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Australian Digital Health Agency

National Guidelines

Using My Health Record to store and access
advance care planning and goals of care documents

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Introduction

Advance care planning is a voluntary process of planning for future health and personal care whereby a person makes their beliefs, values and preferences known so they can be used to guide future decision-making in the event that the person is unable to make or communicate decisions.[1] Australians are living longer and are increasingly living with chronic diseases or illnesses. Consequently, all Australians are being encouraged to consider advance care planning earlier. However, evidence shows that many Australians are not undertaking advance care planning even when this would seem to be important. As a result, many people are admitted to hospital or start a program of treatment without a documented Advance Care Plan in place.

Complementary to advance care planning is the process of agreeing goals of care that would apply in the event of a person's clinical deterioration and at end of life. This person-centred process occurs during admission to hospital or at the start of a new treatment program and involves a discussion and shared decision-making between a health professional, the person and their family/carers. The process captures the person's beliefs, values and preferences as they apply to the current episode of care. Goals are documented in a goals of care plan that may include or complement a medical treatment plan. The National Safety and Quality Health Service Standards[2] emphasise that such shared decision-making and goal setting should be routine in care planning and delivery for all health interventions. In the setting of advanced disease, acute life-threatening illness and especially end-of-life care, it is particularly important to agree and document goals of care with a focus on supporting treatment decisions if the patient loses capacity.

While interest in advance care planning and goals of care discussions is increasing in Australia, significant challenges remain in documenting plans and in locating and accessing relevant documents at the point of care. These challenges are compounded by variation within and across jurisdictions in terminology, types of documentation and in the underpinning legislation.

Progress is being made to address these challenges. The National framework for advance care planning documents[1] (the National Framework) provides principles-based information to support a nationally consistent approach to advance care planning and associated documents. The National Framework highlights that, to be useful, the existence of such documents must be known and easily located.

My Health Record has created a discrete, easily identifiable platform to store and view documents related to advance care planning and goals of care discussions in the context of end-of-life care. A unique characteristic of My Health Record is that this information remains under the control of the person.

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About the guidelines

These guidelines provide guidance for jurisdictions, health services and health professionals about the use of My Health Record to store and access documents related to advance care planning and goals of care discussions that occur in the context of end-of-life care. While the guidelines are not written for a consumer audience, they may be useful for health professionals in supporting people wishing to use My Health Record to store and view these documents.

The guidelines were developed as part of the National Goals of Care Collaborative, led by the Australian Digital Health Agency and the Western Australian Department of Health (see Appendix I for membership).

Terminology

The guidelines mirror terminology in the National Framework.[1]

- **'Advance care planning documents'** is used as a collective term to describe person-led documents that result from advance care planning, including:
  - **Advance Care Directives:** instruments recognised in each jurisdiction under legislation for medical treatment decisions or common law
  - **Advance care plans:** documents that do not meet the requirements for statutory or common law recognition due to the person's lack of competency, insufficient decision-making capacity or lack of formalities (such as inadequate person identification, signature and date).
- **'Goals of care'** in this document refers to medical and non-medical goals of care in the context of end-of-life care, determined through a shared decision-making process between health professionals, patients and families/carers. 'Goals of care' may be captured in a goals of care plan or similar clinical document.

My Health Record considers any document generated by, or on behalf of, a person, which articulates their beliefs, values and preferences for care and is intended to inform future care delivery, especially where the person can no longer speak for themselves, as **'advance care planning information'**. This includes person-led documents, such as Advance Care Directives and advance care plans, and those developed by health professionals such as goals of care documents developed in the context of end-of-life care.

See Appendix II for a Glossary of terms used in the National Framework and in My Health Record as well as including terms for advance care planning used in different jurisdictions.

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Using the guidelines

The guidelines include brief contextual information and guidance for jurisdictions, health professionals and health services about how My Health Record can be used to store and access documents related to advance care planning and goals of care in the context of end-of-life care.

Implementation of the guidelines will require consideration of state and territory legislation and policies related to advance care planning and setting goals of care in the context of end-of-life care as well as available digital systems to store and access relevant documents. Implementation may also need to be tailored according to the healthcare setting and will require consideration of the specific needs of different population groups.

The guidelines complement the National Framework[1] and are intended to be used alongside other existing guidelines and frameworks. Useful resources are highlighted throughout the guidelines. Appendix III provides a detailed listing of relevant resources.

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Points to remember when using the guidelines

LOCAL IMPLEMENTATION

Terms used to describe documents related to advance care planning and goals of care discussions that occur in the context of end-of-life care differ between jurisdictions.

Each jurisdiction has its own legal context governing Advance Care Directives and the functions of substitute decision-makers.

Digital health technology is an evolving space. The digital infrastructure available to support storage, sharing and access to advance care planning and goals of care documents varies by jurisdiction. My Health Record is one solution to support storage and access to these documents.

Discussions about beliefs, values and preferences that influence healthcare and health decisions will require sensitive consideration of individual needs and personal circumstances and may need to be tailored according to the healthcare setting.

MY HEALTH RECORD IMPLEMENTATION

Use of My Health Record is evolving:
- functionality of My Health Record is improving over time
- the amount of content uploaded by health professionals and individuals is increasing
- consumer confidence in accessing and interacting with My Health Record is increasing.

Uptake and use of My Health Record varies between individuals, health professionals and health services.

Uptake and use of My Health Record varies in different populations and communities; consideration of issues related to language, literacy and cultural safety requires ongoing focus.

The way in which different clinical software systems access My Health Record varies. Some clinical software systems need to be upgraded to support all My Health Record functionality.

Some health professionals will need to use the read-only National Provider Portal to access My Health Record.

CLINICAL APPLICATION

A person's My Health Record will not be a complete reflection of every interaction with health services and as such is a supplement to other sources of patient and clinical information.

Storage of advance care planning information in My Health Record does not replace the need for discussions between health professionals, their patients and families, carers and/or the substitute decision-maker about a person's beliefs, values and preferences at the point of care.

Storage of advance care planning information in My Health Record is not a substitute for thorough clinician-to-clinician handover but can be useful in supporting transitions of patient care.

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Guideline sections

The guideline sections do not need to be read in order. Users may wish to select the guidance most relevant to their needs.

CONTEXTUAL INFORMATION

Section 1:
Advance care planning and goals of care

Overview of the processes, types of documents, legislation and policy related to advance care planning and goals of care discussions that occur in the context of end-of-life care in Australia

Section 2:
My Health Record and advance care planning

Overview of My Health Record and the benefits of using My Health Record to store and access advance care planning information

GUIDANCE

Section 3:
System and process requirements
Guidance for jurisdictions and health services

Guidance on the system and process requirements to support appropriate use of My Health Record to store and access advance care planning information

Section 4:
Roles and responsibilities
Guidance for health professionals and health services

Guidance on who can upload, remove, view and download advance care planning information in My Health Record

Includes considerations for using advance care planning information stored in My Health Record as part of clinical care

Section 5:
Uploading, removing, viewing and downloading documents
Guidance for health professionals and health services

Guidance on the steps to upload, download, view and remove advance care planning information in My Health Record

APPENDICES

- Acknowledgements (Appendix I)
- Glossary of terms (including terms used in different jurisdictions) (Appendix II)
- Useful resources (Appendix III)
- Challenges and enablers for advance care planning (Appendix IV)
- National standards relating to advance care planning (V)
- Tips for consumers wishing to use My Health Record to store and access advance care planning information (VI)

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Advance care planning and goals of care

Advance care planning and discussions about goals of care in the context of end-of-life care are separate but related processes. Both are used to align a person's future care with their beliefs, values and preferences in the event that the person's ability to make or communicate decisions is lost. Advance care planning is a voluntary person-led process that outlines a future plan for health and personal care. Goals of care discussions are led by a health professional using a shared decision-making process and, in the context of these guidelines, relate to decision-making in the event of a person's clinical deterioration during end-of-life care.

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1.1 Overview

Advance care planning can occur at any time and at all stages of life. The process helps family, carers and health professionals know what treatment and care a person would want in the event they become unable to make or communicate decisions.[3] A **goals of care** discussion can occur in relation to many aspects of healthcare. In the context of these guidelines, goals of care refer to goals set in the context of advanced disease, increasing frailty and in the setting of end-of-life care, in which there is a perceived risk of clinical deterioration during an episode of care.[4] Advance care planning and goals of care discussions are separate processes but can be complementary,[5] each providing an entry point for the other.

The names and legal basis of documents used to capture these processes vary by jurisdiction (see **Table 1** and **Appendix II**). Advance care planning can occur on a continuum from a conversation or development of a written or oral **Advance Care Plan** to development of an **advance care directive** that is recognised by legislation or common law. An advance care directive can include the appointment of a **substitute decision-maker** who can make decisions about a person's healthcare if the person becomes unable to make or express their own decisions.[3,6] Outcomes of goals of care discussions in the context of end-of-life care can be summarised within goals of care plans, comprehensive care plans, clinical care plans or other similar documents.

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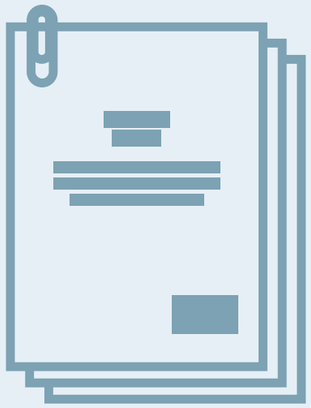
1.2 Legislation and policy

Advance Care Directives are governed by specific state-based legislation or common law.[6,7,8] All jurisdictions except for New South Wales and Tasmania have legislation governing the creation of Advance Care Directives. In New South Wales and Tasmania, Advance Care Directives are covered under common law. An advance care directive made in one jurisdiction may or may not be legally recognised in another jurisdiction. This has implications for people who travel regularly or live in a border location who may receive care in a state or territory that has different laws to those in which the document was created.[6]

All jurisdictions have legislation regarding appointment of a substitute decision-maker defining the powers these people can be given.[3] A person can have more than one substitute decision-maker. In certain situations (for example if a person's capacity is impaired), a substitute decision-maker may be assigned by law or appointed by a guardianship tribunal.

Advance care planning and the broad use of goals of care are also supported by national level policy.[9]



- Ethical considerations and best practice principles for advance care planning documents are outlined in the **National framework for advance care planning documents.**[1]
- The **National Consensus Statement: essential elements for end of life care**[10] and **National Palliative Care Strategy 2018**[11] include priorities for increasing advance care planning.
- The **National Safety and Quality Health Service Standards**[2] include standards for development and use of advance care plans and broad use of goals of care to support patient-centred care and shared decision-making (in particular Standard 5.1: Comprehensive Care Standard).
- The **Aged Care Quality Standards**[12] include standards related to advance care planning.

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Table 1: Overview of processes and documents related to advance care planning and goals of care discussions

Aligning care with a person's beliefs, values and preferences in the event they can no longer make or communicate decisions

Process	**Advance care planning** *Typically person-driven* A voluntary process of planning for future health and personal care whereby a person makes known their beliefs, values and preferences to guide decision-making at a future time when that person cannot make or communicate their decisions.		**Goals of care discussions in the context of advanced disease or end-of-life care** *Health professional-driven* The process of agreeing medical and non-medical goals of care in the context of end-of-life care that will apply in the event of a person's clinical deterioration during an episode of care.	
Documentation	**Advance Care Directives** Legally recognised documents focused on a person's future health and medical decisions written by a person with capacity. May include a values directive, instructional directive and appointment of a substitute decision-maker.*	**Advance care plans** Instruments developed by or on behalf of a person capturing beliefs, values and preferences for care that do not meet the requirements for a document with legal standing. May be written or oral (written documents are preferred).	**Goals of care** A statement of aims for a person's episode of medical treatment in the context of advanced disease or end-of-life care, as agreed between the person, their family and healthcare team, that will apply in the event of their clinical deterioration.	**Comprehensive care plans** Documents written by a health professional describing agreed goals of care and outlining planned medical, nursing and allied health activities for a patient.
	◀ Documents collectively described as 'advance care planning information' in My Health Record ▶			
Who can complete	Completed by a person with capacity about themselves. A substitute decision-maker is appointed by a person with capacity. (A substitute decision-maker may be assigned by law or tribunal for people younger than 14 years or who lack capacity.)	Completed by: • a person with capacity about themselves • someone else on behalf of a person who lacks capacity.	Completed by a health professional using a shared decision-making process with the person (wherever possible) and/or their family/carer(s) or substitute decision-maker.	Completed by a health professional together with the person through shared decision making.
Legal Basis	Recognised under state/territory legislation (statutory) or common law (non-statutory).	Not legally binding. Jurisdictions may vary in how common law is applied.	Underpinned by policy rather than law. Relate to the episode of care for which the plan was developed and, in some jurisdictions, may help to inform future episodes of care Not legally binding	
Examples	Advance care directive Advance health directive	Non-legislated advance care directive Notes, letters, videos My Values statement	Resuscitation plan Not for CPR plan	Goals of patient care 7-step pathway

**Some documents appointing a substitute decision-maker also contain valid health directions.*

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1.2 Legislation and policy

The **Advance Care Planning Australia** website contains:

- information about advance care planning and forms used in each state and territory[13]
- a **report** summarising legislation relating to advance care planning in Australia.[14]

The Queensland University of Technology **End of Life Law in Australia website** contains information on the law on Advance Care Directives and appointment of a substitute decision-maker in each state and territory.[8]

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1.3 Tailoring approaches to individual needs and circumstances

A person's views on acceptable and unacceptable health outcomes, healthcare interventions, death and dying are influenced by a range of personal, cultural and faith-based factors. Understanding of the purpose and implications of advance care planning and goals of care discussions and associated documentation will also be influenced by the person's literacy and health literacy. Discussions about advance care planning and goals of care in the context of end-of-life care should be undertaken in a way that is sensitive to a person's individual circumstances and needs. See Sections 3.2 and 4.4 for more information.

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Frequently asked questions about advanced care planning

1. **Are there Medicare items available to support advance care planning?**

   Yes. Advance Care Planning Australia has a factsheet on: **Advance care planning in general practice: Guidance on the use of Medicare Benefits Schedule Items.**

2. **What are some of the known challenges and enablers for advance care planning?**

   Key barriers for advance care planning relate to a lack of understanding of advance care planning, as well as jurisdictional differences in legislation and documentation (see Appendix V).

   Advance Care Planning Australia has developed **responses to some of the most common myths** about advance care planning. These responses can be helpful in discussions with patients and their families to help address individual level barriers.

3. **Why should people share their advance care planning documents with others?**

   People are encouraged to share advance care planning documents with key people involved in their care. This helps ensure that their values, beliefs and preferences are considered in planning and delivery of treatment and care in the event the person is no longer able to make or communicate decisions.

4. **Should documents related to advance care planning and goals of care be stored in a person's medical record?**

   Yes. Advance care planning documents provided to a health professional should be stored in the person's medical record in hard copy or electronic format.

   Documents capturing goals of care discussions in the context of end-of life-care are clinical documents that will already be stored in the person's medical record.

   Electronic storage of such documents means that they are more likely to be available at the point of care.

5. **Where else might a person's advance care planning documents be stored?**

   Some jurisdiction-level repositories have been developed to house advance care planning documents.

   Queensland has a statewide, standardised clinical approach to receive, review and upload advance care planning documents to clinical software. The **Office of Advance Care Planning** adds advance care planning documents to the Queensland Health electronic hospital record, which are then accessible across health environments in Queensland.

   MedicAlert and **My Values** record and hold advance care planning documents on behalf of a person, and documents can be made available to health professionals on request. These services require health professionals to be made aware of the location of advance care planning documents and how to access them. Routine use of these services in a clinical setting is limited.

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My Health Record and advance care planning

My Health Record is a person-controlled health summary that provides a nationally available solution to address the challenge of storing documents related to advance care planning and goals of care discussions that occur in the context of end-of-life care.

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2.1 About My Health Record

My Health Record is a secure online summary of a person's health information. My Health Record allows people to store and access their health information and share information with their health professionals.

Use of My Health Record by health professionals and health services is governed by legislation (see Appendix V).[15] Health professionals authorised by their health service or organisation can view a person's My Health Record and add relevant health information as part of the provision of healthcare. My Health Record does not replace existing paper-based or electronic medical records. Rather, it supplements these with a high-value, shared source of a person's health information that can improve care planning and decision-making.

Benefits for health professionals and health services of using My Health Record include:

- access to a person's health information and history, including advance care planning information
- access to a person's test results and medication history and communication about prescribed medications
- access to information about a person's treatment and care across different health services, settings (primary care, hospital and community-based care) and states/territories
- knowledge of which health professionals are involved in a person's health and care.

Together these benefits enhance capacity for healthcare coordination and for supporting patients and carers, resulting in better continuity of care across a person's healthcare journey.

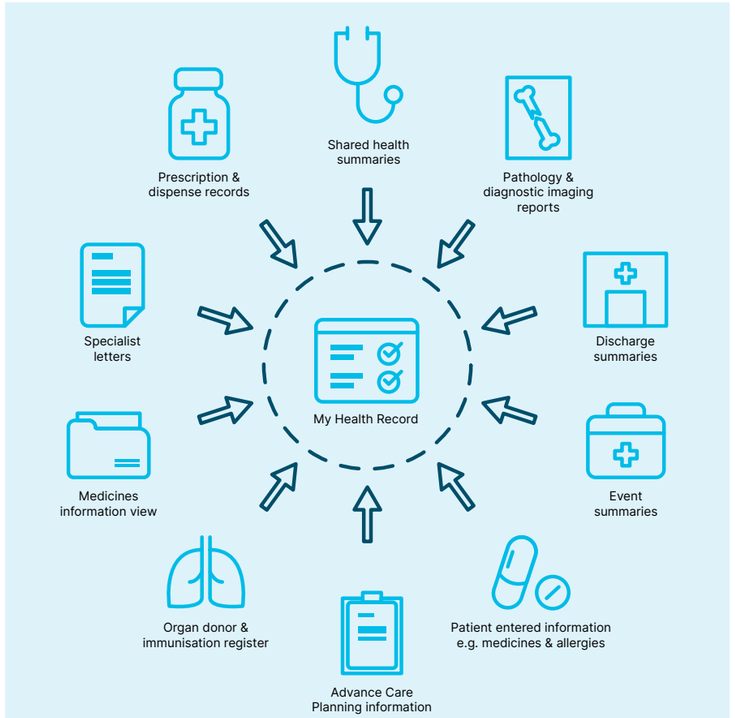

Figure 1: Information that can be uploaded to a person's My Health Record

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2.2 Access to and uptake of My Health Record by health services

Jurisdictions and health services have different levels of readiness when it comes to connecting to and using My Health Record. Content is growing as more public and private health services and health professionals connect and upload health information. In time, this will improve the way health services manage care for their patients.

Information and statistics about use of My Health Record in Australia is available through the **My Health Record website.**

In order for a health professional to access My Health Record for the purposes of providing healthcare, the organisation in which they work must be registered and authorise them to use the system. Once authorised, a health professional can access the My Health Record system for the purpose of providing healthcare using either:

- **conformant clinical software:** allows health professionals to view, download and upload information from and to a person's My Health Record (subject to any access controls the person may have set)
- **the National Provider Portal:** a read-only platform that allows health professionals to view a person's My Health Record (available for health professionals who do not have access to conformant clinical software).

The My Health Record website includes:

- information about **how to register to use My Health Record**
- a **list of conformant clinical software products**
- information about the **National Provider Portal**
- a range of **other information and training resources about My Health Record.**

Consumer access to My Health Record is via the National Consumer Portal. This has a different interface to the National Provider Portal and conformant clinical software.

The My Health Record website includes:

- information about **how to use My Health Record**
- information about My Health Record in **Aboriginal and Torres Strait Islander languages**
- information about My Health Record in **languages other than English.**

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2.3 Using My Health Record to store advance care planning information

The *National framework for advance care planning documents*,[1] Advance Care Planning Australia[9] and Palliative Care Australia[16] recommend use of My Health Record to store documents related to advance care planning and goals of care discussions that occur in the context of end-of-life care. Uploading such documents to a person's My Health Record allows them to be accessed by the person and by their health professionals regardless of location. This is particularly important for people who receive healthcare in multiple settings and practices, use public and private health services, are cared for by multiple health professionals and for those who travel regularly.

Differences exist in terminology used to describe advance care planning processes and documents between the National Framework and My Health Record. Main areas of commonality and difference are summarised in Figure 2. Further information is provided in the guidance sections of the guideline.

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My Health Record terminology for documents related to advance care planning and goals of care in the context of end-of-life care

Advance care planning information

Any document prepared by, or on behalf of, a person that states the person's preferences for health and personal care and health outcomes, for example an advance care directive or document appointing a substitute decision-maker for health-related purposes.

Two document types meet this definition in My Health Record:

Advance care planning document

- A statement of a person's preferences for medical treatment and health outcomes, which may or may not have legal standing / be legally binding.
- Documents in the National framework for advance care planning documents[1] that are considered in this category include Advance Care Directives and advance care plans.
- Typically uploaded to My Health Record by the person or their authorised or nominated representative*, via the National Consumer Portal.
- May be uploaded by a health professional if the person or their authorised or nominated representative* instructs them to do so.

Goals of care document

- A statement of preferences for medical and non-medical goals of care in the context of end-of-life care that would apply in the event of clinical deterioration during an episode of care.
- Documents in the National framework for advance care planning documents[1] are goals of care documents.
- May be uploaded to My Health Record by a health professional if instructed by the person via the health professional's clinical software.

Advance care document custodian

- A person and/or organisation who holds a copy of a person's advance care planning document(s).
- This term is unique to My Health Record.
- Advance care document custodian† details are uploaded to a My Health Record by the person or their authorised or nominated representative*, via the National Consumer Portal.
- A health professional should contact a person's advance care document custodian to obtain a copy of the person's advance care planning document(s) should the need arise.

Other clinical information

- My Health Record may include other clinical documents and information that may support clinical decision making in an end-of-life situation. Not all documents conform with the My Health Record definition of 'advance care planning information'.
- Documents of this nature referred to in the National framework for advance care planning documents[1] include comprehensive care plans and clinical care plans.
- Where a document does not conform with the My Health Record definition of 'advance care planning information' a health professional does not require the person's instruction to upload it to My Health Record.

**For more information on authorised and nominated representatives for My Health Record see Section 4.3. An authorised or nominated representative for My Health Record may or may not be the person's substitute decision-maker.*

†An advance care document custodian may or may not be the person's authorised or nominated representative and/or a substitute decision-maker

Figure 2: Overview of how advance care planning and goals of care documents are described in My Health Record

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2.3 Using My Health Record to store advance care planning information

Importantly, the benefits of storing advance care planning information in My Health Record can only be realised if health professionals involved in the person's care have access to the system at the point of care. Challenges and enablers for using My Health Record to store advance care planning information are summarised in Figure 3.

	Challenges	Enablers
Person	**Lack of awareness of/experience** using My Health Record (including concerns and misconceptions about privacy and permanency of documents)	**Awareness campaigns about My Health Record** and its use, including information to alleviate concerns about privacy and concerns that information cannot be removed once uploaded
	Lack of practical support to assist in uploading documents to My Health Record	**Promotion of the benefits of uploading advance care planning information to My Health Record**
	Information and communication technology (ICT) challenges (including access to computers/scanners, limitations of technology to upload required file sizes and ICT literacy)	**Availability of support** to help people upload advance care planning information to My Health Record (support may be provided by health professionals, public services or via the My Health Record helpline)
	Health literacy challenges (including challenges interpreting electronic templates for advance care planning documents)	
	Language, cultural and faith-based challenges (including understanding of forms and cultural considerations for decision-making and end-of-life care)	
	Physical and cognitive barriers influencing the ability to upload, access or view electronic documents	
Health Professional	**Lack of awareness/experience** using My Health Record	**Awareness campaigns for healthcare providers** about the benefits of using My Health Record to store and access advance care planning and goals of care documents in the context of end-of-life care
	Uncertainty about health professional and individual obligations in relation to documenting advance care planning and goals of care discussions that occur in the context of end-of-life care	**Education and training for health professionals** about uploading and accessing advance care planning information in My Health Record
	Uncertainty about the legal validity of advance care planning information sourced from the My Health Record system	**Clinical workflows** highlighting how and when to incorporate advance care planning information from My Health Record
	Time constraints (lack of time to discuss advance care planning and goals of care / lack of time to access systems to view documents)	
System	**Lack of digital versions** of document templates	**Increasing use of electronic medical records** and improvements in design/ functionality
	Functionality of clinical software systems that do not support integration with My Health Record	**Functionality of clinical software systems** that support integration with My Health Record, including easier visibility of advance care planning documents

Figure 3: Challenges and enablers for using My Health Record to store advance care planning information[17, 18]

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Frequently asked questions about My Health Record and its use to support advance care planning

1. **How many people have a My Health Record?**

   Approximately 90% of Australians have a My Health Record. Not all records currently contain health information or advance care planning information.

2. **How secure is information in My Health Record?**

   The My Health Record system meets the strictest cyber security standards. It has robust multi-tiered security controls to protect the system from malicious attack. The system has been built and tested to Australian Government standards to protect the confidentiality, integrity, and availability of information within a person's My Health Record. Harsh criminal and civil penalties apply for inappropriate or unauthorised use of information in a My Health Record.

3. **Which clinical software is conformant for My Health Record?**

   The My Health Record Register of Conformity lists clinical software products and the versions that have been assessed for conformance with national digital health requirements.

4. **Can all health professionals view information in My Health Record?**

   Only health professionals authorised to access My Health Record by a registered healthcare organisation can view information in a person's My Health Record. Viewing must only be for the purpose of managing the person's healthcare. There are significant penalties for unauthorised access.

5. **Does a health professional need consent to view a person's My Health Record?**

   An authorised health professional does not need consent to view a person's My Health Record. The record can be accessed outside a consultation if access is for the purpose of providing healthcare to the person. A person may choose to enable privacy settings to control which health services / health professionals can access their My Health Record.

6. **Is it useful to upload advance care planning information to My Health Record even if the record does not contain other information?**

   The number of people and health services using My Health Record is increasing over time. Uploading advance care planning information to My Health Record is helpful even if there is limited other health information in the record.

7. **What is the legal validity of advance care planning information uploaded to My Health Record?**

   Storage in My Health Record of Advance Care Directives, advance care plans or documents summarising goals of care in the context of end-of-life care does not have any bearing on the legal standing or validity of the original documents.

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My Health Record is a person-held summary of health information. It is intended to complement, not replace, information in local clinical information systems or information given to a health professional by a patient or their substitute decision-maker. My Health Record provides an additional channel through which information can be obtained at the time it is required.

8. **What support is available to help people manage advance care planning information in their My Health Record?**

   General support for My Health Record is available via the My Health Record Helpline: 1800 723 471 and via the My Health Record website.

   If a person does not have capacity to manage their My Health Record, an authorised representative can manage it for them. An authorised representative may be a parent, carer, family member, or someone with enduring power of attorney.

   A person who has capacity for decision-making but who requires support in managing their My Health Record can invite a trusted person to help them. This person is known as a nominated representative. Different levels of access can be given to nominated representatives (see Section 4.3).

9. **When should advance care planning information stored in My Health Record be reviewed and updated?**

   It is important that Advance Care Directives, advance care plans and / or details of a person's substitute decision-maker stored in My Health Record are current. People should be encouraged to review advance care planning information stored in My Health Record regularly and/or when a health change or transition occurs.

   While documents uploaded to My Health Record cannot be changed, they can be removed and replaced with an updated version if required.

   Documents related to goals of care typically relate to an episode of care. It can be helpful for health professionals to see past goals of care documents to help inform future discussions. Documents related to past episodes of care can be retained on My Health Record to provide this history.

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Health services and health professionals using My Health Record to upload, store and access advance care planning information should understand the different types of documents and adhere to relevant policies and procedures. Use of My Health Record to store advance care planning information requires access to digital infrastructure.

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3.1 Document types and inclusions

Although My Health Record does not restrict which documents can be uploaded, it is recommended that advance care planning information stored in My Health Record reflects jurisdictional and local legislation and policy.

There are no set parameters for the type, name or format of advance care planning or goals of care documents that can be uploaded to My Health Record. Table 3 provides a list of recommended inclusions for each type of document to be considered by the person uploading the document.

Person-driven documents		Health professional-driven documents
Advance Care Directives	**Advance care plans**	**Goals of care plans**
It is recommended that Advance Care Directives uploaded to My Health Record: • meet legal requirements of the jurisdiction in which the document was created • identify the jurisdiction in which the document was developed • are reviewed / updated regularly or when there is a health change or transition. The National framework for advance care planning documents[1] states that Advance Care Directives should include: • personal details (such as name, date of birth, address) • substitute decision-maker's details (if appointed) • preferred health outcomes • values and preferences relating to future care • date the advance care directive was made or reviewed • preferences relating to organ donation.	It is recommended that advance care plans uploaded to My Health Record: • identify the jurisdiction in which the document was created • are reviewed regularly and reviewed/updated when there is a health change or transition.	It is recommended that goals of care plans and related clinical documents developed in the context of end-of-life care: • are authorised by the treating health professional(s) • include information about who was present for the discussion (e.g. patient, family, substitute decision-maker) • describe the episode of care to which the document relates • include a record of the patient's instruction to upload the document to My Health Record*.
All documents should include the name (family name and given name), date of birth, and gender of the person to whom the document relates, name of the person who created the document, date of document creation† and Indigenous status of the person (if provided). *Instruction to upload can be indicated via a tick box on the relevant form; signature is not required. See Section 3.3 for further information. †Date of document creation should ideally be the date the document was authored, not the date of upload to My Health Record.		

The Advance Care Planning Australia website houses a resource library of advance care planning forms available in each state and territory.

The *National framework for advance care planning documents*[1] includes a detailed checklist for inclusions in Advance Care Directives.

Table 3: *Recommended inclusions for advance care planning information uploaded to My Health Record*

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3.2 Communication

Health services should establish and maintain processes for appropriate communication about advance care planning and goals of care in the context of end-of-life care regardless of whether documents are stored in a person's My Health Record.

The presence in My Health Record of advance care planning information does not replace the need for open communication between health professionals and their patients, families and carers, and between different healthcare providers about a person's beliefs, values and preferences in relation to healthcare. Sensitive and open communication by health professionals is critical in discussions about advance care planning and goals of care in the context of end-of-life care. This includes confirming that documents held in My Health Record reflect the person's beliefs, values and preferences at the point of care.

A range of factors may influence a person's openness and level of comfort in discussing and documenting beliefs, values and preferences related to end-of-life care.[19] It is important for health professionals to consider these in discussions with the person and with their family and carers. The National framework for advance care planning documents[1] highlights a number of cultural, faith-based and personal factors that may influence a person's views on quality of life, interventions, death and dying and affect how discussions are held.

Particular consideration may need to be given to discussions with:

- people from culturally and linguistically diverse communities
- Aboriginal and Torres Strait Islander peoples
- lesbian, gay, bisexual, transgender, intersex, queer and/or gender-diverse people
- people living with chronic conditions and/or conditions affecting ability, including cognitive impairment such as dementia
- people living with mental health condition(s) (both temporary and long term)
- people who are homeless
- people living in long-term institutional care (including being incarcerated)
- ageing and/or frail people
- people living in rural and remote areas
- children and adolescents.

It is important for health professionals not to make assumptions about a person's preferences based on age, personal circumstances, cultural background, abilities, sexuality or faith. The person's literacy, health literacy and level of digital engagement will also be an important consideration.

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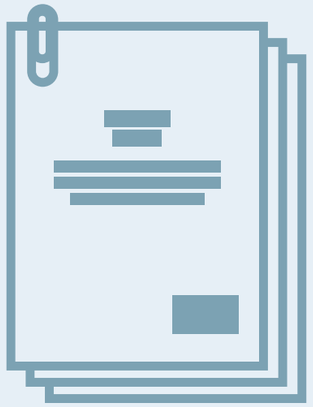
3.2 Communication



- The **National Consensus Statement: Essential elements for safe and high-quality end-of-life care**[10] describes appropriate communication practices relevant to establishing and respecting a person's views and preferences for care.
- Advance Care Planning Australia has developed **tips for communicating with patients and their families about advance care planning**.
- **My wishes, My Plan: Advance Care Planning** is a fact sheet about My Health Record and advance care planning written for a lay audience.
- The Program of Experience in the Palliative Approach (PEPA) has developed **Cultural considerations: Providing end of life care for Aboriginal and Torres Strait Islander peoples**.
- A range of websites and booklets provide information about cultural considerations for advance care planning. See Appendix III for more information.

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3.3 Working in accordance with a person's wishes

Consent is an important consideration in relation to discussing and implementing advance care planning and goals of care in the context of end-of-life care.

It is important that health professionals using My Health Record to store and access advance care planning information act in accordance with the person's wishes. Under My Health Record legislation, a health professional can only upload advance care planning information to a person's My Health Record if instructed to do so by the person (see box below). This includes advance care planning documents and goals of care plans developed in the context of end-of-life care.

The other important consideration is for a health professional to confirm that advance care planning information sourced from a person's My Health Record reflects the person's beliefs, values and preferences before using this information at the point of care.

Instruction to upload advance care planning information to My Health Record

Under the **My Health Records Act 2012**, health professionals and healthcare provider organisations are authorised to upload clinical information to the My Health Record system. Upload of clinical information does not require consent from the person.

However, instruction from the person (or their authorised representative or full access nominated representative) is required for a health professional to upload advance care planning information (including documents summarising goals of care in the context of end-of-life care) to a person's My Health Record. This is because these documents contain preferences and aims for care for the individual.

Forms used to document goals of care in this context should include a box to indicate that the person has asked to have the document uploaded to their My Health Record. Implicit within this instruction is the fact that the person understands the content of the document and its intent.

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3.4 Digital infrastructure

Jurisdictional and local strategies should facilitate and promote the benefits of digital storage and sharing of documents related to advance care planning and goals of care discussions in the context of end-of-life care within and across hospital, aged care and primary and community care sectors.

Each jurisdiction has its own plans and strategies for establishing, embedding and integrating digital health systems to support and improve the delivery and quality of health services. Digital health strategies are at different stages of development and implementation and this will affect system capability to upload and view advance care planning information in My Health Record. The digital health infrastructure available to support access to My Health Record also varies across different healthcare settings.

The Australian Digital Health Agency maintains a **Developer Centre** with resources for developers and implementers, providing a single point of reference for all resources and specifications relating to Australian digital health development.

The Developer Centre includes **specifications for a range of clinical documents**, including:

- **Advance Care Document Custodian**
- **Advance Care Planning**

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3.5 Policies and procedures

Health services (including self-regulated healthcare providers) using My Health Record to access advance care planning information should establish and promote policies and procedures to ensure this occurs appropriately. Policies and procedures should be developed in line with national, state and territory strategies, guidelines and legislation.

My Health Record policy

All healthcare organisations using My Health Record are required to develop, communicate, uphold and review (at least annually) an organisational policy regarding appropriate use, including training and security measures. While it is not a requirement for such policies to specifically mention advance care planning information, the measures included will help to ensure the privacy and security of relevant documents.

The **My Health Records Rule 2016** outlines areas that should be covered in an organisational policy for use of My Health Record (rule 42 Healthcare provider organisation policies).

The **overview of digital health policies for My Health Record** describes the requirements of healthcare providers and healthcare provider organisations for participating in digital health, including the requirements outlined in My Health Records Rule 2016. This overview includes a link to a sample My Health Record policy.

The My Health Record website also includes a **checklist for requirements** to be incorporated into an organisation's security and privacy policy.

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Advance care planning policy and protocols

It is recommended that jurisdictional and organisational advance care planning policies and protocols reference appropriate use of My Health Record to access advance care planning information.

Reference to My Health Record in advance care planning policies and protocols may include guidance on:

- when it is / is not appropriate for a health professional to upload, view, download and / or remove documents related to advance care planning or goals of care discussions in My Health Record, including requirements for when instruction from the person is required
- the responsibility of the health professional to check that the document being used is current / the most recent version
- considerations for particular population groups or healthcare settings:
  - emergency access and/or access to My Health Record for people without capacity
  - considerations based on language, culture and faith
  - literacy and health literacy considerations
  - people with **low digital inclusion**
  - support for people who are physically unable to upload documents to My Health Record.

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3.6 Health professional and health service staff training and education

Health professionals and health service staff should continue to access training in My Health Record. Training should cover how to use My Health Record to store and access advance care planning information.

My Health Record training should include:

- how to use My Health Record appropriately to upload, view and remove documents related to advance care planning and goals of care in the context of end-of-life care (including requirements for instruction from the person before uploading)
- how to support people to upload, view and remove advance care planning documents to their My Health Record, where appropriate
- quality, safety and privacy considerations.

Training about use of My Health Record to store and access advance care planning information can also be incorporated into training related to advance care planning and goals of care.

The My Health Record website includes **training and education resources** about My Health Record for health professionals in different healthcare sectors.

A range of education and training resources for advance care planning are available for health professionals in different healthcare sectors. The **Advance Care Planning Australia** website has a comprehensive list of resources. For other specific examples, see Appendix III.

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3.7 Quality improvement

Quality improvement processes are important for supporting appropriate use of My Health Record for storage and access to advance care planning information.

Existing or new quality assurance activities could incorporate an assessment of the following:

- The existence of organisational policies relevant to the use of My Health Record in processes related to advance care planning, including requirements for patient instruction before uploading documents (e.g. policy, procedure or guideline audits within health services)
- Staff awareness of and compliance with the requirement for instruction from the person before uploading documents (e.g. through clinical audits or staff surveys)
- Staff understanding and capability regarding roles and appropriate use of My Health Record in processes related to advance care planning and goals of care discussions in the context of end-of-life care (e.g. via staff survey, education and training session evaluations)
- Health professional reported use of My Health Record to access advance care planning information (e.g. via staff survey, education and training session evaluations)
- Patient awareness of the ability to store and remove advance care planning documents in My Health Record, and awareness of how to set up SMS / email notifications about document changes (e.g. via patient survey or during bedside audits).

National standards covering advance care planning and goals of care include:

- health services: **National Safety and Quality Health Service Standards**[2]
- aged care services: **Aged Care Quality Standards**.[12]

Appendix V lists the relevant standards related to advance care planning in each of these documents.

In addition, the Royal Australian College of General Practitioners **Standards for General Practice**[20] include reference to advance care planning in primary care.

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Frequently asked questions about using My Health Record to store advance care planning information

1. **Whose responsibility is it to check that the recommended inclusions are applied to advance care planning information uploaded to My Health Record?**

   The recommended inclusions for advance care planning information uploaded to My Health Record listed in Table 3 are not mandated. Application of these recommendations will help in strengthening the national consistency of documents related to advance care planning and goals.

   Health professionals can only take responsibility for the inclusions of clinical documents. However, they can direct people to information about advance care planning documents and encourage recommended inclusions are used.

2. **Is access to a person's My Health Record limited to health professionals?**

   The My Health Records Act allows for healthcare provider organisations to approve staff to access the record for the purposes of delivering care. An organisational policy regarding appropriate use must be in place. In some instances, policies may allow for non-health professional staff to access the record for the purposes of delivering care.

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Frequently asked questions about roles and responsibilities related to using My Health Record to store and access advance planning information

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My Health Record is a person-owned health summary. The My Health Records Act has rules guiding who can upload and view advance care planning information in a person's My Health Record.

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4.1 Summary

Advance care planning documents (Advance Care Directives, advance care plans)

Consumers can upload advance care planning documents to My Health Record.

These documents can also be added to a person's My Health Record by:

- the person's authorised or full access nominated representative*
- a health professional (if requested by the person or their authorised / full access nominated representative).

Documents summarising goals of care discussions in the context of end-of-life care

Goals of care documents developed in the context of end-of-life care can be uploaded to My Health Record by the person's health professional.

These documents should only be uploaded to a person's My Health Record on instruction by the person (or their authorised or full access nominated representative*).

*See Section 4.3 for more information about authorised and nominated representatives

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4.2 Consumers

A person can upload their advance care planning documents to My Health Record.
They can also add the name(s) and contact details of their advance care document custodian.

Advance care document custodian

An advance care document custodian is a term used in My Health Record for a person and/or organisation who holds a copy of a person's advance care directive or advance care plan. Details of an advance care document custodian are the most common type of advance care planning information stored in My Health Record.

A health professional should make every effort to contact a person's advance care document custodian to obtain a copy of these documents should the need arise and should check that the documents are current.

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4.3 Authorised and nominated representatives

Authorised and nominated representatives are people who can access My Health Record on behalf of someone else.

Authorised representatives

An authorised representative is responsible for managing the My Health Record of someone who cannot manage their own record. This is typically a parent, carer or legal guardian of a child under 14 years.

A person can apply to be the authorised representative of a person older than 14 years who lacks capacity. In such cases, the authorised representative would typically be someone with legal authority to act on the person's behalf.

An authorised representative can do anything in a person's My Health Record that the person can do. This includes:

- viewing information
- removing documents
- adding personal health information
- adding personal notes about health and development
- choosing whether Medicare information is uploaded to the record
- choosing which healthcare providers can access the record
- adding or removing nominated representatives
- viewing details of other authorised representatives
- cancelling the My Health Record registration resulting in the record being deleted.

Nominated representatives

A nominated representative is someone invited by a person to view and/or help them manage their My Health Record. Three types of access can be given:

- General access: the representative can view all documents, except those marked as 'restricted'
- Restricted access: the representative can view all documents, including those marked as 'restricted'
- Full access: the representative can view all documents and add information to the person's My Health Record.

The My Health Record website includes information about **authorised representatives** and **nominated representatives** for My Health Record.

Terminology

The terms 'advance care document custodian', 'authorised representative' and 'nominated representative' are terms used in My Health Record. They should not be confused with the term 'substitute decision-maker' used in advance care planning to describe a person authorised to make decisions about another person's care if they are unable to make or communicate decisions (see Section 1.1).

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4.4 Health professionals

A health professional can upload a person's advance care planning documents or goals of care documents related to end-of-life care to a person's My Health Record if instructed by the person (see Section 3.3). Documents should be uploaded to the 'Advance Care Planning Overview' section of My Health Record. This requires the clinical software used by the health service to be configured to support this functionality.

Understanding the legal basis for advance care planning information in My Health Record

It is important that health professionals understand the legal basis for advance care planning information in My Health Record in order to apply this information appropriately in clinical practice.

Information in My Health Record is intended to supplement standard clinical care and should be used appropriately and in line with legislation, policies and best practice.

The presence of advance care planning information in a person's My Health Record does not replace the need for health professionals to establish the legal validity and currency of the document, recognising that:

- legal requirements for Advance Care Directives vary by jurisdiction
- an advance care directive viewed in a different state or territory to where it was created may not be legally recognised in that jurisdiction.

Talking with patients and families about using My Health Record to store advance care planning information

The *National framework for advance care planning documents*[1] lists a range of triggers for advance care planning. Interactions in which it may be appropriate to ask whether a person has an advance care directive or advance care plan, including whether it could be uploaded to My Health Record include:

- when a person or their family member asks about current or future treatment goals
- at a 75+ health assessment or when an older person receives their annual flu vaccination
- at diagnosis of:
  - a life-limiting illness
  - early dementia or a disease that could result in loss of capacity
- when there are changes in a care plan, for example at the start of palliative or end-of-life care
- when there are changes in care arrangements (e.g. admission to a residential aged care facility).

Health professionals can encourage people to store their advance care planning documents in My Health Record by:

- asking whether a person has a current document and whether the latest version has been uploaded to My Health Record
- suggesting that people add or update advance care document custodian information on My Health Record if the document is stored elsewhere (e.g. with a family member)
- answering questions from the person / their family about the

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privacy and security of advance care planning information in My Health Record

- helping people upload or view advance care planning information in My Health Record if instructed.

Health professionals can ask people whether they would like documents summarising goals of care discussions in the context of end-of-life care to be uploaded to My Health Record. Such discussions may occur:

- during periods of acute illness
- during hospital admission for a condition that may require an emergency response
- during the process of diagnosis and ongoing care for a person with a life-limiting illness
- prior to admission to or on discharge from the intensive care unit
- on admission to a rehabilitation ward.

In all situations, communication should take account of sensitivities and considerations for different population groups and healthcare settings (see Section 3.2).

Tips for health professionals

- Familiarise yourself with the **relevant advance care planning legislation in your state/territory** and refer patients to relevant sources of information
- Understand and comply with jurisdictional and organisational policies for advance care planning
- Understand the **role you can play in supporting advance care planning** according to the setting in which you practice
- **Increase your knowledge, skills and confidence in talking about advance care planning with patients**
- Talk with colleagues about how you can better coordinate the approach to advance care planning within your service
- Learn more about using **My Health Record**
- Refer patients if needed to the My Health Record Helpline (1800 723 471) or to their local MyGov office for assistance

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Frequently asked questions about roles and responsibilities related to using My Health Record to store and access advance care planning information

1. **What obligations does an authorised or nominated representative have?**

   Under the My Health Records Act, authorised and nominated representatives must make reasonable efforts to find out and act in accordance with a person's preferences in relation to their My Health Record.

   If it is not possible to find out a person's actual preferences, the authorised or nominated representative must make reasonable efforts to find out and act in accordance with the likely preferences of the person (i.e. what would the person like to happen if he/she were able to voice their preferences?).

   If it is not possible to find out the person's actual or likely preferences, the authorised or nominated representative must act in a way that promotes the personal and social wellbeing of the person.

2. **Can an authorised or nominated representative provide the instruction for a health professional to upload advance care planning documents to a person's My Health Record? For example, if the person is unable to do so?**

   Yes, under the My Health Records Act, an authorised representative or full access nominated representative is authorised to do anything that the Act authorises or requires the person to do.

3. **Is My Health Record the only source of advance care planning information for a person?**

   No. My Health Record is one possible storage option for a person's advance care planning documents.

   A person may also choose to share their advance care planning documents with:

   - their substitute decision-maker(s) and/or carer, family members
   - their GP, local doctor and/or specialist(s)
   - a residential aged care home
   - their local hospital or health service.

4. **If a person already has an advance care directive or advance care plan, how does this affect the process of agreeing goals of care in related to end-of-life care?**

   Advance care planning and the process of discussing goals of care in the context of end-of-life care are separate but related processes. One does not replace the need for the other.

   If a person already has an advance care planning document, this can be a helpful starting point when discussing goals of care for an episode of care.

   Similarly, although goals of care documents relate to an episode of care, the fact that discussions have been held about goals and values in the context of end-of-life care can provide a starting point for broader discussions about advance care planning.

   If a person has a current advance care directive that includes an instructional directive this would override a goals of care document.

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Uploading, removing, viewing and downloading documents

Uploading advance care planning information to My Health Record enables access to this information, should the need arise. Controls are in place around who can upload, view, remove and download documents related to advance care planning and goals of care discussions.

Terminology

My Health Record considers any document generated by, or on behalf of, a person, which articulates their beliefs, values and preferences for care and is intended to inform future care delivery, especially where the person can no longer speak for themselves, as **'advance care planning information'**. This collective term includes person-led documents, such as Advance Care Directives and advance care plans, and those developed by health professionals such as goals of care documents developed in the context of end-of-life care.

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5.1 Uploading advance care planning information to My Health Record

Advance care planning documents or documents relating to goals of care discussions in the context of end-of-life care are added as 'Advance care planning information' within the 'Documents' section of My Health Record.

A health professional will only be able to upload documents to the 'Advance care planning information' section of a person's My Health Record if their clinical software is conformed to support this functionality. The interface to upload documents varies according to the software provider.

A health professional can only upload advance care planning documents or goals of care documents related to end-of-life care to a person's My Health Record if instructed to do so by the person.

Updating advance care document custodian details

It is recommended that people maintain up-to-date details of their advance care document custodian in My Health Record.

An advance care document custodian may be a person or organisation. If a person has stored advance care planning documents with a service such as MedicAlert or MyValues, it is recommended that they provide details in the advance care document custodian section of their My Health Record. It is important that details are current. Health professionals can encourage people to check that their advance care document Custodian details are current.

Some people choose only to include details of their advance care document custodian in My Health Record without uploading an advance care planning document. For example, if a person captures information about advance care planning in a non-written form (for example, a video or audio recording), the person or organisation who holds a copy of this can be listed as the advance care document custodian.

The My Health Record website has information about how to add an Advance Care Plan and **how to add an advance care document custodian**.

Steps to upload documents to My Health Record via the National Consumer Portal differ to those used by health professionals. Appendix VI includes a list of tips for about uploading and viewing documents in My Health Record.

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5.2 Removing advance care planning information from My Health Record

A person's preferences about the care they receive in the event they are no longer able to make or communicate decisions may change over time. This may result in a change to their advance care directive or advance care plan. These documents cannot be edited in My Health Record. A person may wish to remove documents that are no longer current or contain an error and replace them with an updated version. This is particularly important for documents that have legal standing. There are strict controls over who can remove advance care planning information from My Health Record (see below).

The same controls apply to goals of care documents developed in the context of end-of-life care. Multiple documents may be developed over this period of time. Retaining all goals of care documents in My Health Record helps health professionals understand how a person's preferences have influenced the care they have received. Documents can be removed and replaced if they contain an error.

Removal of advance care planning information from My Health Record can be undertaken by:

- the person
- the person's authorised representative or full access nominated representative:
  - if the document was uploaded by the person, their authorised representative or full access nominated representative will be prompted to call the My Health Record Helpline for support to remove the document
  - if the document was uploaded by the authorised representative or full access nominated representative, they can remove the document without support from the My Health Record Helpline.

Advance care planning information can only be removed from My Health Record by a health professional if the document was uploaded by the health professional.

A person's My Health Record has a Record Access History, which shows when documents are added to or removed from the record. The Record Access History is visible to the person only (or their authorised representative or full access nominated representative).

The My Health Record website has information for consumers about:

- **how to remove an Advance Care Plan**
- **how to see who has accessed your My Health Record.**

Appendix VI includes a list of tips for consumers about removing documents from My Health Record.

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5.3 Viewing advance care planning information in My Health Record

Health professionals should only view advance care planning information in a person's My Health Record if this is required as part of healthcare provision.

A person can view advance care planning information stored in their My Health Record at any time. Information can also be viewed by the person's authorised representative or full access nominated representative.

Only health professionals or health services involved in a person's care and who are authorised / registered to use My Health Record are allowed, by law, to access the person's My Health Record; this includes viewing advance care planning information.

Health professionals or health services can view a person's advance care planning information in My Health Record using:

- conformant clinical software: steps depend on the software provider; some clinical software interfaces include a flag highlighting that a person's My Health Record includes advance care planning information
- the National Provider Portal: via the Health Record Overview; this page flags whether the person's My Health Record includes advance care planning information and provides read-only access.

The My Health Record website includes detailed information for health professionals and healthcare providers about how and when to **view a person's My Health Record**.

This includes information and simulations for accessing My Health Record using different clinical software products, as well as a **demonstration on how to use the National Provider Portal**.

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Privacy considerations and access in an emergency

A health professional or health service can access a person's My Health Record in an emergency situation.

In most instances, health professionals will have open access to the information in a person's My Health Record. However, people have the option of adding extra privacy controls on their My Health Record, which may limit health professional access:

- a record access code (RAC) can be used to limit which healthcare providers can view or update their My Health Record
- a limited document access code (LDAC) can be used to control access to certain documents (an LDAC cannot be used to restrict access to advance care planning information).

In certain urgent situations, defined in the My Health Records Act 2012 (section 64), it may be permissible for a health professional to bypass these access codes using an 'emergency access function' available through the health service's clinical information system.

This is sometimes referred to as a 'break glass' function. It is important to understand when this function can be used lawfully.

Situations in which emergency access may be appropriate include those in which access to advance care planning information may be important, including where there is a serious threat to the person's life, health or safety and their consent cannot be obtained (e.g. because they are unconscious).

The My Health Record website includes information about **controlling access to My Health Record** including:

- how to **restrict access to My Health Record**, including deciding which healthcare providers can access My Health Record
- how to **see who has accessed their My Health Record**
- **emergency access to My Health Record**

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5.4 Downloading advance care planning information from My Health Record

Local health service policies should outline a process for storing copies of a person's advance care directive, Advance Care Plan or goals of care plans within their medical record. Local policies should also identify the steps health professionals should follow if they use advance care planning information in the person's My Health Record for the purpose of providing healthcare. It is important for local policies to reiterate that the presence of such documents in a person's My Health Record does not have any bearing on the legal status or validity of the original document(s).

As My Health Record is a person-controlled record, access to these documents may change over time.

High-level guidance for downloading and / or copying advance care planning information from My Health Record is provided below.

- If advance care planning information viewed in My Health Record is not already held in the person's medical record, a discussion should be held with the person (if practical) to assist in determining the currency / validity of relevant documents. The steps health professionals should follow to determine the legal status or validity of original document(s) are dependent on jurisdiction legislation.
- The National Safety and Quality Health Service Standards[2] recommend that relevant document(s) should be downloaded, copied (if required) and stored in the person's medical record in line with local health service policy.
- If document(s) held in My Health Record cannot be downloaded or copied, a note or alert should be included in the person's medical record indicating that such information is available in My Health Record.
- If document(s) held in My Health Record cannot be downloaded or copied, and are used to inform the person's care, a note should be included in the person's medical record to this effect. This note could include the document identification (ID) and any relevant content.

Steps to download advance care planning information from My Health Record will depend on the conformant software used to view the person's My Health Record.

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The National Goals of Care Collaborative is a key priority under the Australian Digital Health Agency's Enhanced Models of Care (EMOC) Program. The EMOC is one of seven strategic priorities designed to enable digitally enhanced models of care that improve the accessibility, quality, safety and efficiency of healthcare through the better use of information and technology, including My Health Record and other national systems and services.

Development of the guidelines has included advisory input and expert review, a process of targeted consultation and incorporation of feedback. The guidelines draw on available national and international evidence and policy and represent consensus by relevant experts and organisations.

The Australian Digital Health Agency and Western Australian Department of Health acknowledge and thank all the individuals and organisations involved in the development of these guidelines.

Membership of the national steering committee for the National Goals of Care Collaborative

Role	Participant	Jurisdiction
Chair	Dr Simon Towler, Clinical Lead, National Goals of Care Collaborative, Department of Health, Western Australia	Western Australia
Deputy Chair	Pip Brennan, Executive Director, Health Consumers Council Western Australia	Western Australia
Member	Rupert Lee, General Manager, Partnerships and Clinical Use, Australian Digital Health Agency	Commonwealth
Member	Dr Emma Spencer, Physician, Department of Health, Northern Territory Government	Northern Territory
Member	Haley McNamara, Manager, Care at the End of Life, Department of Health, Queensland	Queensland
Member	Liz Junck, Director, Community Care & Priority Populations, Health and Social Policy Branch, Ministry of Health, New South Wales	New South Wales
Member	Heather Needham, Patient Experience Leader, Quality and Safety Division, Canberra Health Services	Australian Capital Territory
Member	Frits Kadijk, Manager, Patient Choice, Policy and Planning Branch, Health and Wellbeing, Department of Health and Human Services	Victoria
Member	Lisa Hagstrom, eCare Strategy and Planning, Department of Health and Human Services	Tasmania

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Member	Dr Peter Sprivulis, Chief Clinical Information Officer, Jurisdictional Health Department representative	Western Australia
Member	Dr Bernie Towler, Principal Medical Adviser, Ageing and Aged Care, Australian Government Department of Health	Commonwealth
Member	Dr Matthew Grant, Palliative Medicine Physician, St Vincent's Hospital, Agency Clinical Reference Lead	Victoria
Member	Dr Robert Herkes, Clinical Director, Australian Commission on Safety and Quality in Health Care	National
Member	Dr Karen Detering, Medical Director, Advance Care Planning (ACP) Australia	National
Member	Rodney Ecclestone, General Manager, Clinical Governance, Australian Digital Health Agency	National
Member	Yvonne Parnell, Consumer Representative, Consumers Health Forum of Australia	National
Secretariat	Project Support Officer, Advance Care Planning and Goals of Care My Health Record Project	Western Australia
Observer	Felicity Reid, Program Director, Enhanced Models of Care, Australian Digital Health Agency	National
Observer	Valerie Colgan, Senior Clinician, WA Cancer and Palliative Care Clinical Implementation Unit	Western Australia
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Term	Definition
Terminology used in the National framework for advance care planning documents[1]	
Advance Care Directives Including, but not limited to: Advance Care Directives, advance health directive, advance personal plan, health direction,enduring powers of attorney, enduring guardian, medical treatment decision-maker or any other similar Advance Care Directives in legislation.	Advance Care Directives is used as a catch-all term to refer to the instruments which are recognised in each jurisdiction under advance care directive legislation or common law. They are voluntary, person-led documents completed and signed by a competent person that focus on an individual's values and preferences for future care decisions, including their preferred outcomes and care. Advance Care Directives are recognised by specific legislation (statutory) or under common law (non-statutory). They come into effect when an individual loses decision-making capacity. Advance Care Directives can also appoint substitute decision-makers who can make decisions about health or personal care on the individual's behalf. Advance Care Directives are focused on the future care of a person, not on the management of his or her assets.
	Common law (non-statutory) advance care directive: a structured document that is completed and signed by a competent adult and that is not a legislated statutory document. This includes: • a document completed and signed by a competent person in a jurisdiction which does not have legislation authorising an advance care directive regarding preferences for care (that is, New South Wales and Tasmania) • an instruction or directive completed and signed by a competent person, in a jurisdiction with advance care planning legislation, but where the document does not comply with the requirements set out in this legislation and is recognised instead by common law.
	Statutory advance care directive: a signed document that complies with the requirements set out by a jurisdiction's legislation.

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Term	Definition
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Advance Care Plan* Including but not limited to: Advance Care Plans, Statements of Choice; Statement of Choices – No Legal Capacity	Documents that capture an individual's beliefs, values and preferences in relation to future care decisions, but which do not meet the requirements for statutory or common law recognition due to the person's lack of competency, insufficient decision-making capacity or lack of formalities (such as inadequate person identification, signature and date). An Advance Care Plan for a non-competent person is often very helpful in providing information for substitute decision-makers and health practitioners and may guide care decisions but are not legally binding. An Advance Care Plan may be oral or written, with written being preferred. A substitute decision-maker named in an Advance Care Plan is not a statutory appointment.
Advance care planning	A process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known to guide decision-making at a future time when that person cannot make or communicate their decisions. Registered and non-registered health practitioners have a role in advance care planning and require capability to facilitate these conversations effectively. The National Quality Standards for aged care, general practice and health services all promote advance care planning. Individuals can also choose to engage in advance care planning with other non-health practitioners, such as friends or family.
Advance care planning documents	A catch-all term to include documents that result from advance care planning. This includes Advance Care Directives and advance care plans.

*Some jurisdictions use the term 'advance care plan' for documents which are completed and signed by a competent adult and that are legally binding by common law. Within this Framework, these documents are considered 'Common law (non- statutory) Advance Care Directives'. In these jurisdictions the definition of 'advance care plan' should be read in conjunction with 'Common law (non-statutory) Advance Care Directives'.

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Term	Definition
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Capacity	The ability to make a decision for oneself. Decision-making capacity can be assessed by trained professionals, and its assessment depends on the type and complexity of the decision to be made. Capacity assessment does not assess whether the decision is considered "good" or "bad" by others such as clinicians or family, but rather considers the person's ability to make a decision and comprehend its implications. Generally, when a person has capacity to make a particular decision they can do all of the following: • understand and believe the facts involved in making the decision • understand the main choices • weigh up the consequences of the choices • understand how the consequences affect them • make their decision freely and voluntarily • communicate their decision. By default, people are assumed to have capacity unless there is evidence to the contrary.
Comprehensive care plan Including but not limited to: clinical care plans, clinical pathway, or medical order	A document or electronic view which describes agreed goals of care, and outlines planned medical, nursing and allied health activities for a patient. Comprehensive care plans reflect shared decisions made with patients, carers and families about the tests, interventions, treatments and other activities needed to achieve the goals of care. The content of comprehensive care plans will depend on the setting and the service that is being provided and may be called different things in different health organisations. For example, a care or clinical pathway for a specific intervention may be considered a comprehensive care plan. A comprehensive care plan is different to an advance care directive. While an advance care directive is completed by an individual, a comprehensive care plan is written by health practitioners together with the individual through shared decision-making (wherever possible). It is appropriate that comprehensive care plans be put in place whether or not the person has made an advance care directive or advance care plan, but when there is an existing document that records directions about care, the comprehensive care plan complements, and therefore should be informed by, the person's documented preferences.

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Term	Definition
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Competency	Competency is a legal term used to describe the mental ability required for an adult to perform a specific task. Competency is recognised in legislation and in common law as a requirement for completing a legal document that prescribes future actions and decisions, such as a will or an advance care directive. A person is deemed to be either competent or not competent – there are no shades of grey. Competency must be assumed unless there is evidence to suggest otherwise.
Goals of care	Clinical and other goals for a patient's episode of care that are determined in the context of a shared decision-making process. Goals of care may change over time, particularly as the patient enters the terminal phase and during end-of-life care. Medical goals of care may include attempted cure of a reversible condition, a trial of treatment to assess reversibility of a condition, treatment of deteriorating symptoms, or the primary aim of ensuring comfort for a dying patient. Non-medical goals of care articulated by the person may include returning home or reaching a particular milestone, such as participating in a family event. Goals of care documents are different to Advance Care Directives. Goals of care are completed by medical practitioners but should align with the preferred health outcomes and treatment decisions made by the individual (to the capacity they have to participate in shared decision-making). The person may or may not have previously completed an advance care directive. Where an advance care directive has been completed, and the individual no longer has decision-making capacity, the goals of care should reflect the advance care directive, and should include a discussion with the person's substitute decision-maker.
Substitute decision-maker also known as surrogate decision-makers	A collective term for a person appointed or identified by law to make substitute decision(s) on behalf of a person whose decision-making is impaired. A substitute decision-maker may be appointed by the person, appointed for (on behalf of) the person, or identified as the default decision-maker within legislation. Substitute decision-makers listed in Advance Care Directives are statutory appointments. Substitute decision-makers listed in advance care plans are not.
Terminology used in My Health Record[21]	
Advance care document custodian	An advance care document custodian is a term used specifically in My Health Record. It refers to the person and/or organisation holding a copy of an individual's current advance care planning document. Health professionals can contact an advance care document custodian to access an individual's advance care planning information should the need arise.
Advance care planning information	A collective term used in My Health Record to describe any document capturing beliefs, values and preferences for care for people who are no longer able to speak for themselves. This includes Advance Care Directives, advance care plans, and documents developed to summarise goals of care in the context of end-of-life care.

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Term	Definition
Terminology used in My Health Record[21]	
Authorised representative	A person authorised to manage an individual's My Health Record on their behalf. Typically, this will be: • a parent or legal guardian of a child under the age of 14 years • someone with enduring power of attorney for an individual who is • 14 years or older and who is not capable of making his or her own decisions. In the absence of someone with parental responsibility or legal authority, a person who is otherwise appropriate to act on behalf of the individual can be an authorised representative. An individual can have more than one authorised representative.
Healthcare provider	A person who is involved in or associated with healthcare delivery. For the purposes of the My Health Record system, a healthcare provider is a person who has a Healthcare Provider Identifier – Individual (HPI-I) and is authorised by a registered healthcare provider organisation to access the My Health Record system on their behalf.
Healthcare provider organisation	An organisation, or part of an organisation, that has conducted, conducts, or will conduct, healthcare.
My Health Record	A secure online summary of an individual's health information that is available to all Australians. My Health Record supplements existing patient/medical records with a high-value, shared source of patient information that can improve care planning and decision-making. Information available through My Health Record can include a patient's health summary, medication prescribing and dispensing history, pathology reports, diagnostic imaging reports, discharge summaries, advance care planning information and other clinical content.
My Health Record system	The Australian Government's digital health record system. The My Health Record system was launched on 1 July 2012 and provides a system of managing health information online. Previously known as a personally controlled electronic health record (PCEHR) or eHealth record.

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Term	Definition
Terminology used in My Health Record[21]	
Nominated representative	A person invited by an individual or the individual's authorised representative to view and/or help them manage their My Health Record. Typically, this will be a family member, carer or close friend. A nominated representative can be given general access, restricted access or full access to an individual's My Health Record (access types are described in the guideline).
Other terminology	
End of life[10]	The period when a patient is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown. This period may be years in the case of patients with chronic or malignant disease, or very brief in the case of patients who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma.
Jurisdiction	A state or territory within Australia.
Digital inclusion[22]	Digital inclusion describes the ability of individuals to be online and able to take advantage of the education, health and social benefits of being connected digitally. The Australian Digital Inclusion Index aims to measure the level of digital inclusion of the Australian population as a whole and monitor this over time.
Shared decision-making[2]	A consultation process in which a clinician and a patient (or substitute decision-maker if the person lacks capacity) jointly participate in making a health decision, having discussed the options, and their benefits and harms, and having considered the person's values, preferences and circumstances.

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Terminology used in different jurisdictions

Term	Alternative terms	Jurisdiction
Advance care directive	Health Direction	ACT
	Advance Care Directive	NSW
	Advance Personal Plan (includes Advance Consent Decision and optional Advance Care Statement)	NT
	Advance Health Directive Advance Health Directive for Mental Health	QLD
	Advance Care Directive	SA
	Advance Care Directive for Care at the End of Life	TAS
	Advance Care Directive (can include an instructional directive and a values directive)	VIC
	Advance Health Directive	WA
Advance Care Plan	Advance Care Plan – Statement of Choices (competent person) Advance Care Plan – Statement of Choices (no legal capacity)	ACT
	Statement of Values and Wishes	NSW
	Advance Care Statement	NT
	Statement of Choices Form A – for persons with decision-making capacity Statement of Choices Form B – for persons without decision-making capacity or requiring supported decision-making	QLD
	My Advance Care Plan	WA

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Term	Alternative terms	Jurisdiction
Goals of care plan	Goals of Care Document	ACT
	Medical Order for Life-Sustaining Treatment	ACT
	Acute Resuscitation Plan	QLD
	Medical Goals of Care Plan	TAS
	Medical Treatment Plan Goals of Care Plan Resuscitation Plan	VIC
	Goals of Patient Care	WA
Substitute decision-maker	Enduring Power of Attorney	ACT
	Enduring Guardian	NSW
	Substitute Decision-Maker (covered within the Advance Personal Plan)	NT
	Statutory Health Attorney Enduring Power of Attorney (for financial and/or personal/health matters)	QLD
	Substitute Decision-Maker (for healthcare, residential, accommodation and personal matters: covered within the Advance Care Directive) Enduring Power of Attorney (for financial matters)	SA
	Enduring Guardianship (for personal, medical and lifestyle decisions) Enduring Power of Attorney (for financial matters)	TAS

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Term	Alternative terms	Jurisdiction
Substitute decision-maker	Medical Treatment Decision-Maker (legal authority to make medical treatment decisions on a person's behalf) Support Person (assist the person in making, communicating and giving effect to their medical treatment decisions and accessing relevant health information) Enduring Power of Attorney (for financial, personal and lifestyle decisions)	VIC
	Enduring Power of Guardianship (for personal, medical and lifestyle decisions) Enduring Power of Attorney (for financial matters)	WA

Abbreviations

ACP	advance care planning
EMR	electronic medical record
ICT	information and communication technology
LDAC	limited document access code
MBS	Medicare Benefits Schedule
NCP	National Consumer Portal
NFR	not for resuscitation
NPP	National Provider Portal
PBS	Pharmaceutical Benefits Scheme
RAC	record access code

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Advance care planning

Setting / audience	Organisation	Resource
All	Advance Care Planning Australia	Advance care planning in different settings and groups
	Advance Care Planning Australia	Educational resources
	Medical Journal of Australia article	Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers
Aged care	palliAGED (Palliative Care Aged Care Evidence) *Funded by Australian Government Department of Health*	Advance care planning Includes information for a range of audiences and healthcare settings
	ELDAC (End of Life Decisions for Aged Care) *Funded by Australian Government Department of Health*	Advance care planning information and tools
	Advance Care Planning Australia	Advance care planning in aged care: A guide to support implementation in community and residential settings
Emergency care	palliAGED (Palliative Care Aged Care Evidence) *Funded by Australian Government Department of Health*	Emergency planning and management
Mental health / cognitive health	University of Sydney Cognitive Decline Partnership Centre	Information and tools to support advance care planning for people with dementia
	National consortium *Funded by Australian Government Department of Health*	Talking end of life with people with intellectual disability
Palliative care	CareSearch	Palliative care e-learning (including information on advance care planning)
	Program of Experience in the Palliative Approach (PEPA) *Funded by Australian Government Department of Health*	Education resources

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Setting / audience	Organisation	Resource
Primary care	HammondCare *Funded by Australian Government Department of Health*	Advance Project
	RACGP	Online modules available through gplearning
	ThinkGP	Advance care planning in primary care
All	Australian Digital Health Agency	My Health Record website
Consumers	Australian Digital Health Agency	My wishes, my plan: advance care planning factsheet
Consumers	Australian Digital Health Agency	Add an advance care plan
Mental health	Australian Digital Health Agency	Mental Health Toolkit: e-book for healthcare providers
Emergency	Australian Digital Health Agency	Emergency Department Clinicians' Guide to My Health Record in ED

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Appendix IV: Challenges and enablers for advance care planning

	Challenges	Enablers/drivers
Individual	**Poor public awareness** of what advance care planning is and how to do it[23,24]	**Promotion of the benefits** of advance care planning for the person and for others
	Anxiety and fear about discussing serious and life-threatening illness, leading to avoidance of discussions about mortality and ill-health[25]	**Support** to help people to start, continue and document conversations about advance care planning
	Perception that advance care planning documents cannot be changed, and a reluctance to make such plans when the future is uncertain[3,24]	Use of **decision aids** to support a shared decision-making approach to discussions about goals of care[26]
Substitute decision-maker	**Lack of understanding** of what the role of substitute decision-maker entails	**Information** about the role of substitute decision-maker
	Lack of knowledge of the person's beliefs, values and preferences	**Support** to help substitute decision-makers start, continue and document conversations about advance care planning
	Difficulty advocating on the person's behalf during times of illness	
Health Professional	Different expectations between patients and health professionals about who will **initiate conversations about prognosis/end-of-life care**[27]	**Upskilling of health professionals** in effective communication around prognosis, advance care planning, end-of-life care, and provision of tools/ resources to support this[27]
	Reluctance of health professionals to discuss end-of-life issues particularly if people with a life-limiting illness report feeling well [28]	**Processes to share** advance care planning documents and other relevant documents during transitions of care[10]
	Lack of training for health professionals in initiating/having conversations about serious illness and end-of-life care,[25,27] and discussing advance care planning and goals of care[5]	**Prompts within clinical workflows** to remind health professionals to discuss advance care planning with patients at relevant times
	Challenges in particular healthcare settings and situations such as **during emergency care, in emergency departments and where a person's health deteriorates rapidly**[5, 29, 30]	
System	An **emphasis within the health system on life-sustaining treatment** and care[25]	**Electronic advance care planning and goals of care document templates**[31]
	The **complexity of legal frameworks**, including variation across Australian jurisdictions[6]	**Processes to document** advance care planning and goals of care discussions in the person's medical record[10]
	Variation in document types, locations and access[25]	**Funding** to facilitate advance care planning[10]
		National standards formalising requirements for advance care planning and goals of care

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My Health Record legislation

Legislation	Purpose
My Health Records Act 2012	Establishes the role and functions of the My Health Record System Operator (Australian Digital Health Agency) Provides a registration framework for individuals, and organisations providing health services, to participate in the My Health Record system Provides a privacy framework (aligned with the Privacy Act 1988) specifying which entities can collect, use and disclose certain information in the system (such as health information contained in an individual's My Health Record), and the penalties that can be imposed on improper collection, use and disclosure of this information
My Health Records Rule 2016	Supports the secure operation of the My Health Record system by specifying rules for use by registered entities
My Health Records Regulation 2012	Specifies additional information as identifying information and privacy laws that continue to apply to the disclosure of sensitive information
My Health Records (Assisted Registration) Rule 2015	Specifies requirements for registered healthcare providers that assist individuals to register for a My Health Record (through 'assisted registration')

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Standards related to advance care planning

National Safety and Quality Health Service Standards[2]

Standard	Item	Action
5. Comprehensive care standard	Planning for comprehensive care	5.9 Patients are supported to document clear advance care plans
	Using the comprehensive care plan	5.14 The workforce, patients, carers and families work in partnership to: a. Use the comprehensive care plan to deliver care b. Monitor the effectiveness of the comprehensive care plan in meeting the goals of care c. Review and update the comprehensive care plan if it is not effective d. Reassess the patient's needs if changes in diagnosis, behaviour, cognition, or mental or physical condition occur
	Comprehensive care at the end of life	5.17 The health service organisation has processes to ensure that current advance care plans: a. Can be received from patients b. Are documented in the patient's healthcare record
		5.19 The health service organisation has processes for routinely reviewing the safety and quality of end-of-life care that is provided against the planned goals of care
		5.20 Clinicians support patients, carers and families to make shared decisions about end-of-life care in accordance with the National Consensus Statement: Essential elements for safe and high-quality end-of-life care
2. Partnering with Consumers	Healthcare rights and informed consent	2.5 The health service organisation has processes to identify: a. The capacity of a patient to make decisions about their own care b. A substitute decision-maker if a patient does not have the capacity to make decisions for themselves

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Standard	Item	Action
	Sharing decisions and planning care	2.6 The health service organisation has processes for clinicians to partner with patients and/or their substitute decision-maker to plan, communicate, set goals, and make decisions about their current and future care
		2.7 The health service organisation supports the workforce to form partnerships with patients and carers so that patients can be actively involved in their own care
6. Communicating for Safety	Clinical handover	6.8 Clinicians use structured clinical handover processes that include: a. Preparing and scheduling clinical handover b. Having the relevant information at clinical handover c. Organising relevant clinicians and others to participate in clinical handover d. Being aware of the patient's goals and preferences e. Supporting patients, carers and families to be involved in clinical handover, in accordance with the wishes of the patient f. Ensuring that clinical handover results in the transfer of responsibility and accountability for care
	Documentation of information	6.11 The health service organisation has processes to contemporaneously document information in the healthcare record, including: a. Critical information, alerts and risks b. Reassessment processes and outcomes c. Changes to the care plan
8. Recognising and responding to acute deterioration	Partnering with consumers	8.3 Clinicians use organisational processes from the Partnering with Consumers Standard when recognising and responding to acute deterioration to: a. Actively involve patients in their own care b. Meet the patient's information needs c. Share decision-making

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Standard	Item	Action
1. Governance, leadership and culture	Healthcare records	1.17 The health service organisation works towards implementing systems that can provide clinical information into the My Health Record system that: a. Are designed to optimise the safety and quality of health care for patients b. Use national patient and provider identifiers c. Use standard national terminologies
		1.18 The health service organisation providing clinical information into the My Health Record system has processes that: a. Describe access to the system by the workforce, to comply with legislative requirements b. Maintain the accuracy and completeness of the clinical information the organisation uploads into the system

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Aged Care Standards[12]

Standard	Item	Action
Standard 2	Organisation statement	The organisation undertakes initial and ongoing assessment and planning for care and services in partnership with the consumer. Assessment and planning has a focus on optimising health and well-being in accordance with the consumer's needs, goals and preferences.
	Requirement 2(3)(a)	Assessment and planning, including consideration of risks to the consumer's health and well-being, informs the delivery of safe and effective care and services
	Requirement 2(3)(b)	Assessment and planning identifies and addresses the consumer's current needs, goals and preferences, including advance care planning and end-of-life planning if the consumer wishes
	Requirement 2(3)(d)	The outcomes of assessment and planning are effectively communicated to the consumer and documented in a care and services plan that is readily available to the consumer, and where care and services are provided
Standard 3	Organisation statement	The organisation delivers safe and effective personal care, clinical care, or both personal care and clinical care, in accordance with the consumer's needs, goals and preferences to optimise health and well-being.
	Requirement 3(3)(c)	The needs, goals and preferences of consumers nearing the end of life are recognised and addressed, their comfort maximised and their dignity preserved
	Requirement 3(3)(d)	Deterioration or change of a consumer's mental health, cognitive or physical function, capacity or condition is recognised and responded to in a timely manner

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Uploading advance care planning documents to My Health Record

1. Log in to your My Health Record
2. Select the **Documents** menu in the top navigation menu
3. Select **Advance Care Planning**
4. Click on **Add an Advance Care Planning Document**
5. Browse and select the document you want to add to your record
6. Enter the date that the document was last updated
7. Enter the name and contact number of the person who wrote the document (usually the person to whom the document applies)
8. Click **Prepare document for review and upload:** the selected document will be displayed
9. Review the document:
   a. check it is the right way up
   b. check the document is complete
   c. check the document contains the correct information
10. Click the **Confirm and Add to my record** button
11. Enter the names and contact details of the people you have shared the document with including your advance care document custodian/s (these details can be changed at any time)
12. Once advance care planning document(s) have been uploaded they can be viewed from any computer or mobile device with an internet connection

Tips on saving documents to make upload to My Health Record easier

- Paper-based forms should be scanned and saved as a PDF (include the person's name, date and type of document in the title).
- When naming the document, include the author's name, date and type of document (e.g. advance care directive, advance care plan, goals of care plan). This will not appear on My Health Record but will make the document easier to locate.
- File size should ideally be less than 5 MB (files larger than 21 MB will not upload to My Health Record).
- Scanning documents in black and white can help to reduce the file size.

Adding or amending an advance care document custodian in My Health Record

1. Go to the **Advance Care Planning Overview** page of My Health Record
2. Select the **Add a custodian** button on the
3. Enter one or more custodian names:
   These are the people who you have shared your advance care planning documents with; your doctors will be able to contact these people if you are not well enough to tell your doctors about views and wishes for your healthcare. You can update these names and contact details at any time.
4. Select the **Save** button.

Australian Government
Australian Digital Health Agency

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Removing advance care planning documents from My Health Record

1. Log in to your My Health Record
2. Select the **Documents** menu in the top navigation menu
3. Select **Clinical Records**
4. Select **Advance Care Plans**
5. Choose the document you wish to remove and select **Manage Access**
6. Select **Remove Document**
7. Before saving changes, scroll down the page to check you have selected the correct document
8. Select **Save**
9. Select **Yes** to confirm your changes

Viewing an advance care planning or goals of care document in My Health Record

1. Log into your My Health Record
2. Select the **Documents** tab
3. Select **Advance Care Planning**
4. Scroll down to **Advance care planning documents available on this record**
5. Select the document you want to view

Finding out who has viewed a person's My Health Record

1. Log in to your My Health Record
2. Select the **Privacy and Access** tab
3. Scroll down to **Record Access History**
4. Select **View** to see the access history for the last 12 months

Setting up notifications to see when someone accesses a person's My Health Record

1. Log in to your My Health Record
2. Select the **Profile and Settings** tab and then **Notification Settings**
3. Select whether you would like to be notified by email or SMS and enter your contact details
4. You can then choose which notifications you want to receive

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