

# **Advance Care Planning My Health Record Conformance Profile**

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### **Table of contents**

| 1     | Introduction      |   |    |
|-------|-------------------|---|----|
|       | 1.1<br>1.2<br>1.3 | Purpose   | 5  |
| 2     | Rele              | evant Specifications                            | 6  |
| 3     | Con               | formance Requirements for Advance Care Planning | 7  |
|       | 3.1               | Requirements for Document Producing Systems     | 7  |
|       | 3.2               | ·   |    |
| Acror | nyms              |   | 17 |
| Gloss | ary               |   | 18 |
| Refer | ence              | 25  | 20 |

#### 1 Introduction

### 1.1 Purpose

This document summarises the requirements for producing systems and consuming systems of Advance Care Planning documents that connect to the My Health Record System.

This document lists the specific conformance requirements for Advance Care Planning documents that are in addition to the common conformance profile for clinical documents [NEHTA2015]. Together, both documents represent the complete conformance requirements for Advance Care Planning documents.

#### 1.2 Intended Audience

The intended audience includes the following:

- Healthcare Providers;
- Vendors and developers of connecting systems; and
- Software test laboratories.

### 1.3 Scope

The scope of this Conformance Profile is the use of Advance Care Planning documents in the context of the My Health Record System.

An Advance Care Planning document is created by an authoring Clinical Information System (CIS) or a consumer portal.

The Advance Care Planning document is a Clinical Document Architecture (CDA) document that contains a single PDF attachment of a copy of the Advance Care Planning document.

The following roles may be performed by software systems:

- Advance Care Planning Document Producing System A software system used by a healthcare provider or healthcare individual to create and upload the Advance Care Planning document.
- Advance Care Planning Document Consuming System A software system that can download and render an Advance Care Planning document.

### **2** Relevant Specifications

Related detailed conformance requirements are listed below:

- 1 Clinical Documents Common Conformance Profile [NEHTA2015] provides common conformance requirements that must be adhered to unless specifically contradicted in this document.
- 2 *eHealth Advance Care Planning Structured Content Specification* [DH2017a] specifies the data elements and constrained values for an Advance Care Planning document at a logical level.
- 3 *eHealth Advance Care Planning CDA Implementation Guide* [DH2017b] specifies the mapping from the structured content specification into an Advance Care Planning document using an HL7 CDA structure.

### 3 Conformance Requirements for Advance Care Planning

This document summarises the requirements for producing systems and consuming systems of Advance Care Planning documents that connect to the My Health Record System. It lists the specific conformance requirements for Advance Care Planning documents that are in addition to the common conformance profile for clinical documents [NEHTA2015].

This section describes the conformance requirements specific to Advance Care Planning documents when used in communication with the My Health Record system.

These Advance Care Planning requirements focus on the upload of a PDF version of a pre-existing Advance Care Plan.

### 3.1 Requirements for Document Producing Systems

In this section, the term "producing system" refers to software that creates and prepares the Advance Care Planning CDA document for upload to the My Health Record System. It is often the same software that uploads the CDA document.

|  | 023512 | Advance C | Care Planning | Producing 5 | Systems |
|--|--------|-----------|---------------|-------------|---------|
|--|--------|-----------|---------------|-------------|---------|

An Advance Care Planning Producing System SHALL NOT be a:

Registered Repository Registered Provider Portal

**Priority** Mandatory

Additional Notes Clinical Information System (i.e. a Healthcare Provider CIS), registered consumer portal and CSP System can be document providers by permitting the Advance Care Planning document to be attached to a CDA document and

facilitating the upload of that CDA package.

023590 Document conformance levels

An Advance Care Planning document sent to the My Health Record System SHALL conform to the requirements of one, and only one, of the following conformance levels: either 3A or 3B as defined in the Clinical Documents –

Common Conformance Profile [NEHTA2015].

**Priority** Mandatory

024980 Confirm individual electronic communication details to be included

Software SHALL allow document authors to confirm which (if any) of their individual electronic communication details (e.g. email address, phone number or fax number) may be automatically included. The default SHALL be

to include no details.

023513 Single valid Advance Care Plan

The software SHALL upload the Advance Care Planning document to the My Health Record system as a new document and SHALL NOT upload the document as a superseding document.

**Priority** Mandatory

Additional Notes Updated Advance Care Planning documents should be uploaded as a new and unique document to alleviate any potential issues regarding currency

and validity.

The My Health Record System will not allow amended documents. It will

only allow a new document upload.

027151 Labelling attachment author

The software SHALL record, in the narrative, the attachment author and the attachment author SHALL be recorded as "Author of the advance care

planning document".

**Priority** Mandatory

Additional Notes

027152 Labelling contact number

When known, the software SHALL record in the narrative, one and only one contact phone number for the attachment author and the contact phone number SHALL be recorded as "Contact number for the author of the

advance care planning document".

**Priority** Mandatory

Additional Notes

027153 Labelling contact details

The software SHOULD record, in the narrative, contact details such as additional phone numbers, email addresses and addresses associated with

the "Advance Care Planning document author".

**Priority** Recommended

Additional Notes

#### 027154 Labelling Date attachment written

The software SHALL record, in the narrative, the date the attachment was written as "Date advance care planning document was written".

**Priority** Mandatory

Additional Notes

#### 027490 CDA document has a PDF packaged attachment

A CDA document SHALL reference one, and only one, attachment that is an electronic representation of the Advance Care Planning document. The attachment SHALL be a PDF packaged attachment.

**Priority** Mandatory

# Additional Notes

This requirement applies only to attachments that are Advance Care Planning documents and not to other attachments (e.g. a company logo). The attachment should be in PDF format to ensure the presentation and rendering is as expected by the author.

The PDF file is expected to be viewable by the healthcare individual and any healthcare provider that is a My Health Record participant. For example, PDF file should not have any of these features:

- - Encryption
- - Password protection
- - Printing or copying restriction
- Embedded fonts (as not all PDF viewers support them)

#### 027491 Relaxation for mandatory HPI-I for a healthcare provider author

If the CDA document author is a healthcare provider the value of one document author entity identifier SHALL be a HPI-I if one is available to the authoring system, otherwise it SHALL have a value that identifies the document author and the value SHALL not be an absent value.

See requirement 27576 for information about absent values.

**Priority** Conditional

# Additional Notes

It is permissible for a healthcare provider or organisation to upload an advance care planning document written by the individual or by a representative. This relaxation supports the ability for a healthcare organisation to upload advance care planning documents in situations where the document was not prepared by a healthcare provider.

027600 No abnormal values

When recording a nullFlavor, the document SHALL only contain absent values according to requirement 27576.

**Priority** Mandatory

Additional Notes

The document is not to contain a nullFlavor value other than those described in requirement 27576.

See the structured content specification [NEHTA2017a] for more information on abnormal and absent values.

**027576** Permissible absent values

When including an absent value for any element in the document, the absent value SHALL only be one of the following:

NI - No information UNK - Unknown

ASKU - Asked but unknown NAV - Temporarily unavailable

NASK - Not asked MSK - Masked NA - Not applicable

**Priority** Mandatory

Additional Notes

See section C.4 in the structured content specification for more information  $\label{eq:content} \begin{subarray}{c} \end{subarray}$ 

[NEHTA2017a].

#### 027575 Mandatory values

When producing an Advance Care Planning document, the following elements SHALL be provided and SHALL NOT contain an absent value:

- Subject of care > Family name
- Subject of care > Sex
- Subject of care > Date of birth
- Subject of care > Indigenous status

CDA document author > Electronic communication details for the organisation (if healthcare provider)

CDA document author > Electronic communication details for the individual (if not healthcare provider)

Advance care information > Related document > Document author > Family name

**Priority** Mandatory

Additional Notes

This requirement overrides the CDA Implementation Guide when uploading

an Advance Care Planning document to a My Health Record. See requirement 27576 for more information about absent values.

027599 Related document author electronic communication details

The element:

Related document > document author > Electronic communications details

MAY be omitted or contain an absent value.

**Priority** Mandatory

**Additional Notes** 

This requirement relaxes the CDA Implementation Guide when uploading an

Advance Care Planning document to a My Health Record.

See requirement 27576 for information about abnormal values.

027601 Support for upload by care agency employees

The document SHALL permit a care agency employee identifier to be stored

as the document author's identifying number.

**Priority** Mandatory

Additional

In some cases, the author of an individual's Advance Care Planning document Notes

may be a care agency employee whose identity is not associated with an IHI

or HPI-I. The care agency employee identifier may be used instead of an IHI

or HPI-I.

#### On screen warnings and help text 3.1.1

027489 Display text at point of upload

> Where this document requires the display of help text, that help text SHALL be displayed at the point of upload and for each and every upload, or prior to

each download, depending on the requirement and the action to be

performed.

**Priority** Mandatory

**Additional** 

Help text and warnings are to be displayed on each occurrence of document **Notes** 

upload and downloads to ensure the uploader/downloader is informed.

023514 Display text to advise for automated system notifications If the software is a CIS, the software SHALL provide help text to remind Healthcare Providers to recommend that the healthcare individual opts to receive email or SMS notifications from the My Health Record system when changes are made to the Individual's Advance Care Planning document on the My Health Record system.

The help text SHALL display:

"Healthcare providers should recommend healthcare individuals choose to receive a SMS text message or an email notification when an advance care planning document is uploaded, reinstated or removed from their My Health Record by an Authorised Representative, their Full Access Nominated Representative or a healthcare provider."

#### **Priority** Mandatory

# Additional Notes

Healthcare individuals need to be aware of any changes made to their Advance Care Planning documents. This is due to the nature of the document (life and death decisions), and the implications it can have to the medical treatment they receive.

#### 023510 Display text to advise about Healthcare Provider's obligations

If the software is a CIS, the software SHALL provide help text advising Healthcare Providers they have obligations in relation to Advance Care Planning documents stored on a My Health Record.

The help text SHALL display:

"Healthcare providers have obligations when reading advance care planning documents stored on an individual's My Health Record. Healthcare providers can upload advance care planning documents only when requested by the individual."

#### **Priority** Mandatory

#### Additional Notes

To ensure Healthcare Providers are aware that there are obligations when reading Advance Care Planning documents on the My Health Record system.

#### 023507 Display text to advise about informing Advance Care Document Custodians

The software SHALL provide help text to advise the user that the Advance Care Document Custodian should be informed whenever an Advance Care Planning document is uploaded or removed from the healthcare individual's My Health Record.

If the software is a CIS then the help text SHALL display:

"If you change any advance care planning document(s), including uploading or removing documents from the My Health Record, you should recommend the individual informs their Advance Care Document Custodian."

If the software is a registered consumer portal then the help text SHALL display:

"If you change any advance care planning document(s), including uploading or removing documents from your My Health Record, you should inform your Advance Care Document Custodian."

**Priority** Mandatory

Additional Notes

It is important that the Advance Care Document Custodian is aware of the currency of the individual's Advance Care Planning documents.

#### 023595 Display text to advise about malicious content

If the software is a registered Consumer Portal, the software SHALL provide help text to the person uploading the document to refrain from uploading inappropriate or malicious content.

The help text SHALL display:

"To ensure inappropriate or malicious content is not uploaded, you should keep all your computer security measures and OS (operating system) regularly updated. Run your anti-virus and anti-spyware software often and use them to scrutinise all downloaded files before you open them. Delete dangerous files and malware immediately."

**Priority** Mandatory

Additional Notes The My Health Record system is unable to verify the content of a file that is uploaded, creating a risk that inappropriate files containing malicious content could be uploaded to a My Health Record.

#### 023593 Display text to advise who can upload

If the software is a registered Consumer Portal, the software SHALL provide help text to cover the following points:

- Healthcare individuals should be encouraged to keep a copy of Advance Care Planning documents and discuss Advance Care plans with their family members, friends, care givers and providers;
- Healthcare individuals should be encouraged to keep the Advanced Care Custodian record in the My Health Record system up-to-date;
- It should be clear that any person who can access the record is able to view Advance Care Planning documents.

The help text SHALL display:

- "You should provide a copy of your advance care planning document to your doctor and to someone to hold on your behalf (a custodian for the document), and discuss your advance care plans with your family members, friends, care givers and providers."
- "We recommend that you keep the Advance Care Document Custodian record in the My Health Record system up-to-date."
- "Once you have uploaded your document(s) to your My Health Record, healthcare providers that are connected to the My Health Record system and any representatives you may have will be able to see your advance care planning document(s). These documents are important and will be available to anyone who can access your My Health Record."

#### **Priority** Mandatory

# Additional Notes

Individuals should be made aware of their options with regard to Advance Care Planning documents, as well as what they should be doing to ensure future health planning.

#### 027393 Display text to advise healthcare individuals

If the software is a registered Consumer Portal, the software SHALL provide help text to advice that people other than the healthcare individual can upload and view Advance Care Planning documents.

The help text SHALL display:

"Healthcare providers, individuals, Authorised Representatives and Full Access Nominated Representatives can upload and view advance care planning documents on a My Health Record."

# Additional Notes

Other people (such as Authorised Representative, A Full Access Nominated Representative or Healthcare Provider) besides the healthcare individual should be made aware of their options with regard to Advance Care Planning documents, as well as what they should be doing to ensure future health planning.

#### 023508 Display text to advise documents may not be legally binding

If the software is a registered Consumer Portal, the software SHALL display on screen advice that the wishes expressed in an Advance Care Planning document may not be legally binding to Healthcare Providers.

The help text SHALL display:

"You should be aware that there are variations in state and territory laws which may affect the way in which a healthcare provider is able to respond to your advance care planning document(s)."

**Priority** Mandatory

Additional Notes

Each State and Territory of Australia legally recognises Advance Care Planning documents differently. All healthcare individuals should be informed of these legal limitations.

# 023594 Display text to advise on limitation on information added to a My Health Record

If the software is a registered Consumer Portal, the software SHALL display information about the limitations of Advance Care Planning document added to a My Health Record.

The help text SHALL display:

"You, or people acting on your behalf (such as an Authorised Representative or Full Access Nominated Representative) can add your advance care planning documents to your My Health Record.

Your document(s) should be:

- Written in English, signed and dated by you;
- Scanned in PDF format and saved on a computer;
- Uploaded to your record (from the 'add an advance care planning document page) from a computer; and
- Received by you to make sure it displays correctly on the screen

   check that no pages are missing and the document is the right
   way up.

You should be aware that not all healthcare providers are able to access your My Health Record and are not obligated to access it where they do have access. You should not rely on your My Health Record as the only place in which you make your future healthcare wishes known."

**Priority** Mandatory

Additional Notes Healthcare individual's need to be made aware of the implications of adding Advance Care Planning documents to a My Health Record.

### 3.2 Requirements for Document Consuming Systems

An Advance Care Planning document may be consumed by:

- Clinical Information Systems;
- CSP Systems;
- Registered Consumer Portals;
- Registered Provider Portals; and
- Registered Repositories.

#### 023511 Display text advising no guarantee of safety of attached file

The software SHALL display advice that the My Health Record System Operator can make no guarantees as to the safety of file content uploaded by third-parties. Healthcare Individuals and Healthcare Providers download and display the attachment at their own risk.

The help text SHALL display:

"My Health Record System operator makes no guarantees as to the safety of file content uploaded by third-parties. Individuals and healthcare providers download and display the attachment at their own risk."

### **Priority** Mandatory

# Additional Notes

The My Health Record system is unable to verify the content of a document that has been uploaded to the My Health Record, therefore there may be some risk that document consuming systems may be vulnerable to malicious code contained within documents.

## Acronyms

| Acronym | Description                    |
|---------|--------------------------------|
| CDA     | Clinical Document Architecture |
| CIS     | Clinical Information System    |
| CSP     | Contracted Service Provider    |
| HL7     | Health Level Seven             |

# Glossary

| Term                                 | Meaning   |
|--------------------------------------|---|
| Clinical Document Architecture (CDA) | An HL7 standard intended to specify the encoding, structure and semantics of clinical documents for exchange.   |
| Clinical Documents (archived)        | These are the documents with clinical information available in the Consumer and provider portals. These include: Shared Health Summary, Event Summary and Discharge Summary   |
| clinical information system (CIS)    | A system that deals with the collection, storage, retrieval, communication and optimal use of health related data, information, and knowledge.  A clinical information system may provide access to information contained in an electronic health record, but it may also provide other functions such as workflow, order entry, and results reporting.                                       |
| conformance                          | A measurement (by testing) of the adherence of an implementation to a specification or standard.  |
| contracted service provider (CSP)    | A third-party organisation that supplies health software as a service to healthcare organisations.  |
| Health Level Seven (HL7)             | HL7 provides standards for the exchange, management and integration of data that supports clinical patient care and the management, delivery and evaluation of healthcare services. Specifically, HL7 creates flexible, cost effective approaches, standards, guidelines, methodologies which enable healthcare information system interoperability and sharing of electronic health records. |
| healthcare individual                | An individual who is, or could be, the subject of care in the context of a healthcare event.  |
| producing system                     | A software system that has the role of generating and issuing conformant clinical documents suitable for use by other digital health participants.  |
| registered consumer portal           | A third-party portal used by consumers to access information on the My Health Record system that is registered with the My Health Record system as a registered portal operator.  |
| registered provider portal           | A third-party portal used by healthcare providers to access information on the My Health Record system that is registered with the My Health Record system as a registered portal operator.   |
| registered repository                | A third-party repository used to store clinical documents and other clinical data that connects to the My Health Record system. A repository may store clinical documents in either a proprietary format or a CDA format.   |

| Term   | Meaning  |
|--------|--|
| SHALL  | This word, or the term REQUIRED, means that the statement is an absolute requirement of the specification.   |
|        | Source: Network Working Group, 1997, RFC2119 - Key words for use in RFCs to Indicate Requirement Levels.   |
| SHOULD | This word, or the term RECOMMENDED, means that there may exist valid reasons in particular circumstances to ignore a particular item, but the full implications must be understood and carefully weighed before choosing a different course. |
|        | Source: Network Working Group, 1997, RFC2119 - Key words for use in RFCs to Indicate Requirement Levels.   |

### References

| [NEHTA2015] | Clinical Documents - Common Conformance, Version 1.6, NEHTA, 2015   |
|-------------|---|
| [DH2017a]   | Advance Care Information Structured Content Specification, Version 1.0, Digital Health Agency, 5 April 2017 |
| [DH2017b]   | Advance Care Information CDA Implementation Guide, Version 1.0, Digital Health Agency, 5 April 2017         |