaching sections 16 and 36 of the *Human Rights Act 2019*, Right to life and Right to health services.

**Considering the potential for serious legal consequences for people making unlawful decisions when completing Form B on behalf of another, I suggest use of Form B should be immediately suspended. In my view Form B should only be used if substantial amendments are made to the form to ensure the obligations of legally appointed decision-makers are clarified in the form and only lawful treatment options are included to minimise any breaches of the law. No treatment**

**decisions to withdraw or withhold life prolonging treatment should be taken based on Form Bs unless the decisions are consistent with good medical practice. Further, I would suggest that the Office of Advance Care Planning undertake an audit of all registered Statements of Choices and remove all Form Bs that have been invalidly completed on behalf of another person, and steps taken to contact the person's representatives and inform them of the situation and suggest alternative advance care planning arrangements, if that is possible.**

In relation to the 'Usual Doctor's Statement' in Form B, in addition to the issues also raised in relation to Form A, **I am concerned about the ability of any person to confidently attest to the statement contained in the form.** For completeness I have replicated the statement below:

As a registered medical practitioner, I believe that the person for whom this form applies currently does not have the decision-making capacity necessary to complete a Statement of Choices on their own. I also believe that the person completing this form understands the importance and implications of this document and is acting in the best interests of the person for whom this form applies. I am not an appointed attorney in the Enduring Power of Attorney document or Advance Health Directive, or a beneficiary under the will of the person for whom this form applies.

If the doctor signing the form is the person's usual doctor as is suggested by the title of this section, it would seem appropriate that this be acknowledged in the statement. For example, the statement could commence, '[A]s a registered medical practitioner and the usual doctor of ...'

Further, **it is unclear on what basis the doctor has formed the view that the person the subject of the form does not have decision-making capacity.** The use of the language 'I believe', rather than, 'following an assessment of the person' in relation to the doctor's view of the person's decision-making capacity suggests that the doctor has not undertaken a capacity assessment and may have relied on information provided by another (unnamed) person. There are significant risks associated with such an approach, and questions about whether it would meet professional standards.

**In relation to the doctor's statement about the intentions of the person completing the form on behalf of another, it would be dangerous for a doctor to rely on a brief meeting with a third party who is not the person's legally appointed substitute decision-maker (if such a meeting even occurred) as the basis for making a statement about that person's intentions in terms of acting in the best interests of the person.** These concerns may not necessarily apply where the medical practitioner is the usual doctor of the person the subject of the form and has met the person completing the form on previous occasions and is aware of their on-going relationship. However, where the doctor has not previously met either the person making the form on behalf of the other or the person for whom the form was made, if at all, the signing of such a statement is problematic. Accordingly, in its current form, the doctor's statement raises a range of questions and concerns that need to be addressed as part of this review.

Again, thank you for the opportunity to provide input into the Statement of Choices Form Review 2021. If you require clarification of any matters raised in this correspondence please contact me on 3738 9510.

Yours sincerely



Mary Burgess  
**Public Advocate**