Accessibility of advance care plans in Victoria

Advance Care Planning May 2017

Advance Care Planning Australia

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Acknowledgements

Medical Treatment Act 1988 and Medical Treatment Planning and Decisions Act 2016

This report spans changes to legislation in Victoria relating to medical treatment and advance care plans. The Medical Treatment Act is being replaced with the Medical Treatment Planning and Decisions Act, which will come into effect in March 2018. The new legislation invokes different terms in relation to advance care planning documents and appointed substitute decision-makers.

When referring to the new Act, advance care plans will be referred to as 'advance care directives' and substitute decision-makers will be referred to as 'medical decision-makers'.

Further information reporting this report can be obtained by contacting the Advance Care Planning Program Director at Austin Health on phone +61 3 9496 5660 or email acpa@austin.org.au. A copy of the report is available at advancecareplanning.org.au.

Recommended citation:

Disclaimer:

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Part A: Executive summary

Introduction

The accessibility of advance care plans and substitute decision-maker documents in Victoria is a recognised challenge among health services.

Since 2014, the Department of Health and Human Services has commissioned the Austin Health Advance Care Planning Department to undertake activities to support the implementation of Advance care planning: Have the conversation – A strategy for Victorian health services 2014–2018 (Department of Health 2014). One of these activities is this summary options paper examining the accessibility of advance care plans in Victoria. Scoping of the current situation in Victoria and elsewhere was undertaken during 2015–16 to inform recommendations regarding the safest and most reliable methods of accessing advance care plans within and between health organisations, patients and substitute decision-makers.

Key findings

- The accessibility of advance care plans varies across Victorian health services and jurisdictions.
- Health professionals have concerns regarding privacy and confidentiality of advance care plans; however, patients do not seem to share these concerns. Consumers routinely have a copy of their own advance care plan; however, they do not consistently share these documents with relevant parties or store documents in locations that are easy to find.
- The current situation in Victoria is diverse, complex and inefficient in relation to information technology (IT) systems and interfaces, making it challenging to identify the presence of, and access to, advance care plans.
- Health services are currently accessing patient information via e-health systems. Advance care plans could potentially utilise existing systems to create greater visibility and access.
- Examination of various personal responsibility and electronic systems options for uploading and accessing advance care plans did not initially reveal a clear advantage for any personal or system option.
- It is clear that the government and health sector are rapidly moving towards e-health ('digital health'). The Australian Digital Health Agency is developing a national digital health strategy to improve health outcomes, including My Health Record (formerly 'Patient Controlled Electronic Health Record').
- There is increasing uptake of My Health Record by consumers and health organisations.
- The Medical Treatment Planning and Decisions Act comes into effect in March 2018, with clear requirements for health organisations to ascertain the presence of an advance care directive and/or appointed medical treatment decision-maker. The Act creates an opportunity to increase awareness and uptake of digital platforms to increase the accessibility of advance care planning documents.

My Health Record

- 'My Health Record' is the name of the national digital health record system (replacing the Patient Controlled Electronic Health Record).
- My Health Record stores health information (e.g. allergies, medical conditions, treatments, medications, and test and scan results, and can be accessed through one system.
- Healthcare providers (doctors, specialists, hospital staff) in Australia can see it online if their service has registered as a Healthcare Provider Identifier – Organisation (HPI-O). Consumers are able to upload an advance care plan and substitute medical decision-maker documents, which can also be viewed by healthcare providers.
- In the process of finalising this paper, My Health Record has emerged as the system with the most potential for patients and the health system to access advance care plans and related documents in Victoria.

Recommendation

The department should identify My Health Record as the recommended platform for accessing advance care plans and substitute decision-maker documents

There is national investment in My Health Record. The Australian Digital Health Agency has conducted community and health sector consultations and is in the process of forming a national strategy to improve health outcomes using e-health and My Health Record. There is potential for Victoria to engage the Australian Digital Health Agency in relation to advance care planning and My Health Record.

Other options for storage and access of advance care planning documents assessed in this work were not recommended given their inability to provide breadth of access for all who may use it.

There are a number of actions to be considered in relation to progressing My Health Record as the preferred mechanism for storing and accessing advance care plans and substitute medical decision-maker information for Victorian health organisations and consumers/patients. These include:

- Engage with Australian Digital Health Agency to advocate for improved mechanisms to generate, upload and access advance care planning activities and advance care plan alerts.
    - Currently health professionals can view advance care plans but cannot create or upload one on behalf of patients.
    - Health professionals cannot create an alert in relation to an advance care planning activity they have conducted.
- Engage with Victorian health services to increase awareness of and improve connectivity to My Health Record in relation to advance care planning.
- Engage with Victorian health services and health professionals regarding pending Victorian health legislation requirements in relation to advance care planning.
- Advise consumers, patients and health professionals of the benefits of My Health Record for storage and access of their advance care planning documents.

Further detail regarding the above points can be found in part F of this paper. This paper is informing the next phase of work to improve access to advance care plans and substitute decision-maker documents in Victoria. This will be by utilising My Health Record and other relevant electronic platforms as the main mechanism for accessibility and transferability of advance care plans and substitute decision-maker documents in Victoria.

Part: B Accessibility of advance care plans

Advance care planning is the process of planning for future health and personal care whereby a person's values, beliefs and preferences are made known so they can guide clinical decision-making at a future time when that person cannot make or communicate their decisions due to lack of capacity. This may result in the development of a written advance care plan, a term that encompasses a range of documents that people may use to express their values and preferences for care and treatment (Department of Health 2014).

In 2014, the Victorian Department of Health released *Advance care planning: Have the conversation – A strategy for Victorian health services 2014–2018*.The purpose of the strategy is to enhance opportunities for people in Victoria to develop advance care plans and for these to then be activated, as required. This process puts the person at the centre of their care and helps to align the person's specific healthcare goals with the actual care they receive. The strategy aims to provide clear and useful information to guide the implementation of advance care planning across Victorian health services. It promotes consistent practice and informs the development of processes, policies, guidelines, training, governance and quality structures that support advance care planning. The primary audience includes publicly funded health services, private hospitals and services, primary care providers, community provides, aged care providers and ambulance services.

Purpose

Accessibility of advance care plans has been identified as a key barrier to the successful implementation of advance care planning across Victoria **(AHACPD 2015a,b,c).** The Department of Health and Human Services commissioned the Austin Health Advance Care Planning Department to undertake a number of activities to support the implementation of *Advance care planning: Have the conversation – A strategy for Victorian health services 2014–2018*. The development of this summary options paper, to address issues of accessibility of advance care plans in Victoria, is one such activity.

Objectives

- To describe the importance of advance care planning accessibility, the background principles regarding successful accessibility of advance care plans and any associated risks.

- To undertake a literature review regarding principles of successful accessibility of advance care plans.

- To undertake an environmental scan to investigate existing systems' nationally and internationally and identify mechanisms to support accessibility of advance care plans.

- To describe the quantitative and qualitative scoping survey data received from Victorian health services regarding accessibility of advance care plans.

- To consult with key organisations; health services, Ambulance Victoria, residential aged care facilities, general practitioners, Royal District Nursing Service and consumers.

- To undertake a SWOT (strengths, weakness, opportunities and threats) analysis and cost estimate for each option.

- To provide a summary and future considerations for accessibility options.

Advance care planning

Advance care planning is an iterative process of reflection, discussion and communication wherein people have the opportunity to plan for future decision-making, particularly planning for a time when they may not be able to make decisions for themselves. Advance care planning helps people to determine their own healthcare priorities, and thereby to align their healthcare preferences with the actual care they receive.

Advance care planning supports people to identify their personal values, beliefs and goals for health care. It may also include consideration as to what would be an 'unacceptable outcome' for the individual and whether there are any specific treatments the person would not wish to receive, either at all or under particular circumstances. Advance care planning is an ongoing process, which evolves over time, as the person's health and circumstances change (ACPA 2017). Advance care planning can also help facilitate and clarify current decision-making for a person who retains capacity.

Advance care planning usually involves communication with a number of people including family and friends, future substitute decision-makers and healthcare providers. It may result in documentation in an advance care plan. People are encouraged to document outcomes of their discussions to provide support and guidance for their substitute decision-makers, family, and health and care providers. Documentation also helps to make the information readily available when needed.

Embedding advance care planning as part of routine care gives people the opportunity to talk about and review their preferences at clearly identified points along their care journey (Department of Health 2014, p. 24). The ultimate goal of advance care planning is to align the care the person actually receives with their preferences. In order for this to occur, advance care planning information needs to be accessible when required, and treatment plans need to be developed in accordance with the person's values, goals, beliefs and specific treatment preferences. The advance care planning cycle can be conceptualised into four key stages: develop, document, review and activate (refer to Figure 1).

Figure 1: The advance care planning cycle
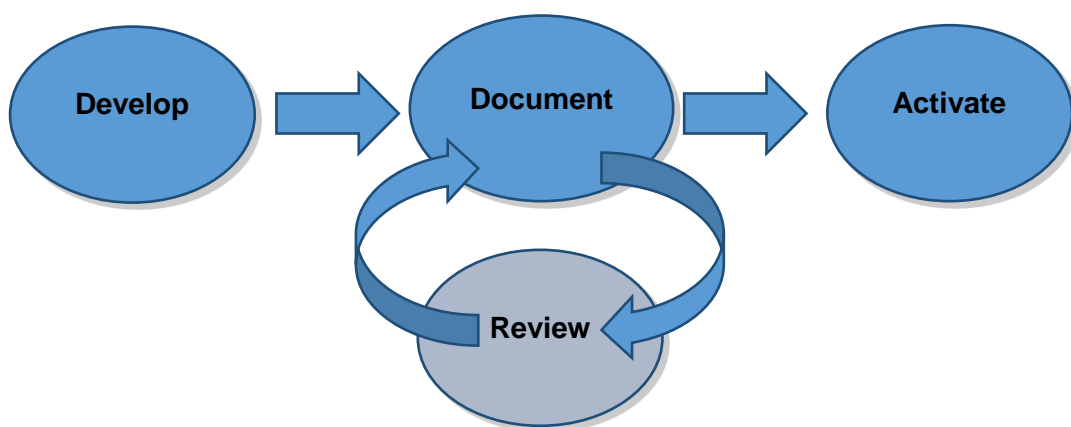
Source: Adapted from Department of Health 2014, p. 26.

Develop

Advance care planning conversations occur in many contexts, with discussions about and the development of advance care plans occurring both within and outside the health service and care settings. Health service and care settings include aged care services (e.g. home care package services), registered aged care facilities, primary health care, outreach services, specialist services (e.g. specialist practices), palliative care services and hospitals (both publicly funded and private services).

People may also have advance care planning conversations outside a health and care service context. A person may choose to complete some or all of this process by themselves or with their family or substitute decision-maker. They may use specific resources available including online tools (e.g. 'MyValues', advance care planning websites) other resources, and written advance care planning guides.

Document

Advance care planning may result in one or more of the following documented outcomes:

- Appointment of a medical substitute decision-maker.

- 'A values based' advance care plan outlining the person's values and beliefs, and specific goals for care. This may include elements such as preferences for the site of care and spiritual care requirements.

- Written instructional directives specifying treatments wanted or not wanted. This may include detail regarding circumstances in which these treatments preferences are to apply.

Documentation may occur in a variety of formats, including:

- legislated documents (in Victoria): Refusal of Treatment Certificate, Medical Treatment (Enduring Power of Attorney) Act 1990, Medical Treatment Act 1988

- legislated documents from other Australian states and territories (Carter, Detering & Silvester 2015)

- other structured advance care planning templates

- other formats, such as a letter, written by the people themselves, or written by health professionals outlining the person's preferences.

Review

Review of advance care planning can take place at any time, and may occur within and outside the health service setting. This may be prompted by a change in health or personal circumstances, and may result in documentation of a new advance care plan. For many people, review of advance care planning may occur in settings different from where the original plan was developed or documented.

Activate

Activation of advance care plans can occur in a range of settings. Due consideration needs to be given to an advance care plan, whatever format this takes. It is important that a person's preferences be taken into consideration when medical treatment plans are developed.

Medical treatment plans

It is important that clinical care plans written by clinicians are consistent with the person's expressed values and preferences for medical care, including specific medical treatments, as documented in their advance care plan, or as articulated by the person themselves (or where appropriate) by their substitute decision-maker. Specific types of clinical care plans may be particularly relevant when the person has an advanced, incurable illness and/or frailty and where communication of urgent or semi-urgent decisions regarding life-sustaining treatments may be required. In the development of clinical care plans, doctors and others in the treating team need to understand and interpret possible medical treatment options in the context of the person's values and preferences for health care, and to discuss these with the person, or, where appropriate, the substitute decision-maker. Once determined, specific medical treatment decisions can then be documented on forms such as a 'Goals of Care' Form, a 'Medical Treatment Plan' or a 'Resuscitation Plan', or may be outlined in a letter written by the doctor.

The importance of advance care plan accessibility

The primary purpose of *Advance care planning: Have the conversation – A strategy for Victorian health services 2014–2018* is to enhance opportunities for people to develop advance care plans and for these to be activated in health services at the appropriate time (Department of Health 2014). Advance care plan accessibility is a pivotal component for successful advance care planning, as advance care plans need to be available at the point of care delivery, so they can inform medical treatment decisions if the person themselves is unable to participate in decision-making at that time. This is especially important when urgent treatment decisions are required, and when the substitute decision-maker is not available or is unsure of the detail in the advance care plan. The site of activating the advance care plan may be different from the setting in which it was initially developed or revised. Along the patient's journey, the advance care plan needs to be quickly and easily available so that medical treatment decisions reflect the person's preferences. Health professionals need to know who to speak to on behalf of an individual who lacks capacity. For most people, advance care planning is an ongoing process over time, so access to advance care plans at varying points of care is an integral part of the process, particularly if advance care planning is to be incorporated routinely into usual care in an efficient and effective way.

The Victorian advance care planning strategy (Department of Health 2014) outlines the following expected outcomes:

- Victorians are supported in using advance care planning to communicate their future healthcare choices.

- Health services approach advance care planning in a systematic way.

- Mutual recognition of advance care plans occurs across services and sectors along the person's care pathway.

- Advance care planning is integrated into routine health care.

- Preferences are known and respected after the person loses decision-making capacity.

- Clinical treatment plans written by clinicians are consistent with the person's expressed values and preferred care outcomes, as recorded in their advance care plan.

While outside the scope of this report, accessibility of care plans—such as medical treatment plans, resuscitation plans and goals of care documents, with specific information regarding urgent care decisions—is also warrants future consideration. This is especially relevant where there is sudden deterioration in a person with advanced illness where there is need for emergency assistance. To be most effective, these plans need to be available at the point of care. The principles relevant to accessibility of advance care plans will also apply to the accessibility of clinical care plans.

The principles of successful accessibility

Health services need the ability to store and access patient information in a timely and secure fashion. This includes advance care plans. Storage does not necessarily need to be on health services individual systems, but could rely on accessing information stored centrally.

The 11 Victorian Health Privacy Principles

The Victorian Health Privacy Principles are requirements that people and organisations who handle health information in Victoria must meet in order to comply with the law. Outlined in Table 1 is a summary of key information in the privacy principles for quick reference. Detailed information can be found in Schedule 1 of the Health Records Act.

Table 1: The 11 Victorian Health Privacy Principles

Collection	Sets out when data can be collected, what can be collected & by whom.
Use and disclosure	Sets out when data collected can be used, what for and when it can be disclosed to another party.
Data quality	Requires that data collected needs to be of good quality.
Data security and retention	Requires that data collected is securely held and retained for a certain period, depending on the type of data it is.
Openness	Sets out how organisations are to advise individuals as to what information they hold about a person and how it will be used.
Access and correction	Sets out the principle of the subject of the data (the person) having access to the record and being able to correct information that is held therein.
Identifiers	Explains how an organisation can assign identifiers to information in order to complete the functions of the organisation safely.
Anonymity	States that individuals must have the option of being anonymous when giving information to organisations where it is lawful and practical.
Trans-border data flows	Sets out the conditions under which information about a person that are health related can be transferred to another agency in another state.
Transfer/closure of health service provider	Applies to instances when a health practice or business of a health service provider is to be sold, transferred or closed down.
Making information available to another health service provider	Outlines responsibilities when an individual requests a health service provider to make health information relating to the individual held by the provider available to another health service provider.

Source: Adapted from *Health Records Act 2001*.

The risks of accessibility and the risks to accessibility

One common concern regarding the routine access to advance care plans is the need to protect a person's privacy. Thus a paradox occurs: on the one hand, there is a responsibility to respect and manage the person's privacy; on the other hand, there is a critical need for advance care plans to be readily available as required, understanding that this may occur at unpredictable times, in a variety of locations, and in locations that may be different from where the plan was created. Thus, careful consideration is required in the development of methodology that enables the ready access of information across clinical areas within organisations, across organisations, across settings, and across borders within Australia—while at the same time protecting the person's privacy.

Some issues regarding the importance of advance care plan accessibility will be further detailed in the literature review section of this report. In summary, concerns and debate relate to:

- the purpose and ownership of advance care plans and other documents such as clinical care plans

- who should own and be responsible for the broad range of medical information about a person

- the risk to privacy and confidentiality

- whether advance care plans should be included as part of a person's complete medical record, or whether they should be stored separately from of other medical information

- jurisdictions within Australia having different approaches to advance care planning implementation and legislation, and e-health records and digital health initiatives

- the difficulties with intra-operability of different systems and how best to overcome these

- how best to manage the costs of implementing e-health systems

- how to best support the community and health and aged care workers in gaining knowledge, training and access to e-health initiatives

- how to ensure a pragmatic approach to the e-health system for users

Advance care plan accessibility and key stakeholder responsibilities

There are many stakeholders who have important responsibilities in the processes of advance care planning. These responsibilities include the translating outcomes of successful advance care planning discussions into documents such as advance care plans and facilitating the accessibility of these plans.

The key stakeholders and a summary of their principal roles are outlined below:

- It is important that the **individual** has a copy of their most recent advance care plan, and informs relevant health professionals, substitute decision-makers and their family that they have an advance care plan; informs them of their preferences; and ensures the document is stored in a suitable location where it can be easily located. The person may choose to delegate these responsibilities to someone else, such as their substitute decision-maker or a trusted caregiver to assist them with these processes.

- The **substitute decision-maker** needs to be aware they have been assigned this important role, and that they understand what the role entails, and to ensure they are aware of the person's preferences, including their preferences for decision-making. They need to be willing to communicate the person's values and preferences when clinical care plans are being developed or activated if the person themselves is unable to, or chooses not to, make their own decisions. If the substitute decision-maker is not aware of the individual's values, goals and preferences for care, or if they are unclear about their role and responsibility, they need to be supported to obtain information about these factors.

- **Health and care staff** are key in raising awareness of advance care planning and assisting people with advance care planning discussions and documentation. This may include providing assistance to understand and document their specific goals, values and preferences for care, and to understand their current health situation and what options for treatment or care might be available. Doctors and other healthcare professionals have important roles in ensuring clinical care plans reflect the person's goals, values and preferences for medical treatment and care. Health and care staff need to be able to locate and activate advance care plans.

- **Healthcare and aged care organisations** also have key roles in supporting staff to undertake advance care planning conversations, assist people to complete documentation and ensure care delivered is consistent with the person's preferences. This requires having systems, policies/guidelines and staff training that support all aspects of advance care planning, including discussions, development of advance care plans and activation of plans when needed. For these tasks to be achievable, organisations also require clinical systems that can alert staff to the existence of advance care plans, and methodology to enable rapid access to advance care plans.

- **Governments** have important roles in policy and availability of funding and resources to support individuals, staff and organisations to perform their respective roles, and to support systems that facilitate accessibility of advance care plans. Given the mobile nature of the Australian population, there is also a need to consider mechanisms to improve accessibility and the ability to activate plans across state and territory borders within Australia, given that there is variation in legislation (Carter, Detering & Silvester 2015).

Part C: Advance care plan accessibility in Victoria

Accessibility of advance care plans is a recognised challenge for health services in Victoria. The following surveys were undertaken to investigate the current processes in place and views of key stakeholders and organisations in terms of advance care plan accessibility:

- Advance Care Planning in Victorian Health Services: Scoping Survey Results and Evaluation (AHACPD 2015a)

- Advance Care Plan Accessibility Survey for Health Organisations (AHACPD 2015b)

- Advance Care Plan Accessibility Survey for Consumers (AHACPD 2015c).

Results from each of these surveys are summarised below.

Advance Care Planning in Victorian Health Services: Scoping Survey Results and Evaluation

Following the release of *Advance care planning: Have the conversation – A strategy for Victorian health services 2014–2018*, a detailed scoping survey of Victorian publicly funded health services was completed (AHACPD 2015a). The survey was conducted during August–October 2014 and comprised 34 questions across the four key priority actions outlined in the strategy. Health services were asked a number of questions relating either directly, or indirectly, to accessibility of advance care plans. Questions broadly related to the following:

- mechanisms for sharing and receiving advance care plans

- external relationships health services have in place to support the implementation of advance care planning

- alert mechanisms currently implemented

- direct enquiry as to whether individuals have an advance care plan and/ or substitute decision-maker.

Results

Of the 84 health services that were approached, 78 (93 per cent) responded. This included all 14 metropolitan health services and 64 (out of 70) regional health services.

Service development

As outlined in Figure 2, health services reported they were at various stages of advance care planning service implementation. The majority of health services (51 per cent) were in the 'establishing systems' phase of service development, whereas as 17 per cent of respondents reported having advance care planning embedded into usual care within their organisation. Services, especially those more focused on earlier stages of implementation, may not have yet been ready to consider the issues related to accessibility in any detail.

Figure 2: 'How established is advance care planning across your health service?'

Category	Total (%)	Regional (%)	Metropolitan (%)
Initial planning phase	27	33	0
Establishing systems	51	48	64
Becoming part of usual care	35	31	50
Embedded into usual care	17	17	14
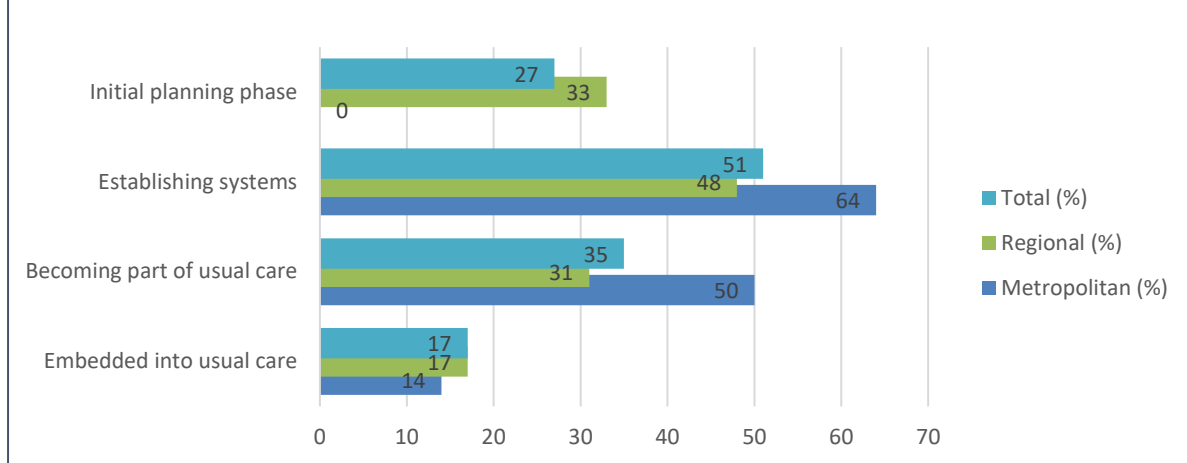
Source: AHACPD 2015a.

Sharing and receiving advance care plans

Seventy-eight per cent of health services reported that they advise their clients to provide copies of their advance care plans (or assisted them to do so) to the following (one or more):

- GP (72 per cent)
- RACF (59 per cent)
- substitute decision-maker (56 per cent).

While the majority of health services have implemented processes to assist with dissemination of advance care plans, some health services would still benefit from establishing processes to assist in this information sharing.

Relationships that support advance care planning implementation

Many health services reported having engaged in some external liaison in order to further progress advance care planning implementation.

- Forty-five per cent of health services had developed linkages with aged care facilities.
- Forty-one per cent of health services had developed linkages with primary care. Regional services reported increased primary care associations compared to metropolitan services.

'In the implementation phase our plan is to liaise with general practitioners and residential aged care facilities.' – Scoping survey respondent

'Initial conversations have occurred with Medicare Locals.' – Scoping survey respondent

- Twenty-five per cent of health services had engaged with Ambulance Victoria.
- Ten per cent of health services had liaised with tertiary hospitals to gain further guidance around service development.

Alert mechanisms currently in use

Health services identified a number of alert mechanisms in relation to advance care plans (refer to Figure 3). Seventeen per cent of health services identified no method for advance care plan alert, but the majority of health services had alert mechanisms in place, with the most prevalent method reported as being paper based.

Figure 3: 'What alert mechanisms do you currently use?'
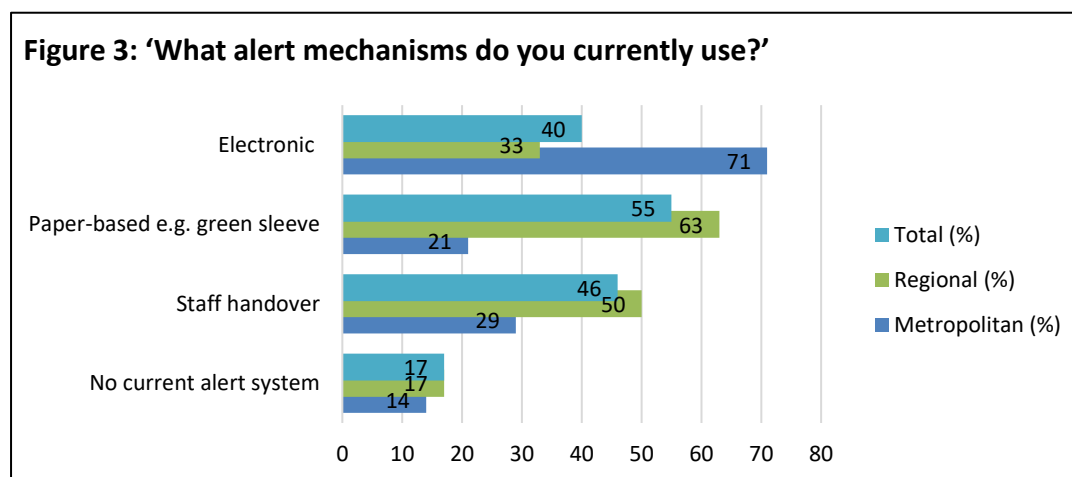
Source: AHACPD 2015a.

Direct enquiry as to whether there is an advance care plan or substitute decision-maker

Thirty per cent of services directly enquired whether the person has an advance care plan on admission. Some services are looking at mechanisms that would embed this as routine.

'We are looking at the feasibility of adding a question related to substitute decision-maker and advance care plan onto admission and discharge paperwork.' – Scoping survey respondent

'The limitation of treatment form has a question regarding the medical power of attorney.' – Scoping survey respondent

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Key findings: Advance Care Planning in Victorian Health Services: Scoping Survey Results and Evaluation (AHACPD 2015a)

- Accessibility is a recognised issue for health services across Victoria.

- The majority of Victorian health services reported that they were in the establishment phase of advance care planning service development.

- While the majority of health services had alert mechanisms in place, the most prevalent method was paper based.

- Many services are working with stakeholders, both internally and externally, to improve advance care planning processes, with plans in place to continue to strengthen these relationships.

- Health services included suggestions about how accessibility could be improved and have already independently investigated ways to improve accessibility within their organisations.

Advance Care Plan Accessibility Survey for Health Organisations

In 2015, a more detailed survey was conducted with health organisations to further investigate the accessibility of advance care plans in Victoria (AHACPD 2015b). This online survey comprised 22 questions pertaining to:

- current storage systems for advance care plans

- mechanisms for sharing, receiving and storing patient information, including advance care plans

- concerns (if any) related to accessibility of advance care plans

- suggestions as to how advance care plan accessibility could be improved.

Email invitations were sent to 84 Victorian publicly funded health services, one representative from the Ambulance Service, and two Royal District Nursing Service representatives. Advertisements were also posted in newsletters for Networking Health Victoria, Aged and Community Services Australia and Leading Aged Services Australia to target general practice, aged care facilities and community health and aged care services respondents. No private hospitals were included.

Results

Sixty-eight responses were received. Most (52) were from publicly funded health services (76 per cent), and included metropolitan and regional services. There was one response from Ambulance Victoria, and two responses from the RDNS. Other responses were from aged care facilities (five), GPs (two), community health services (two), after hours deputising services (two), a multipurpose service (one) and the Motor Neurone Disease Association of Victoria (one).

Current storage of advance care plans

Organisations reported using a variety of systems for storing patient information. Many reported more than one system in use:

- Eight (12 per cent) did not use any electronic systems.

- Twenty-seven (40 per cent) used paper-based systems, either alone or in conjunction with other systems.

- Twenty (29 per cent) had a scanned medical record.

- Two (3 per cent) services and Ambulance Victoria were able to access My Health Record.

- Forty-five (66 per cent) stated that their IT system allowed the uploading and storage of patient information including advance care plans.

- Organisations also reported variance in their systems regarding the storage of advance care plans. The majority of respondents relied upon paper-based records:

- Forty-five (66 per cent) stored advance care plans in their paper-based records.

- Twenty-six (38 per cent) stored advance care plans in their electronic record.

- Eleven (16 per cent) uploaded the plan directly into their IT systems.

- Five (seven per cent) reported they did not store advance care plans.

Receiving patient information from other health organisations

Sixty-three (93 per cent) respondents stated that they received patient information from other health organisations. The methods of information sharing varied between organisations:

- Fifty-seven (84 per cent) received information via fax.

- Forty-five (66 per cent) relied on the patient to provide information.

- Twenty-eight (41 per cent) received information via email.

- Fifteen (22 per cent) received information via secure messaging devices.

The most common patient information received from other health organisations were pathology results (65 per cent) and medical imaging results (66 per cent). Twenty-three (34 per cent) reported routinely receiving discharge summaries and only eight (12 per cent) received advance care plans.

How organisations find out if their patient has an advance care plan

A variety of different processes are implemented by organisations to determine whether patients have an advance care plan:

- Sixty (88 per cent) found out if their patient has an advance care plan by asking them.

- Forty-six (68 per cent) relied upon the patient to self-report their advance care plan.

- Thirty-three (49 per cent) used advance care plan alerts on their IT system. Only 23 (34 per cent) have the advance care plan stored on their health organisation's IT system.

- Sixteen (24 per cent) used discharge summaries to find advance care plans.

Sharing of patient information with other health services

Forty-eight (71 per cent) services reported that they notify other relevant health organisations of a patient's advance care plan. Methods used to assist with advance care plan dissemination included:

- Eighteen (26 per cent) used fax.

- Sixteen (24 per cent) used mail services.

- Thirteen (20 per cent) used phone calls or teleconference.

- Thirteen (19 per cent) used email.

- Eight (12 per cent) used secure messaging services.

The following health professionals and organisations are routinely notified of advance care plans:

- Forty-three (62 per cent) notified the GP.

- Thirty-two (47 per cent) notified the patient's local hospital.

- Twenty-one (31 per cent) notified Ambulance Victoria.

- Seventeen (25 per cent) notified specialists.

The following comment highlights the commitment to sharing, but also the challenge with lack of consistency in process for advance care planning document sharing:

'There is no current infrastructure to routinely share this kind of information—we try and just do the best we can.' – Accessibility survey respondent (health organisation)

Retrieval of advance care plans

Identified methods for retrieving advance care plans included via paper-based medical records, from the patient themselves, and from IT systems. In terms of ease of retrieval of an advance care plan, 45 (66 per cent) reported ease with retrieval, 20 (29 per cent) reported retrieval was somewhat difficult and three (five per cent) reported that it was very difficult.

'Hard to find in scanned medical records—as not always labelled or filed correctly, especially if the format of the document is not the one staff is used to.' – Accessibility survey respondent (health organisation)

'If we get the plan, it gets added to the system, and it is really easy to find it when needed.' – Accessibility survey respondent (health organisation)

Concerns related to the accessibility of advance care plans

Responses were analysed and common themes are summarised under the following headings.

Patient privacy and confidentiality issues

Forty-two per cent of respondents identified concerns related to issues with patient privacy or confidentiality.

'Confidentiality, security. We do not have secure email and use fax for a lot of things.' – Accessibility survey respondent (health organisation)

'We should be obtaining consent to send plans—if we haven't done this the patient misses out. We need a better system.' – Accessibility survey respondent (health organisation)

One respondent outlined the paradox between confidentiality and being able to have the plan available when needed:

'Well, confidentiality is important, but really, you need to be able to locate the plans, or otherwise what is the point?' – Accessibility survey respondent (health organisation)

Laborious and manual systems

Thirty-five per cent of respondents identified issues with the accessibility of advance care plans in relation to systems issues, processes and time required.

'Someone needs to decide how this is to be done. We can then make it happen. Currently we spend a lot of time trying to make it work, and we are all doing it differently.' – Accessibility survey respondent (health organisation)

'The systems are too complex; staff need simple solutions.' – Accessibility survey respondent (health organisation)

Multiple systems

Twenty-five per cent of respondents noted issues related to multiple IT systems and how this created confusion:

> *'We have multiple electronic systems that don't talk to each other.' – Accessibility survey respondent (health organisation)*

> *'The IT capabilities between the community and the hospital make it almost impossible.' – Accessibility survey respondent (health organisation)*

Organisations recognise the importance of advance care plan accessibility

Sixty-two per cent of respondents reported challenges with organisations recognising and responding to issues with advance care plan accessibility.

> *'Our organisation has a long way to go, sharing and receiving information electronically. This is the way of the future and will allow better clinical handover between the health services and other organisations/community GP.' – Accessibility survey respondent (health organisation)*

> *'Patients who need advance care planning the most (frail, elderly, chronic illness) are not used to taking control of their health care. We need to help them do this, and share their plans. They cannot be expected to do it all themselves.' – Accessibility survey respondent (health organisation)*

Suggestions for improving accessibility

Fifty (74 per cent) respondents provided suggestions for improving document accessibility, which included greater use of My Health Record, improved security, and standardisation of patient information. In addition, 23 (34 per cent) respondents endorsed the use of a universal system.

> *'There needs to be a centralised repository.' – Accessibility survey respondent (health organisation)*

> *'Secure electronic system that all service providers can utilise, including all GP practices.' – Accessibility survey respondent (health organisation)*

> *'Develop statewide guidelines for staff regarding sending and receiving advance care plans.' – Accessibility survey respondent (health organisation)*

> *'Standard naming and labelling across differing health settings so documents are easily recognised.' – Accessibility survey respondent (health organisation)*

Ambulance Victoria

The ambulance service stores information through the Victorian Ambulance Clinical Information System (VACIS) and My Health Record. VACIS is a computer-based patient data collection system linked to the service's data warehouse.

Ambulance Victoria reported it receives a limited number of advance care plans, usually via email, but these cannot be uploaded onto their system. Consequently, a summary of the plan is loaded onto the Computer Aided Dispatch system, which allows the information to be provided to the responding paramedics via the vehicle data terminal. The responsibility for providing the advance care plan is with the patients themselves. Ambulance Victoria noted difficulty with getting and uploading plans, making it hard to know if the plan is the most recent one, and also had concerns with how plans are linked to patients as evidenced by the following comment.

'The alert is tied to the address of the incident. If the patient is not at the address, we will not see mention of the advance care plan.' – Accessibility survey respondent (health organisation)

Limitations

While there was good representation from hospitals in the 68 survey responses, there are limited responses from GPs and RACFs. This is most likely related to the methodology used for the survey. As a result, the survey findings may not accurately reflect the views of these health services.

Key findings: Advance Care Plan Accessibility Survey for Health Organisations (AHACPD 2015 b)

- Accessibility is an issue for the majority of health services involved in this survey. Health services recognise the importance of accessibility and realise that improving systems will lead to better advance care planning.

- Many services have concerns related to privacy and confidentiality of advance care plans. This raises an interesting paradox in that if the plans are inaccessible, or private, they may not be available when required. This appears to be more of an issue for health professionals, rather than patients, when comparing the findings of the Advance Care Plan Accessibility Survey for Consumers (AHACPD 2015c).

- The current situation in Victoria is diverse, complex and inefficient. There are many different IT systems, with different capabilities and difficulties with interface. Many services have ad hoc processes, and services use various measures to attempt to overcome difficulties with the accessibility of advance care plans.

- Many services use paper forms, which leads to challenges including the time required for successful accessibility, and also concerns regarding confidentiality (i.e. fax, non-secure email). Difficulty with alert systems was also identified.

- Services offered suggestions for improvement. These included universal e-health systems, such as My Health Record, a central repository for advance care plans, or a Victorian health database.

- Health services are currently successfully accessing other patient information, most commonly pathology and radiology data. Advance care plans could potentially utilise existing systems and this could be explored further. Likewise, including advance care plans with discharge summaries would also likely improve accessibility.

Advance Care Plan Accessibility Survey for Consumers

Twelve patients who had previously completed advance care plans at Austin Health were contacted via telephone and asked to complete a 10-question survey relating to storage and accessibility of their advance care plans. Ten participants agreed to participate. Further recruitment did not occur given the majority of participants gave similar answers and it was felt unlikely that further helpful information would be obtained by more surveying (AHACPD 2015c). Responses from participants were grouped into the following themes.

Development of their advance care plans

The majority of respondents (nine) (90 per cent) reported a nurse had assisted them in developing their advance care plan, the remaining individual had an allied health professional assist them. Seven (70 per cent) also had a family member assist them in the process.

Location of their advance care plans

Participants stored their advance care plans in a variety of locations:

- nine (90 per cent) had a copy of their own advance care plan

- six (60 per cent) gave a copy to family (this included the person who did not own a copy of their plan)

- five (50 per cent) reported their power of attorney (medical treatment) had a copy

- one participant provided a copy to their GP.

Storage of advance care plans

Respondents stored their advance care plans in a variety of locations. Many of the documents were stored at their homes.

'With all my medical records in the back room.' – Accessibility survey respondent (consumer)

'Filed away in the spare room.' – Accessibility survey respondent (consumer)

Ease of ambulance officers locating advance care plans if necessary

Six (60 per cent) responded that ambulance officers would not be able to locate their advance care plans within their home. Only two (20 per cent) respondents stated that ambulance officers would be able to find their advance care plans.

Concerns about health professionals accessing their advance care plans

All respondents stated that they did not have any concerns about health professionals accessing their advance care plan. This response is at odds with concerns previously identified by health professionals regarding confidentiality and privacy.

Storage of advance care plans electronically for health professional access

All respondents stated that they would be happy to have their advance care plan stored electronically for all health professionals to have access.

Key findings: Advance Care Plan Accessibility Survey for Consumers (AHACPD 2015c)

- The majority of respondents had a copy of their advance care plan and more than half had shared this document with their family or appointed medical power of attorney.

- Patients may lack understanding of the need to make their plans more widely available. For example, only one respondent gave a copy to their GP and only two felt the ambulance service would be able to locate their plan.

- Patients did not have concerns about health professionals accessing their advance care plans and were happy for their plans to be stored electronically.

- Patients appear to lack information and awareness as to how to best share and store their plans. This could be an important area for future implementation to improve availability of plans.

Summary of Victorian findings

Victorian survey findings demonstrated a number of challenges impacting upon successful advance care plan accessibility within Victoria. Health services have different IT systems with different levels of capability, and often use multiple IT programs. This creates issues with access and intra-operability. Health services are also at different stages of implementation of advance care planning, with some not yet at the point of investigating methods for storing and sharing advance care plans.

Many organisations have developed their own systems and processes to ensure advance care plans are shared. Some services reported difficulties in achieving regular success with document sharing, including some services at more advanced stages of advance care planning implementation. Large numbers of organisations are using paper-based systems thus increasing the likelihood of errors and issues with confidentiality, especially when combined with fax as the method of sharing. Some organisations make it the individual's responsibility to ensure their GP, the substitute decision-maker, specialists, ambulance services and local hospitals receive a copy of their plan. This gives the person empowerment to manage their health care; however, this approach also relies upon the individual to understand their responsibilities and take the appropriate measures to disseminate their documentation. Given the population who may benefit most from advance care planning may need some assistance with these aspects, organisations may need to take a larger role in supporting advance care plan accessibility.

Many services are working with internal and external stakeholders to improve advance care planning processes. Services provided suggestions about how accessibility of advance care plans could be improved and some have independently investigated ways to improve access within their organisations. Suggestions included universal e-health systems, such as 'My Health Record', a central repository for advance care plans, or a Victorian health database.

Consumers routinely have a copy of their advance care plan; however, they do not consistently share documents with relevant parties or store documents in easy to find locations. This is concerning given organisations reliance upon individuala to disseminate their plans. Of particular note is the fact that consumers did not express concerns about health professionals having access to their advance care plan and were agreeable to having their documents stored electronically.

Part D: Evidence relating to advance care plan accessibility

A review of the literature and the environment

Advance care planning

Advance care planning literature universally acknowledges the need to share advance care planning information and to ensure the existence and content of advance care plans are accessible at the point of care (Lund, Richardson & May 2015; Sinuff, Dodek, You et al. 2015; Bernacki, Block & ACPTF 2014). Sharing of advance care plans is an identified issue within and between healthcare organisations (Lund, Richardson & May 2015; Mullick, Martin & Sallnow 2013), and robust e-health systems are an important mechanism to assist with the provision of timely and informed person-centred care (Lund, Richardson & May 2015; Bernacki, Block & et al 2014). Improvements in accessibility will come from information communication and technologies (Sinuff, Dodek, You et al. 2015; Bernacki, Block et al 2014; Green & Levi 2013; Chiarchiaro, Arnold & White 2015).

Despite the recognised need to share advance care plans, there is minimal literature regarding successful advance care plan accessibility. However, there is literature focusing on exchange of end-of-life plans (Lund, Richardson & May 2015; Bernacki,Block et al 2014; Green & Levi 2013; Schmidt, Zive & Fromme et al. 2014), and recommendations here are likely to be relevant for advance care plan accessibility. For example, in a 2014 literature review of communication about serious illness care goals (Bernacki, Block et al 2014), it was reported there was significant variation in the location and quality of the documentation available in e-health records, and specific recommendations were made regarding standardisation as a mechanism to overcome this issue. It is reasonable to conclude this would also apply to advance care plans.

Furthermore, there is also literature that considers the importance of a structured approach overall to advance care planning and to serious illness planning as a mechanism to improve care (Lund, Richardson & May 2015; Bernacki, Block et al Schmidt, Zive & Fromme et al. 2014; Scott, Mitchell, Reymond et al. 2013). An important component of these emerging recommendations include specific detail related to the routine sharing of information in a systems-based manner. As way of example, Lund et al. (2015) concluded that 'health care provider organisations need to find ways to make clear their commitment to identifying, recording, sharing and acting upon patient preferences and to explicitly embed these commitments into their own clinical governance procedures'. Despite this literature, and the intuitive nature of these recommendations, there is currently lack of an evidence base to support these specific recommendations.

International experiences relating to digital health

Electronic health records (EHR) have good representation in the literature. Most developed countries have some type of EHR system in place (Jolly 2011; NEHTA 2016). These systems are at various stages of development related a range of factors. Creating and introducing successful e-health policies is complex, and has and will continue to challenged challenge health services and providers. Introducing 'e' into health care requires significant adjustments within systems and the transformation of attitudes of all participants. Digital health policy implementation has been strongly shaped by the type of government institutions and policy frameworks of each country, as well as local health, social welfare, telecommunications needs and a variety of stakeholders.

Principles of e-health and how e-health facilitates advance care plan accessibility

An EHR, the digitalisation of health information, may be owned and updated by health services and staff, the person themselves (or their proxy) or both. Many EHRs also store uploaded documents. Potential benefits of EHRs generally (and more specifically for advance care planning) include:

- ease and timeliness of access compared to traditional paper-based files: EHRs are likely to facilitate transferability of advance care plans in an efficient manner

- improved legibility: typed information reduces likelihood of errors.

- avoiding duplication: information is readily available; alerts can notify existence of advance care plans, and the name and contact details of the substitute decision-maker

- increased prevalence of some interventions: computerised reminders on EHRs can increase interventions such as vaccinations, and potentially advance care planning

- data availability for measurement and quality improvement initiatives

- supported decision-making: clinical support tools and integrated e-planning tools could be used to assist the person to undertake advance care planning and complete documentation, and the outcomes could then be automatically uploaded into the person's EHR (e.g. My Values, My Directives). Prompts and tools to assist clinicians to develop clinical care plans that reflect the values and preferences outlined in advance care plans could also be developed

- continuity and improved quality of care (Green & Levi 2013; Menachemi & Collum 2011).

International experience of digital health implementation

Denmark (NEHTA 2016; Jolly, R. 2011)

Denmark is often cited as the shining example of digital health implementation. Under the Danish system, the Ministry of Health is responsible for policy and coordination of e-health, and two independent organisations provide national e-health infrastructure. One of these is a centralised healthcare data network which almost all primary care medical practitioners, all hospital physicians and all pharmacists have access. This national e-health portal, launched in 2005, provides a single point of access to healthcare services for citizens and healthcare professionals. The second Danish organisation develops, tests, distributes and ensures the quality of electronic communication and information in the healthcare sector. All Danish citizens have a unique personal ID, which is used for identification in all public registries, including health databases.

The Danish system began by getting some common components that were foundations of e-health systems, such as medication, laboratory results and discharge summaries. By focusing on these commonalities, the Danish system was able to standardise large volumes of daily transactions to create a critical mass in favour of the EHR.

Postulated reasons for the success of the Danish e-health implementation include that in Denmark the trust in federal government is high, and Danish citizens are IT savvy. Furthermore, the healthcare system is run by the public sector, and the Danish government placed a high priority on engaging doctors in determining the content of e-health records and setting the standards for data. This included quicker payment for physicians using EHRs, financial incentives to primary care for phone and email consultations. There was also strong engagement across sectors and specialities.

United Kingdom (NEHTA 2016; Jolly, R. 2011)

The National Programme for IT in the National Health Service was the largest public sector IT program ever attempted in the United Kingdom. Unfortunately, it was largely unsuccessful. The project experienced significant delays, had insufficient clinical engagement, gaps in stakeholder engagement and expectations, problems with technology and other implementation issues. The program ceased in 2011. The program failed to develop essential foundations such as governance, clinical coding, and standards of information system architecture, and failed to address key issues such as the required clinical transformation and key stakeholder engagement and collaboration.

More recently the focus in the United Kingdom has been on the Summary Care Record (SCR), which stores a limited range of data (current medication, adverse reactions and allergies) for all patients except those who opt out. GP practices are required to provide an automated upload of their summary information to the SCR or have plans to do this. As of June 2015, SCRs have been created for 96 per cent of people in England, with an opt-out rate of just 1.4 per cent.

United States (NEHTA 2016; Jolly, R. 2011)

In 2009 the *Health Information Technology for Economic and Clinical Health Act* (HITECH Act) was passed, and significant funding was provided aiming to encourage medical practitioners and hospitals to adopt electronic record keeping and sharing, and to facilitate patient engagement through patient portals. While the HITECH Act has likely increased EHR adoption, several barriers inhibit nationwide interoperability. These include: absence of a universal patient identifier in the United States; that electronic health information lacks structure and standardization, and therefore is not fully computable when accessed or received; differences in relevant statutes, regulations, and organisational policies; and that patient portals do not connect with multiple providers.

New Zealand (NEHTA 2016; Jolly, R. 20-11)

New Zealand's use of IT in healthcare is very high, and already has unique patient identifier, governed by a robust legal health information privacy code. In 2010 the National IT Board introduced a four-year program to build on proven successes carefully consider future achievable options. The program set implementation goals and deadlines for a regional approach rather than national targets. However, an independent review found that the landscape was diverse, with wide variation in the maturity of clinical information systems and approaches, and varied repositories for clinical information. In October 2015, the New Zealand government announced a decision to build a single national EHR, which will enable clinicians to view comprehensive information in one place.

Canada (NEHTA 2016)

Canada has a variety of e-health systems operating and no strategy to overcome issues with interoperability. There is no national strategy, no national patient identifier, and significant issues with multiple systems and approaches, leading to intra-operability issues. Patient access to personal medical records is not standardised and varies across jurisdictions and there has been inadequate involvement of clinicians.

In EHRs, authorised clinicians in more than one healthcare organisation can create and manage an individual's health-related information. Patient health records are patient-controlled tools, which allow patient access to health data, and they can manage and update this.

> **Summary of international experiences and common challenges with the implementation of EHRs (NEHTA 2016; Jolly, R. 2011; Laur 2015)**
>
> - Overcoming interoperability problems to ensure computer systems from different health sectors can communicate structured clinical information with one another. This can be challenging given the constant evolution of technology, and the availability of new and better products.
>
> - Lack of adequate IT resources, including hardware, IT staff, effective back-up systems.
>
> - Costs of implementation, time to manage and update, time required for training and support of staff.
>
> - Coding patient clinical information at the time of entry is critical.
>
> - Dealing with legal and practical concerns regarding privacy and confidentiality. Countries working on EHRs have all implemented legislation to protect confidential medical information (Laur 2015) and have promoted measures to prevent breaches in privacy. Furthermore, lessons should be learnt from other industries, such as the financial industry, where cloud-based tools allow easy access to information and have been shown to be secure (Chiarchiaro, Arnold & White 2015).
>
> - The need for protection of access, which results in increased user complexity for patients and providers such as the need to create and validate access via registration and PINs, which increase complexity and potentially reduce ease of user access.
>
> - Issues related to health professional and patient uptake, including the need to move culture from paper and process to digital.

E-health in Australia: A brief overview (NEHTA 2016; Jolly, R 2011).

E-health in Australia began in the 1990s and was seen as a way to overcome distance; ease pressures within the health system; and provide better, more flexible services, reduce duplication, reduce medical errors, and improve care for patients. However, early on, e-health was seen as 'add on' experiment, rather than part of usual care, with minimal uptake or engagement by health professionals or patients. Concerns regarding privacy emerged, implementation was fragmented, and there was minimal engagement from healthcare professionals or patients.

In 1999 the National Health Information Management Advisory Council was established, and coordinated collaboration between Commonwealth, state and territory governments and relevant health stakeholders. The focus of these efforts was on data protection; tailoring information and services to meet consumers' expectations for more information, choice and a greater say in their own health and wellbeing; and supporting clinical care by sharing information, to provide coordinated and more efficient health care.

In 2005, the Council of Australian Governments established the National E-health Transition Authority (NEHTA). The aims of NEHTA included the need for a national collaborative organisation to raise the profile of e-health in Australia, to provide national coordination of Australian e-health initiatives, and to develop policy, infrastructure, stakeholder relationships and partnerships, and training, support and change management strategies for successful e-health implementation.

Following the Australian Government commissioned review of the Personally Controlled E-Health Record (PCEHR) (Department of Health 2013), a new agency, the Australian Digital Health Agency, was established and commenced operations on 1 July 2016. The agency is the single accountable organisation for digital health services, systems and governance in Australia. This included the transition of relevant activities and resources from NEHTA, and also from the national My Health Record system operation activities managed by the Department of Health.

Health*Connect* 2004–2009 was established and informed foundations, infrastructure and policy. Health*Connect*, a national change management strategy of state- and territory-based projects, was endorsed by Australian health ministers. This project aimed to improve safety and quality in health care by improving access to key health information at the point of care through the use of electronic communication.

Some of the individual Health*Connect* projects have led to significant evolutions in the way e-health has been incorporated into policy and practice today. These include: NSW Healthlink, MyEHR (NT) and My Health Record.

NSW Healthlink

This Health*Connect* initiative bought together summaries of health information from GPs, hospitals and community health centres into one secure computerised record. Consumers could opt out if they wished. This project was able to demonstrate a repository could bridge an information gap between tertiary and primary care in NSW and provided actionable lessons for an 'opt-out' approach and consent process for sharing of health information.

HealthConnect NT: MyEHR

MyEHR is an example of a successfully implemented shared EHR system that has become embedded as a tool in the delivery of health care. Lessons from the Northern Territory's experience have informed national initiatives. The Northern Territory is leading the country in cross-sector information exchange and provider experience using e-health solutions in the delivery of care, and evaluation of the MyEHR has shown efficiency and health outcome benefits.

My Health Record

The Australian Department of Health has operated the PCEHR since July 2012. In January 2016, it was renamed My Health Record. It is an online summary that allows healthcare providers and hospitals to view and share an individual's health information.

E-health systems have been in place within Australia for more than 10 years, with these initially led by the NEHTA, and more recently (since 1 July 2016) by the Australia Digital Health Agency. The 2008 National eHealth strategy, 2009 National eHealth partnership agreement and 2012 Memorandum of understanding signed by all Australian governments have guided these efforts. Changes to the My Health Record legislative framework were made in November 2015 through the *Health Legislation Amendment (eHealth) Act 2015* (Cwlth).

Australia's main initial focus has been on accelerating digital health through national leadership and infrastructure and solving interoperability challenges. Last decade, NEHTA developed standards for patient and provider identifiers, interoperable systems between providers, secure messaging and clinical and medicines terminology sets. During this time, the national digital health record was offered to consumers on an opt-in basis. A key feature of the national EHR is that people are able to control what details are stored and decide which health providers can view or add to their files.

The 2013 independent review of PCEHR (Department of Health 2013) demonstrated that while stakeholders positively endorsed the digital national infrastructure, uptake and utilisation of the EHR has been slow. In May 2015, less than 10 per cent of Australians had an EHR, and despite over 90 per cent of general practices maintaining computerised patient records, many did not utilise the PCEHR. The review made a number of recommendations to improve the uptake and use of the EHR.

In 2015, the Australian Government committed further funding to the EHR system and announced changes. These included changing the name from PCEHR to My Health Record, improving the usability of the system, increasing the clinical content in records, reviewing existing incentives to encourage use, refreshing training materials for healthcare providers on how to use the system and trialing new participation arrangements for individuals, including an opt-out system for consumers. As part of this final initiative, in mid-2016, approximately one million people living in North Queensland and the Nepean Blue Mountains of New South Wales region had a My Health Record created (unless they opted out). Table 2 outlines information in My Health Record.

Table 2: Information that can be added and accessed in My Health Record

Through their clinical information systems, GPs can:	• **View hospital discharge summaries** • **View specialist letters** • **View and add medications** • **View an Event Summary contributed by another doctor** • **<u>View a person's Advance Care Plan</u>** • **Add a Shared Health Summary** • **Add an Event Summary**
Through their patient administration systems, hospitals can:	• View medications • View Shared Health Summaries • View and create specialist letters • View Event Summaries • <u>View a person's Advance Care Plan</u> • Add hospital discharge summaries
Individuals can:	• View their Shared Health Summary and other health documents in their record • View Medicare or PBS claims • Add important information on allergies • Add emergency contact details • Add other medication they are taking • <u>Add an Advance Care Plan</u> • Set access controls

My Health Record Statistics

As of 27 February 2017 (Department of Health n.d.), over 4.6 million people have a My Health Record, with one new record being created every 38 seconds. This represents approximately 19 per cent of the Australian population. Of those registered, 54 per cent are female. There is variation by state, with Victoria having the equal lowest per cent of the total population (refer to Table 3). Of those aged 65 or older, 16 per cent have a My Health Record. There are 794 'Advance Care Planning Documents' and 12,609 'Advance Care Directive Custodian Reports' in the system.

Table 3: My Health Record (as at 27 February 2017)

State/Territory	% Population
Australian Capital Territory	22%
New South Wales	20%
Northern Territory	19%
Queensland	26%
South Australia	17%
Tasmania	19%
Victoria	14%
Western Australia	14%

Key Australian e-health achievements

Key national e-health foundations and solutions have been implemented to provide ongoing support for digital health adoption, including My Health Record, usage and innovation in Australia (NEHTA 2016). These are discussed below.

Healthcare identifiers (HI) and the HI service

The *Healthcare Identifiers Act 2010* (Cwlth) has facilitated progress as it provides a way of ensuring that an entity that provides, or an individual who receives, health care is correctly matched to health information that is created when health care is provided. A unique identifying number is assigned to each healthcare provider and healthcare recipient. In order to protect a person's privacy, and to reduce the risk of 'function creep', the legislation provided 'that the use of healthcare identifiers would be limited to functions associated with the delivery of a healthcare service'. There is also a very strict audit trail so that any individual can know that someone has accessed their record in the system.

There are three types of healthcare identifiers:

- Individuals: Individual healthcare identifier (IHI)

- Healthcare provider: Individual (HPI-I)

- Healthcare provider: Organisation (HPI-O)

Authentication

The National Authentication Scheme for Health allows consistent, reliable authentication of all registered healthcare participants connecting to the national infrastructure. The national scheme and healthcare identifiers ensure appropriate access to patient information and ensure newly acquired patient information is matched correctly with existing patient records.

National e-Health Security and Access Framework

The framework provides standards, tools and guides for the Australian healthcare sector to build and implement secure systems that protect patient data. This is important for ensuring patient safety and privacy, which is pertinent to the sharing of health data.

Secure messaging

Secure messaging specifications support interoperability between commercial vendors. This is intended to allow a provider using one type of software to receive a message from another provider using different software. A clinician using any system that conforms to the secure messaging standards can read documents using standard terminology and structured according to these specifications and sent via secure messaging. Communication directly between clinicians, hospitals and other healthcare professionals can now be done securely and electronically using national standards, specifications and infrastructure. Adoption of this specification has progressed but more slowly than anticipated, and there is variation across Australia.

Specifications for structured clinical documents and interoperability

Specifications define how commonly used documents in clinical settings should be structured so that data items can be broken down into their discrete component parts, accessed and shared in other systems. These clinical documents include hospital discharge summaries, electronic referrals and specialist letters. Specifications were developed through extensive consultation with healthcare providers, consumers, government and software vendors. This is supported by clinical terminology—standard terminology facilitating the safe exchange of information.

Additional clinical documents identified in My Health Record systems include shared health summary, event summary, and consumer entered information such as location and custodian of an advance care directive. There is a potential in the future to include other documents such as clinical care plans, goals of care documents and medical treatment plans to this section, whereby plans for urgent clinical deterioration would be readily available.

Part E: System options

Environmental scan of mechanisms to support accessibility

A limited environmental scan was performed from mid- to late-2015 to identify and consider existing mechanisms that might facilitate advance care plan accessibility in Victoria, or to assist with future work in this area. This included in Victoria, Australia and internationally (AHACPD 2015b).

The scan aimed to investigate existing systems and processes, to identify mechanisms or elements that could support the accessibility of advance care plans across the broad service system, including hospitals, Ambulance Victoria, RACFs, general practice, other doctors, nursing services and consumers. Consultation with some developers and users enabled a more complete understanding of the system functions, to identify enablers and barriers and consider possible risks, technical issues and cost estimates associated with each mechanism.

As part of the scan, strengths, weaknesses, opportunities and threats (SWOT) analysis was made for each option. These investigations did not include access to IT staff. A detailed discussion of these options from a cost and IT implementation perspective was outside the scope of this report.

A total of 16 options were investigated, including international, national and local programs. They included a mix of manual and e-health options. Many of these options included considering advance care planning separate from more detailed health information.

The options were divided into two groups: personal responsibility options and system options.

Personal responsibility options

These are options that the individual consumer would be primarily responsible for, and could participate in, without assistance of (at least potentially) healthcare providers.

Eight options were identified (refer to Appendix A):

1	My Health Record	5	Better Health Channel
2	Australian Organ Donor Register	6	Yellow Envelope
3	My Directives	7	Substitute decision-makers as custodians
4	Alert Card and USB	8	Mobile phone apps

System options

These are options where the key responsibility sits with the healthcare professionals to facilitate the process. Eight options were identified (refer to Appendix B):

1	Coordinate My Care	5	Referral Net
2	Medicare	6	Service coordination tool template (SCTT)
3	The Viewer	7	Cerner
4	Secure messaging systems (Argus)	8	cdmNET

The SWOT analysis did not identify a preferred option for ease of access to and transfer of advance care plans. No clear advantage has been demonstrated for any particular personal or system option.

During the development of this summary options paper, the Australian Government announced there was to be continuation of the personally controlled EHR, (My Health Record), with key changes as outlined in the 'E-Health in Australia' overview section. Considering previous and planned federal government investment, it is pertinent to further explore My Health Record as the preferred option over others at this juncture. The potential advantages now appear to outweigh the other options considered in this paper. However, challenges to using My Health Record for advance care plan accessibility also need to be considered, assessed and addressed.

The following section considers why the Victorian Department of Health and Human Services should explore My Health Record as a preferred option for storage and, accessibility of advance care plans and related documents.

My Health Record: rationale for preferred option

It has become clear over the course of developing this summary options paper that e-health or digital health is the direction that the government and health sector is rapidly moving towards. The Australian Digital Health Agency is developing a national digital health strategy to improve health outcomes. The agency is responsible for all national digital health services and systems, focusing on engagement, innovation and clinical quality and safety. This includes development and improvements to My Health Record platforms.

In its *Corporate Plan for 2016–17* (February 2017), the Australian Digital Health Agency outlines a clear desire for consumers and health professionals to inform the strategy in relation to My Health Record. Consumer and health sector consultations have heard from advance care planning champions in Victoria who have suggested (and advocated for) more user-friendly My Health Record processes to upload advance care plans and related documents and create alerts.

Furthermore, the Australian Digital Health Agency is working to incorporate other vital elements of a person's medical information in My Health Record. For example, My Health Record is being considered as the repository for pathology and radiology results, medication, hospital discharge summaries, and other clinical summaries. There is an opportunity for Victoria to advocate for advance care planning documents as an equally vital component of an EHR and recommend that the Australian Digital Health Agency include advance care plans in My Health Record. This is more logical than developing a separate electronic entity that only stores advance care plans.

My Health Record uptake

At 23 March 2016, approximately 11 per cent of the Australian population had active digital records and 8,139 organisations were registered to use My Health Record (mostly general practices and pharmacies). Systems utility continues to progress as more people register for a digital record, more provider organisations connect, and clinical content flows into the system. As of February 2017, approximately 19 per cent of the population (4.6 million people) had registered for a My Health Record. The uptake of My Health Record is likely to continue to progress, particularly with the 'opt out' approach being progressively investigated and implemented. Utilising more commonly available and immediately relevant documentation such as medications, pathology and radiology results, and discharge summaries, may provide important levers for health services and healthcare providers in the uptake of the My Health Record, and facilitate uptake and access of equally important aspects of care such as advance care planning, and advance care directives.

Current situation: Victoria

The ability to upload an advance care plan into My Health Record is not widely understood and is not frequently done by consumers, health professionals and health services (Fullarton 2017).

What can consumers do?

Consumers are able to upload a PDF copy of their advance care plan to My Health Record. To upload an advance care plan document to My Health Record, a moderate to high degree of computer literacy is required.

The population targeted to complete advance care plans includes older Australians, who may or may not have computer literacy.

Many consumers do not have a My Health Record, although if My Health Record becomes opt-out rather than opt-in this will change.

What can health services do?

If health services are able to communicate with My Health Record (i.e. they are registered as an HPI-O), they can transmit discharge summaries and copies of specialist letters to My Health Record. However, they are unable to transmit advance care plans into the patient-held advance care plan section of My Health Record. In addition, only 14 per cent of health services in Victoria are currently able to transmit documents to My Health Record. The figure is much higher in other states (e.g. 100 per cent in Queensland) (Department of Health n.d.). Hospitals can view advance care plans created by patients, add discharge summaries and specialist letters. If aspects of advance care planning form part of the discharge summary or specialist letter, they will not be flagged as an advance care plan or generate an advance care planning alert.

What can primary care/GPs do?

GPs can view a patient's advance care plan but not create one. They can view and create event summaries and shared health summaries. If aspects of advance care planning form part of the shared health summary, they will not be flagged as an advance care plan or generate an advance care planning alert.

Summary of current situation in Victoria

1. Uptake of My Health Record in the community is low. This will be improved by the plans to make My Health Record 'opt out' rather than 'opt in'.

2. Awareness of consumers' ability to upload advance care plans into My Health Record is low.

3. For a consumer to upload a document takes moderate to high computer literacy.

4. The ability of healthcare providers to upload any health information to My Health Record is currently low. Usual work flows do not include checking My Health Record for an advance care plan. However, from March 2018, when the Medical Treatment Planning and Decisions Act takes effect, under Section 98 – Record Keeping Requirements (p. 73) the *'operator of a health facility must take reasonable steps to ascertain whether either of the following is in force in relation to any patient in the facility: a) an advance care directive (b) an appointment of an appointed medical treatment decision maker or a support person'.* This will be an incentive for health organisations to improve the connectivity to My Health Record in Victoria and seek information about advance care directives and substitute medical decision-makers.

5. Currently all publicly funded health services are required to report the number of advance care plans

and appointments of substitute decision-makers to the Department of Health and Human Services via the Victorian Admitted Episodes Dataset and the Victorian Integrated Non-admitted Health dataset. This also provides an incentive for organisations to improve their own internal administrative and patient management systems and explore how to make connections with systems such as My Health Record, which has capacity to provide information regarding advance care planning that has occurred elsewhere in the health system.

6. Health services are not able to upload an advance care plan to My Health Record and have it identified as an advance care plan. This could be remediated if Australian Digital Health Agency produced an advance care plan template as part of the clinical documents section (under discussion).

Part F: Recommendation

The department should identify My Health Record as the recommended platform for accessing advance care plans and substitute medical decision-maker documents for health professionals and consumers.

The following considerations would help to progress this recommendation:

1. Support My Health Record as the preferred option for enabling access to advance care planning documentation for Victorian health services and consumers/patients.

2. Undertake foundation work to identify issues and barriers to operationalising the implementation of advance care plans within My Health Record within and across health services, including:

   a. Map and describe the current system: map the end-to-end process within a health service for identifying, recording, storing and retrieving advance care planning information from triage and at all points of entry into the health service to:

      i. understand the business process

      ii. identify necessary process and practice changes so that advance care planning information is available across the health service.

   b. Work with health services to map this for their own service, acknowledging different systems in use.

   c. Understand the potential of existing systems to interface/integrate with My Health Record.

   d. Identify opportunities and barriers to My Health Record interoperability.

3. Develop an implementation plan to support health services operationalise their interface with My Health Record.

4. Consider system access to other clinical items that inform medical decision-making that align with a patient's values and wishes such as medical treatment plans, goals of care documents, resuscitation status.

Further considerations to progress this recommended option include the following:

Australian Digital Health Agency

Explore options for working with the Australian Digital Health Agency regarding improved processes for healthcare providers and consumers/patients to develop and upload advance care planning documents into My Health Record.

Explore HL7 mechanisms that can transfer advance care plans/directives into My Health Record.

Explore smartphone applications (apps) that may have potential to transfer advance care plans/directives into My Health Record (e.g. Healthi, My Child's e-health Record).

Explore options that consumers could use to develop advance care plans that could then be automatically uploaded into My Health Record (e.g. 'MyValues', My Directives').

Explore options for the Australian Digital Health Agency to increase consumer e-literacy in relation to My Health Record.

Legislation

- Consider and allay health professional legislative concerns regarding privacy and confidentiality in relation to accessing and viewing advance care plans using My Health Record.

- The Department of Health and Human Services should include the following content in preparing education forums for required practice changes as a result of the Medical Treatment Planning and Decisions Act:
  - ensure that Section 50 and other relevant sections are included education
  - include My Health Record in content as a resource for identifying presence of advance care plans and substitute decision-makers
  - consider changes required in health practitioner workflows for health professionals to use My Health Record to view advance care plans and substitute decision-maker appointments.

Consumers/patients

- Explore options for engaging with patients in Victorian health organisations regarding the benefits of registering for My Health Record and uploading advance care planning documents.

- Develop resources to assist consumers to upload their advance care plans into their My Health Record (e.g. printed resources, website information, YouTube video).

Appendix A: Personal responsibility options

Option	Description	Country	Strengths	Weaknesses
My Health Record (formerly known as PCEHR)	A secure online summary of a person's health information. It can be accessed by the person themselves, others the person nominates, healthcare providers and hospitals. Thus, it can be used to view and share an individual's health information, including diagnoses, investigation results, allergies and medications. Advance care plans can be uploaded and shared, but these must be uploaded by the person or their proxy.	Australia	A national system available to all Australians There is government funding supporting uptake by consumers and healthcare providers, including the need for ease of access for all healthcare professionals and the consumer Governance structures are in place Issues related to privacy have been addressed Has the potential to significantly improve issues regarding accessibility of a range of healthcare information including advance care planning Already has capability to load advance care plans Can store substitute decision-	Current opt-in enrolment Current consumers need to upload plans No current mechanism for healthcare providers to upload advance care plans Complexity of enrolment for elderly and pending IT capabilities Complexity of enrolment for healthcare providers/organisations Lack of functions currently Difficulties in uploading capabilities

Option	Description	Country	Strengths	Weaknesses
			maker details	
			Opt-out options being trialed	
			19 per cent of Australians currently have a My health Record	
Australian Organ Donor Register	A national network of DonateLife agencies and hospital-based medical and nursing specialists provide a coordinated approach to organ and tissue donation for transplantation. The organ and tissue authority is an independent authority that leads DonateLife.	Australia	Web-based central repository – the donor registry is in place Has significantly improved issues around accessibility of information regarding potential organ donors Easy access for all healthcare professionals and the consumer Similar interjurisdictional qualities and governance structure Potential for a national auditing system	Current opt-in enrolment Complexity of enrolment Very few people allowed to access the register Does not include other health information
My Directives	An online advance care planning service that is secure, legal, easy to understand, and free to consumers to use. Accessible by health professionals and consumers.	Developed in US however international options	Universal system Web-based Mobile app Patient-centred Provides educational	Free service to consumers, but significant cost to services Medical Enduring Power of Attorney must register before being able to access advance care planning documents

Option	Description	Country	Strengths	Weaknesses
			resources 24/7 worldwide usability Ability to also load video messages	Does not link with other health information Only includes Do Not Resuscitation Forms
Alert card and USB	Alert cards can be used to alert health professionals/other individuals of a number of different health conditions. The alert card is kept with the patient so they can produce it at any point of care. Includes details such as personal details, Medical Enduring Power of Attorney details, emergency contact, and GP.	Australia	Easy/quick to develop and implement Relatively cheap compared to changing IT systems	Dependent on consumer to remember to inform all relevant health professionals Reliant on health professionals/family member to find alert card and USB if consumer cannot communicate It is a manual system – there is not central storage of information, so if card / USB is absent – do not know if present or not Not able to extract data onto other systems
Better Health Channel	Website providing health and medical information that is quality assured, reliable, up to date, easy to understand, regularly reviewed and locally relevant. It has a rigorous quality assurance and approval process to ensure information is evidence based and reflects current best practice.	Australia	Potential opportunity for storage of educational material to view or download (e.g. video clips, advance care planning forms, kit, documents in languages other than English)	Privacy issues regarding patient information will need addressing Does not link into systems Not part of integrated health information

Option	Description	Country	Strengths	Weaknesses
Yellow Envelope	A communication tool that assists staff of RACFs, Non-Emergency Patient Transport, Ambulance Victoria and hospitals to provide relevant medical information about patients transferred between hospitals and RACFs.	Australia	Advance care plan checklist already in place on the envelope Compact Short-term fix Quick and easy to implement	Paper-based system Manual Slower than IT transfer Likely to have minimal impact for acute health
Substitute decision-makers as custodians	The Victorian Office of the Public Advocate (OPA) has promoted the rights, interests, and dignity of people with disability living in Victoria. The Public Advocate, OPA staff and more than 900 volunteers provide guardianship and advocacy services for people with disability.	Australia	The educational aspects of the OPA would be useful for SDMs The resources developed by OPA for substitute decision-makers can be used as a guide when considering options for substitute decision-makers	Relies on substitute decision-maker to be available, and knowledgeable, and remember to bring advance care plans Not everyone will have a substitute decision-maker Manual system, and likely to be labour intensive for staff in different locations
Mobile phone apps	Apple iPhones have a 'medical ID' option that is a record of important personal health-related information in the event of an emergency. A number of health-related apps exist that allow for storage of medical information and could be adapted to advance care planning information.	Australia	Easily accessible health information Portable device that can be carried by the individual	iPhone is limiting because it only covers small portion of the market Cannot be a central repository Costs likely to be high to develop further Not linked to broad health information

Appendix B: Systems options

Option	Description	Country	Strengths	Weaknesses
Coordinate My Care	A web-based electronic end-of-life system holding immediately accessible information about an individual's advance care plan and other medical information, which is available to a wide range of relevant professionals.	United Kingdom	Only needs internet access for users Central repository for all advance care plans Flagging device within software for emergency services Ease of authorisation	Cost to implement unknown Not linked to other medical information Consumers may not be able to load documents
Medicare	Medicare is Australia's universal health scheme. It is an Australian Government program that guarantees all citizens (and some overseas visitors) access to a wide range of health services at little or no cost. Could develop a similar program based on the principles of the National Bowel Cancer Screening Program and adapt for advance care planning.	Australia	Limits risk of losing hardcopies Significantly improves issues around uptake of advance care panning Easy access for all healthcare professionals and the consumer Can be a national program National auditing system	No central storage for advance care plans Costs related to secure access by consumers, large number of healthcare professionals No mechanism to alert existence of advance care plan
The Viewer	A web-based app that displays key information from a number of Queensland Health clinical and administrative systems and from the national PCEHR.	Australia	Access to patient information held in the national My Health Record Access to patient information from clinical systems at a variety of facilities	Prolonged amount of time to implement Very costly to develop Ongoing costs for maintenance, support and improvements Duplication of efforts of My

Option	Description	Country	Strengths	Weaknesses
			Significantly improves issues around transferability	Health Record
Secure messaging systems (Argus)	Encryption software packages that facilitate secure electronic communication of patient-related information between healthcare providers. For practitioners with a patient management system or clinical software, electronic correspondence can be viewed and filed electronically against a patient file.	Australia	Allows secure transmission of information	Facilitates transmission, but is not a central storage Does not link other medical information
Referral Net	A secure message delivery system for the exchange of confidential clinical and patient information. It includes referrals, reports, pathology and radiology requests and results, and discharge summaries.	Australia	Secure and reliable Eliminates the need to scan reports and results Eliminates the need to fax or post referrals Reduces costs associated with manual processing Integrates with clinical systems A centralised Cloud version is available Compliant with all specifications required to assist interoperability with other messaging vendors Strong audit and reporting facilities	Does not link to other health information Would need to ensure the person themselves could access and update their information

Option	Description	Country	Strengths	Weaknesses
Service coordination tool templates (SCTT)	A suite of templates developed to facilitate and support service coordination. The SCTT support the collection and recording of initial contact, initial needs identification, referral and coordinated care planning information in a standardised way.	Australia	Successful referral system for service coordination Existing widespread mechanism Embedded in GP settings	Lack of linkages with hospitals Variable implementation Need to pay for upgrades of software No ability to store information centrally
Cerner	A patient management system operating at more than 18,000 facilities worldwide. Provides a wide range of services to support the clinical, financial and operational needs of organisations of every size.	Australia	Large patient management system with a good functionality System already in use within some larger Victorian health services	Can only send patient information to others if they have HL7 (a set of international standards for transfer of clinical and administrative data) Cannot upload documents to discharge summaries (e.g. advance care plans) Only accessible by healthcare professionals
cdmNET	An online patient-centric care management tool for healthcare providers and patients that enables better management and coordination of care. In use by over 25,000 registered health professionals, 50,000 patients, major GP corporates, included in 19 of the 31 primary health networks, and used by Victorian, West Australian and New South Wales governments.	Australia	Cost-effective, accessible anywhere, anytime Manages the full advance care plan lifecycle from adoption through to storage and retrieval through to follow-up, review, and update Infrastructure is proven and already in use for major programs nationally,	Requires internet access (though possible to cache on download) Costs to extend service to all services Costs to facilitate people to upload advance care plans

Option	Description	Country	Strengths	Weaknesses
			including the Victorian Government	

Abbreviations

ACPA	Advance Care Planning Australia
ACPTF	American College of Physicians High Value Care Task Force
AHACPD	Austin Health Advance Care Planning Department
GP	general practitioner
EHR	electronic health record
HI	health identifiers
HL7	a set of international standards for transfer of clinical and administrative data
HPI-I	Healthcare provider: Individual (HPI-I)
HPI-O	Healthcare provider: Organisation (HPI-O)
IHI	Individuals: Individual healthcare identifier (IHI)
IT	information technology
NEHTA	National E-health Transition Authority
OPA	Office of the Public Advocate
PCEHR	Personally Controlled E-Health Record
RACF	residential aged care facility/ies
RDNS	Royal District Nursing Service
SCR	summary care record
SWOT	strengths, weaknesses, opportunities and threats
VACIS	Victorian Ambulance Clinical Information System

Glossary

Advance care directive: A way of formally recording an advance care plan. An advance care directive is a type of written advance care plan recognised by common law or authorised by legislation that is completed and signed by a competent adult. An advance care directive can record the person's preferences for future care and appoint a substitute decision-maker to make decisions about health care and personal life management (Department of Health 2014).

Advance care plan: Is made by a competent person and supported by legislation or common law. It records directions about medical treatment, appoints a substitute decision-maker, and states preferences about health and personal care, and preferred health outcomes (Department of Health 2014).

Advance care planning: The process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known so they can guide decision-making at a future time when that person cannot make or communicate their decisions (Department of Health 2014).

Health service: In Victoria, these include:

- publicly funded health services
- private hospitals and services
- primary care providers, particularly GPs
- community providers, including primary care organisations
- aged care providers
- ambulance services.

References

Advance Care Planning Australia (ACPA) 2017, ACPA, Melbourne, viewed March 2017, <http://advancecareplanning.org.au/advance-care-planning>.

Austin Health Advance Care Planning Department (AHACPD) 2015a, *Advance care planning in Victorian health services: Scoping survey results and evaluation*, Austin Health, Melbourne.

Austin Health Advance Care Planning Department (AHACPD) 2015b, *Advance care plan accessibility survey for health organisations*, Austin Health, Melbourne.

Austin Health Advance Care Planning Department (AHACPD) 2015c, *Advance care plan accessibility survey for consumers*, Austin Health, Melbourne.

Australasian Legal Information Institute. Health Records Act 2001, Schedule 1. The Health Privacy Principles. Viewed July 2017.
http://www.austlii.edu.au/au/legis/vic/consol_act/hra2001144/sch1.html

Bernacki, RE, Block, SD & American College of Physicians High Value Care Task Force (ACPTF) 2014, 'Communication about serious illness care goals: A review and synthesis of best practices', *JAMA Internal Medicine*, vol. 174, no. 12, pp. 1994–2003.

Carter, RZ, Detering, KM, Silvester, W, et al. 2015, 'Advance care planning in Australia: What does the law say? *Australian Health Review,* 16 November.

Chiarchiaro, J, Arnold, RM & White, DB 2015, 'Reengineering advance care planning to create scalable, patient- and family-centered interventions', *Journal of the American Medical Association*, vol. 313, no. 11, pp. 1103–4.

Department of Health n.d., Department of Health, Canberra, viewed February – April 2017, https://myhealthrecord.gov.au

Department of Health 2013, Department of Health, Canberra, <https://health.gov.au>.

Department of Health 2014, *Advance care planning: Have the conversation – A strategy for Victorian health services 2014-2018*, State Government of Victoria, Melbourne, viewed June 2017, <http://www.health.vic.gov.au/acp/strategy>.

Fullarton, S 2017, *My Health Record ACP transferability. Advance Care Planning Australia. Austin Health, Melbourne*,

Green, MJ & Levi, BH 2012, 'The era of "e": The use of new technologies in advance care planning', *Nursing Outlook*, vol. 60, no. 6, pp. 376–83.

Jolly, R 2011, *The e health revolution—easier said than done*, Social Policy Section, Parliament of Australia, Canberra.

Laur, A 2015, 'Fear of e-Health records implementation?', *Medico-legal Journal*, vol. 83, no. 1, pp. 34–9.

Lund, S, Richardson, A, May, C 2015, 'Barriers to advance care planning at the end of life: an explanatory systematic review of implementation studies', *PloS One*, vol. 10, no. 2.

Menachemi, N & Collum, TH 2011, 'Benefits and drawbacks of electronic health record systems', *Risk Management and Healthcare Policy*, vol. 4, pp. 47–55.

Mullick, A, Martin, J & Sallnow, L 2013, 'An introduction to advance care planning in practice', *British Medical Journal*, vol. 347.

National E Health Transition Authority 2016, *Evolution of eHealth in Australia: Achievements, lessons, and opportunities*, NEHTA, Sydney.

Schmidt, TA, Zive, D, Fromme, EK, et al. 2014, 'Physician orders for life-sustaining treatment (POLST): Lessons learned from analysis of the Oregon POLST Registry', *Resuscitation*, vol. 85, no. 4, pp. 480–5.

Scott, IA, Mitchell, GK, Reymond, EJ, et al. 2013, 'Difficult but necessary conversations: The case for advance care planning', *Medical Journal of Australia*, vol. 199, no. 10, pp. 662–6.

Sinuff, T, Dodek, P, You, JJ, et al. 2015, 'Improving end-of-life communication and decision making: The development of a conceptual framework and quality indicators, *Journal of Pain and Symptom Management*, vol. 49, no. 6, pp. 1070–80.