Use Case Scenario Summary

Use Case Scenario Name:	Caregiver Contact Information
Use Case to Which Scenario Belongs	Consumer Preference Management
Sponsor:	Michigan Department of Health and Human Services
Date:	March 8, 2019

Executive Summary

> *This brief section highlights the purpose for the use case and its value. The executive summary gives a description of the use case's importance while highlighting expected positive impact.*

"Caregiver" is most frequently defined as a person who provides direct care (as for children, elderly people, or the chronically ill)[1]. The term typically implies a family member, friend or paid assistant, such as a home health aide. The term also often refers to someone performing this role without compensation. An estimated 34 million unpaid caregivers were caring for others in the United States in 2008.[2] A majority of caregivers are family members (83%).[3]

Caregivers are often the best source of information about the patients for whom they provide care. Unfortunately, healthcare providers (doctors, pharmacists, health plans, etc.) may not know contact information for a patient's caregiver, or even that a patient has a caregiver. This lack of information can create additional work for healthcare professionals, can delay treatment or care, and in worst cases can lead to negative outcomes because needed information about the patient cannot be found.

Care team members need a way to find contact information for caregivers involved in their patients' care quickly and efficiently.

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[1] "Caregiver", accessed July 5, 2017, https://www.merriam-webster.com/dictionary/caregiver
[2] "Family Caregiving: The Facts," Centers for Disease Control and Prevention, accessed June 19, 2017, https://www.cdc.gov/aging/caregiving/facts.htm
[3] Ibid

Purpose of Use Case Scenario: The Caregiver Contact Information use case scenario allows a consumer to share contact information for their chosen caregiver(s). This contact information can then be made available to a consumer's care team members.

Overview

> *This overview goes into more details about the use case.*

Caregivers are an integral part of healthcare, particularly for the chronically ill and elderly.[4] About 16% of Americans serve as a caregiver to a friend or family member.[5] Family members and friends can offer support in many ways, including:

- Oversight of care routines
- Administration of medication
- Transportation
- Finances

Caregivers play a key role in transitions of care, assisting around important and necessary tasks such as helping patients understand their care instructions, care plan updates, and providing supportive information.

As noted in *Health Affairs:*

> Because of the critical role of family members in the delivery of transitional care and the unique challenges faced in assuming this role, dedicated investments should be made to prepare and support informal caregivers.[6]

Recognizing this importance, the Michigan Legislature passed the Designated Caregiver Act in 2016 to support the collection and use of caregiver contact information.

This use case scenario gives consumers the ability to access the Statewide Consumer Directory to view, change or delete their caregiver's contact information using patient portals or other mobile apps.

The scenario also allows healthcare professionals to share caregiver contact information that is collected at the point of care when the consumer gives permission to send the caregiver contact information to the Statewide Consumer Directory. This caregiver information can be sent as part of standard messages that are already being sent to the

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[4] M. Naylor, et al., "The importance of transitional care in achieving health reform," *Health Affairs* 30(4 2011), 746-754.

[5] J., Coughlin, "Estimating the impact of caregiving and employment on well-being," Center for Health Research, Healthways, Incorporated (2010).

[6] Ibid.

statewide health information network for other use cases. The caregiver information will be available to those healthcare professionals who have a relationship with the patient as defined by the Active Care Relationship Service.

Statewide Consumer Directory

The Statewide Consumer Directory acts as a repository of consumer information and a central "switchboard" for determining a consumer's preferences and permissions for sharing their health information with other people such as their care team members, family members, etc. Patient portals, consumer apps, or connected healthcare professionals can access the directory to find or send consumer preference information.

Active Care Relationship Service® (ACRS®)

The Active Care Relationship Service (ACRS) identifies providers who have declared an active care relationship with a patient. ACRS promotes better-coordinated transitions of care by enabling physicians and care management teams to receive notifications when there are updates in a patient's status. Using ACRS helps improve post-discharge transitions, prompts follow-up with patients, and improves communication among providers to support patients, especially those with multiple or chronic conditions.

Persona Story

To explain this use case, this section follows a persona example from start to finish.

Viola Campbell has never liked giving up control, especially around her health. She has had to be careful her whole life, beginning when she was diagnosed with epilepsy in her late teens.

Taking care of her epilepsy has been difficult, but something she could manage with the right medication. Yet as she has gotten older it has become more difficult to remember her medications, and, more troublesome, whether she had already taken a pill.

A few months ago, Viola started to notice some decline in her ability to participate in daily activities. Thanks to her lifelong dedication to oversee her own healthcare, she had a care team in place and knew who to call. Soon, she was diagnosed with glaucoma and chronic obstructive pulmonary disease. It was then that she felt she needed to make a change and, more importantly, she needed help.

Viola asked her daughter, Jessica Campbell, to act as her caregiver, assisting with medication and her care routine. Thanks to the Caregiver Contact Information use case scenario, Jessica has designated herself as the caregiver contact for her mother.

Recently, one afternoon Viola fainted and hit her head. Confused and panicking, Viola called emergency services who rushed her to the hospital. Viola was so dizzy she couldn't remember the names of her medications.

The hospital was able to quickly find Jessica's contact information as Viola's designated caregiver. Jessica shared important information about her mother's health and medication with the hospital staff. Because the correct information was available at the start of Viola's care, the hospital staff members were able to efficiently start Viola on the path for diagnosis and recovery.

Diagram

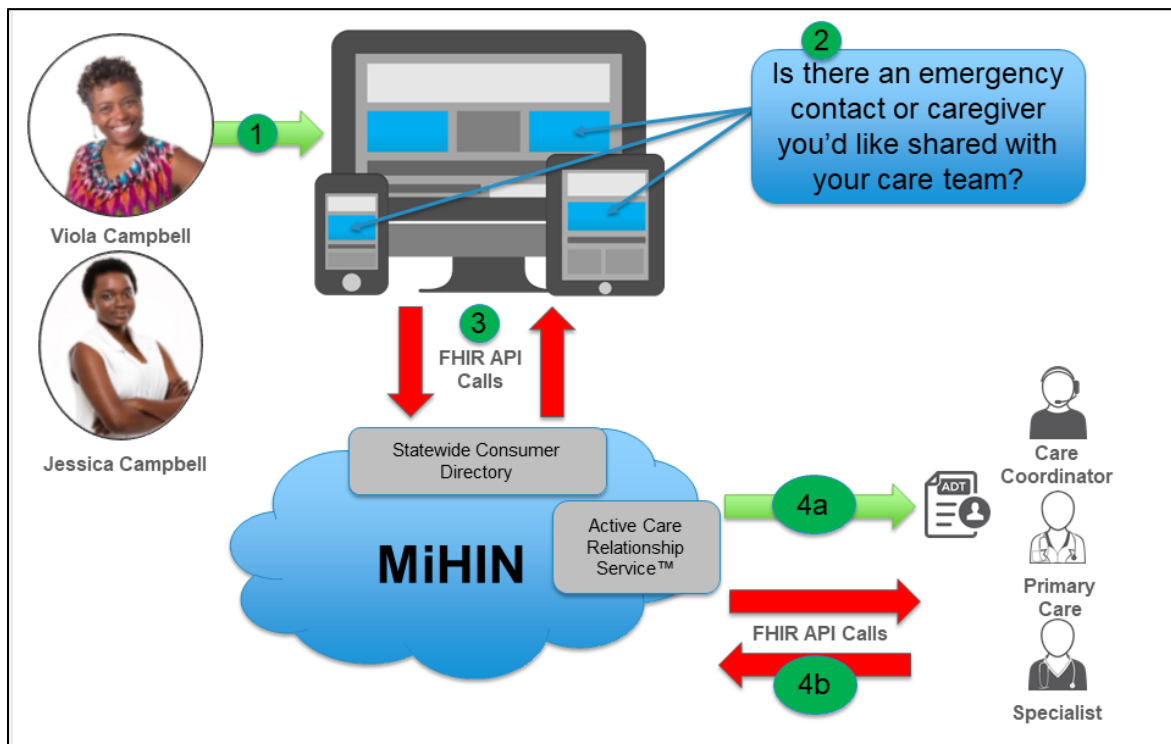*This diagram shows the information flow for this use case.*

Figure 1. Data Flow for Caregiver Contact Information Use Case Scenario

1. Jessica Campbell logs into a consumer-facing application with her mother Viola
2. The consumer-facing application, which is connected to the Statewide Consumer Directory, offers the Campbell family the option of providing caregiver contact information
3. The name and contact information provided by Viola and Jessica are sent via API (application program interface) back to the Statewide Consumer Directory
4. Caregiver contact information is made available to care team members as defined by the Active Care Relationship Service by either:
     a. Delivering a message to care team members that includes the caregiver contact information
     b. Responding to a care team member's query for the caregiver contact information

Regulation

This section describes whether this use case is being developed in response to a federal regulation, state legislation or state level administrative rule or directive.

Legislation/Administrative Rule/Directive:

☒ Yes
☐ No
☐ Unknown

- ■ Michigan Act 85 of 2016 (Designated Caregiver Act)

Meaningful Use:

☒ Yes
☐ No
☐ Unknown

Cost and Revenue

This section provides an estimate of the investment of time and money needed or currently secured for this use case.

The development costs for the Caregiver Contact Information use case scenario are absorbed by the Statewide Consumer Directory project.

A final pricing/revenue model has not been determined as of this writing. Some components of the current model include:

- No fees will be assessed by MiHIN on end users (i.e. patients/consumers), although third-party organizations may include fees to consumers in their business models.

- Fees may be assessed to provide connectivity and caregiver contact data to third-party organizations such as hospitals, personal health records, patient portals, mobile app vendors, etc.

- Revenue sharing with third parties also may be explored to cover operating costs related to this use case scenario and its required infrastructure.

Implementation Challenges

This section describes the challenges that may be faced to implement this use case.

The primary implementation challenge will be to engage consumers in the places they are already active, to ensure that caregiver contact information is collected for enough consumers to make the scenario useful for professionals coordinating care.

The secondary implementation challenge will be to work with each third-party portal/mobile app/website that wishes to participate. This includes:

- Establishing ongoing secure connections with MiHIN and the consumer directory
- Presenting information from MiHIN within their display environments (apps, portals, etc.) using APIs and the directory's software development kit (SDK)
- Working with MiHIN to assist in their app/portal development, integration, testing and interoperability using consumer directory features offered through its Software Development Kit and consumer portal, both developer tools that allow for easier implementation of the caregiver contact feature
- Communicating accurate consumer preferences to MiHIN consumer directory using its APIs and SDK

Vendor Community Preparedness

This section addresses the vendor community preparedness to readily participate in the implementation of this use case.

The Consumer Preference Management use case and its scenarios (including this one) partly rely on vendors who offer personal health records, consumer apps, and other appropriate health portals (e.g. patient portals) to establish a connection with the Statewide Consumer Directory and share information with the health information network.

This allows those portals/apps/PHRs to query the directory to determine consumer preferences and then to query the Active Care Relationship Service to display patient-provider relationships within their own environment, giving consumers the capability to manage the caregiver and care team relationships.

These vendors will establish secure connectivity with MiHIN and develop the ability to:

- Display information received from MiHIN
- Transport information to MiHIN using the Statewide Consumer Directory APIs

The labor and time investments for this integration are relatively small due to the ease of use of the APIs and software development kit for the directory, as well as availability of the MiHIN consumer portal, implementation guides, and other helpful documentation and support from MiHIN.

Support Information

This section provides known information on this support for this use case.

Political Support:

☐ Governor
☐ Michigan Legislature
☐ Health Information Technology Commission
☒ Michigan Department of Health and Human Services or other State of Michigan department
☐ CMS/ONC
☐ CDC
☒ MiHIN Board

Sponsor(s) of Use Case

This section lists the sponsor(s) of the use case

- Michigan Department of Health and Human Services

Metrics of Use Case

This section defines the target metrics identified to track the success of the use case.

The goal is for consumers to utilize the service. Key metrics for this use case scenario include:

- Number of portals, mobile apps, other tools actively participating in this use case scenario by accessing the statewide consumer directory and offering features/functions to their customers based on this use case scenario
- Number of unique consumers who provide caregiver contact information
- Number of caregiver contact entries provided by health care providers
- Number of enhanced messages with caregiver contact information sent
- Number of queries for caregiver contact information

Other metrics may be added as appropriate.