

Advance Directives as a Data Class

Over the last year the Post-Acute Care Interoperability (PACIO) project has been developing a FHIR (Fast Health Interoperability Resources) Implementation Guide (IG) to support advance directive interoperability. By way of background, the PACIO Project, established February 2019, is a collaborative effort between industry, government, and other stakeholders, with the goal of establishing a framework for the development of FHIR implementation guides to facilitate health information exchange. The PACIO Advance Directives Interoperability (in FHIR) Project Scope Statement was approved by HL7 in December of 2020. Under this charter, PACIO has been actively engaging both the provider and data standards communities in weekly meetings and enabling participation in testing events (HL7 Connectathons) to validate consensus guidance for representing advance directive information using FHIR. The FHIR IG resulting from this work will be balloted in January of 2022. Through this process, previously established HL7 CDA and C-CDA IG's for advance directive information have been leveraged to support the development of the new FHIR IG.

Testing activities and experience has validated the use of existing data templates and increased community involvement has expanded understanding of the advance directive data class. This maturation process also has advanced the clarity and specificity of the terms used to describe the data elements associated with this important class of data.

One of the most important aspects to appreciate about advance directives is the complexity of the information due to authorship by different stakeholders. Data provenance is critical for advance directive information. To address this complexity, the community has defined three categories of advance directive information.

One of the categories describes information authored by patients themselves and the other two categories address information authored by practitioners. For the two categories of practitioner-authored information, one category addresses patient preferences for medical interventions related to the current episode of care, such as a DNR or DNAR order. The other category addresses orders for life sustaining treatments should a future medical event require those decisions need to be made, based on a patient's confirmed wishes. There are multiple forms that are in use across the U.S. to represent this type of content such as POLST, MOLST, POST, MOST, and the like.

Below is a description of the three categories of advance directive information needed for interoperable data exchange that facilitates care and care planning.

Type I: Patient-Authored Advance Directive Information

- Patient-authored information
- Used as a tool for sharing an individual's (patient's) medical treatment and intervention goals, preferences, and priorities (GPP)
- Provides guidance that a patient would want known as part of ensuring their care or treatment plan is informed by this guidance during a potential future medical emergency, in the case where the patient is unable to communicate for himself or herself

Type II: Practitioner-Authored Encounter-Centric Advance Directive Information

- Practitioner-authored

- Physician documentation in the form of an order or chart note, created directly from the patient’s stated goals, preferences, and priorities,
- Instructions are relevant to the current episode of care
- The patient, or healthcare agent, has provided direct input that practitioners take into consideration when creating instructions about treatments that shall or shall not be utilized during a medical emergency occurring within the current episode of care.

Type III: Orders for Life-Sustaining Treatments

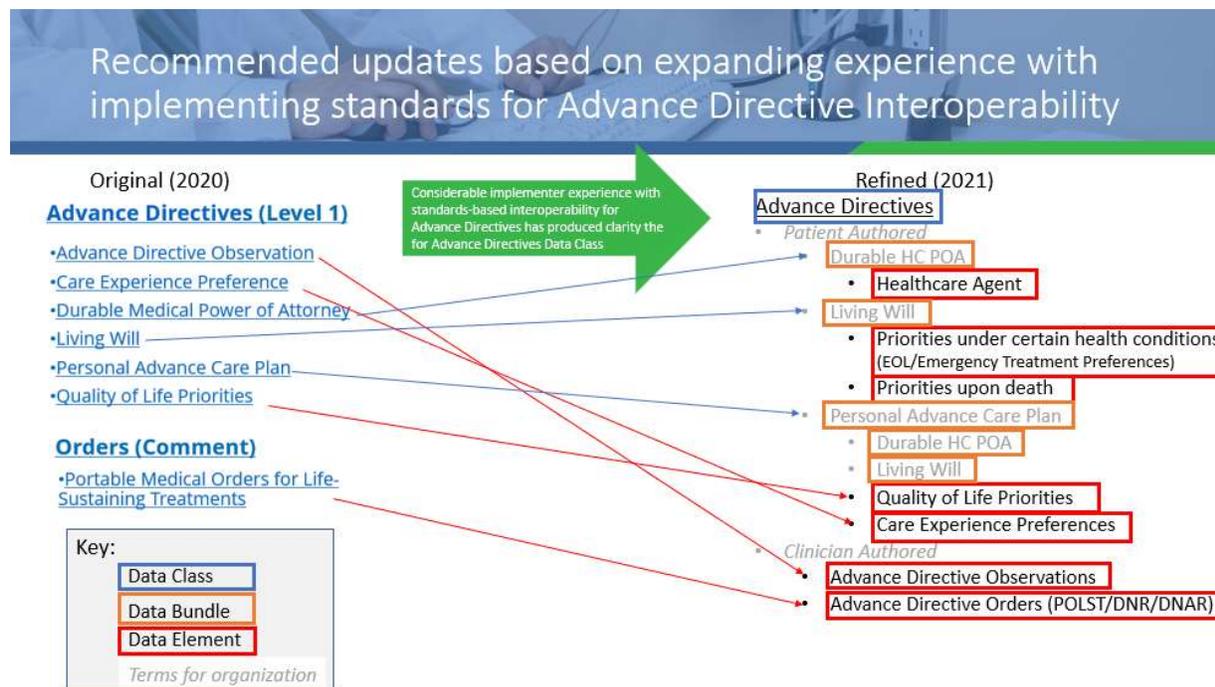
- Practitioner-authored
- A set of medical orders intended to travel with a patient and be available across the continuum of care
- The patient, or healthcare agent, provides direct input in the creation of the instructions.
- These orders document a provider’s directions regarding treatments that shall or shall not be performed during a future medical emergency. The orders are based on a patient’s wishes for or against the treatments under specific circumstances.

	Author	Informed By	Applies to Time Frame
Advance Directive Information <i>Content Type I</i>	Person / Self	Person / Self	Potential Future Event
Episode-Centric Patient Instructions <i>Content Type II</i>	Practitioner	Patient	Potential Future Event within Current Episode / Immediate
Portable Medical Orders for Life-Sustaining Treatment <i>Content Type III</i>	Practitioner	Patient	Potential Future Event

Over the past year, the work and testing within HL7 and the PACIO Community has brought about greater community consensus, drawn more implementers of the standard, and provided increased learning and experience with data exchange of standards-based advance directive information. These learnings have enabled greater clarity about the Advance Directive Data Class and Data Elements previously proposed in 2020, including how the previously proposed Advance Directive Data Elements included concepts represented at different levels of organization. While some were specific data elements, others were collections that represented a bundle of data elements rather than a single data element. The feedback provided below explains recommended updates based on the considerable

implementation experience with standards-based advance directive interoperability gained during the past twelve months.

Based on the ongoing maturation in this area, there are recommendations for updates to the previously proposed Data Elements in the Advance Directives and Orders Data Class. These modifications provide clarification of data elements and bundling of data elements. This complete write-up is being submitted to provide an overview of the full set of recommendations for advancement of this Data Class and the included Data Elements.



Update “Advance Directive” Data Class to USCDI Level 2

Although the new PACIO Advance Directives Interoperability FHIR IG won’t ballot until January 2022 and publish in early- to mid-2022, considerable progress has been made on implementer consensus about how to represent and exchange advance directive information. The additional maturity should be recognized in an upgrade from Level 1 to Level 2. Following ballot reconciliation and publication of the FHIR IG, The Advance Directive Data Class should be added to USCDI ONDEC submission for V4 in 2022.

Modify “Durable Medical Power of Attorney” to “Healthcare Agent” and Advance to USCDI Level 2

While the concept of “Durable Medical Power of Attorney” remains important to be included in the USCDI, further community discussion led to modifying the data element from “Durable Medical Power of Attorney” to “Healthcare Agent”. The notion of “Durable Medical Power of Attorney” is better described as a collection of data elements which may establish one or more “Healthcare Agents” and may include additional details about the specific powers or limitations associated with that established

role. The concept of “Durable Medical Power of Attorney” would more accurately be described as a data bundle because it includes multiple data elements, the most prominent being “Healthcare Agent”. Over the past year multiple organizations have used both CDA and FHIR standards to share this important patient-generated information. In addition, the CDA guidance has been balloted twice within HL7, the FHIR IG is preparing to be balloted in January 2022.

- There are LOINC Codes that represents this data element and it is part of both CDA and FHIR IGs. (81335-2 Patient Healthcare agent)
- There is a well-established value set for representing a primary, secondary, or tertiary healthcare agent when multiple agents are established. (Healthcare Agent or Proxy Choices, urn:oid: 2.16.840.1.113762.1.4.1046.35)

We strongly recommend this data element be advanced to USCDI Level 2.

Modify “Living Will” to “Priorities Under Certain Conditions” and “Priorities Upon Death” and Advance to USCDI Level 2

While the concept of “Living Will” remains important to be included in the USCDI, further community discussion led to modifying the data element from “Living Will” to “Priorities Under Certain Conditions” and “Priorities Upon Death”. The notion of “Living Will” is better described as a bundle of data elements which identify a person’s “Priorities Under Certain Conditions” or “Priorities Upon Death”. Over the past year multiple organizations have used both CDA and FHIR standards to share this important patient generated information. In addition, the CDA guidance has been balloted twice within HL7, the FHIR IG is preparing to be balloted in January 2022.

- There are LOINC Codes that represents these data elements (81336-0 Patient Goals, preferences, and priorities under certain health conditions and 81337-8 Patient Goals, preferences, and priorities upon death) and instructions for using both are included in the CDA and FHIR IGs.
- Value sets for common treatments a patient may prefer to receive or not receive under certain conditions as well as priorities upon death are defined and available for use in the NLM VSAC. (Intervention Preferences at End of Life, urn:oid:2.16.840.1.113762.1.4.1115.9 and Health Goals at End of Life Grouping, urn:oid:2.16.840.1.113762.1.4.1115.7)

We strongly recommend these data elements be advanced to USCDI Level 2.

Remove “Personal Advance Care Plan” as a data element.

While the concept of “Personal Advance Care Plan” remains important to be included in the USCDI, further community discussion led to clarification of the request of this item. The “Personal Advance Care Plan” concept is better described as a bundle of information which includes the data elements of “Healthcare Agent”, “Priorities Under Certain Conditions”, “Priorities Upon Death”, “Quality of Life Priorities” and “Care Experience Preferences”. The recommendation to advance the data elements that are part of the bundled Personal Advance Care Plan items are identified and justified in each specified data element.

Advance “Quality of Life Priorities” to USCDI Level 2

The “Quality of Life Priorities” data element provides details on a person’s quality of life priorities based on their personal values for what is important to them in order to have a good quality of life. The need and maturity of this data element has been validated by the PACIO community. In addition, the CDA guidance has been balloted twice within HL7, the FHIR IG is preparing to be balloted in January 2022.

- There is a LOINC Code that represents this data element (81340-2 Goals And/Or preferences in order of priority [Reported]) and it is part of both CDA and FHIR IGs.
- There is a well-established value set for representing priorities. (Health Goals at End of Life Grouping, urn:oid:2.16.840.1.113762.1.4.1115.7)

We strongly recommend the “Quality of Life Priorities” data element be advanced to USCDI Level 2.

Advance “Care Experience Preference” to USCDI Level 2

The current data element of “Care Experience Preference” provides details on a person’s preferences for their care experience based on cultural, religious or spiritual, and personal preferences. The need and maturity of this data element has been validated by the PACIO community. Over the past year multiple organizations have used both of these CDA and FHIR standards to share this important patient generated information. In addition, the CDA guidance has been balloted twice within HL7, the FHIR IG is preparing to be balloted in January 2022.

- There is a LOINC Code that represents this data element (81338-6 Patient Goals, preferences, and priorities for care experience) and it is included in both CDA and FHIR IGs defining standardized exchange of advance directive information.
- There is a well-established value set for representing care experience preferences. (Care Experience Preferences at End of Life Grouping, urn:oid:2.16.840.1.113762.1.4.1115.11)

We strongly recommend this data element be advanced to USCDI Level 2.

Update “Advance Directive Observation” Data Element to USCDI Level 2

The current practitioner-authored data element of “Advance Directive Observation” is critical to ensuring clinicians can record and share information about available patient-documented goals, preferences and priorities for treatments and interventions regarding future medical care that may be considered under certain circumstances. This data element is routinely captured in the context of a Patient Summary or Encounter Summary authored by a clinician or assembled by clinician’s EMR system. This observation is recorded when a clinician verifies the presence of a patient’s advance directive information or confirms the patient has medical orders for life-sustaining treatments and documents reviewing this information.

We strongly recommend this data element be advanced to USCDI Level 2.

Change “Portable Medical Orders for Life-Sustaining Treatments” to “Advance Directive Orders” and Move to USCDI Level 2 in the Orders Data Class

While the concept of this data element remains important to be included in the USCDI, further community discussion led to modifying the data element from “Portable Medical Orders for Life-Sustaining Treatments” to “Advance Directive Orders”. It is recognized that the previous concept of “Portable Medical Orders for Life-Sustaining Treatments” was too narrowly focused and additional practitioner-authored orders should be included. These orders regarding life-sustaining treatment 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.

We strongly recommend this data elements be added within the Orders Data Class in USCDI Level 2.

Conclusion

The recommendations provided for consideration continue to mature through thoughtful discussion and testing in the open community of PACIO. The result of the proposed changes will incorporate the involvement of patient, provider, and data standards community. We strongly encouraged the Health Information Technology Advisory Committee to move the data elements contained in this document as recommended. The data elements as proposed and listed below are on cycle to progress to USCDI V4 in 2022 upon the balloting of the PACIO FHIR IG in January 2022 and development and balloting of a POLST Portable Medical Orders CDA IG in early to mid-2022.

Recommended Advancement for Advance Directives USCDI Level 2

2021 USCDI Level 2

Advance Directives

Patient Authored

- Healthcare Agent
- Priorities under certain health conditions (EOL/Emergency Treatment Preferences)
- Priorities upon death
- Quality of Life Priorities
- Care Experience Preference

Clinician Authored

- Advance Directive Observation

2021 USCDI Level 2

Orders

- Advance Directive Orders (POLST/DNR/DNAR)