

April 15, 2024

The Honorable Micky Tripathi, PhD, MPP
National Coordinator for Health Information Technology
Office of the National Coordinator for Health Information Technology
U.S. Department of Health and Human Services
330 C St SW, Floor 7
Washington, DC 20201

RE: U.S. Core Data for Interoperability (USCDI) version 5

Dear National Coordinator Tripathi:

On behalf of Compassion & Choices, the nation's oldest, largest, and most active nonprofit working to improve care and expand options at life's end, we strongly support the Office of the National Coordinator of Health Information Technology's continued efforts to drive widespread adoption of national data standards and interoperability. We applaud the focus on prioritizing data classes and elements needed to address patient treatment goals, particularly those for decisions related to healthcare at the end of life.

Compassion & Choices recommends data elements that enable individuals to express their personal values and healthcare preferences so that clinicians honor these individual decisions throughout an individual's life, including at the end of life. Expanding the health data class "Goals" to "Goals and Preferences" clearly indicates that patients have both, including preferences to treat and not to treat. We appreciate this change.

In addition, we support including "Treatment Intervention Preferences" and "Care Experience Preferences" data elements within classes related to advance planning documents, as this change would center the person receiving healthcare and honors their voice even if they lose capacity to make their own care decisions. These elements should be included in a way that highlights treatment and care preferences regardless of when during a person's life they are seeking care, including at the end of life.

Furthermore, we call your attention to recommendations to describe care planning documents like advance directives, living wills, medical power of attorney documents, and medical orders related to life sustaining treatments in a way that is easily available, understood, and supported regardless of the healthcare system in which an individual seeks care. Standardizing a data class for care planning documents in these systems, for example using an Advance Healthcare

Directive data class, could better indicate patient preferences to clinicians and those working in patient records.

We also support recommendations to use terms and standards that indicate clinicians must follow the preferences described in a valid advance healthcare planning document.

Compassion & Choices includes clinicians within its planning and work. Our team of doctors, nurses, and social workers can be available to discuss best practices for the proposed standards. We stand ready to galvanize Congressional and grassroots support for the effort. If you have any questions, please contact Bernadette Nunley, National Director of Policy, at 502-396-0255, bnunley@compassionandchoices.org.

Sincerely,

Bernadette Nunley
National Director of Policy
Compassion & Choices