



# The Data of Advance Care Planning

Workshop Series Summary and  
Findings

August 2023

# Executive Summary

## White Paper Abstract

Michigan Health Information Network Shared Services (MiHIN)—as the state-designated entity for health information exchange and a lead entity in Michigan’s five-year Health Information Technology (HIT) Plan— is taking the lead on learning to understand the current state of information or data flow to support serious illness care.<sup>1</sup>

Between April – May 2023, MiHIN hosted a three-part workshop series to explore how processes, documents, conversations, and information movement could be changed to support serious illness conversations. This workshop series provided a platform for care teams, nurses, doctors, payers, hospitals, and more to share their professional perspectives on capturing and utilizing advance care documents.

This document contains the following:

- An understanding of MiHIN’s role in the State of Michigan
- An explanation of relevant Advance Care Planning (ACP) terms
- An overview of MiHIN’s involvement with ACP to date
- A summary of comprehensive research on the shortcomings of ACP to achieve the intended quality outcomes
- An outline of the MiHIN ACP workshop series goals and list of attending organizations
- A compilation of the key workshop takeaways

MiHIN’s hope is that the Michigan Department of Health and Human Services (MDHHS) and the HIT Commission utilize these findings and consider the recommendations in their ongoing efforts to steer Michigan’s Health Information Technology landscape.

## Overview of Michigan Health Information Shared Services (MiHIN)

MiHIN is Michigan’s non-profit, statewide entity that legally, technically, and securely provides critical and comprehensive patient information to its network of care providers. This network comprises doctors, clinics, federally qualified health centers, hospitals, pharmacies, health insurance providers, public health, and more. MiHIN serves its network of participants by providing an interoperable digital fabric designed to facilitate statewide connectivity between all the entities responsible for the health and wellness of their patients, clients, and members.

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<sup>1</sup> Michigan Department of Health and Human Services. (2022, June). Michigan Health IT Roadmap “Bridge to Better Health” Report. *Health Information Technology Commission*. <https://www.michigan.gov/mdhhs/doing-business/commissions-boards/hitcomm>

In short, MiHIN builds the technical and legal infrastructure—a critical foundation needed for Health Data Utility— that ensures the availability of data and information where and when needed to improve care coordination and inform clinical decision-making at the patient and population levels.

MiHIN’s stakeholders find value in the meaningful exchange of health data at every level of the healthcare ecosystem. This is because clinical needs drive MiHIN’s developed technology. To understand the landscape around particular health topics, MiHIN convenes relevant stakeholders to share their insights. This is currently done in the form of virtual workshops. MiHIN uses community and clinical insights to shape future technologies that will meet care team needs and allow equitable, high-quality care to flourish.

## Introduction to Advance Care Planning

To understand the clinical perspective of what documents and data are needed to support end-of-life care, MiHIN hosted three stakeholder workshops between March – May 2023. These workshops focused on the topic of Advance Care Planning (ACP).

ACP is the process of discussing what treatment and care an individual may or may not want and whom that individual would want to speak for them if they cannot speak for themselves. Part of the ACP process involves the creation of documents which outline the individual’s preferences and decisions, which by design were intended to ensure that future care adheres to the individual’s choices, thereby allowing patient self-determination. These documents collectively are known as advance directives (AD)<sup>2</sup>.

AD documents outline treatment preferences, designate an alternate decision maker (patient advocate), and in some spaces are beginning to document patient values intended to guide care teams in conversations about treatment for serious illness. There are several documents and various formats for this information capture. Still, the only legally-binding AD in the State of Michigan is the Patient Advocate Designation (also known as the Durable Power of Attorney for Healthcare).

Public and private payers financially support ACP conversations between individuals and care teams and have been now since at least 2016. It is important to note that producing an advance directive is not a required outcome for providers to be reimbursed for ACP conversations.

## MiHIN’s Role in Advance Care Planning

Funding partnerships with the Michigan Department of Health and Human Services (MDHHS) have previously supported MiHIN to develop a centralized repository where care teams and individuals could store and retrieve AD documents. MiHIN’s Advance Care Document (ACD) Use Case supports the electronic storage and retrieval of ACDs from any organization participating in the ACD Use Case. This use case allows users to query, retrieve, and display ACP documents from one vendor repository.

Additionally, MiHIN has a strategic business unit called Making Choices Michigan (MCM). In 2010, MCM began an independent organization to promote ACP conversations and ACP processes in healthcare and

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<sup>2</sup> Advance Care Planning: Glossary of Terms (2023). *Henry Ford Health*. <https://www.henryford.com/visitors/advance-care-planning/glossary>

communities. In 2020, MiHIN adopted MCM as a strategic business unit following a merger with a regional HIE.

MCM's primary services include training ACP facilitators, facilitating individual ACP conversations, and convening statewide ACP thought leaders and volunteers. MCM is modeled on the Respecting Choices® care model, a commercial vendor with proprietary training and education. Between 2020 – 2022, MCM staff trained 66 people from 24 organizations across the Midwest and maintained a system of volunteers to conduct ACP conversations within communities.

## National Trends with Advance Care Planning

There has been a national movement around ACP since the 1990s. For over three decades, ACP has been regarded as a critical element in the quest for the elusive Triple Aim in healthcare, which led to widespread initiatives promoting and incentivizing ACP. These assumptions led to widespread initiatives promoting ACP.

However, in recent years, extensive research studies and systematic literature reviews bring current ACP approaches into question. These research efforts and literature reviews could not identify meaningful differences in healthcare use, patient quality of life, or goal-concordant care with ACP<sup>3,4,5</sup>.

Additionally—despite the promotion of ACP conversations—these efforts rarely result in the creation of documentation that reflects individuals' care choices at the time critical choices need to be made<sup>6</sup>. It has been noted in the literature and through research that without the context of imminent serious illness, individuals cannot reliably predict the choices they would make when serious illness occurs<sup>7</sup>. With this research and data in mind, the most reliable course of care is identifying a patient advocate who can engage in conversations when the patient cannot.

## Workshop Series Objectives & Goals

The purpose of the 2023 Advance Care Planning workshop series was for MiHIN and Michigan stakeholders to confer on the following: how should processes, documents, conversations, and information movement be changed to support serious illness conversations? This level of dialogue parallels current national conversations that shift the focus away from documenting predetermined decisions that align with care choices and move towards identifying values and goals that guide conversations throughout the spectrum of health and illness across all ages.

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<sup>3</sup> Malhotra, C., Sim, D., Rehman Jaufferally, F., Lim, J., Chuang, C., Finkelstein, E. (2020, January 25). Impact of a Formal Advance Care Planning Program on End-of-Life Care for Patients With Heart Failure: Results From a Randomized Controlled Trial. *Journal of Cardiac Failure*, 26(7). <https://doi.org/10.1016/j.cardfail.2020.01.015>

<sup>4</sup> Halpern, S., Small, D., Troxel, A. (2020, March 30). Effect on Default Options in Advance Directives on Hospital-Free Days and Care Choices Among Seriously Ill Patients: A Randomized Clinical Trial. *Critical Care Medicine*. <https://doi.org/10.1001/jamanetworkopen.2020.1742>

<sup>5</sup> Morrison, R., Meier, D., Arnold, R. (2021, October 26). What's Wrong With Advance Care Planning? *Journal of the American Medical Association*. <https://doi.org/10.1001/jama.2021.16430>

<sup>6</sup> Schneider, M. (2022, May). Rethinking Advance Care Planning. *ACP Internist*. <https://acpinternist.org/archives/2022/05/rethinking-advance-care-planning.htm>

<sup>7</sup> Lakin, J., Gundersen, D., Linvall, C., Paasche-Orlow, M., Tulsy, J., Brannan, E., Pollak, K., Kennedy, D., McLeggon, J., Stout, J., Volandes, A. (2021, July 16). A Yet Unrealized Promise: Structured Advance Care Planning Elements in the Electronic Health Record. *Journal of Palliative Medicine*. <https://doi.org/10.1089/jpm.2020.0774>

Under this big umbrella, the workshop series provided an opportunity for facilitated discussion across the broad stakeholder groups to determine recommendations on the following:

- What does successful serious illness care look like in Michigan? What information, data, and/or documents must move between care environments to support serious illness care planning?
- What is available in the State of Michigan for training and leadership collaboration surrounding serious illness conversations? What resources are available in the state for individuals to have serious illness conversations?
- Are there policy barriers that create the need for technical workarounds?

MiHIN created this workshop white paper to share with the State of Michigan’s Health Information Technology (HIT) Commission and MDHHS, legislatures, care teams, payers, etc. who may find this information beneficial in planning for future activities and funding to promote quality.

## Workshop Attendees

Over the three-part workshop series, 67 individual professionals participated. Excluding MiHIN staff, six professionals attended all three workshops, and 19 professionals attended at minimum two of the three workshops. Attendees provided insight from the following sectors and organizations:

- MDHHS
- Tribal Governments
- Health Information Networks
- Physician Organizations
- Pharmaceutical
- Health Technology
- Commercial Health Plans
- Medicaid
- Hospital Systems and Clinical Specialists
- Hospice Care
- Community-Based Organizations
- Colleges and Universities

360care	Greater Flint Health Coalition	Munson Healthcare
Administrative Network Technology Solutions	Harbor Hospice	MyMichigan Health
ADVault Inc	Harbor Palliative Care	Nottawaseppi Huron Band of the Potawatomi
Aging with Dignity	HealthBridge	Pfizer, Inc.
Answer Health Physician Organization	Hills and Dales Healthcare	Priority Health
Augusto Digital	Holland Hospital	Saint Joseph Mercy Health System
Baptist Health	Holland PHO	Smile Digital Health
Baylor Scott and White Health	Hypertension Nephrology Associates	Sparrow Care Network
Blue Cross Blue Shield of Michigan	iMPROve Health	Superior Health Quality Alliance
Cancer & Hematology Centers of Western Michigan	Jewish Family Services	Torrie Fields Analytics
Care Solutions	LTC Physician Care	Training & Treatment Innovations, Inc.
CareAdvisors	MDHHS Health IT Commission	United Physicians
Contexture	Medicaid Management Services	United Way of Genesee County
Corktown Health	Michigan Department of Health and Human Services (MDHHS)	University of Michigan

Davenport University	Michigan Multipayer Initiatives	Upper Peninsula Health Plan
Dickinson County HealthCare System	Michigan Public Health Institute	Urban Aging News
Emergent Holdings, Inc.	Mid-State Health Network	Vascular Health Center
Genesys PHO	Milliken Medical	West Michigan Cancer Center
Grace Health	MSU Health Care	Wolverine Dermatology

## Key Workshop Takeaways

### **MiHIN’s Advance Care Documents Use Case efforts should prioritize getting patient advocate designations signed and exchanged.**

- Stakeholders confirm that the Patient Advocate Designation is the most impactful piece of information to deliver value for patient care at all stages of health and wellness.
- Attending professionals agree that creating Patient Advocate Designations and making them accessible to care teams and individuals is the priority.
- Patient Advocate Designation is the only legally binding advance directive recognized in the State of Michigan.
- MiHIN will not exclude the ability to share other advance care documents through its use case.
- Metrics should be used to track efforts towards increasing the number of individuals with patient advocate documents in the repository. MiHIN can facilitate these metrics.

### **Electronic signature capture should lessen barriers to completing Patient Advocate Designations.**

- Getting four witness signatures in paper format can be challenging and can cause a lengthy delay in document completion.
- Legal electronic signature technology exists and is widely used in healthcare and other industries.
- 94% of workshop attendees agree that electronic signature capture for Patient Advocate Designations would simplify the process.
- Stakeholders also indicate that enabling electronic signature capture just for the patient advocate’s signature alone would be an improvement, as many patient advocates are family members who live out of state.
- Stakeholders confirm that the availability of patient advocate forms in the statewide health information exchange would lessen the burden for healthcare providers in searching for patient advocate forms
- With funding, MiHIN can conduct a feasibility study to determine if electronic consent management can reduce barriers to Patient Advocate Designation signatures.

## Michigan should investigate the Next of Kin Law as a possible policy tool impacting serious illness care.

- The lack of a Next of Kin Law in Michigan has negative implications for patients, their families, healthcare institutions, and payers. It should be investigated as a means of improving serious illness care.
- A lack of Next of Kin Law forces clinical staff to make decisions based on perceived family consensus.
- Individuals in the hospital without a patient advocate already appointed can have a family member make decisions for them. Hospitals have largely agreed to allow family members to make decisions when no patient advocate is appointed while in the hospital.
  - Should that same individual require movement outside the hospital setting, the family members who have been making decisions no longer can.
  - At this point, the hospital must face legal challenges to obtain an official patient advocate designation, which can sometimes take up to three months.
  - This legal challenge can cause significant delays in appropriate treatment and keep individuals in the hospital where the best standard of care could be outside of the hospital (i.e., skilled nursing facility, rehab, hospice, palliative care, etc.).
  - A state appointment decision maker may or may not be a family member or someone known to the individual.
- If a patient doesn't have a designated patient advocate, the current law may leave a patient without a decision maker; at the same time, the lack of a Next of Kin Law is intended to protect a patient's wishes and ensure they have autonomy, in some instances, this is causing direct harm as a result of delayed care.
- This situation requires the hospital to pursue a legal determination to gain a state-appointed patient advocate designation, delaying appropriate treatment and creating hardship for the family, individual, and institution.

## A statewide, multidisciplinary, cross-sector Palliative Task Force could be created to drive better serious illness care and the necessary data, information, and process changes.

- 21 U.S. states have advisory councils that inform providers and consumers about palliative care for individuals with serious illnesses. Most of these advisory councils are required by legislation<sup>8</sup>. These may serve as models for creating a Michigan Palliative Care taskforce.
- The task force could utilize the findings from these stakeholder sessions to inform best practices with serious illness documentation, processes, and information movement.
- Michigan recently adopted Michigan Physician Orders for Scope of Treatment (MI-POST) to aid in serious illness care for Michigan residents. MI-POST is an optional, short medical order with a person's wished-for care in crisis<sup>9</sup>.

<sup>8</sup> States with Palliative Care Information Programs. (2023, June 30). *National Academy for State Health Policy*. <https://nashp.org/map-public-education-programs/>

- Because MI-POST is a new tool, process changes can occur to drive awareness and effective use of MI-POST. This may be an appropriate topic for the Palliative Care Taskforce.
- The task force should be cross-sector and multidisciplinary.
  - Viewing this only from a healthcare institutional perspective does not capture cultural differences and needs in various communities.
  - Because this work impacts many across healthcare sectors, communities, faith groups, etc., expanding this to include multiple perspectives is necessary to ensure equitable representation.
  - It is also crucial for the palliative task force to have representation across healthcare positions— especially those directly interacting with patients—as their lived professional experience with serious illness care provides rich and practical insight.
- Based on stakeholder feedback during these workshop sessions, a Michigan Next of Kin Law may improve serious illness processes. However, creating a Next of Kin Law requires comprehensive input from healthcare professionals. This is an appropriate topic for this task force.
- Convenings should be driven with greater authority than MiHIN (possibly through MDHHS).
- MiHIN’s Making Choices Michigan was the only statewide convening body for ACP strategic planning that could be identified.
  - In the process of the stakeholder engagement sessions, this convening body was discovered to have a very narrow focus.
  - MiHIN's Making Choices Michigan convening should be replaced by such a task force.
  - MiHIN's role in such a task force would be to act as a subject matter expert for data interoperability.
- To gain traction on essential aspects of care, tools such as financial incentivization and policy levers should be considered.

**There may be a need for training on obtaining legal Patient Advocate Designation; however, this is outside the scope of MiHIN expertise.**

- Workshop attendees agree there is a need for healthcare professionals to have simple and clear guidance on how to get valid, legal, signed Patient Advocate Designations.
- Stakeholders also agree there is a need for affordable training that teaches care team members how to have conversations about serious illness care.
- 92% of workshop attendees agree that statewide licensing requirements could include training on serious illness conversations and advance directive documentation completion.
- Stakeholders understand that MiHIN’s role as a Health Information Exchange does not include community training and facilitation for ACP.
  - Making Choices Michigan started as an independent nonprofit and was later brought under the umbrella of services with Great Lakes Health Connect (GLHC). After the GLHC merger, MiHIN adopted MCM as a strategic business unit.

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<sup>9</sup> Michigan Physician Orders for Scope of Treatment (MI-POST). (2023, June 23). *Michigan Department of Health and Human Services*. <https://www.michigan.gov/mdhhs/inside-mdhhs/legislationpolicy/ems/news/mi-post>



- Making Choices Michigan is modeled on the Respecting Choices proprietary model of care, and that program is prohibitively expensive for small- and mid-sized health organizations. MiHIN is a neutral steward of data and an agnostic intermediary, and therefore should not promote a proprietary that is financially inaccessible to all its stakeholders.
- MiHIN can advance effective ACP by continuing to enable the ability to capture, query, and retrieve advance directives through its use case; MiHIN can also enable the use of electronic signature capture for Patient Advocate Designations, if deemed feasible.

### **Statewide licensure education requirements should be considered as a mechanism for standardized education on the use and importance of a Patient Advocate Designation.**

- Stakeholders agreed that standardized education may have a role in clarifying the importance of Patient Advocate Designations to serious illness care.
- The historical ACP processes may also be essential to place in context and use as a tool to distinguish the path forward in Michigan.
- Legal vs. subjective documentation intended to support care throughout the health and illness spectrum has long confused care teams. Clarity may come from educational processes.
  - 92% of stakeholders in attendance support training and education that is nonproprietary and equitably accessible across the state.

### **Conclusion**

MiHIN's stakeholder convenings provide a platform for professionals across the healthcare ecosystem to share their perspectives and needs, ultimately guiding technology solutions that improve health outcomes, increase efficiencies, and decrease healthcare costs. 87 professionals representing 57 diverse organizations attended at least one session of MiHIN's three-part ACP workshop series in Spring 2023.

This white paper outlines the six most prominent and agreed-upon solutions to increasing the documentation and interoperability of advance directives, as identified by Michigan's healthcare professionals. MiHIN requests that MDHHS and the HIT Commission consider these findings in their mission to advance Michigan's Health IT landscape.