

Proposed Medical Treatment Planning and Decisions Act: Feedback on planning and implementation

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Introduction

cohealth welcomes the proposed Medical Treatment Planning and Decisions Act as a key initiative to enhance people's active participation in decisions about, and control over, their medical care and treatment. cohealth has been actively supporting and promoting advanced care directives and believes that the proposed Act will support this work. cohealth's work in this area to date includes:

- Promotion of advanced care plans with clinical staff, and encouragement to have a conversation with clients about this
- Developing/adapting resources including a template for advanced care plans, and an 'options document' to inform people about possible future health conditions and treatment options
- Staff training through the Decision Assist program.

cohealth is also engaged in the Inner North West Melbourne Health Advanced Care Planning Project, as part of the North West Melbourne Collaborative (a partnership between North Western Melbourne PHN, Melbourne Health, cohealth and Merri Health - see <http://collaborative.org.au/advance-care-planning/>). The project is intended to increase the awareness and use of advanced care plans among older people in the region, with a particular focus on culturally and linguistically diverse groups. The project aims to:

- Support participating health service providers to systematically incorporate advanced care planning in usual practice, including through the development of shared pathways, tools, documentation, and cross-organisational training; and
- Develop clear systems for mutual recognition and transfer of ACP information across providers and sectors.

In this submission we identify issues relating to the planning and implementation of the proposed Act, as they relate to clients, and to health professionals and health services.

See Appendix 1 for further information for further information about cohealth.

Issues for clients

cohealth is committed to a person-centred approach, and the clear expression of preferences in regard to future medical care and treatment is one application of this principle. Our support for person-centred care is founded on a rights-based approach which recognises the inherent right of all people to be active agents in decisions that affect them. This is underpinned by the Victorian Charter of Human Rights and Responsibilities Act (2006) and the Australian Charter of Healthcare Rights (2008).

As a community health service, we work with many groups who experience barriers to accessing mainstream health care services. These groups experience vulnerability to poor health outcomes, and include, for example, Aboriginal and Torres Strait Islander people, refugees and asylum seekers, people from culturally and linguistically diverse backgrounds, people who use alcohol and other drugs, recently released prisoners, people who are experiencing, or at risk of homelessness, people who live with serious mental illness, and LGBTIQ communities.

We are concerned about the potential barriers for groups such as these to taking advantage of the new opportunities to document their wishes and preferences. We would like to see specific, targeted supports for groups that may need assistance to avail themselves of these opportunities. This may include providing educational materials, guides, templates, forms and information sessions in languages other than English, and in non-written formats, such as pictographic, video, and audio.

Proactive efforts to engage with and educate groups such as these (rather than relying on them to seek out mainstream resources) are likely to be required to support equitable access to the opportunity to make ACDs.

We would also like to see recognition of directives and preferences documented in non-written modes, such as audio or video recordings.

Many, probably most, people have limited knowledge and understanding of future possible medical conditions, and the options for their management. In order to produce Advanced Care Directives (ACDs) which are able to effectively inform future decision making, many people will need support to understand these possibilities and options. As noted above, we are using a simple 'options document' to assist clients with this. There are also online tools available to assist people.

In addition, some people have limited experience of exercising choice in relation to their care and treatment, and will need support and education to inform them of their opportunities to do so. Failure to provide this support and education will result in inequitable access to opportunities to complete ACDs, and hence in the capacity to have medical care and treatment in line with personal, individual preferences and values.

It is likely that, in many cases, it will fall to health care and social care professionals to provide this support and education. It could also be provided by independent advocacy organisations, as long as resourcing to do so is provided, and the services are promoted widely to health and social care organisations so that they can refer clients to them. Resourcing of this should be provided as part of the implementation of the strategy.

Recommendations:

- 1. Provide templates and educational resources in languages other than English, and in non-written formats.**
- 2. Provide easy to understand information about future possible medical conditions, and the options for their treatment and management.**
- 3. Enable/recognise non-written Advanced Care Directives (audio or video).**
- 4. Resource education and support services to ensure that everyone has the opportunity to understand their options, articulate their preferences, and exercise their choices.**

Issues for health professionals and health services

Implementation of ACDs to guide medical treatment and care decisions will represent a major paradigm shift in the dynamics of client/provider relationships. The traditional model, particularly within the medical domain, situates power and control with the health/medical professional rather than the client. As noted above, cohealth strongly supports greater control and empowerment of clients.

Legislative change is an important platform, but will not be sufficient in and of itself to drive the required major culture and practice change. We recommend engaging patients/clients in the process of education and change management for health professionals. This sends a powerful message and is empowering for clients as well.

The implementation of the Mental Health Act 2014, which also necessitated major practice changes, provides an opportunity to review what worked and what didn't in that case, and draw on these lessons to support effective implementation of the proposed Act. There are also unresolved questions about how the proposed Act will impact on mental health treatment and care, including the status of existing advance statements.

There is growing use of health-justice partnerships, and these represent a fruitful avenue to explore to support effective implementation of the proposed Act. The Victorian Legal Services Board (VLSB) has funded 10 health-justice partnerships since 2013 under its grants program. In addition, a new National Centre for Health Justice Partnerships has just been established in Melbourne. cohealth is an active participant in one VLSB project, an elder abuse prevention project which is a partnership between cohealth and Justice Connect. It entails a lawyer working from our sites, providing secondary consultations and education to health professional staff, supporting the introduction of policies and procedures to identify and respond to elder abuse, and providing legal advice directly to our older clients. cohealth also has drug outreach lawyers at both of the Specialised Alcohol and other drug Primary Health Services (SAPHS, i.e., Innerspace and Health Works); as well as a homelessness outreach lawyer at the Central City site (which is a specialist, integrated health and support service for people experiencing, or at risk of, homelessness).

Health-justice partnerships provide a good model for legal support and advice to both health professionals and clients, to support ACDs being completed in a way that enables them to effectively inform future decision making.

The proposed Act will also represent a major change for non-medical registered health professionals (& paramedics), who will have new obligations. A key issue for these professionals in particular, but also medical professionals (among whom understanding of the existing regimes is highly variable), is confidence in understanding the requirements of ACDs as legal documents and the associated processes, and their role in relation to them. Health professionals want to be able to support their clients to complete ACDs, but need to feel confident to do so.

The issue of confidence, skills and knowledge extends not only to the legal aspects of the process, but also the capacity to engage sensitively in conversations about end of life care, and death.

Health professionals also have concerns about whether they are expected to assess the capacity of an individual to make a directive, and if so, the basis on which they should make that assessment. They are also concerned about understanding exactly what their obligations will be in making "reasonable efforts" to locate an ACD, and in "giving effect to" an ACD, especially if it is a values statement rather than an instructional directive.

Possible mechanisms to support the implementation may include:

- Developing guidelines for modules suitable for inclusion in established training programs (basic training, CPD)
- Amending accreditation requirements for training programs for registered professions, to mandate inclusion of education about the Act
- Providing a hotline or advice service for secondary consultation by health professionals or other forms of support such as health-justice partnerships.

Finally, a key issue for the health system in implementation of the proposed Act is mechanisms to support access to ACDs. Unless health professionals are able to locate and access ACDs, they can not be used in decision making. A key enabler of this is eHealth, including electronic health records and effective transfer of information between organisations.

Recommendations:

5. **Actively engage patients/clients in the process of education and change management for health professionals about the proposed Act.**
6. **Review the implementation of the Mental Health Act 2014 to identify effective (and ineffective) approaches to implementation and change management.**
7. **Utilise health/justice partnerships, building on existing projects, to support effective implementation of the proposed Act.**
8. **Support health professionals to develop the required skills, knowledge and confidence through:**
 - a. **Mandatory inclusions in basic training programs for registered health professionals and paramedics**
 - b. **Comprehensive continuing professional development in advanced care planning**
 - c. **Secondary consultation opportunities such as an advice service for professionals.**
9. **Clarify who will have responsibility for assessing the capacity of people to make directives, and what guidance they will have on how to do so.**
10. **Clarify how the new legislation will impact on mental health treatment and care.**

Appendix 1: About cohealth

cohealth is a not-for-profit community health service operating across the north and western regions of Melbourne. cohealth provides an *integrated platform* of health care and social support services. This integrated platform includes medical, dental, allied health, counselling, mental health, health promotion and prevention, youth services, community support services and other programs to promote community health and wellbeing. These services are delivered from over 30 sites across 14 local government areas in the north and west of Melbourne.

cohealth prioritises people who experience disadvantaged social circumstances and who are consequently marginalised from many mainstream health and other services. This includes people who are experiencing or at risk of homelessness, people who live with serious mental illness, vulnerable families, Aboriginal and Torres Strait Islanders, refugees and asylum seekers, people who use alcohol and other drugs, recently released prisoners and LGBTIQ communities.

cohealth's approach is based on human rights and a social model of health. We believe that health services should be provided to individuals and communities that are locally based and tailored to the community through a process that involves the community in the design of services. This response is founded on an empowerment model which emphasises the rights of communities rather than the needs of communities.