

The Role of Health Information Exchange in Advanced Care Planning

Last Update Date: June 2022

The purpose of this document is to share the value of leveraging Maine's statewide Health Information Exchange (HIE) infrastructure to enable the collection, storage, and review of patients' Advanced Care Planning (ACP) information. ACP information comprises the decisions that patients and their caregivers may need to make at the end of life or in the event of an emergency, and are often documented in the form of living wills, healthcare power of attorney forms, and pre-hospital medical care directives (e.g., do-not-resuscitate (DNR) and do-not-intubate (DNI) orders, organ and tissue donation decisions, and Physician Orders for Life-Sustaining Treatment (POLST) and Medical Orders for Life-Sustaining Treatment (MOLST) forms).

The Need to Capture ACP Information in the Statewide HIE

Maine's population is aging. By 2025, estimates show that over 25% of the state's population will be 65 years of age or older. That makes our state the oldest in the country. Between the rising costs of long-term support services (which exceed the budgets of most Maine households) and the decreasing availability of long-term support staff (which is projected to dip to just two working-age adults for every one person 65 years of age or older by 2026), our state is constantly searching for ways to meet the needs of its aging population.

To this end, in an effort to bolster the care coordination efforts for patients transitioning to-and-from and in-and-out of Maine's long-term care facilities, HealthInfoNet recently connected the majority of post-acute care providers located throughout the state to the statewide HIE. These providers can now ascertain much more information about their patients than before, including their adverse effects to medications, histories of diagnoses and chronic conditions, and recent laboratory test results. However, because the HIE does not currently collect ACP documentation from its participants, these providers are left without one of the most valuable pieces of information that could be used to guide their clinical decision-making when it comes to addressing their patients' end-of-life care wishes.

Meeting the needs of Maine's aging population can also drive change that benefits all. As providers increasingly turn to the statewide HIE during the ongoing COVID-19 pandemic to receive critical information on their patients' healthcare activities, it underscores yet another use case for digitalizing and making available patients' ACP information to care teams. These front-line providers are often faced with the pressing need to attend to their COVID-positive patients' emergent end-of-life care preferences. Never before has the accessibility of electronic ACP information been so essential to delivering care to these patients who may be without their decision-making caregivers for the first time or who find themselves unexpectedly unable to express their values and desires for themselves.

By incorporating patients' ACP documentation into the statewide HIE in conjunction with their longitudinal medical and social health histories, it would give Maine's providers access to important information from which subsequent conversations could be had in order to inform clinical decision-making at the point of care either in emergency situations or not.

Overcoming the Challenges Associated with Capturing ACP Information Electronically

Paper-based ACP documentation leads to numerous barriers, burdens, and adverse patient outcomes during care transitions, as providers may not have immediate access to patients' end-of-life wishes at the point of care. For that reason, providers have turned to traditional methods (e.g., scanning) for ingesting paper-based information into their EHRs for electronic capture and ongoing reference. Furthermore, more recently the clinical community has pushed to collect, exchange, and use ACP information through standards-based efforts. The Health-Level Seven (HL7) Advance Directive Interoperability workgroup, for example, has been tasked with converting existing documents stored in clinical systems into standardized formats as well creating a template that can be used to author new documents by providers in collaboration with their patients.

These evolving efforts demonstrate the clinical community's acknowledgment of the need to account for data across the continuum of care and beyond the traditional healthcare system, as well as their interest in capturing the information digitally and in a format easily accessible by authorized care team members. Yet the argument for capturing ACP information electronically and storing it in a centralized location has not gone unchallenged. Most common is the concern that ACP information is subject to change over time, and therefore how can providers know – better yet, why should providers be *responsible* for knowing – that the most recent versions of their patients' documentation is updated in their EHR systems at any given time.

But just as providers study and ask questions about the many other data elements currently available in their patients' HIE health records ultimately before basing their clinical decisions, the same would be true for ACP documentation. As always, providers would be instructed to use the documentation to *facilitate* conversations with their patients to determine the most appropriate care plan; and, in the case of an emergency, the documentation would serve to *guide* possible actions and outcomes, especially if caregivers were not available for confirmation or discussion. In fact, this process of confirming communications is no different from what occurs with paper-based documentation today.

Using the HIE as a Source of ACP Information

Today, the statewide HIE is used by more than 870 healthcare providers located throughout the state to help improve the quality, safety, and delivery of patient care. It serves as the most comprehensive, accurate, and timely blueprint of Maine patients' healthcare activities. As a result, Maine's providers turn to HealthInfoNet's systems to receive critical information on their patients to inform appropriate care management and coordination activities. However, by not recording patients' available ACP documentation, the HIE currently falls short in meeting its mission. The effort of collecting, storing, and sharing data across the continuum of care to benefit patients' healthcare experiences ends with ACP documentation. This information will help Maine's provider community continue to better respond to the needs of the state's aging population, those affected by the COVID-19 pandemic, as well as those who encounter unexpected emergency situations in their or their loved ones' lives.

To that end, HealthInfoNet is currently engaging select participants to pilot the collection, exchange, and display of ACP information within the HIE's Clinical Portal electronic health record system. As efforts continue, additional participants will be prioritized for integration opportunities.

For questions or additional information, please contact HealthInfoNet's Client Engagement team via email at clientengagement@hinfonet.org.

