

# ISA and USCDI Recommendations

Interoperability Standards Advisory and US Core Data for Interoperability

Advance Directives Data Class Recommendations

Unsolicited Proposal  
Submitted on June 4, 2020  
Revised on October 20, 2020

L. Scott Brown  
ADVault, Inc.  
Lisa R. Nelson, MS, MBA  
MaxMD

## Contents

Introduction .....	3
Advance Directives Data Class .....	4
Durable Medical Power of Attorney .....	4
Living Will .....	4
Advance Care Plan or Personal Advance Care Plan .....	4
Personal Health Goals for End of Life, Personal Care Experience Preferences .....	6
Advance Directive Observation .....	9
Patient Instructions Data Class .....	12
Obligation Instructions or Prohibition Instructions for Life-Sustaining Treatments .....	12
Medical Orders Data Class .....	14
Portable Medical Orders .....	14
Medical Orders for Life-Sustaining Treatments .....	14
Portable Medical Orders for Life-Sustaining Treatments .....	14
Current State of Portable Medical Orders for Life-Sustaining Treatments .....	14
Current Implementation of Advance Directive standards .....	15
Data Provenance Considerations .....	16
Use of New Assembler Role .....	16
Digitally Signed C-CDA Documents .....	17
Expressing Advance Directives Data Using FHIR Resources .....	17
Conclusion .....	17

## Introduction

The following information is an unsolicited proposal for including a new Advance Directives data class in the US Core Data for Interoperability (USCDI). The Advance Directives data class has been an optional part of Consolidated CDA (C-CDA) since release 1.1 and it has undergone additional review and balloting to produce a supplement to C-CDA R2.1 to update and improve the templates based on implementer feedback and domain analysis work done in the HL7 Patient Care Work Group. The C-CDA R2.1 Supplemental Templates for Advance Directives specification includes updated value set definitions and additional templates aligned with more precise data element definitions that distinguish a patient's future wishes for consideration by decision-makers from instructions that document treatment choices that have been made which obligate or prohibit care providers from performing specific types of healthcare services and medical interventions.

The HL7 CDA R2 Implementation Guide: Personal Advance Care Plan (PACP) Document, Release 1 US Realm specification was first published in 2016 and establishes templates describing how to create and exchange patient-authored documents that describe the person's goals and preferences for care under potential future situations. This specification also addresses how to represent living will and durable medical power of attorney information. The PACP specification was re-balloted in September 2019 and Release 2 was published in August 2020.

Current work undertaken by the PACIO FHIR Accelerator Community under the sponsorship of the HL7 Patient Empowerment Work Group will produce additional implementer guidance for the exchange of the Advance Directives data class. Implementer testing of FHIR-based exchange will begin in 2020 and ballot in May 2021. Implementer adoption of the CDA-based exchange began in 2016, and adoption continues to expand within the US.

In light of the recent response to COVID-19 where healthcare professionals clearly need and would benefit from knowing patients' wishes regarding specific treatments under certain conditions, enabling standardized exchange of advance directives information seems more important now than ever before. A recent article in the Journal of AHIMA titled COVID-19 Highlights HIM's Advance Care Planning Expertise states, "The documentation detailing a person's wishes for the medical interventions they receive at the end of their life is amongst the most sensitive data that health information management (HIM) professionals will ever handle. But for the providers that use that data to make life or death decisions, those records are frequently incomplete, contradictory, or missing entirely. In a pandemic where patients are making decisions isolated from their families and advocates, healthcare professionals are looking at advance care planning (ACP) documentation with new urgency."<sup>i</sup> In preparation for a predicted second wave of COVID-19, and in recognition of the maturity of this data class in terms of the template specifications and value set work completed through HL7, the following information is being provided to be included in the Interoperability Standards Advisory and considered as a potential data class for the USCDI.

## Advance Directives Data Class

The term “advance directive” describes information a person documents regarding his or her healthcare preferences in advance of when it may be needed to support medical interventions decision-making. It is a way of planning for the future and getting affairs in order, for a time in the future when the person’s wishes would need to be taken into consideration by caregivers and medical personnel. The information is often collected on a form which differs by state, traditionally used by a person to express his or her medical treatment wishes. Advance directives are typically classified as either a “durable medical power of attorney” or a “living will,” depending on the type of information they contain.

### Durable Medical Power of Attorney

A person uses a durable medical power of attorney to appoint one or more people to serve as advocates or “healthcare agents” empowered to make medical treatment decisions on behalf of the person if he or she is incapacitated and cannot communicate with medical personnel.

### Living Will

In a living will, a person specifies whether he or she wants (or does not want) “life-sustaining treatments” (*e.g.*, artificial nutrition or hydration, dialysis or the use of a ventilator to help with breathing), external cardiac compression (CPR), the application of an electric current to the heart (defibrillation), or the use of a tube placed into the windpipe through the mouth or nose to help the person breathe, should that person suffer a medical emergency and be unable to communicate with the care team. A living will includes information that helps the healthcare agent make treatment decisions on the person’s behalf, and is used by medical professionals to inform their treatment plans.

### Advance Care Plan or Personal Advance Care Plan

Advance care plan is a general term for any documentation or other recordation of a person’s medical treatment goals, preferences, and priorities for some future point in time, under certain circumstances when the individual cannot make medical treatment decisions or communicate his or her goals, preferences, and priorities with the care team. An advance care plan places an emphasis on communication, as opposed to legal formalities. A PACP is a term specifically defined by HL7 as a template to facilitate the sharing of information expressed in advance care plans.

A PACP may include the type of information contained in a living will and/or a durable medical power of attorney, and it also may include other medical interventions experience preference and instructions that help a healthcare agent make treatment decisions on the person’s behalf, and can be used by medical professionals to inform their medical interventions and treatment planning for the patient.

Within the family of documents that have been defined under Consolidated CDA, the PACP document can be classified as a type of patient generated document. The PACP document

facilitates digital exchange of information previously and currently captured and shared using paper documents. Digital exchange of this type of data has become particularly critical within the context of COVID-19. To reduce the spread of disease, hospitals have disallowed patient family members and/or representatives to be present when the patient is admitted and as medical interventions are rendered, while also prohibiting acceptance of paper documents due to concerns of contagion.<sup>ii</sup>

A PACP may include information relating to the appointment of a healthcare agent and alternate agents and establishing their authorized powers and limitations. It also may include information relating to any or all of the following: goals, preferences, and priorities for medical interventions (*e.g.*, palliative and/or hospice care), including medical treatment preferences, based on the patient’s individual values, spiritual and religious beliefs, and personal definitions of quality of life; instructions to be followed after death (*e.g.*, organ donation and autopsy); and information about who has signed, witnessed, and notarized the information authored by the individual, if available and appropriate.

The set of recognized kinds of advance directive documents include concepts from the value set: Advance Directives Categories urn:oid:2.16.840.1.113883.11.20.9.69.4 which is openly available for reference in the National Library of Medicine’s Value Set Authority Center. It can be referenced using this url:

<https://vsac.nlm.nih.gov/valueset/2.16.840.1.113883.11.20.9.69.4/definition>

Figure 1. Common collections of Advance Directive information

Data Element	Code	Definition
Power of Attorney (meaning Durable (Medical) Power of Attorney)	64298-3 LOINC urn:oid:2.16.840.1.113883.6.1	A power of attorney or POA is a legal document which authorizes someone to act on behalf of someone else. The person granting the power of attorney is known as the principal, granter, or donor, while the person authorized to act is called an agent, attorney-in-fact, or attorney. There are many different types of POAs, and each can be further customized to suit the requirements of the granter. In short, it all depends on the content of the contract. Power of attorney documents in LOINC represent a medical or durable power of attorney.
Living Will	86533-7 LOINC urn:oid:2.16.840.1.113883.6.1	Documents the life-sustaining treatments a person does or does not want should that person suffer a medical emergency and be unable to communicate with the care team.

Data Element	Code	Definition
Power of Attorney and Living Will (meaning Durable (Medical) Power of Attorney and Living Will)	92664-2 LOINC urn:oid:2.16.840.1.113883.6.1	A combined power of attorney and living will form. Power of attorney in LOINC represents a medical or durable power of attorney.
Personal Advance Care Plan	81334-5 LOINC urn:oid:2.16.840.1.113883.6.1	This term may be used as either the document or section code for the Personal Advance Care Plan. This term was created for, but is not limited in use to, the HL7 Implementation Guide for CDA Release 2: Personal Advance Care Plan Document (US Realm) Standard for Trial Use Release 2.

Personal Health Goals for End of Life, Personal Care Experience Preferences

A PACP may contain information similar to that contained in a living will or a durable medical power of attorney, as well as other personal health goals relevant to end-of-life treatment preferences, and medical interventions preferences. The list below summarizes the finer-grain data elements contained within a PACP. These data elements, in the context of a PACP, are authored by the patient.

Figure 2. Data elements used within a PACP

Data Element	Code	Definition
<b>Healthcare Agent Appointment</b>	Section.code identifier urn:hl7ii:2.16.840.1.113883.4.823.1.3.3:2020-06-10 (open)	This section records the appointment of healthcare agents. It should include appointment of a primary healthcare agent and may include an alternate healthcare agent and a second alternate healthcare agent.
<i>Range: N/A</i>		
Healthcare Agent Selection	Participant.type identifier urn:hl7ii:2.16.840.1.113883.4.823.1.4.2:2020-06-10 (open)	This clinical statement represents a person's appointment of a healthcare agent. The statement permits the person to indicate if the selection is for a primary healthcare agent, a first alternate healthcare agent or a second alternate healthcare agent.
<i>Range:</i> Healthcare Agent or Proxy Choices urn:oid:2.16.840.1.113762.1.4.1046.35 (SHALL) Personal And Legal Relationship Role Type urn:oid:2.16.840.1.113883.11.20.12.1 (SHOULD)		
Healthcare Agent Authority	Entry.code urn:hl7ii:2.16.840.1.113883.4.823.1.4.4:2020-06-10	This template is used to represent a power granted to (or limitation imposed upon) a person acting as healthcare agent.
<i>Range: N/A</i>		

Data Element	Code	Definition
<b>Goals, Preferences and Priorities For End-of-Life or Severely Debilitating Condition</b>	Section.code identifier urn:hl7ii:2.16.840.1.113883.4.823.1.3.4:2020-06-10 (open)	This section includes information about the author's goals, preferences and priorities for care and interventions at the end-of-life or when faced with a severely debilitating condition.
<i>Range: N/A</i>		
Personal Health Goal	Entry.code identifier urn:hl7ii:2.16.840.1.113883.4.823.1.4.6:2020-06-10 (open)	This template is used to represent a personal health goal. The author is constrained to be the recordTarget. This template was designed with the intention to support other types of personal health goals in the future through the use of other or expanded value sets. This should be encouraged, should designers consider creating a larger family of various different personal health goal clinical statement patterns.
<i>Range:</i> Health Goals at End of Life Grouping urn:oid:2.16.840.1.113762.1.4.1115.7 (SHOULD)		
MOLST Observation	Entry.code Identifier: urn:hl7ii:2.16.840.1.113883.4.823.1.4.8:2020-06-10 (open)	This template is used to indicate if a person has a medical order or physician order for life-sustaining treatments (MOLST or POLST). This observation does not indicate what orders are included in the MOLST or POLST. It indicates if a MOLST or POLST exists.
<i>Range: N/A</i>		
Personal Intervention Preference	Entry.code identifier urn:hl7ii:2.16.840.1.113883.4.823.1.4.5:2020-06-10 (open)	This template is used to represent a personal preference for a type of medical intervention (treatment). Preferences are thoughts (observations) and have a moodCode of INT to indicate that the statement represents the person's intention. The observation has a "future orientation."
<i>Range:</i> Intervention Preferences at End of Life Grouping urn:oid:2.16.840.1.113762.1.4.1115.9 (SHOULD)		
Personal Priorities Organizer	Entry.code identifier urn:hl7ii:2.16.840.1.113883.4.823.1.4.7:2020-06-10 (open)	This template is used to represent a set of personal goals or preferences in a prioritized order. It can be used to represent quality of life priorities.
<i>Range: N/A</i>		
<b>Goals, Preferences and Priorities For Personal Care Experience</b>	Section.code identifier urn:hl7ii:2.16.840.1.113883.4.823.1.3.6:2020-06-10 (open)	This section includes additional personal observations that can be considered when planning the care experience.
<i>Range: N/A</i>		

Data Element	Code	Definition
Care Experience Preference	Entry.code identifier urn:hl7ii:2.16.840.1.113883.4.823.1.4.10:2020-06-10 (open)	This clinical statement presents the author's personal thoughts about something he or she feels is relevant to his or her care experience and may be pertinent when planning his or her care.  This template was designed with the intention to support other types of Care Experience Preferences in the future through the use of other or expanded value sets.
<i>Range:</i> Care Experience Preferences at End of Life Grouping urn:oid:2.16.840.1.113762.1.4.1115.11 (SHOULD)		
Personal Priorities Organizer	Entry.code identifier urn:hl7ii:2.16.840.1.113883.4.823.1.4.7:2020-06-10 (open)	This template is used to represent a set of personal goals or preferences in a prioritized order.
<i>Range: N/A</i>		
<b>Goals, Preferences and Priorities Upon Death</b>	Section.code identifier urn:hl7ii:2.16.840.1.113883.4.823.1.3.5:2020-06-10 (open)	This section includes the author's goals, preferences, and priorities regarding decisions that will be made upon or following death. The template has a flexible design that permits all types of goal, preference and priority clinical statements because the author of the document should not be limited in what he or she wants to express as his or her directives following death.
<i>Range: N/A</i>		
Organ Donation Observation	Entry.code identifier urn:hl7ii:2.16.840.1.113883.4.823.1.4.12:2020-06-10 (open)	This template is used to represent the author's thoughts about organ donation.
<i>Range: N/A</i>		
Autopsy Observation	Entry.code identifier urn:hl7ii:2.16.840.1.113883.4.823.1.4.14:2020-06-10 (open)	This template is used to represent the author's thoughts about autopsy.
<i>Range: N/A</i>		
<b>Administrative Information</b>	Section.code identifier urn:hl7ii:2.16.840.1.113883.4.823.1.3.7:2020-06-10 (open)	This section includes administrative information about if there is record of the author signing the information contained in this Personal Advance Care Plan document. This section should indicate if the person has signed the advance care plan information and, if so, when.
<i>Range: N/A</i>		
Subject	RCT CodeSystem: HL7RoleCode urn:oid:2.16.840.1.113883.5.111	The recordTarget records the patient whose advance care plan directives are described by the clinical document.
<i>Range: N/A</i>		
Custodian	CST CodeSystem: HL7RoleCode urn:oid:2.16.840.1.113883.5.111	The custodian element represents the organization or person that is in charge of maintaining the original document.
<i>Range: N/A</i>		



Data Element	Code	Definition
Guardian	GUARD CodeSystem: HL7RoleCode urn:oid:2.16.840.1.113883.5.111	An entity that acts or is authorized to act as the guardian of the patient.
<i>Range:</i> Personal And Legal Relationship Role Type urn:oid:2.16.840.1.113883.11.20.12.1 (SHALL) This describes the guardian’s relationship to the patient.		
Author	AUT CodeSystem: HL7RoleCode urn:oid:2.16.840.1.113883.5.111	This represents the creator of the clinical document content. In the case of a Personal Advance Care Plan, the subject of the document (the recordTarget) is always the author as well.
<i>Range:</i> ONESELF CodeSystem: HL7 RoleCode urn:oid:2.16.840.1.113883.5.111 In the case of a Personal Advance Care Plan the author is the patient		
Notary or Witness	Authenticator typeCode = WIT CodeSystem: HL7ParticipationType urn:oid:2.16.840.1.113883.1.11.20106 <a href="http://terminology.hl7.org/CodeSystem/v3-ParticipationType">http://terminology.hl7.org/CodeSystem/v3-ParticipationType</a>	In the case of a PACP, the notary or witness attests to the identity of the author who created the document.
<i>Range:</i> Personal And Legal Relationship Role Type urn:oid:2.16.840.1.113883.11.20.12.1 DYNAMIC (SHOULD)		

### Advance Directive Observation

In the context of a Patient Summary or Encounter Summary authored by a clinician or assembled by a clinician’s EMR system, an Advance Directive Observation records the clinician’s verification of a patient’s advance directive information or medical orders for life-sustaining treatments.

Figure 3. Data Elements used in a Patient Summary or Encounter Summary to summarize information about a patient's Advance Directives.

Data Element	Code	Definition
<b>Advance Directives</b>	Section.code identifier: urn:hl7ii:2.16.840.1.113883.10.20.22.2. 21:2017-05-01	This section contains information describing the patient’s advance directives. The description includes the kind of advance directive source documents and the type of advance directive content included in each kind of advance directive source document.
<i>Range:</i> N/A		

Data Element	Code	Definition
Advance Directive Observation	Entry.code Identifier: urn:hl7ii:2.16.840.1.113883.10.20.22.4.48:2017-05-01 (open)	An Advance Directive Observation template is used to record information about a document authored by the person and containing goals, preferences, and priorities for care. The observation records that the document was available and may have been reviewed (verified). It records the kind (category) of advance directive document, where the document can be accessed, who verified it, and the type of content that was determined to be present.
<i>Range:</i> Advance Directives Categories urn:oid:2.16.840.1.113883.11.20.9.69.4 (SHOULD)		Indicates the kind of Advance Directive information. Possibilities are: Power of attorney, Patient Personal advance care plan, Patient Living will, and Power of attorney and Living will.
Advance Directive Content Type SCT urn:oid: 2.16.840.1.113762.1.4.1115 (SHALL)		Indicates the type of content present in a person's advance directive.
Verifier	VRF HL7ParticipationType urn:oid:2.16.840.1.113883.5.90	A clinician who verified the patient's advance directive.
<i>Range:</i> Healthcare Provider Taxonomy urn:oid:2.16.840.1.114222.4.11.1066 (SHOULD)		The verifier's healthcare specialty.
Healthcare Agent	CST HL7ParticipationType urn:oid:2.16.840.1.113883.5.90	A legal representative for healthcare decision-making who is acting in that capacity and participating in care decision-making during the documented care encounter.
Healthcare Agent or Proxy Choices urn:oid:2.16.840.1.113762.1.4.1046.35 (SHOULD)		Indicates the healthcare agent or proxy's role that the patient designated.
<i>Reference:</i> externalDocument containing verified Advance Directives.		
MOLST Observation	Entry.code Identifier: urn:hl7ii:2.16.840.1.113883.4.823.1.4.8:2020-06-10 (open)	This template is used to indicate if a person has a medical order or physician order for life-sustaining treatments (MOLST or POLST). This observation does not indicate what orders are included in the MOLST or POLST. It indicates if a MOLST or POLST exists.
<i>Range:</i> Boolean where true means the person does have an order regarding life-sustaining treatment and false means the person does not have an order regarding life-sustaining treatment.		
<i>Reference:</i> externalDocument containing verified Advance Directives.		

In a Patient Summary or Encounter Summary, Advance Directive Observations indicate if a person has a Personal Advance Care Plan, where the current source document can be referenced, if it was verified, and optional observations about what types of wishes the patient has expressed in his or her generated advance directive information, and if the person's advance directive documentation has been verified.

The set of recognized types of content include concepts from the value set: Advance Directives Content Type SCT urn:oid:2.16.840.1.113762.1.4.1115.5 which is openly available for reference in the National Library of Medicine’s Value Set Authority Center. It can be referenced using this url: <https://vsac.nlm.nih.gov/valueset/2.16.840.1.113762.1.4.1115.5/definition>

Type of content that may be found in a person's advance directives.

Figure 4. Types of care experiences and treatment preferences a patient may express in an advance directive.

Data Element	Code
Palliative care (regime/treatment)	103735009 SNOMED CT 2.16.840.1.113883.6.96
Organ donation (procedure)	271298009 SNOMED CT 2.16.840.1.113883.6.96
Healthcare decision making (observable entity)	405083000 SNOMED CT 2.16.840.1.113883.6.96
Autopsy pathology procedure AND/OR service (procedure)	108259003 SNOMED CT 2.16.840.1.113883.6.96
Care regime (regime/therapy)	225365006 SNOMED CT 2.16.840.1.113883.6.96
Enteral feeding (regime/therapy)	229912004 SNOMED CT 2.16.840.1.113883.6.96
Antibiotic therapy (procedure)	281789004 SNOMED CT 2.16.840.1.113883.6.96
Intravenous fluid replacement (procedure)	281800008 SNOMED CT 2.16.840.1.113883.6.96
Patient management procedure (procedure)	363259005 SNOMED CT 2.16.840.1.113883.6.96
Management of funeral arrangements (procedure)	385741000 SNOMED CT 2.16.840.1.113883.6.96
Hospice care (regime/therapy)	385763009 SNOMED CT 2.16.840.1.113883.6.96
Mutual goal setting (regime/therapy)	386367000 SNOMED CT 2.16.840.1.113883.6.96
Intubation (procedure)	52765003 SNOMED CT 2.16.840.1.113883.6.96

Data Element	Code
Tube feeding of patient (regime/therapy)	61420007 SNOMED CT 2.16.840.1.113883.6.96
Procedure (procedure)	71388002 SNOMED CT 2.16.840.1.113883.6.96
Life support procedure (procedure)	78823007 SNOMED CT 2.16.840.1.113883.6.96
Cardiopulmonary resuscitation (procedure)	89666000 SNOMED CT 2.16.840.1.113883.6.96

## Patient Instructions Data Class

Instructions regarding medical treatments that a person wants (or does not want) should a particular circumstance arise while that person is under the care of an identified medical treatment provider.

### Obligation Instructions or Prohibition Instructions for Life-Sustaining Treatments

When a person is about to undergo a medical procedure where he or she will be sedated, or about to have an inpatient stay, or a stay at a nursing or rehab care facility, care providers may ask the patient to make decisions about medical treatments he or she does or does not want should a circumstance arise when this choice would need to be taken into consideration. A patient may make these decisions for himself or herself, or if the patient cannot make these decisions, the healthcare agent may decide.

These medical treatment decisions are made in the present. They are instructions provided by the patient or a surrogate decision-maker. The patient makes these decisions by himself or herself. There is no requirement for the patient to make decisions which are consistent with thoughts they may have previously documented in advance directives, but it is possible their prior thoughts may influence their current choices. If the patient is unable to communicate, then a healthcare agent or surrogate decision maker may make these decisions. Ideally, these decisions are informed by the values, beliefs, and quality of life priorities documented previously by the patient as advance directives.

These instructions are closely related to advance directives, in that they say, if x happens, then do y. Or, if x happens, do not do y. For this reason, they are often recorded with a person's advance directives. However, they are not advance directives because they represent treatment instructions that have, in fact, been given by the patient or the patient's healthcare agent or other surrogate decision-maker. For example, when a person consents to forego attempts at resuscitation and instructs care providers not to perform CPR in the course of care, the patient's instructions establish obligations and prohibitions for the providers engaged in treating the patient at the time.

A set of recognized types of obligation instructions that a patient or his or her healthcare agent may provide is documented in the value set Obligation or Prohibition Instruction Type urn:oid:2.16.840.1.113883.11.20.9.69.17, which is openly available for reference in the National Library of Medicine’s Value Set Authority Center. It can be referenced using this url: <https://vsac.nlm.nih.gov/valueset/2.16.840.1.113883.11.20.9.69.17/expansion/Latest>

Figure 5. Kinds of Obligation or Prohibition instructions a patient may provide to express a treatment preference.

Data Element	Code
Palliative care (regime/treatment)	103735009 SNOMED CT 2.16.840.1.113883.6.96
Enteral feeding (regime/therapy)	229912004 SNOMED CT 2.16.840.1.113883.6.96
Cardiac support using extracorporeal membrane oxygenation circuitry (procedure)	232969009 SNOMED CT 2.16.840.1.113883.6.96
Antibiotic therapy (procedure)	281789004 SNOMED CT 2.16.840.1.113883.6.96
Intravenous fluid replacement (procedure)	281800008 SNOMED CT 2.16.840.1.113883.6.96
Hospice care (regime/therapy)	385763009 SNOMED CT 2.16.840.1.113883.6.96
Intubation (procedure)	52765003 SNOMED CT 2.16.840.1.113883.6.96
Tube feeding of patient (regime/therapy)	61420007 SNOMED CT 2.16.840.1.113883.6.96
Life support procedure (procedure)	78823007 SNOMED CT 2.16.840.1.113883.6.96
Cardiopulmonary resuscitation (procedure)	89666000 SNOMED CT 2.16.840.1.113883.6.96

These types of instructions provide the patient’s care team with information needed to establish the patient’s plan of care. They form the basis for establishing the medical orders placed in the EMR for the patient’s care.

## Medical Orders Data Class

Medical orders guide what medical interventions providers will perform.

### Portable Medical Orders

A portable medical order is a type of medical order. Portable medical orders are not authored by patients. They are authored by practitioners in the context of an electronic medical record system. The medical orders are provided to the patient in the form of a document so the orders can travel with the patient and be exchanged with other care providers who do not have access to the EMR where the orders originated.

### Medical Orders for Life-Sustaining Treatments

Medical orders regarding life-sustaining treatments are established by a practitioner regarding treatments that restore, sustain or prolong a patient's life. These types of medical orders are intended to be consistent with the patient's instructions and wishes. Orders to perform or not perform specific types of life-sustaining treatments are documented by physicians as medical orders within the EMR system used by the organization providing care or the practitioner's EMR.

### Portable Medical Orders for Life-Sustaining Treatments

When medical orders regarding life sustaining treatment are produced in a portable format, they are portable medical orders for life sustaining treatment.

### Current State of Portable Medical Orders for Life-Sustaining Treatments

There is no national standard for the expected content in a portable medical order for life-sustaining treatments, as the content can vary by State and EMR system. All doctors, emergency medical professionals, and other healthcare professionals, must follow these medical orders as the patient moves from one location to another (hospital, care facility, home, etc.), unless a treating physician examines the patient, reviews the medical order for life-sustaining treatment, and through conversation with the patient detects the need for a replacement order or as a result of their own clinical judgement creates a replacement order. In an emergency situation, characterized by a life-threatening health crisis, if the patient is unable to speak for themselves, life-sustaining treatments and procedures that are legally required of medical and emergency personnel can be overridden by a valid portable medical order.

Depending on the state, a portable medical order may go by any of the following names:

- MOLST (Medical Orders for Life-Sustaining Treatment)
- POLST (Physician Orders for Life-Sustaining Treatment)
- MOST (Medical Orders for Scope of Treatment)
- POST (Physician Orders for Scope of Treatment)
- TPOPP (Transportable Physician Orders for Patient Preferences)
- Out-of-hospital Do Not Resuscitate (DNR) Orders

The above forms have historically been paper-based and siloed in EMRs that might contain a scanned image, or a clinical note that details the decisions documented in the portable medical order. Emergency and treating care teams do not have mechanisms for establishing that the copy they are provided is the most current version and that another, more recent portable medical order doesn't exist that would contradict the order they are reviewing. These uploaded copies of the portable medical order for life-sustaining treatment are considered to be just as valid as the original paper medical order that was provided by a physician to the patient for whom it was written.

The currently supported digital interchange format for portable medical orders is a pdf document, as there are not standard interoperable data elements. The pdf document can be represented as a C-CDA Unstructured Document or a FHIR DocumentReference to enable key administrative information to be processed.

Figure 6. Portable Medical Orders for Life Sustaining treatment are a type of Medical Order.

Data Element	Code	Definition
Portable medical order form	93037-0 LOINC urn:oid:2.16.840.1.113883.6.1	Physician Order for Scope of Treatment which encompasses Physician Orders for Life-Sustaining Treatment (POLST) or Medical Orders for Life-Sustaining Treatment (MOLST).

## Current Implementation of Advance Directive standards

Several organizations engaged in educating and empowering individuals to document their care and treatment goals, preferences and priorities are using the HL7 C-CDA R2.1 and HL7 PACP specifications to exchange advance directive information, if they are doing so in an interoperable manner. In 2018, a national registry was launched where advance care planning documents like advance directives, PACPs and portable medical orders for life-sustaining treatments are now being registered and exchanged using Integrating the Healthcare Enterprise (IHE) and HL7 standards.

USA-based ADVault, Inc. is the creator of MyDirectives, a digital advance care planning platform. In addition to its own proprietary digital advance care planning process, MyDirectives also enables users to upload, store and share the advance directives, advance care plans and portable medical orders (POLST, MOLST, MOST, etc.) they already have on paper. ADVault has additional technology solutions that allow healthcare providers (doctors, hospitals, LTPACs and SNFs) to upload and make advance directives and portable medical orders siloed in their health information systems accessible across the healthcare eco-system. All of the information created or uploaded using MyDirectives and/or ADVault's provider-facing solutions is securely transported and stored in ADVault's global registry and repository, with versioning controls that ensure the most recent/current documents available are returned when the information is

requested by care providers. ADVault works with healthcare providers and health information exchanges to ensure that the information is securely and seamlessly available on demand, whenever and wherever needed.

## Data Provenance Considerations

The HL7 standards developed for the Advance Directives data class have focused on issues of data provenance from inception. Templates and guidance for this data class clearly defines how to represent the semantics needed to clarify what information was authored by the patient himself or herself, or by someone on the person’s behalf under their direct guidance (as in the case of a PACP), and what information was authored by a healthcare provider (as in the case of portable medical orders for life-sustaining treatments) or recorded by a healthcare provider who is facilitating a patient’s creation of advance directives. The recently published Release 2 of the PACP specification also clarifies how to record information about an organization that plays the role of an “assembler,” merely outputting patient authored information in a standardized exchange format and not authoring any new content about the patient.

### Use of New Assembler Role

PACP documents that are created for exchange correctly represent the system a person uses to exchange his or her information as an “Assembler” rather than an author. This is important to note because Provenance is in the USCDI, and more needs to be done to establish clarity around who is a data author and who is not.

Below shows the author and participant area of the header in a PACP document. This carries clear semantics that the patient is the author (not some device) and the registry acts only as an assembler of the information in the exchange document.

```
<author>
  <!-- Patient Generated document has an author with assignedPerson that is the same as
the Subject -->
  <functionCode code="116154003" displayName="Patient (person)"
codeSystem="2.16.840.1.113883.6.96" codeSystemName="SNOMED
CT"></functionCode>
  <time value="20191206011130.107-0400" />
  <assignedAuthor>
    <id root="2.16.840.1.113883.4.6" extension="66666" />
    <id root="2.16.840.1.113883.4.823.1"
extension="5fd39ab355364898b5dcca37e7ef491c" />
    <id root="2.16.840.1.113883.4.3.12" extension="33487" />
    <id root="2.16.840.1.113883.4.1" extension="555-12-1246" />
    <code code="ONESELF" codeSystem="2.16.840.1.113883.5.111"
codeSystemName="RoleCode" displayName="Self" />
    <addr use="HP">
      <streetAddressLine partType="SAL">12345 Main Street</streetAddressLine>
```



```

<city partType="CTY">Orlando</city>
<state partType="STA">FL</state>
<postalCode partType="ZIP">75219</postalCode>
<country partType="CNT">US</country>
</addr>
<telecom value="tel:+14692382858" use="HP" />
<telecom value="tel:+12144979529" use="MC" />
<assignedPerson classCode="PSN" determinerCode="INSTANCE">
  <name use="L">
    <given partType="GIV">Roger</given>
    <given partType="GIV">Rienman</given>
    <family partType="FAM">McBee</family>
  </name>
</assignedPerson>
</assignedAuthor>
</author>

```

## Digitally Signed C-CDA Documents

The included C-CDA example POLST document shows a signed C-CDA Document that also demonstrates the use of the HL7 Digital Signature standard which defines how to digitally sign C-CDA documents. It has two digital signatures which are conformant to the HL7 specification.

The document is only an example, so the patient and physician authenticators are people who developed the sample. In a production environment the actual signing physician can be included in the role of legalAuthenticator, and the patient (or any other relevant family member(s)/decision-maker(s)) can be in the role of authenticator(s).

## Expressing Advance Directives Data Using FHIR Resources

The PACIO FHIR Accelerator Community is presently engaged in creating a FHIR Implementation Guide to show implementers how to represent and share advance directives information. The new FHIR IG will leverage the mature work previously developed for exchange of advance directives information using CDA and for the representation of patient-generated documents and portable medical orders for informing and guiding care plan information.

## Conclusion

The C-CDA R2.1 Supplemental Advance Directives Templates IG and the CDA Personal Advance Care Plan IG are mature standards that provide clear guidance on how to represent the full range of data elements relevant to the Advance Directives data class for exchange. These additional data element definitions and standards specifications should be considered for inclusion in the next update to the Interoperability Standards Advisory and considered as a potential data class for the USCDI. New work produced within the PACIO FHIR Accelerator Community under the sponsorship of the HL7 Patient Empowerment Work Group will produce additional implementer guidance for the exchange of the Advance Directives data class using

FHIR. Implementer testing of FHIR-based exchange will begin in 2020 and ballot in May 2021. Implementer adoption of the CDA-based exchange began in 2016, and adoption continues to expand within the US.

COVID-19 has distanced healthcare agents from those they represent and created a reluctance in providers to allow patients to bring paper documents into a care facility. The severity of this disease often leaves patients unable to communicate with their care team. As a result, neither healthcare agents nor traditional paper documents used by patients to express their personal healthcare goals and treatment preferences are available. Never before has the availability of verifiable digital advance directives information been so essential to delivering person-centered care.

Given the maturity of these data standards and the urgency to express and share advance directive information, patient instructions and medical orders for life-sustaining treatments to address care delivery in the midst of the COVID-19 pandemic, inclusion of the Advance Directives data class, and associated data elements relevant to patient-generated advance directives information, as well as the inclusion of the Patient Instructions data class and the Medical Orders data class, with relevant data elements, should be considered for the next version of the US Core Data for Interoperability.

---

<sup>i</sup> *“An advance care plan says, in the event I’m not able to speak for myself here is the treatment course that I would like, and here are the individuals that can speak for me. The great thing about advance care planning is it’s moved into the 21st century . . . Now there’s a way to do it on your smart phone and do it for free. There are companies . . . that allow you to create an advance care plan for yourself, on your smart phone and share it with your loved ones.”* [Kerry Weems](#), former Acting CMS Administrator.

*“Hospital ER and ICU staff are constantly asking during COVID-19 how people can help us do our jobs better. It’s simple: tell us your goals of care and who speaks for you, if you can’t speak yourself via an Advance Care Plan and an advance directive.”* [Dr. Dan Morheim](#), Maryland legislator and author.

*“I think it’s really important for families at this time . . . to be honest and have conversations . . . I’m a big proponent of people having advance care plans and making sure that they talk to their family members about what their wishes would be if there was an emergency.”* [Dr. Elizabeth Clayborne](#), ER Physician at Prince George’s Hospital Center.

*“What’s important for people as this pandemic goes along is for us to talk about . . . what their goals are and who speaks for them when they get so very, very sick . . . We want people to have a voice in their care . . . That needs to become the normalized conversation now . . . One of the biggest recommendations I have is to . . . fill out a free advance care plan . . . so that . . . [doctors in the ER] will be able to care for you in exactly the way you want.”* [Dr. Rita Manfredi](#), Associate Professor of Clinical Emergency Medicine, Hospice and Palliative Physician at George Washington University Hospital.

*“Among the most important recommendations is one all Americans can do right now: Make an advance care plan of their own. Medical providers can provide the best care when they know both their patients’ goals of care and who speaks for them if they can’t speak for themselves. Health insurers, employers and government officials should encourage us all to make a plan, keep it updated, share it with family and friends and — most of all — make sure it is easily accessible digitally in a crisis.”* [Dr. Michael Wasserman](#), board-certified geriatrician, certified medical director and president of the California Association of Long-Term Care Medicine.

The [Coalition to Transform Advanced Care](#) has released the full version of a report designed to identify strategies that could be used to boost the use of advance care planning (ACP), a practice that is now more important than ever as we face the

---

uncertainties of the COVID-19 pandemic. Discern Health, a healthcare quality and research advisory organization, developed the report.

<sup>ii</sup> *Covid-19 Highlights HIM's Advance Care Planning Expertise*. Journal of AHIMA. June 3, 2020. Accessed on June 4, 2020 at <https://journal.ahima.org/covid-19-highlights-hims-advance-care-planning-expertise/>.