



Care and Choice at the End of Life

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September 30, 2021

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: Draft U.S. Core Data for Interoperability (USCDI) version 3

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 (ONC) efforts to drive widespread adoption of national data standards and interoperability. We applaud the focus on prioritizing data classes and elements needed to address public health emergencies and structural inequality.

We echo the recommendation submitted by OCHIN on September 30, 2021, regarding advance directives. OCHIN is a national nonprofit health information technology organization with two decades of experience transforming health care delivery to advance health equity through technology, data insights and expertise.

RECOMMENDATION: Include Advance Directives Domains and Elements in USCDI version 3 or allocate resources to accelerate development.

The COVID-19 public health emergency has underscored the importance of increasing preparation and ready accessibility of current advance care planning tools to aid patients and their clinicians when patients are in extremis. The need to support national standards to facilitate interoperability in the context of natural disasters is also becoming more common and frequent and highlights the need for easily exchanged advance directive observation, care experience preference, durable medical power of attorney, living will, personal advance care plan, and quality of life priorities. In addition to facilitating interoperability for certified health information technology data exchanges, such standards will guide work among states

developing registries as well as developers creating tools to support advance care planning. This continues to be an important priority.

Increasing Patient-Directed Care at the End of Life

COVID-19 has revealed the need to improve our advance care planning policies, so providers and caregivers alike are not forced to make uninformed care decisions. In the absence of an advance directive, we continue to see the tragedy of loved ones and providers making life-altering decisions with limited or no information. According to a recent article in the Journal of AHIMA, documentation detailing a person's end-of-life wishes is important now more than ever. "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."¹

This problem is not a new phenomenon, and the impact lack of planning has on providers and those who are left behind is noteworthy. Furthermore, the decision a loved one would make may also violate the wishes and values of the patient and may be futile.

During COVID-19, there has been some increase in advance directive completion.² However, if hospitals do not have readily-available access to patient advance directives, we will not know whether these advance directives will surface or be honored. Allocating resources to Advance Directive Observation will provide needed end-of-life instructions to caregivers and providers, offering people a far greater chance their wishes will be fulfilled.

Removing Obstacles for Underserved Populations

End-of-life care challenges are even more pervasive among communities of color, who face barriers related to end-of-life care planning at higher rates than white communities.³ Just one in three of our nation's adults are known to have completed an advance directive, leaving too many physicians and family members in the midst of this pandemic to make last minute, agonizing, life-and-death decisions for an individual. The figures are more alarming among racially and ethnically diverse populations; for example, 15% of Black Americans and 11% of Hispanic Americans, as compared with 35% of white Americans have documented their end-of-life wishes.⁴

¹ Butler M. COVID-19 Highlights HIM's Advance Care Planning Expertise. Journal of AHIMA. June 3, 2020. Available from: <https://journal.ahima.org/covid-19-highlights-hims-advance-care-planning-expertise/>.

² Auriemma CL, Halpern SD, Asch JM, et al. Completion of Advance Directives and Documented Care Preferences During the Coronavirus Disease 2019 (COVID-19) Pandemic. *JAMA Network Open*. 2020;3(7):e2015762. Available from: <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2768372>.

³ Orlovic M, Smith K, Mossialos E. Racial and ethnic differences in end-of-life care in the United States: Evidence from the Health and Retirement Study (HRS). *SSM-Population Health* 7(100331). 30 Nov. 2018. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6305800/>.

⁴ Kaiser Family Foundation, Apr 2017. Views and Experiences with End-of-Life Medical Care in the U.S. Available from: <https://www.kff.org/report-section/views-and-experiences-with-end-of-life-medical-care-in-the-us-findings/>

Advance care planning helps ensure future medical treatment conforms with an individual's beliefs and values, mitigates bias to ensure people get the full breadth of care they want, and protects against excessive, unwanted treatment. Unfortunately, we live in a highly fragmented healthcare system, where clinicians providing medical care often have no knowledge or ability to access a patient's advance directive.

Now, more than ever, individuals need to engage in informed discussions about what end-of-life care they want or do not want if they get seriously ill and who will make health care decisions on their behalf if they are unable to do so. Compassion & Choices believes that standardizing advance directives should be a national priority. We ask that ONC elevate this issue now and allocate the necessary resources to help expedite the process to move advance directives standards forward.

Compassion & Choices includes physicians within its planning and work. Our team of doctors 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