

**A NATIONAL FRAMEWORK
FOR ADVANCE CARE DIRECTIVES**

**CONSULTATION COMPANION GUIDE
FOR THE DRAFT FRAMEWORK**

2010

**THE CLINICAL, TECHNICAL AND ETHICAL PRINCIPAL COMMITTEE OF THE
AUSTRALIAN HEALTH MINISTERS' ADVISORY COUNCIL**



This consultation companion guide for the draft National Advance Care Directives Framework national consultation process is intended to guide submissions and responses. It was prepared by the Advance Care Directives Working Group of the Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council.

The Advance Care Directives Working Group comprises members with backgrounds in: health law; health ethics; health and aged care policy development; and clinical care, including intensive care and palliative care. A list of the membership of the Working Group can be found at Appendix B of the draft Framework.

SUMMARY

Advance Care Directives can appoint a decision-maker, record preferences or both

The Framework takes the following approach:

- It applies only where there is an Advance Care Directive in place [page 5]
- It is aspirational, and is designed to be facilitative rather than regulatory [page 5]
- It is intended to be used by policy and law makers to guide legislative and policy change towards national consistency over time [page 6]
- It uses an agreed national terminology [page 12]

The Framework comprises:

- The Code for Ethical Practice which sets Principles to guide clinical practice, which could be applied across Australia under current laws [page 18]
- The Best Practice Standards which set Standards for the development of law, policy and forms and guidelines for the public and professionals [page 20]

The Framework:

- promotes discussions with substitute decision-makers and the recording of personal values and preferred outcomes rather than medical instructions [page 20]
- acknowledges the discussion about a person's wishes is more important than completing the form [page 29]
- recommends that witnesses should assure themselves that the person understands the consequences of completing their Advance Care Directive [page 36]
- recognises it is the substance of a person's wishes that are significant when decisions are made, not the legal format nor the jurisdiction in which they have been expressed [page 30]
- provides a decision-making pathway for substitute decision-makers, and recommends they make decisions based on contemporaneous substituted judgement [page 27]
- affirms the value of expert clinical knowledge and advice when care decisions are being made [page 23]

MAKING A SUBMISSION

The consultation website is at www.hwlebsworth.com.au/acdframework.

Please refer to the specific consultation questions and instructions on making a submission on page 7.

The deadline for submissions is 11 October 2010.

What does the draft Framework aim to do?

Recognising the diversity of legislation across Australia, the challenging nature of decision-making under Advance Care Directives and the barriers to their completion and use, the Australian Health Ministers Council in 2009 asked the Clinical, Technical and Ethical Principal Committee to progress the development of nationally consistent guidelines for Advanced Care Directives and to recommend nationally consistent terminology. Health Ministers also asked that each jurisdiction's legislation be reviewed and that the implications be identified for each jurisdiction's legislation should the guidelines be accepted nationally.

The Working Group established to develop the national guidelines realised that harmonising legislation would be a slow process, and that in the first instance an agreed standard for Advance Care Directives would be most useful to enable policy-makers and legislators to gradually align legislation across states and territories.

This draft National Framework therefore is designed to influence the movement of policy, legislation and practice over time towards a common approach which would enable Advance Care Directives to become more consistent across Australia and allow for their recognition across jurisdictional boundaries. National adoption of a common set of terms and concepts as used in this draft Framework will be critical for national harmonisation of Advance Care Directives.

The Framework takes a permissive but protective approach, and is designed to be facilitative rather than regulatory. It is intended to be aspirational rather than necessarily reflecting current practice. It combines new and existing concepts, applying a 'best practice' approach to their inclusion. The adoption of the national Framework will create an environment in which national harmonisation of Advance Care Directives can be fostered, and it provides a tool for policy-makers to enable this to happen.

What is an Advance Care Directive?

The draft Framework defines an Advance Care Directive as a written document intended to apply to future periods of impaired decision-making capacity that provides a legal means for a competent adult to:

- appoint and instruct a substitute decision-maker and/or
- record preferences for future health and personal care.

It provides for Advance Care Directives that can operate during any temporary period of impaired capacity as well as a gradual or sudden permanent loss of decision-making capacity. The intent is to ensure a person's preferences are known and can be honoured whenever decision-making capacity is impaired, and not only at the end of life.

This may be a change from how this term is currently used or understood in some jurisdictions.

Why do we need a national Framework?

As the Australian population ages the interest in advance care planning, and specifically the use of Advance Care Directives, is increasing. This interest extends from state and federal governments, across the health and aged care sectors, to the broader community.

There is wide public and professional recognition of the potential for Advance Care Directives to improve the care of people with diminished decision-making capacity if their wishes for care and life-management are known in advance. However, there are barriers that make wider and mainstream adoption of Advance Care Directives challenging.

- This is a complex area of law where widespread misperceptions and confusion across the professional and community spectrum raise ethical, legal and clinical issues.
- There is inconsistency in the terms used across Australia to describe and implement advance care planning generally, and Advance Care Directives specifically.
- Legislation and/or common law in the various jurisdictions recognises a person's right to make decisions about current and future treatment and care, and allow for previously expressed wishes to be respected when a person no longer has sufficient capacity to make such decisions for him or herself. However, the different legal bases for Advance Care Directives across jurisdictions are not well understood and have created some concerns about mutual recognition across jurisdictions.
- The uptake of Advance Care Directives may be higher in aged care settings, but remains low in other care settings and in the community. Consequently, many health care professionals are unfamiliar with them and may not understand the role of appointed substitute decision-makers.
- International evidence over the last two decades has illuminated the limitations of Advance Care Directives where these are used as stand-alone, written instructions for refusing specific medical interventions. Some Australian clinicians have expressed ambivalence and doubts about the application, effectiveness and authority of Advance Care Directives. However, what is also emerging in Australia and internationally is that advance care plans and Advance Care Directives that appoint and instruct a substitute decision-maker are increasingly embraced by the public and are often helpful to clinicians in health and aged care settings.

Options to improve practice in this area range from legislation to the development of nationally consistent guidelines. Australia's Health Ministers agreed to progress the development of nationally-consistent principle-based guidelines that would address these concerns and facilitate national harmonisation of Advance Care Directives over time.

What does the draft Framework seek to change?

This draft Framework acknowledges the improvements Advance Care Directives may make to care and decision-making during times of impaired capacity, especially towards the end of life. It also recognises that Advance Care Directives currently present challenges for those writing, interpreting, applying and abiding by them and seeks to define and clarify their proper scope and usage. Many people are familiar with the appointment of substitute decision-makers to manage health, personal and financial matters during future periods of impaired capacity, although individuals who complete such documents often struggle to write instructions for their chosen decision-makers.

The Working Group recognised that many of the difficulties presented by Advance Care Directives are related to interpretation, especially of written medical instructions, or to attitudes and social relationships. Most difficulties have arisen when people write medical instructions often many years before any diagnosis of a life-limiting illness or injury. People find it difficult to write specific medical directions and decision-makers cannot always interpret and apply these instructions when they are medically uninformed, too specific to account for new treatments or too non-specific to guide medical decisions. People change their stated medical treatment preferences over time but fail to update their Advance Care Directive, especially as priorities change towards the end of life.

Australia needs a new approach to Advance Care Directives that addresses these barriers to the completion, use and application of Advance Care Directives. This draft Framework seeks to address these practical and ethical challenges with concepts and mechanisms that respect the rights of people to have a say about future care which will be provided when their capacity to make decisions is impaired or lost, but that also fit with norms of informed consent and clinical practice within Australian health and aged care settings.

The draft Framework:

- recognises the importance of the person's wishes and preferences being known and respected, and therefore encourages discussions with substitute decision-makers
- promotes the recording of personal values and beliefs, preferred outcomes of care and levels of acceptable functional ability rather than detailed medical instructions
- recognises that the person determines what personal circumstances they would find intolerable or unacceptable and what interventions are overly burdensome or intrusive
- acknowledges the discussion about a person's wishes with their substitute decision-maker and health and aged care professionals is just as important for decision-making in the future as what may be recorded on the form
- recommends that witnesses should assure themselves that the person understands what an Advance Care Directive does and that their decision to complete the form is freely taken
- provides a decision-making pathway for substitute decision-makers and accommodates family, cultural and community decision-making norms
- recognising the diversity of interpretations of 'best interests', applies the more commonly understood concept of 'substituted judgement' as the primary decision-making standard where there is an Advance Care Directive in place
- recognises that when presented with an Advance Care Directive from another jurisdiction or on a different form, the person's expressed wishes should still inform substitute decision-making
- affirms the value of expert clinical knowledge and advice when care decisions are made and that medical practitioners are not obliged to offer treatments that are not medically indicated.

The draft Framework recognises the importance of taking into account an individual's values, beliefs, wishes and expectations when determining appropriate health and personal care, especially for a person whose decision-making capacity is impaired or lost. It promotes the optimum circumstance when a person:

- completes an Advance Care Directive
- appoints their chosen substitute decision-maker
- records values and preferred outcomes of care rather than specific medical directions, and
- discusses these with their substitute decision-maker, their family and their treating health professional.

Who is the draft Framework written for?

The draft National Framework for Advance Care Directives has been developed for regulators and policy-makers, however it takes into account the needs of:

- the person (client, patient or resident)
- significant others (substitute decision-makers, families and carers)
- health and aged care professionals (including medical, nursing, ambulance and allied health professionals).

What does the draft Framework include?

Components of the Framework

The draft Framework includes a set of principles incorporated into a Code for Ethical Practice complemented by a series of Best Practice Standards.

- The draft Code for Ethical Practice sets out principles to guide practice where Advance Care Directives are applied in health, aged care and community settings. The principles and most of

the standards in the draft Framework can be applied within current legal and policy systems without legislative change.

- The draft Best Practice Standards set benchmark standards to which jurisdictions would aim to enable them to move toward national consistency over time. They describe what should be included in Advance Care Directive laws, policies, forms and guidelines for professionals and the public, in order to move toward alignment with the national Framework.
- The draft Framework also contains a summary of how statutory and common law Advance Care Directives are currently used and applied, discusses the general concerns about Advance Care Directives, and explains how these have been recognised and considered in the draft Framework.
- A 'snapshot' summary of relevant legislation in each State and Territory is provided at Appendix A of the draft Framework¹.
- As required by Health Ministers, these documents are underpinned by a consistent national terminology that will enable a common understanding across jurisdictions.

This draft Framework applies to written Advance Care Directives, including those written on forms prescribed by legislation and also those that meet common law standards. It does not apply to statutory directives that only allow for financial and legal substitute decisions. Readers are encouraged to refer to the section on national terminology in the draft Framework for clarity of this and other terms and definitions used in the Framework.

Issues not addressed

Given the ethical and legal complexity of this area and the number of clinical and other contexts in which Advance Care Directives might be used, a number of important issues were identified that have not been addressed by this draft of the Framework. The Working Group is interested in hearing views about whether such matters should be covered by the Framework or addressed through other mechanisms. These include:

- the role of Advance Care Directives for people with episodic mental illness, and the role of substitute decision-makers in making decisions in these cases
- recording directions about organ and tissue donation and autopsies in Advance Care Directives
- permitting mature minors (16-17 years) to complete an Advance Care Directive and in particular, appointing a substitute decision-maker..

What happens next?

The draft Advance Care Directives Framework will be revised in the light of submissions received. The finalised Advance Care Directives Framework will be submitted to the Australian Health Ministers' Advisory Council and to Health Ministers for approval.

To a great extent, health and aged care professionals in all jurisdictions will be able to adopt and implement the Code for Ethical Practice under their current laws. Once the Framework is agreed, jurisdictions will need to adopt the agreed national terminology and assess current laws, policies and protocols against the Framework's Code for Ethical Practice and the Best Practice Standards and adapt them as necessary to comply to the extent that current legislation permits. State and Territory governments who are contemplating amending their legislation or policies that regulate Advance Care Directives should endeavour to align them with the Code for Ethical Practice and Best Practice Standards. In this way incremental movement towards a more consistent national approach and greater uniformity across Australia will be achieved.

¹ NOTE The Framework does not take account of recent amendments to the WA *Guardianship and Administration Act 1990* which commenced after the draft Framework was completed.

How can you have your say?

The Working Group is seeking general comments on the draft Framework from a targeted selection of stakeholders, including:

- policy advisors, ethicists, legislators and lawyers involved in the regulation of Advance Care Directives
- organisations representing clients, patients and aged care residents and substitute decision maker/s
- peak bodies representing consumers, community groups and professionals and
- professionals working in health, hospital, community and aged care settings

The Working Group invites you to consider the following questions and to answer those of particular interest or relevance to you:

1. Does the Framework meet its objective to provide guidance to policy makers and legislators to enable national harmonisation of legislation, policy and practice for Advance Care Directives over time?
2. Would the Framework assist with awareness of, and respect for, a person's wishes?
3. Would the Framework make it easier to recognise and apply Advance Care Directives across jurisdictional boundaries?
4. Is the structure of the draft Framework appropriate? Useful?
5. Is the Code for Ethical Practice clear? Appropriate?
6. Are the Best Practice Standards helpful? Practical?
7. Is the decision-making pathway clear? Useful?
8. Are there gaps in the draft Framework? What are they?
9. Would the Framework adequately inform future review and development of policy on Advance Care Directives?
10. What opportunities would the Framework provide to promote and assist with revising your State or Territory's legislation?

You are also invited to comment generally on the implications for implementation and practice of the:

- Code for Ethical Practice
- Best Practice Standards
- Decision-making Pathway
- National terminology.

All submissions will be reviewed and considered, and will inform the finalisation of the Framework.

The deadline for submissions is 11 October 2010.

This Companion Consultation Guide and the draft Framework can be downloaded from www.hwlebsworth.com.au/acdframework.

Please email your submission to:

acdframework.submissions@hwlebsworth.com.au

or post to

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The Terms of Reference for the National Advance Care Directives Working Group

Background

The Australian Health Ministers Conference requested that the Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council progress the development of nationally consistent guidelines for Advance Care Directives and related matters.

Aim

To provide a consultative forum representative of all jurisdictions to develop a National Framework and Guidelines for Advance Care Directives under the governance of the Clinical Technical and Ethical Principal Committee.

Objectives

To develop the following:

- A National Framework and Guidelines for Advance Care Directives
- A nationally consistent glossary and lexicon for Advance Care Directives
- A summary of relevant national laws and the implications for each jurisdiction's legislation should the Framework and Guidelines be endorsed by AHMAC.

To review and process the final document through the Clinical, Technical and Ethical Principal Committee and Australian Health Ministers' Advisory Council.