Use Case Summary

NAME OF UC:

EXCHANGE ADVANCE DIRECTIVES

Sponsor(s): MDHHS / MiHIN

Date: 09/29/15

The purpose of this Use Case Summary is to allow Sponsors, Participants, and other readers to understand the purpose of the Use Case (UC), the value proposition the UC represents, and what the Use Case does, requires, and how the UC operates at a high level. The summary is intended to assist the HIE and HIT Community understand where this UC fits within the overall roadmap for statewide sharing of health information.

This UC Summary has several sections allowing readers to understand the impact of this UC in the following areas: health outcomes, regulation, cost and revenue, implementation challenges, vendor community, and support.

Executive Summary

In this section provide a brief (3-5 sentence) summary of the UC's function and purpose. Also include a brief description of the importance and highlight the expected positive impact from implementation of this UC.

Medical situations sometimes arise during which patients are unable to speak for themselves, such as being in a coma or on life support. Some people leave written *directions*, in *advance*, of their wishes for major healthcare decisions should they be in such a situation. These written instructions are called "Advance Directives."

Advance Directives are legal documents which express a patient's instructions for healthcare providers to make certain decisions if the patient is unable to do so. Patients may wish to *direct* their care team in *advance* not to provide certain types of potentially life-saving, yet potentially drastic and costly medical treatments based on the patient's individual values and beliefs. Examples of documents that are considered Advance Directives (ADs) include a living will, a durable power of attorney (DPOA), organ donor wishes, Patient Advocate designations, "Do Not Intubate," and "Do Not Resuscitate" instructions.

It is noteworthy that unexpected end-of-life situations can occur at any age; however, focus is often placed on elderly patients preparing ADs.

Typically a patient's Advance Directives are recorded only on paper and are usually stored by patients with other valuable effects or important documents in a safe-deposit box or special place in their home, or copies are given to close relatives or a guardian. However, when a medical situation arises where the Advance Directives would be used to make critical decisions and abide by the patient's wishes, frequently health care providers and even family members are unable to locate the documents or even know whether they exist.

Advance Directives can be created as digital documents or scanned from paper to create digital copies but the dual problems of both discovering the existence of the digital documents and then locating valid copies of the ADs still remain. Just because an Advance Directive document is digital does not mean it is any easier to find when a relevant medical situation arises.

Purpose of Use Case:
The purpose of this Use Case is to enable participation in a standard, statewide means by which ADs are stored, located, and retrieved when needed. Patients need a way to indicate where their ADs are stored and how the ADs can be accessed by healthcare providers, so that their care team, family members and/or legal representatives will be better able to honor the patient's decisions and choices.

By allowing patients to specify the location of their ADs, and by promoting a service for authorized persons to access ADs, higher numbers of patients of all ages may decide to complete and store ADs to be accessible in the event of an emergency.

The Exchange Advance Directives Use Case utilizes a directory model which provides point-of-care access to Advance Directive information. Normally digital ADs are stored in a special registry or repository, such as a patient portal or a Personal Health Record (PHR) system, or the Peace of Mind Registry. Storing a patient's preferences for locating and sharing their ADs in a Statewide Consumer Directory ensures that if a patient is in an emergency or has a condition rendering them unable to make decisions about their medical care, their wishes can be located, retrieved, and considered by the care team.

For the purpose of this Use Case, patients should access the Statewide Consumer Directory to specify the repository where they want their Advance Directives to be stored and who has permission to access them. A patient should create and/or upload digital copies of their Advance Directives in preparation for potential medical situations that might require the ADs. Patients can upload digital copies of their ADs to their preferred repository from a variety of sources such as from home, a hospital, a doctor's office or clinic, an attorney's office, or directly using a health plan portal such as MyHealthPortal, the Medicaid Member Portal in Michigan.

After uploading, the patient's digital AD is stored at the patient's designated repository such as a patient portal, their Personal Health Record (PHR) such as Microsoft HealthVault or NoMoreClipBoard, or the Peace of Mind Registry for Medicaid members in Michigan. Alternatively, if a patient already has ADs stored in a repository, for this Use Case patients should merely access the Statewide Consumer Directory and specify in which repository their Advance Directives are stored along with who has permission to access them. This will allow the Advance Directives to be located and retrieved electronically and quickly should the need arise.

Diagram

In this section, provide a diagram of the information flow for this UC. The diagram should include the major senders and receivers involved and types of information being shared.

The Exchange Advance Directives Use Case can help distribute advance directive documents to target repositories/registries as shown in the first diagram below, or it can be used simply to identify the location of advance directive documents as shown in the second diagram below.

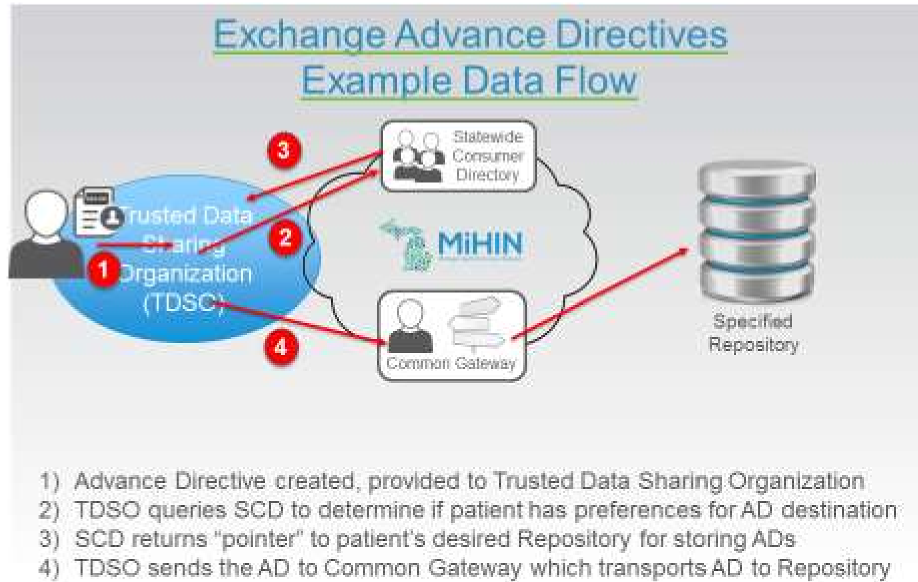

Figure 1: Exchange Advance Directives Example Data Flow

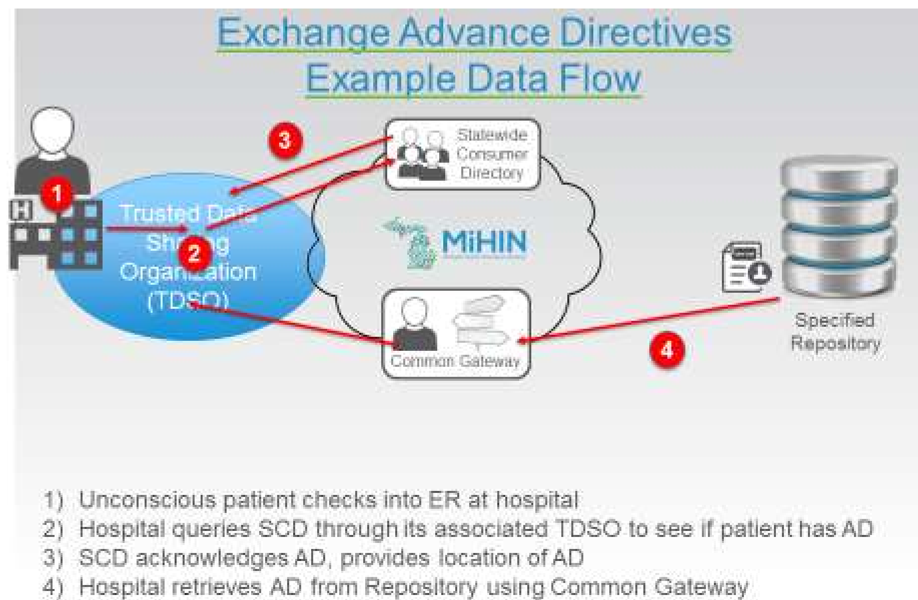

Figure 2: Exchange Advance Directives Example Data Flow

Persona Usage Scenario

In this section, assign a persona to this use case and provide an example of the persona following use case flow from start to finish.

Persona: Jerry Goodwall

Jerry Goodwall, a 79-year-old recently hospitalized veteran, has a variety of complex conditions that increase his risk of fatality or re-hospitalization: heart disease, osteoarthritis and recent stroke resulting in partial paralysis. Jerry recently transferred from an extensive physical rehabilitation facility into a skilled nursing facility (SNF). His recent near-death experience and loss in core motor and linguistic functions have bolstered his motivation to complete an Advance Directive.

Jerry always took pride in his self-sufficiency, but now that he has to rely on others for assistance in daily living and has a hard time quickly communicating his wishes, he is determined to have something on file that guarantee his requests will be met. During his initial visit with his new primary care physician (employed through the SNF) he discusses his desires regarding potential emergency medical care and completes an Advance Directive. As a dual-eligible beneficiary his Advance Directive was uploaded to MyHealthPortal and the Peace of Mind Registry.

Two months later, Jerry is rushed to the emergency room with a 105-degree fever and acute respiratory distress. ER doctors believe he has contracted a severe case of aspiration pneumonia and will require immediate medical care to reduce risk of fatality. While Jerry's condition prevents him from communicating his wishes regarding medical care, his Advance Directive is stored at the Peace of Mind Registry. Because the hospital is connected to Michigan's health information 'network of networks' through a Trusted Data Sharing Organization, the emergency room physicians are able to send a query to Peace of Mind and retrieve Jerry's Advance Directive, and provide the level of care appropriate to Jerry's established wishes.

Regulation

In this section, describe whether this UC is being developed in response to a federal regulation, state legislation or state level administrative rule or directive. Please reference the precise regulation, legislation, or administrative act such as Public Law 111-152 (Affordable Care Act), Public Law 111-5; Section 4104 (Meaningful Use), 42 CFR 2 (substance information), MCL § 333.5431 (Newborn Screening), PA 129 (standard consent form), etc.

Additionally, provide information if this UC will allow Eligible Professionals/Providers (EP) or Eligible Hospitals (EH) to meet an attestation requirement for Meaningful Use.

Legislation/Administrative Rule/Directive:

☒ Yes
☐ No
☐ Unknown

Name or number of legislation, rule, directive, or public act:
This Use Case supports the adoption of the Peace of Mind Registry (MI Public Act 179 of 2012).

Meaningful Use:
☐ Yes
☒ No
☐ Unknown

This Use Case does not singularly meet the requirements of Meaningful Use Patient Engagement, but it provides consumers with tools to direct their information and engage in the management of their care.

Cost and Revenue

In this section provide an estimate of the investment of time and money needed or currently secured for this UC. Be sure to address items such as payer incentives, provide incentives, revenues generated (e.g. SSA transaction payments) or cost savings that could be realized (i.e. reduction of administrative burden).

As information is known or available, provide information on the resources and infrastructure needed to move this UC into production.

This Use Case utilizes existing infrastructure to transport the AD via Direct Secure Messaging (DSM) or via the Common Gateway using CONNECT and NwHIN (now the Sequoia Project) protocols.

The cost to Data Sharing Organizations to implement this Use Case will likely be technical/staff resources to develop and/or test the end-to-end service with HIN to ensure they can create and/or receive the AD.

Implementation Challenges

In this section, as information is known or available, describe challenges that may be faced to implement this UC. Be sure to address whether the UC leverages existing infrastructure, policies and procedures, ease of technical implementation, or impacts current workflows (short term and long term).

One challenge is prompting Data Sharing Organizations to prioritize connecting to MiHIN and the registries to receive and respond to requests for Advance Directives.

Another challenge is promoting the use of ADs by consumers. For providers to rely on this service and have confidence that information will be available if they search for it, consumers must be educated that they have the ability to complete and store their ADs and specify the providers with whom these documents may be shared.

A third challenge involves keeping the AD current and managing multiple ADs stored in multiple places. This challenge will be addressed during implementation by managing versions of ADs within the PHR and/or AD registries and effectively "federating" multiple storage locations.

Once an AD is posted it must remain current so that providers will have confidence that they are carrying out the current wishes of the consumer. Some providers may not be willing to accept an AD that is

considered to be old or outdated. This may be addressed by assigning dates of validity to an AD, specified by the consumer.

Additionally, ADs are often required at the time of hospital admission. A consumer may have an AD on file at one hospital and another possibly conflicting AD stored in their PHR. Conflicts need to be managed and "trusted sources" maintained so that a treating provider is confident that any action taken respects the most current wishes of the consumer.

Vendor Community Preparedness

In this section, address the vendor community preparedness to readily participate in the implementation of this UC. Speak to whether this UC will utilize current or future technical capabilities of the vendor products. If this UC requires new functionality at the vendor level provide information as known to the timeliness of when product updates may be available and any potential costs to the HIE community.

The transport of ADs may not be included as base functionality for some EHR/PHR vendors; however, if it is not current functionality, it is likely to be on their future road map.

Support Information

In this section, provide known information on the support for this UC.

Support can come from multiple levels (Governor, Federal or State Legislative, MI HIT Commission, Michigan State Departments, CMS/ONC/CDC, MiHIN Board, Qualified Organizations, Payer Community, Interest Group [ex: MSMS, MHA], or Citizen support).

Please note any concerns or oppositions with the Use Case.

Political Support:

☒Governor
☒Michigan Legislature
☒HIT Commission
☒MDCH or other SOM Department
☐CMS/ONC
☐CDC
☒MiHIN Board
Other:

Concerns/Oppositions: None noted

Sponsor(s) of Use Case

Who are the major sponsors of the use case?

Michigan Department of Health and Human Services (MDHHS)
MiHIN Shared Services (MiHIN)

Metrics of Use Case

In this section, define metrics for the Use Case to be successful.

- Number of Data Sharing Organization (e.g. myHealthPortal) connecting with repositories/registries for advance directives (e.g. the Peace of Mind Registry) to the extent that an AD can be loaded (submitted) and queried from another Data Sharing Organization.
- Number of consumers managing advance directive documents through the Statewide Consumer Directory.
- Number of ADs managed through the Statewide Consumer Directory
- Number of providers accessing ADs through the Statewide Consumer Directory

Other Information

This section is to afford the sponsor(s) an opportunity to address any additional information with regard to this UC that may be pertinent to assessing its potential impact.