Submission to Inquiry into
End of Life Choices

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Table of Contents
Introduction ........................................................................................................................... 3
Executive Summary .............................................................................................................. 4
Issues................................................................................................................................ 4
Recommendations ............................................................................................................. 4
Description of current systems ........................................................................................... 4
Description of proposed systems ....................................................................................... 5
Required Outcome ......................................................................................................... 5
Pre-requisites - Computer .............................................................................................. 5
Pre-requisites – Legislative Change and Organisational Change ................................... 5
Summary .............................................................................................................................. 6
Introduction

Networking Health Victoria (NHV) is a state-funded organisation working with Primary Health Networks to better coordinate general practice, primary health care providers and the broader health system.

Formerly General Practice Victoria, which worked extensively with Divisions of General Practice under the previous system, NHV has evolved from an organisation that focuses primarily on general practice to one that now encompassing the broader health system. Over a period of almost twenty years NHV developed considerable strengths in engaging general practice, supporting and promoting a population health approach and successfully collaborated with many other organisations to improve the health of Victorians.

The Department of Health and Human Services (DHHS) in Victoria has worked in partnership with NHV to identify three consortia to develop processes and tools that support health services to implement and sustain advance care planning across organisations within a defined catchment area. An Advance Care Plan (ACP) may be defined as “a range of documents that people may use to express their values and preferences for care and treatment”.

Organisations have been identified by the three consortia as partners to increase the number of conversations about advance care planning in their catchments and to identify systems to create, store and secure retrieval of ACP documentation amongst stakeholders.

NHV regularly liaises with DHHS about this project and provides on-going support to these three consortia. The projects started in mid 2015 with two anticipated to finish in December 2016 and the other in June 2016.

One of the key focuses of this initiative is the transferability of ACPs between organisations. Each of the three consortia have engage similar partner organisations: Ambulance Victoria, Residential Aged Care Facilities (RACF), general practice, hospitals, Royal District Nursing Service, Palliative Care Australia, Health Issues centre and the Ethnic Communities Council of Victoria.

Consortia A is focusing on general practice while incorporating other organisations. Consortia B is focusing on RACFs, general practice and community health while still actively involving other organisations and the community. Consortia C is focusing on the “lay” community, again directly involving other organisations such as general practice, health services, aged care services and the primary care sector.

This submission addresses the mechanics of creating, storing and sharing ACPs in a secure, timely and reliable manner. It does not address the need for advance care planning itself.
Executive Summary

Issues
- While the Commonwealth-designed Personally Controlled Electronic Health Record (PCEHR) is the platform for the storage and controlled access of consumer medical history, the record does not currently allow storage of ACPs. Currently, the PCEHR can only store information about Substitute Decision Maker(s).
- The majority of consumers seen in the Victorian public hospital system are in hospitals that are not equipped with PCEHR access.
- A number of organisations have the capacity to store ACPs locally, but these ACPs can only be shared by other organisations in hard copy, if at all.
- A number of organisations accept or prepare ACPs in a format that is organisationally unique.
- Electronic versions of signed ACPs do not have their authenticity supported by legislation.

Recommendations
- State government arrange via COAG for ACPs to be able to be stored in the PCEHR in a manner acceptable to all stakeholders.
- State government fast track the implementation and adoption of PCEHR in its hospitals.
- Accreditation standards across various stakeholders be updated to reflect the need for ACPs to be created, stored and accepted/recognised by all stakeholders.
- Legislation be enacted validating the use of ACPs that are stored and signed electronically.
- Access to any consumer health data, wherever it is held, include identifiers that indicate the presence of a valid ACP.

Description of current systems
- Computer systems in general practice do not support the creation of ACPs.
- Some computer systems in RACFs support the creation, storage and retrieval of ACPs within their own systems. It is likely that there are a number of vendors offering different solutions with various levels of sophistication.
- Ambulance Victoria receives ACPs and stores them and makes them available to its officers in a timely manner.
- It is likely that individual public hospitals have their own systems and that individual public hospitals have different requirements for completion and acceptance of ACPs.
Description of proposed systems

Required Outcome

- A central repository of ACPs accessible securely, promptly, easily recognised and accepted by all stakeholders.
- These ACPs can either be created by software or be scanned copies of documents inclusive of consumer signature.
- ACPs be regularly reviewed following prompts from clinical software.

Pre-requisites - Computer

- PCEHR Advance Care Plan functionality.
- Secure data communications between stakeholders.
- Software improved to incorporate Advance Care Planning support for creation, storage, secure retrieval for a range of stakeholders.
- Tools for electronic reminders for individual ACPs to be reviewed.
- Capability to sign documents electronically.

Pre-requisites - Accreditation

Accreditation standards for all stakeholders to adopt not only appropriate ACPs, but also to accept ACPs prepared by others such as:

- RACFs
- GPs and practice staff
- hospitals
- Ambulance Victoria
- Royal District Nursing Service.

Pre-requisites – Legislative Change and Organisational Change

- The Electronic Transactions Act may need modifying to enable electronic signing of a document as significant as an Enduring Power of Attorney (Medical).
- Stakeholders’ acceptance of ACPs prepared by other stakeholders.
- Alignment with Commonwealth strategy.
- Continuous quality improvement processes to review the applicability of individual ACPs.
- Adoption of PCEHR as the sole definitive record.
Summary
The existence of ACPs is not, in itself enough, enough to ensure that they are used in a timely way.

Mechanisms are urgently required to give ACPs the appropriate level of recognition across the service system.

Electronic methods supported by legislative change need to be used for the storage of ACPs and to ensure that they can be accessed in a secure and timely manner. This must be accompanied by large-scale organisational change accepting the relevance of an improved PCEHR.