

# REVISED WESTERN AUSTRALIAN ADVANCE HEALTH DIRECTIVE FORM

THE AUSTRALIAN COLLEGE OF NURSING (ACN) SUBMISSION TO WA HEALTH  
(SEPTEMBER 2020)

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# General Comment

The Australian College of Nursing (ACN) welcomes the opportunity to provide feedback on the, **'Revised Western Australian Advance Health Directive Form'**. As the pre-eminent and national leader of the nursing profession, it is important to highlight that nurses play a critical role in 'Palliative' and 'End of Life (EOL)' care; and that ACN is committed to providing system-wide strategies that safeguard Australia's vulnerable ageing population, particularly at their EOL.

ACN understands that in Australia, EOL care is costly<sup>1</sup> and does not necessarily reflect the values, goals or preferences of individuals.<sup>2</sup> ACN is also aware that whilst the use of Advance Health Directives (AHDs) is considered best practice, many individuals enter palliative/EOL care without any documented wishes; and there is a general lack of community awareness or uptake of AHDs. From a national nursing perspective, an AHD is considered essential in assisting people in exercising their EOL preferences and ensuring these are respected by family and health care professionals. Consistent with the Code of Ethics and Conduct for Nurses,<sup>3 4</sup> ACN strongly believes that an individual's dignity and choice are vital for EOL care and that AHDs, are necessary in achieving this.

ACN's commitment to this topic is evident in the establishment of a dedicated EOL care Policy Chapter which seeks to call on Government(s) to invest in initiatives supporting individuals' choice regarding their EOL, echoing the nursing profession's policy priorities.

Below is a list of recently published work conducted by ACN and the Policy Chapter which may benefit the work of WA Health around the revised WA AHD form:

- ACN 2020. 'Establishing a Nurse-led Palliative Care Service in Australia: An implementation toolkit – A White Paper by ACN 2019', ACN, Canberra. <https://www.acn.edu.au/wp-content/uploads/white-paper-establishing-nurse-led-palliative-care-service-in-australia-implementation-toolkit.pdf>
- ACN 2020. Voluntary Assisted Dying in Victoria: Position Statement. <https://www.acn.edu.au/wp-content/uploads/2018/10/Voluntary-Assisted-Dying-in-Victoria.pdf>
- ACN Submission to the Royal Commission into Aged Care Quality and Safety (July 2020). Investigation into the Impact of COVID-19 on Aged Care. <https://www.acn.edu.au/wp-content/uploads/20200702-impact-of-COVID19-on-aged-care-final.pdf>
- ACN 2019. 'Achieving Quality Palliative Care for All: The Essential Role of Nurses—A White Paper by ACN 2019', ACN, Canberra. <https://www.acn.edu.au/wp-content/uploads/white-paper-end-of-life-care-achieving-quality-palliative-care-for-all.pdf>
- ACN Submission to WA Health (2019). Draft Implementation Plan One 2019-2021: WA End-of-Life and Palliative Care Strategy 2018-2028. <https://www.acn.edu.au/wp->

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<sup>1</sup> Bartel, R. 2016 'Conversations: Creating Choice in End of Life Care', Melbourne: Australian Centre for Health Research (ACHR). Accessed 1<sup>st</sup> September 2020 at: <https://apo.org.au/sites/default/files/resource-files/2016-03/apo-nid62025.pdf>

<sup>2</sup> Jones A, and Silk K 2016. 'Improving end-of-life care in Australia' AHHA, Deeble Institute issues brief. Accessed 1<sup>st</sup> September 2020 at: [https://ahha.asn.au/system/files/docs/publications/deeble\\_institute\\_issues\\_brief\\_no\\_19.pdf](https://ahha.asn.au/system/files/docs/publications/deeble_institute_issues_brief_no_19.pdf)

<sup>3</sup> International Council of Nurses, The ICN Code of Ethics for Nurses, International Council of Nurses, Geneva, Switzerland, 2012.

<sup>4</sup> Nursing and Midwifery Board of Australia, 2018. Code of Conduct for Nurses: ICN Code of ethics for nurses. Accessed 1<sup>st</sup> September 2020 at: <https://www.nursingmidwiferyboard.gov.au/Codes-Guidelines-Statements/Professional-standards.aspx>

[content/uploads/20190717-WA-government-end-of-life-implementation-plan-ACN-response.pdf](https://www.acn.edu.au/wp-content/uploads/20190717-WA-government-end-of-life-implementation-plan-ACN-response.pdf)

- ACN Submission to QLD Government (2018). Queensland Health Palliative Care Services Review Consultation Paper. [https://www.acn.edu.au/wp-content/uploads/2018/10/20180824\\_QLD-palliative-care-services-review\\_ACN-letter-response.pdf](https://www.acn.edu.au/wp-content/uploads/2018/10/20180824_QLD-palliative-care-services-review_ACN-letter-response.pdf)
- ACN Submission to ACT Legislative Assembly (2018). Inquiry into End of Life Choices in the ACT. [https://www.acn.edu.au/wp-content/uploads/2018/03/20180323\\_ACN-response\\_ACT-Leg-Assem-End-of-Life-Inq\\_FINAL.pdf](https://www.acn.edu.au/wp-content/uploads/2018/03/20180323_ACN-response_ACT-Leg-Assem-End-of-Life-Inq_FINAL.pdf)

While ACN strongly supports the intent behind the revised WA AHD form, which is based on recommendations from the [My Life My Choice report](#) (2018) and [Ministerial Expert Panel Report on Advance Health Directives](#) (2019); ACN is concerned that there is a strong emphasis on the work of doctors/general practitioners (GPs) and the process of ‘informed’ consent is not sufficiently detailed.

As frontline workers, it is nurses who are the most accessible health care professional to individuals in EOL care settings; and it is nurses (if permitted) who are likely to engage in discussions centred around AHDs and other EOL care options. For example, an individual with a life-limiting illness may choose the voluntary assisted dying (VAD) option. In fact, Registered Nurses (RNs) and Enrolled Nurses (ENs) are the largest group of health care professionals who provide care to people with life-limiting conditions across all settings.<sup>5</sup> These nurses have a unique and central role in the team as they respond to the range of physical, emotional, social and spiritual needs of people with a life-limiting illness and promote continuity of care across the EOL care trajectory.<sup>6</sup>

Although amendments to the [WA Guardianship and Administration Act 1990](#) make it clear that a request for VAD cannot be included in an AHD,<sup>7</sup> nurses in EOL care settings commonly receive requests for assisted dying (up to 18%), placing them in difficult professional, ethical and legal positions.<sup>8</sup> In considering an AHD, individuals may also consider related aspects such as access to VAD. The reason for doing so vary and may include loneliness, pain and/or inadequate control of other symptoms, concern about burdening loved ones, inability to meaningfully engage in life activities, and inability to perform activities of daily living.<sup>9</sup> Whilst any registered health care professional can conscientiously object to participating in VAD (as per the [Voluntary Assisted Dying Act 2019 \(WA\)](#));<sup>10</sup> legally, nurses must provide safe, person-centred care whilst working within their scope of practice (as per the Code of Conduct and Ethics for Nurses).<sup>11 12</sup>

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<sup>5</sup> ACN 2019. ‘Achieving Quality Palliative Care for All: The Essential Role of Nurses—A White Paper by ACN 2019’, ACN, Canberra. Accessed 1<sup>st</sup> September 2020 at: <https://www.acn.edu.au/wp-content/uploads/white-paper-end-of-life-care-achieving-quality-palliative-care-for-all.pdf>

<sup>6</sup> ACN 2019. ‘Achieving Quality Palliative Care for All: The Essential Role of Nurses—A White Paper by ACN 2019’, ACN, Canberra. Accessed 1<sup>st</sup> September 2020 at: <https://www.acn.edu.au/wp-content/uploads/white-paper-end-of-life-care-achieving-quality-palliative-care-for-all.pdf>

<sup>7</sup> CD Lawyers 2020. Advanced Health Directive and Voluntary Assisted Dying. Accessed 9<sup>th</sup> September 2020 at: <https://www.cdlawyers.com.au/advanced-health-directive-and-voluntary-assisted-dying/>

<sup>8</sup> Health Times, 2017. ‘Dignity and choice vital for end-of-life care’. Accessed 1<sup>st</sup> September 2020 at: <https://healthtimes.com.au/hub/palliative-care/69/news/nc1/dignity-and-choice-vital-for-endoflife-care/3067/>

<sup>9</sup> Australian Medical Publishing Company, 2020. Attitudes towards voluntary assisted dying concerning. Accessed 1<sup>st</sup> September 2020 at: <https://insightplus.mja.com.au/2020/33/attitudes-towards-voluntary-assisted-dying-concerning/>

<sup>10</sup> ACN 2020. Voluntary Assisted Dying in Victoria: Position Statement. Accessed 1<sup>st</sup> September 2020 at: <https://www.acn.edu.au/wp-content/uploads/2018/10/Voluntary-Assisted-Dying-in-Victoria.pdf>

<sup>11</sup> International Council of Nurses, The ICN Code of Ethics for Nurses, International Council of Nurses, Geneva, Switzerland, 2012.

<sup>12</sup> Nursing and Midwifery Board of Australia, Code of Conduct for Nurses, Nursing and Midwifery Board of Australia, Canberra, 2018.

AHDs however present significant ethical issues around 'informed' consent. People who are dying are at the most vulnerable time in their lives and for this reason it is important to protect them from being coerced into EOL care choices that do not reflect their own. This includes not being unduly influenced by health care professionals, family or carers. Health care professionals must avoid imposing their own values on patients and instead listen, be a source of validation for personal choices, not invite discussions around VAD, and not encourage patients out of their legal right to access VAD if fully informed.<sup>13</sup> This would be the case more broadly in relation to AHDs and not just VAD. Family and/or carers must allow their dying loved one to make AHD decisions voluntarily and not influence this for financial gain for example. For this reason, it is important for AHDs to be made whilst the individual is cognitively sound, however some states (e.g. VIC) allow for supported decision making by a supportive guardian if the individual is not cognitively sound.<sup>14</sup>

The *WA Guardianship and Administration Act 1990* requires that a person has full legal capacity at the time of making an AHD. Consequently, there is no provision for supported decision-making in the WA.<sup>15</sup> It is possible, however, for a healthcare practitioner to discuss with a substitute decision-maker, whether the information contained in the AHD applies to the individual's current circumstances. The *WA Guardianship and Administration Act 1990* also specifies when a treatment decision in an AHD may operate.

Interestingly, on 1 March 2020, the Victorian Government introduced the *Guardianship and Administration Act 2019 (Vic)* ('the Act') to protect the rights of people with impaired capacity including disability and cognitive decline/impairment during EOL. The Act includes:

- *"A presumption of decision-making capacity, and a new definition of 'decision-making capacity'.*
- *Recognition of supported decision-making.*
- *Powers enabling the Victorian Civil and Administrative Tribunal (VCAT) to appoint a supportive guardian or administrator.*
- *New offences for guardians or administrators who dishonestly cause financial gain or cause loss to a represented person.*"<sup>16</sup>

In light of this information, it is therefore important that the nursing voice is strongly considered and included in discussions and reports around EOL care and AHDs. Nurses, just like doctors, are likely to face ethical dilemmas when caring for people who are dying, for example, a person's choice about EOL and an AHD may be at odds with a health care professionals' value. Nurses must therefore be protected by policies outlining clear roles and responsibilities on EOL care and an individual's options within AHD. ACN considers it appropriate to develop a well-defined scope of practice to improve respectful care decisions surrounding an individual's choice during all stages of care. Education at a state and territory level is also necessary to ensure a skilled nursing workforce in supporting

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<sup>13</sup> Australian Medical Publishing Company 2020. Attitudes towards voluntary assisted dying concerning. Accessed 1<sup>st</sup> September 2020 at: <https://insightplus.mja.com.au/2020/33/attitudes-towards-voluntary-assisted-dying-concerning/>

<sup>14</sup> QUT End of Life Law in Australia 2020. Supported decision-making in Victoria. Accessed 1<sup>st</sup> September 2020 at: <https://end-of-life.qut.edu.au/treatment-decisions/adults/state-and-territory-laws/victoria>

<sup>15</sup> Department of Justice 2015. WA Guardianship and Administration Act 1990. Accessed 9<sup>th</sup> September at: [https://www.legislation.wa.gov.au/legislation/prod/filestore.nsf/FileURL/mrdoc\\_28305.pdf/\\$FILE/Guardianship%20and%20Administratio%20Act%201990%20-%20%5B05-i0-02%5D.pdf?OpenElement](https://www.legislation.wa.gov.au/legislation/prod/filestore.nsf/FileURL/mrdoc_28305.pdf/$FILE/Guardianship%20and%20Administratio%20Act%201990%20-%20%5B05-i0-02%5D.pdf?OpenElement)

<sup>16</sup> QUT End of Life Law in Australia 2020. Recent Developments: 27 August 2020 - Victoria's new Guardianship laws commence. Accessed 1<sup>st</sup> September 2020 at: <https://end-of-life.qut.edu.au/about/recent-developments>

individual options for EOL care. In particular, nurses and other health care professionals require an improved understanding of EOL laws, AHDs with wider community engagement regarding these. In addition, ACN believes the role of the Nurse Practitioner in the community setting can be better utilised within EOL care.<sup>17</sup>

In summary, ACN believes that the quality of EOL care can be improved by encouraging potentially difficult conversations and promoting public awareness around EOL preferences and AHD; integrating AHD documents within My Health Record; developing a nationally consistent framework around EOL decision making; and improving access to EOL care in different settings including preferred settings. People who are dying are present in nearly all areas of our health care system. For this reason, nurses and their employers must have an awareness of the Australian Palliative Care Education and Training Collaborative's Whole of Workforce Framework as this describes different levels of competencies in EOL care for ALL nurses, whether they practice as a specialist or non-specialist setting.<sup>18</sup>

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<sup>17</sup> ACN 2019. 'Achieving Quality Palliative Care for All: The Essential Role of Nurses—A White Paper by ACN 2019', ACN, Canberra. Accessed 1<sup>st</sup> September 2020 at: <https://www.acn.edu.au/wp-content/uploads/white-paper-end-of-life-care-achieving-quality-palliative-care-for-all.pdf>

<sup>18</sup> ACN 2019. 'Achieving Quality Palliative Care for All: The Essential Role of Nurses—A White Paper by ACN 2019', ACN, Canberra. Accessed 1<sup>st</sup> September 2020 at: <https://www.acn.edu.au/wp-content/uploads/white-paper-end-of-life-care-achieving-quality-palliative-care-for-all.pdf>

# Response to Consultation Questions

## About You

- 1. Which category below best describes the views you will provide in this survey?**  
Professional Nursing Organisation
- 2. Were you born in Australia?**  
N/A
- 3. Do you usually speak a language other than English at home?**  
N/A
- 4. Do you identify as an Aboriginal or Torres Strait Islander?**  
N/A
- 5. In what area do you normally live?**  
N/A
- 6. In this survey are you providing your own individual views, or are the official views of a group or organisation?**  
The view of an organisation – The Australian College of Nursing (ACN)
- 7. What category below best describes the type of organisation you work, volunteer or advocate for?**  
N/A

## Treatment Decisions

- 1. Please rate your level of agreement with the following statements about the consent options listed, and instructions given, in the content above.**  
Strongly agree to: The instructions are clearly worded; The instructions are easy to understand  
Agree to: The treatments listed are comprehensive; There is enough information collected in these questions to allow your decision/s to be followed
- 2. What, if anything, would improve the specific treatment options listed in the AHD? Please give specific consideration to any treatment options that are missing or should be changed.**
  - With reference to Part Two A -Treatment Decisions, ACN questions the use of the words 'being successful' in the following statement: '**AND my treating medical practitioner felt the treatments below would have a reasonable chance of being successful for me**'. It is not clear in what sense and for whom, 'being successful' refers to, as there is reference to the treating medical practitioner and 'me'. ACN is concerned that this may be

confusing, misleading and offer false hope. For example, a well trained and experienced medical officer and nurse will be successful in performing 'CPR', however the measure of success may differ to the patient and for different individuals. ACN suggests it may be appropriate to include some statement here that cross references the person's wishes when the 'treating medical practitioners' are making decisions. That is, what 'success' means is wholly determined by the individual concerned, as far as reasonably possible.

- Reference to **'injury'** here, also complicates the issue. Part Two A combines the words **'seriously ill or injured'** with terminal illness. The treatment and outcomes expected are not or may not be the same. For this reason, ACN suggests separating these words out to avoid confusion. ACN suggests the following change for your consideration. **'AND my treating medical practitioner felt the treatments below would have a reasonable chance of reversing my injury or is likely to result in my preferred outcomes if terminally ill'** (consistent with Part Five – Optional Values Statements).
- ACN finds it concerning that this snapshot only refers to medical practitioners. The significant role of nurses, and namely Nurse Practitioners (NPs) and/or palliative care nurses, is not recognised here. There is also no mention of ethics, except in reference.
- ACN supports the option to **'insert another common treatment decision here'** as there may be something that is left out (e.g. new treatments) or a treatment that becomes redundant. Given this will become legislation, having this option is necessary to avoid unnecessary and time-consuming changes to legislation in the future. ACN is also supportive of the word **'common'** to prevent some unusual options being included (e.g. homeopathic options). To strengthen this option, ACN suggests specifying who will be inserting the **'other common treatment'** decision. The implication is that it is the individual; however, to avoid confusion this must be clearly stated.
- ACN suggests including another common decision treatment in this snapshot. Specifically, **'Renal Dialysis and Life prolonging treatments to keep me alive'**. This may have a significant relevance to people when they plan ahead with AHDs. Expanding other treatment options or comprehensive treatments in an addendum to include more comprehensive options is another suggestion. For example, there could be inclusions on certain investigative procedures and pharmaceutical products if found to be futile or non-beneficial in relation to improving patients' quality of life.
- There is a loaded ethical issue which could result in medical paternalism, with regards to **'medical research'** and use of the phrase **'assessed as being in my best interests'**; even when taking into account the stem and the words **'if in the opinion of my treating medical practitioner/s'**. In our society and based on the ethical principle of respect for autonomy, it is the patient/person themselves or their freely chosen designated decision maker who decides what is someone's best interest as expressed in the person's AHD

### 3. What, if anything, would improve the question above?

- The snapshot in Part Two B/C – Consent to Treatment/Refusal of Treatment, appears to be an advance care directive in itself because it is about consent or withdrawal of consent to treatment broadly. Part Two A appears to be an expansion of Part Two B/C; and for this reason, there needs to be a cross reference here.
- ACN considers the questions in this section to be broad and open ended. While this is not a problem in itself, it is important to note that obtaining *informed* consent will be carried out by the health care professional who will be able to adhere to standard and accepted health care ethical principles in obtaining *informed* consent and clarify treatment/procedures of concern to patients' without using (clinical) jargon. Many

people may find the clinical jargon in the questions difficult to understand.<sup>19 20</sup> It is also important to note that obtaining *informed* consent is a process. The form should be viewed as evidence that this process has taken place and should not be viewed as an endpoint in itself.<sup>21</sup>

- There are no dates on the snapshots in Part Two B/C, nor on any other snapshots. There is also no space for a witness to sign and date this form. ACN believe this is concerning as there is no way of determining if the individual themselves provided *informed* consent and then completed this form. This needs to be clear to prevent elder abuse and coercion. Also, without dates, there is no way of knowing how long the AHD is valid for.

**4. What, if anything, would improve how consent to medical treatment (both life sustaining and specific treatment) is recorded in the AHD in general? Please give specific consideration to anything that is missing or should be changed.**

By their very nature, *informed* consent for AHDs is obtained prior to treatment or hospitalisation and when the individual has decision making capacity. Treatment provided without consent may result in an action in trespass. Treatment provided in circumstances where a person has not been provided information they would consider to be ‘materially significant’ can result in a finding of negligence. On occasion though, the individual may suffer from cognitive impairment or for some other reason, be unable to indicate consent with a signature. A person who does not have decision-making capacity cannot validly complete an AHD. ACN also suggests that the two witnesses have the option to attest to the individuals’ decision-making capacity at the time it is signed.

The Ministerial report includes recommendations that ‘professional bodies’ be consulted in designing the education and that *must* include nurses as not only the majority health care professional group but the majority of the providers of palliative care.<sup>22</sup> ACN believes that nurses must provide the educational examples to clarify the role of health care professionals in any educationally designed materials about *informed* consent in the context of AHD.

## Your Value Statements

**1. In the context of an AHD, how important do you believe it is for health professionals to know:**

**What you value most in life:** Extremely important

**What worries you most about your future:** Extremely important

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<sup>19</sup> ACN 2019. ‘Achieving Quality Palliative Care for All: The Essential Role of Nurses—A White Paper by ACN 2019’, ACN, Canberra. Accessed 1<sup>st</sup> September 2020 at: <https://www.acn.edu.au/wp-content/uploads/white-paper-end-of-life-care-achieving-quality-palliative-care-for-all.pdf>

<sup>20</sup> Government of Western Australia 2019. Ministerial Expert Panel on Advance Health Directives – Final Report. Chapter 3 (pp26-27). Accessed 1<sup>st</sup> September 2020 at: [https://www.parliament.wa.gov.au/publications/tailedpapers.nsf/displaypaper/4012677aa1692816302f1f1a48258465001cef54/\\$file/2677.pdf](https://www.parliament.wa.gov.au/publications/tailedpapers.nsf/displaypaper/4012677aa1692816302f1f1a48258465001cef54/$file/2677.pdf)

<sup>21</sup> Government of Western Australia 2019. Ministerial Expert Panel on Advance Health Directives – Final Report. Chapter 3 (pp26-27). Accessed 1<sup>st</sup> September 2020 at: [https://www.parliament.wa.gov.au/publications/tailedpapers.nsf/displaypaper/4012677aa1692816302f1f1a48258465001cef54/\\$file/2677.pdf](https://www.parliament.wa.gov.au/publications/tailedpapers.nsf/displaypaper/4012677aa1692816302f1f1a48258465001cef54/$file/2677.pdf)

<sup>22</sup> Government of Western Australia 2019. Ministerial Expert Panel on Advance Health Directives – Final Report. Chapter 3 (pp26-27). Accessed 1<sup>st</sup> September 2020 at: [https://www.parliament.wa.gov.au/publications/tailedpapers.nsf/displaypaper/4012677aa1692816302f1f1a48258465001cef54/\\$file/2677.pdf](https://www.parliament.wa.gov.au/publications/tailedpapers.nsf/displaypaper/4012677aa1692816302f1f1a48258465001cef54/$file/2677.pdf)

2. Please rate your level of agreement with the following statements about the 'Your Values Statements' section of the AHD.

The instructions in this section are clearly worded: Agree

The instructions in this section are easy to understand: Agree

3. What, if anything, would improve the questions used to record values about care and treatment in the AHD?

ACN believes that the examples are good, given the questions are broad and can be applied to any range of concerns for different individuals. For example, the question that states 'what worries you most about your future', could be interpreted in a number of ways. This includes concerns relating to personal health, immediate and extended family and many other issues.

## Expressing Feelings About Outcomes of Care

1. Please rate your level of agreement with the following statements about the outcomes listed, and the instructions given, in the table above.

ACN 'agrees' with everything.

2. What (if anything) would improve how feelings towards outcomes of care are recorded in the AHD? Please give specific consideration to any outcomes that are missing or should be changed.

ACN has no comment.

3. Please rate your level of agreement with the following statements about the end of life care preferences listed, and the instructions provided, in the content above.

ACN 'strongly agrees' with everything.

4. What, if anything, would improve the end of life care preferences that are recorded in the AHD? Please give specific consideration to anything that is missing or should be changed.

- ACN suggests changing the question, 'when I am nearing death, the place I would prefer to die is' to 'when I am nearing death, the place I would prefer to be cared for and die is'. This statement more broadly covers the process of dying.
- ACN also views the question in the End of Life Care Preferences Snapshot, 'when I am nearing death, these things are important or comforting to me' is closely related to 'what worries you most about your future' as per the Optional Values Statement Snapshot (Part 5). ACN questions if there should be more detail or context to this question.

## Interpreter Statement

1. Do you know how to find an accredited interpreter?

Yes, ACN is aware of how to find an interpreter.

2. Please rate your level of agreement with the following statements about the interpreter statement section of the AHD.

The instructions in this section are clearly worded: Agree

The instructions in this section are easy to understand: Agree

The interpreter statement contains enough detail: Agree

3. What, if anything, would improve the interpreter statement section of the AHD? Please give specific consideration to anything that is missing or should be changed.

ACN suggests including whether the interpreter was contacted by a healthcare worker/facility or the patients' family for clarity. The details of the person who contacted the interpreter, the date, time and their signature should also be included to increase the authenticity of the document. ACN also suggests including a contact number for finding an interpreter, for individuals or carers who may not know where to look.

## Using AHDs effectively

1. A. Below are options to increase understanding of how to complete an AHD. Please rate how useful you believe each option would be for informing the community about HOW TO COMPLETE an AHD.

Extremely useful for everything

1. B. Below are options for the training of health professionals or educators regarding promoting and implementing the use of AHDs. Please ONLY answer these questions if you have a role in providing health or education services.

Extremely useful for everything

1. C. Please suggest any other strategies to increase community and health professional's ability to complete and use AHDs.

ACN understands that AHD uptake is generally poor nationally, therefore it is essential for a focussed and well-resourced campaign in WA which is different to other jurisdictions as it stands at the moment. In addition, implementation of AHD is also generally poor and with the advent of COVID-19, implementation of AHDs has been made even more difficult. Research shows that AHD prevalence is an issue by itself but more importantly, the ability of relevant clinicians to access existing AHDs when required and applying it in treatment choices as preferred by the patient is poor. ACN suggests a unified approach in the electronic storage site of AHD (e.g. My Health Record) and focussed education on implementing AHDs.

Below is a list of recent work conducted around AHDs:

- Sinclair C, Nolte L, White BP, & Detering KM 2020. Advance care planning in Australia during the COVID-19 outbreak: now more important than ever. Internal Medicine Journal. 50(8):918-923. <https://doi.org/10.1111/imj.14937>. Retrieved 17<sup>th</sup> August 2020, at: <https://apo.org.au/sites/default/files/resource-files/2020-08/apo-nid307382.pdf>

- Osman AD, Rahman MA, Lam L, Lin CC, Yeoh M, Judkins S, Pratten N, Moran J & Jones D 2020. Cardiopulmonary resuscitation and endotracheal intubation decisions for adults with advance care directive and resuscitation plans in the emergency department. Australasian Emergency Care. ISSN 2588-994X; <https://doi.org/10.1016/j.auec.2020.05.003>. Retrieved 17<sup>th</sup> August 2020 at: <http://www.sciencedirect.com/science/article/pii/S2588994X20300439>

**2. A. Below is a list of communication and promotion strategies. Please rate how useful you believe each option would be for raising knowledge and awareness of AHDs.**

Extremely useful for everything

**2. B. Please suggest any other ways to raise knowledge and awareness of AHDs to the community and health professionals.**

No comment

**3. Please select from the two options below, your preference for the functionality of the AHD register.**

Both an electronic and a simple registry

**4. Please detail below any suggestions or comments regarding the development of an AHD register for WA.**

ACN believes it would be useful to include a prompt for the maker to provide the GP and other treating doctors with a copy of the AHD. In addition, given that we are a mobile society, consideration is needed around how the AHD will be accessed by different health facilities within and outside the state of WA if required. ACN suggests a national registry through My Health Record – as this is both electronic and a simple registry which can be accessed across multiple sites and by multiple health care providers whilst at the same time ensuring personal privacy.

## General feedback about the revised Advance Health Directive (AHD)

**1. Based on the information in this survey regarding the draft revised AHD, how likely are you to complete an AHD?**

ACN notes that there are many snapshots, which is potentially onerous to complete, particularly if an individual suddenly becomes ill or is not 'ready' to complete the forms until they are gravely ill. Targeted education on completing AHDs is recommended.

**2. What, if anything, would make it easier for people to complete an AHD?**

While ACN considers witness requirements necessary, the need for an authorised witness and another witness who need to be present at the same time adds to making the process difficult. ACN believes awareness campaigns in different settings such as all higher education institutes and faculties and not only health science institutes/faculties as is the practice now. This group of individuals in this setting can advise their relatives once they understand the

importance of AHD and they themselves will also potentially complete AHD. Given how poor the national uptake of AHD is, including this in some of the generic educational curriculums may be helpful.

**3. Please provide below any general comments or additional feedback about the draft revised AHD.**

General comments can be found at the start of this document. ACN would like to highlight that the significant role of nurses, namely Nurse Practitioners (NPs) and/or palliative care nurses, is not recognised in the revised AHD. There is also no mention of the often profound ethical considerations associated with EOL care or sufficient detail about the process of *informed* consent.