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Department of Health and Human Services
Hubert Humphrey Building, Suite 729
200 Independence Avenue SW
Washington, DC 20201
Submitted electronically to: https://www.healthit.gov/isa/ONDEC

Re: ASTP's Draft United States Core Data for Interoperability (USCDI) Version 6

Dear Mr. Posnack:

We appreciate the opportunity to submit comments on the standardized health data classes and constituent data elements eligible for promotion to version 6 of the USCDI. We particularly want to express our gratitude for specific improvements noted in previous versions of the USCDI, such as adding *Treatment Intervention Preference* and *Care Experience Preference* in v4, complemented by the v5 addition of *Advance Directive Observation* and expanding the health data class *Goals* into *Goals and Preferences*. These data elements reflect clear acknowledgement of the role of the person and what is important to them as they move through our healthcare system. We applaud inclusion of the *Portable Medical Order* data element within the *Order* data class in v6, as it sends a clear message to technical implementers of health technology that ASTP is leading the way to a person-centered healthcare system where care is informed by what is wanted, and not wanted, by the individual with the intent to honor the voices of those receiving care.

As we look to USCDI v6 and those items that will enable individuals to express the most impactful and personally important aspects of their healthcare experience, which when accessed and used by treating care teams can reduce unwanted, low-value care by ensuring systems make those expressed values and preferences for their healthcare journey available across care settings, MyDirectives **strongly recommends** that our suggestions related to the following health data classes and constituent data elements, including clarifications to their naming convention, be considered.

Data Class	Data Element	Recommendation	Reasoning for Recommendation
General comment		General Recognition of the Role of Data Classes in USCDI	We understand that a Data Class within USCDI is an organizing concept and is not intended to be prescriptive or restrictive to the administrative, clinical, financial, or technical processes that capture Data Elements. We further recognize that the use of Data Classes helps the humans reviewing the many Data Elements within USCDI v6 to more accurately understand context for the grouped Data Elements when related to logical categories associated with common healthcare workflows.
Supporting Narrative: An alphabetical list of the USCDI v6 Data Elements, with no organization to the list beyond that, would have the potential to be contextualized incorrectly without the notion of a Data Class to organize them. For example, *Race* and *Ethnicity* are both organized within the *Patient Demographics/Information* Data Class, which clarifies that this kind of data is about the patient and is not about the *Care Team Members*, a different Data Class. **This baseline understanding informs the subsequent comments related to the Data Classes and Data Elements for which we have provided guidance.**			

Level 0 Data Class and Data Element Comments:

Data Class	Data Element	Recommendation	Reasoning for Recommendation
Care Team Members	Proxy Decision Maker	Remove from Level 0 and do not promote	The proposed Data Element's concepts are already accommodated in the "relationship" field expressed in the RelatedPerson FHIR Resource, via a "role" code. We recommend this Data Element be removed and not promoted any further in USCDI. To add this Data Element to USCDI v6 would disregard standards use of these values in FHIR while at the same time enabling yet more disparate terms and references that would complicate and confuse intended data exchange.

Narrative to support removal of the Proxy Decision Maker Data Element from Level 0:
We suggest that this Data Element be removed from Level 0 and not promoted any further within USCDI. The term *Proxy Decision Maker* is one of many terms used to describe a person designated to make medical treatment decisions on behalf of another individual, in the case where the individual in question is not able to communicate with the care team directly.

Among other terms we have encountered in our extensive work in this area, "Durable Medical Power of Attorney" is only found in a subset of existing statutory documents and is a highly prescriptive term with a narrow legal definition. The term "Healthcare Agent" is another often used term, and this broader term encompasses the content that can be identified and exchanged, of which the "Durable Medical Power of Attorney" is a subset. Concepts such as "Resident Representative," "Healthcare Proxy," and "Health Care Surrogate" from existing jurisdictional forms and documents would be expressed in document exchange, and those instruments do not use the "Proxy Decision Maker" term.

Furthermore, in many states, the valid expression of designating a person to speak on the individual's behalf can be done via verbal, recorded, or hand-written means and retains a legal status that is able to be honored without the legal formality that a Durable Medical Power of Attorney requires.

The HL7 Advance Directive Interoperability w/FHIR project has bound the value used to indicate the person who is designated, or legally responsible, for this type of role in the medical care of another individual to a "Personal and Legal Relationship Role" type that uses standard V3 codes plus needed "legal" relationship concepts to accommodate the intent of this concept and its many variations across forms.

Therefore, we recommend that the ASTP rely on existing VSAC value sets and HL7 standards to indicate who is designated to serve in the role of proxy decision maker for another individual. To add the *Proxy Decision Maker* data element to USCDI v6 would disregard standards use of these values in FHIR while at the same time enabling yet more disparate terms and references that will complicate and confuse intended data exchange.

Goals and Preferences	Religious & Spiritual Preferences	Remove from Level 0 and do not promote	The proposed Data Element's concepts are accommodated in the existing value sets and concepts that populate the content found in the *Care Experience Preferences* Data Element and is therefore redundant. Further, it does not refer to the many different *cultural* or *values-based* goals, preferences, and priorities that an individual may want to express so as to guide their care or treatment, making it too narrow to achieve the intended purpose.

			Accordingly, we recommend that this Data Element be removed and not promoted any further in USCDI.

Narrative to support removal of the Religious & Spiritual Preferences Data Element from Level 0:

Religious and spiritual preferences only represent concepts for a couple of personal motivating factors for an individual's preferences related to Care Experience or Treatment Interventions. The U.S. is a melting pot of cultures, and those may impact the individual's preferences as much, or more than, religious and spiritual factors. Additionally, when expressing goals of care or preferences for treatment, the individual may be expressing their own personal values. Both of these motivating factors, and drivers of preference, are omitted in the proposed *Religious & Spiritual Preferences* Data Element, and therefore the proposed Data Element is too narrow for the intended use case.

Data Class	Data Element	Recommendation	Reasoning for Recommendation
Orders	Portable Medical Order for Life-Sustaining Treatment	Remove from Level 0 and do not promote	The name of this Data Element is too narrow and only represents a single type of form or document, thereby excluding other types of portable medical order forms and documents that are common and used across the U.S. *See comment on portable medical order forms later in this comment letter.* We recommend that this Data Element be removed and not promoted any further in USCDI.

Narrative to support removal of the Portable Medical Order for Life-Sustaining Treatment Data Element from Level 0:

The current name of this Data Element is narrow and only represents a single document type out of many that fall into a portable medical order form group of documents. Other portable medical order forms that need to be represented by a Data Element in this Order Class have names such as "Do Not Resuscitate Orders (DNRs)," "Do Not Attempt Resuscitation Orders (DNARs)," "Emergency Medical Services Comfort Care Orders (EMS-CC)," "Do Not Intubate Orders (DNIs)," and "Do Not Hospitalize Orders (DNHs)." This Data Element excludes those important, similar documents, from USCDI as a limiting and excluding naming convention.

We have provided comments on a preferred Data Element, *Portable Medical Order*, that would more comprehensively represent this broad set of documents and the intent of USCDI to guide the data exchange and access of these important documents to inform care.

Level 1 Data Class and Data Element Comments:

Data Class	Data Element	Recommendation	Reasoning for Recommendation
Advance Directives		Remove from Level 1 and do not promote	This Data Class is no longer needed as the concepts that would have been listed as Data Elements in this Data Class can be found in other Data Classes, such as the *Orders, Goals and Preferences*, and *Observations* Data Classes. We recommend that this Data Element be removed and not promoted any further in USCDI.
Narrative to support removal of the Advance Directives Data Class from Level 1: As previously stated in this comment letter, we understand that Data Class is a grouping mechanism for the many Data Elements that reside in USCDI. As many of the Data Elements that represent advance healthcare directive documents are already found under existing Data Classes, we believe that re-arranging existing Data Elements into a new Data Class would be confusing and potentially disruptive to the work already in motion. With that understanding firmly in mind, we recommend that the previously proposed Advance Directive data class be removed and not promoted further within USCDI.			

Data Class	Data Element	Recommendation	Reasoning for Recommendation
Advance Directives	Personal Advance Care Plan	Remove from Level 1 and do not promote	The concepts contained within the *Personal Advance Care Plan* Data Element are already accommodated with other existing Data Elements found in USCDI. We recommend that this Data Element be removed and not promoted any further in USCDI.
Narrative to support removal of the Personal Advance Care Plan Data Element from Level 1: The *Care Experience Preferences*, *Treatment Intervention Preferences*, *Advance Directive Observation*, and *Portable Medical Order* Data Elements will enable the contents of personal advance care plan documents to be made available for data exchange and access, as per the intent of USCDI. A document type Data Element such as the one proposed in USCDI is not necessary. In fact, inclusion of this Data Element could lead to a lack of populating the existing Data Elements as implementers could elect to provide a *Personal Advance Care Plan* Data Element instead of extracting the more important aspects of this document type into the existing Data Elements listed above.			

See comment on portable medical order forms later in this comment letter.

Advance Directives	Quality of Life Priorities	Remove from Level 1 and do not promote	The concepts that could be represented within the *Quality of Life Priorities* Data Element are already accommodated within the *Care Experience Preferences* Data Element and associated value set located within VSAC. We recommend that this Data Element be removed and not promoted any further in USCDI.

Narrative to support removal of the Quality of Life Priorities from Level 1: The *Care Experience Preferences* Data Element enables the concepts associated with *Quality of Life Priorities* to be made available for data exchange and access, as per the intent of USCDI. An additional Data Element in USCDI is not necessary. In fact, inclusion of this Data Element could lead to a lack of populating the existing Data Elements as implementers could elect to provide a *Quality of Life Priorities* Data Element instead of providing *Care Experience Preferences* which contains concepts through a value set location in VSAC related to Quality of Life Priorities, which would be redundant and confusing to implementers.

See comment on portable medical order forms later in this comment letter.

Advance Directives	Living Will	Remove from Level 1 and do not promote	The name of this Data Element is too narrow and only represents a single type of form or document in the many types of advance healthcare directive documents, thereby excluding other types of advance directive and portable medical order forms and documents that are common and used across the U.S. *See comment on portable medical order forms later in this comment letter.* We recommend that this Data Element be removed and not promoted any further in USCDI.

Narrative to support removal of the Living Will Data Element from Level 1: The current name of this Data Element is narrow and only represents a single document type out of many that fall into an advance directive group of documents. The *Care Experience Preferences, Treatment Intervention Preferences*, and *Advance Directive Observation* Data Elements will enable the contents of the living will documents to be made available for data exchange and access, as per the intent of USCDI. A document type Data Element in USCDI is not necessary. In fact, inclusion of this Data Element could lead to a lack of populating the existing Data Elements as implementers could elect to provide a living will document instead of extracting the more important aspects of this document type into the existing Data Elements listed.

See comment on portable medical order forms later in this comment letter.

Advance Directives	Durable Medical Power of Attorney	Remove from Level 1 and do not promote	The name of this Data Element is too narrow and only represents a single type of form or document, thereby excluding other types of Portable Medical Order forms and documents that are common and used across the U.S. *See comment on portable medical order forms later in this comment letter.* We recommend that this Data Element be removed and not promoted any further in USCDI.

Narrative to support removal of Durable Medical Power of Attorney Data Element from Level 1: The current name of this Data Element is narrow and only represents a single document type out of many that fall into an advance healthcare directive group of documents.

The *Care Experience Preferences*, *Treatment Intervention Preferences*, *Advance Directive Observation*, and *Portable Medical Order* Data Elements will enable the designation of a Durable Medical Power of Attorney (and other commonly used terms for this role) to be made available for data exchange and access, as per the intent of USCDI.

A document type Data Element such as is proposed in USCDI is not necessary, in fact inclusion of this Data Element could lead to a lack of populating the existing Data Elements, as implementers could elect to provide a *Durable Medical Power of Attorney* concept for this Data Element instead of extracting the other, important aspects of this document type into the existing Data Elements listed.

See comment on portable medical order forms later in this comment letter.

Level 2 Data Class and Data Element Comments:

Data Class	Data Element	Recommendation	Reasoning for Recommendation
Orders	Portable Medical Order	Modify the Description and Promote from Level 2 to USCDI v6	We recommend that the *Portable Medical Order* Data Element current description be modified to be more accurate with what is the intent of this Data Element and that it be promoted from Level 2 to USCDI v6.

Narrative to support Rename, Re-Describe, and Promote the Portable Medical Order Data Element from Level 2 to USCDI v6:

1. We recommend that the Data Element be renamed as a singular item, *Portable Medical Order*, consistent with other Data Elements found in USCDI.

The term "Portable" indicates that these orders apply across care settings and follow the individual, rather than being applicable to only one encounter of care. Due to the nature of what these documents represent, **we recommend that this Data Element be associated with the Advance Healthcare Directives Data Class.**

While these documents are "order sets" so that associating them with the *Orders* Data Class gives the human viewer context on what is intended with this Data Element, they are not orders in a more traditional sense that they apply to a single episode of care. This concept represents a widely used and relied upon set of jurisdictional forms across the healthcare system.

In addition, portable medical order forms are a familiar concept to the majority of healthcare practitioners and emergency responders who also understand they may include not only those state-specific instruments known as POLST or MOST, but also those forms used to guide emergency care such as DNR Orders or DNAR Orders used predominantly by EMS responders.

2. We also recommend that the description currently shown in USCDI DRAFT v6 be modified as follows:

Current Description:
Provider-authored request for end-of-life or life-sustaining care for a person who has a serious life-limiting medical condition.

Usage note: These are meant to follow a person regardless of when and where such an order might be needed (e.g., hospital, care facility, community, home). There are variations in requirements and names for portable medical orders based on jurisdiction.

Examples include but are not limited to POLST (Portable Medical Order for Life-Sustaining Treatment), MOLST (Medical Orders for Life-Sustaining Treatment), and out-of-hospital DNR (do-not-resuscitate).

Proposed Description:
Information about a provider authored portable medical order document indicating its location, content, type, version of document (current versus superseded, for example), and verification status.

Usage note: The portable medical order may include structured or unstructured data which indicates whether a person has one or more portable medical order documents, the type of portable medical order, the location of the document, and whether it has been verified. Such documents may be used in the event a person is unable to communicate with a treating provider, such as during an emergency or health crisis, to convey their preferences for CPR and/or life-sustaining treatment interventions. These documents often also include goals of care and instructions on whether to transport the patient or provide care in a current care setting.

Examples include but are not limited to an indication that a POLST (Portable Medical Order for Life-Sustaining Treatment), MOLST (Medical Orders for Life-Sustaining

Treatment), out-of-hospital DNR (do-not-resuscitate) or similar document is on file, a reference to the location of the portable medical order document, and the validating provider.

This change to the description, modeled after the *Advance Directive Observation* Data Element added to USCDI v5, supports the need for patients and their providers to access and honor these important documents even as the healthcare industry moves from paper-based and unstructured document (PDF) workflows to more efficient, verifiable, and person-centered data exchange/access document workflows.

As FHIR US Core IG and CDA currently support exchange and access to unstructured data and documents, the projects that are quickly moving to balloted FHIR and CDA IGs for these kinds of documents can provide the needed guidance to support structured data exchange without risk of leaving these critical life-and-death, legally enforceable documents behind.

Systems used across the U.S. have captured scanned images of paper advance healthcare directive documents and stored them without a requirement to make them available to other systems, for many years.

The *Portable Medical Order* Data Element enables those many existing scanned forms, which some individuals intend to take the place of jurisdictional advance directive documents, to further clarify the documented choices in those high-level advance directive documents or "transform" the documented choices of individuals into medical orders to ensure emergency responders or emergency medical teams at acute and emergent care settings are able to honor those preferences for treatment interventions without delay or additional verification needed.

Since 2007, MyDirectives has focused solely on empowering individuals to have a voice in their healthcare experience, especially during those times in their lives when they experience a medical emergency, behavioral health emergency, or health crisis and cannot communicate with those providing care and treatment. MyDirectives provides digital solutions that enable creation and update of structured, interoperable advance healthcare directives, as well as interoperable creation and storage of all types of unstructured, scanned paper ACP documents. Our solutions facilitate advance care planning document management for individuals, providers, care teams, and health systems.

MyDirectives also works with some of the largest healthcare payers in the United States to support engagement of their members in the process of creating, storing, and sharing high-quality digital ACP documents. We provide those health plans with de-identified reports and analytics to help them comply with requirements established by the Centers for Medicare & Medicaid Services (CMS).

In addition to the products we have created, which tangibly demonstrate our company's commitment to supporting the evolution of the U.S. healthcare system to a truly person-centered care delivery model, we have devoted thousands of staff hours to the work HL7® undertakes as they create interoperable data standards to support the data exchange and accessibility of advance healthcare directive documents across transitions of care within the unique care settings.

- Our leadership co-authored the development of the *Personal Advance Care Plan (PACP) CDA Implementation Guide (IG)* in 2015, which has since been through ballot in 2016, 2020, and again in 2023. Our leadership also contributed advance directive section specifications to the *Consolidated CDA (C-CDA) Supplemental Templates for Advance Directives* in 2018 and 2022, and which has since been incorporated into C-CDA 3.0.

- We are also leading the *Advance Directive Interoperability (ADI) Fast Healthcare Interoperability Resources (FHIR) IG* development that enables interoperable data exchange of advance healthcare directive documents using FHIR. This work has diligently endeavored to achieve alignment between the CDA and FHIR data exchange standards, so as to enable implementers to have optimal backward and forward compatibility, while also incorporating changes in the healthcare delivery systems to keep pace with the industry at large.

We remain committed to this important work and are today still actively involved in leading these projects within the standards development organizations.

We are aware of the concerns expressed by other commentators that the inclusion of digital patient treatment and care preferences in the electronic medical record is "too difficult" or "too complicated" due to jurisdictional variations in form, content, and regulation around ACP documents. In our leadership role for the standards creation projects previously mentioned, we have worked with a wide variety of other HL7 standards development participants to conduct exhaustive environmental scans to ensure we included as many versions of these forms as possible to inform our national standards creation work. We have further been guided by large, active communities comprised of healthcare workers, medical professionals, ethicists, electronic medical record vendors, personal health record vendors, and various other thought leaders on this topic. Our company's leadership is often relied upon to advise the industry and associations on the importance of interoperable ACP documents as experts in this space, and we evangelize the work frequently through our speaking engagements, publications, and educational sessions across the country. These projects often bring the opportunity to engage with, and educate, not only stakeholders at CMS, ASTP, and representatives of HHS, but also those executives or front-line workers within the healthcare system, as part of the culture change required to actively lead the nation's efforts to ensure these important documents can be accessed in a secure, interoperable, and standardized manner to inform care and treatment whenever, and wherever, they are needed. Based on the vast amount of these interactions and the work we have witnessed that is currently live and in use in many care settings, we can tell you the standards discussed above are ready, they are mature, and our recommendations related to USCDI v6 are necessary to continue to drive change and improve care.

In addition, inclusion of the above detailed Data Classes and Data Elements in USCDI v6 will drive the broader objectives of HHS, CMS/CMMI, and ASTP: **healthier Americans, reductions in waste due to unwanted over-treatment without withholding care that individuals want**, and **improved patient outcomes, including access to their own health information**.

We believe ASTP, in concert with CMS, has made a great difference in both the healthcare provider space and the health plan payer industry with their recognition of the importance of elevating the voice of the individual through advance care planning documents, including portable medical order forms. However, we believe there are additional steps legislators and government stakeholders can and should take to further enable care teams to deliver, and

individuals to receive, personalized, goal-concordant care that can reduce the cost of unwanted over-treatment or low-value care, that costs the nation billions of dollars each year. Increasing the confidence of individuals who pass through our healthcare system that their ACP documents will be accessible to medical teams to inform the care they receive so that it is personalized and aligns with the medical treatments they want to receive, due to the existence and accessibility of advance healthcare directive document Data Classes and Data Elements aligned with standards that support data exchange by the nation's electronic health information systems, will go a long way to continuing the steady march of our healthcare system to being truly person-centered. Through USCDI we can move the technology companies that enable interoperable health information exchange to add the Data Classes and Data Elements to their systems that inform care and treatment plans based on the patient's values, goals, and preferences for treatment interventions. For these reasons, **MyDirectives strongly recommends the adoption of the suggestions we have provided for USCDI v6.** Thank you for your consideration.

Respectfully submitted,

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