Care Planning and Care Coordination:

A Multi-Part Panel on Implementation of an Electronic Care Plan (eCP) and Technical Specifications

November 14, 2023
3:30 – 5:00 PM

RTI
INTERNATIONAL

Enter to win a *free registration* to the AMIA 2024 Annual Symposium!

Scan the QR code below for more information and to enter.

A winner will be notified via email after the conference.

PANEL

Multiple Chronic Conditions (MCC) eCare Plan

Who We Are and How We Work

Project and Panel

Project Partners and Panelists

Michelle Dougherty, MA
MODERATOR
Senior Manager and Health Informaticist

Evelyn Gallego, MBA, MPH, CPHIMS
CEO and Founder

Dave Carlson, PhD, MBA
Development Team Lead

Laura Marcial, PhD, FAMIA
Senior Director, Center of Informatics

David Dorr, MD, MS, FACMI
Chief Research Information Officer

Project Direction

Joint project between the Agency for Healthcare Research and Quality (AHRQ) and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)

Jenna Norton, PhD, MPH

Program Director

Kevin Abbott, MD, MPH

COR

Neha Shah, MSPH

Scientific Program Analyst

Arlene Bierman, MD, MS

Program Lead

Jaime Zimmerman, MPH, PMP

AHRQ Health Research Lead

Rachael Boicourt

AHRQ Health Research Lead

Project Support and Governance

Funded by the Assistant Secretary for Planning and Evaluation (ASPE) and the Department of Health and Human Services' Patient-Centered Outcomes Research Trust Fund (PCOR-TF)
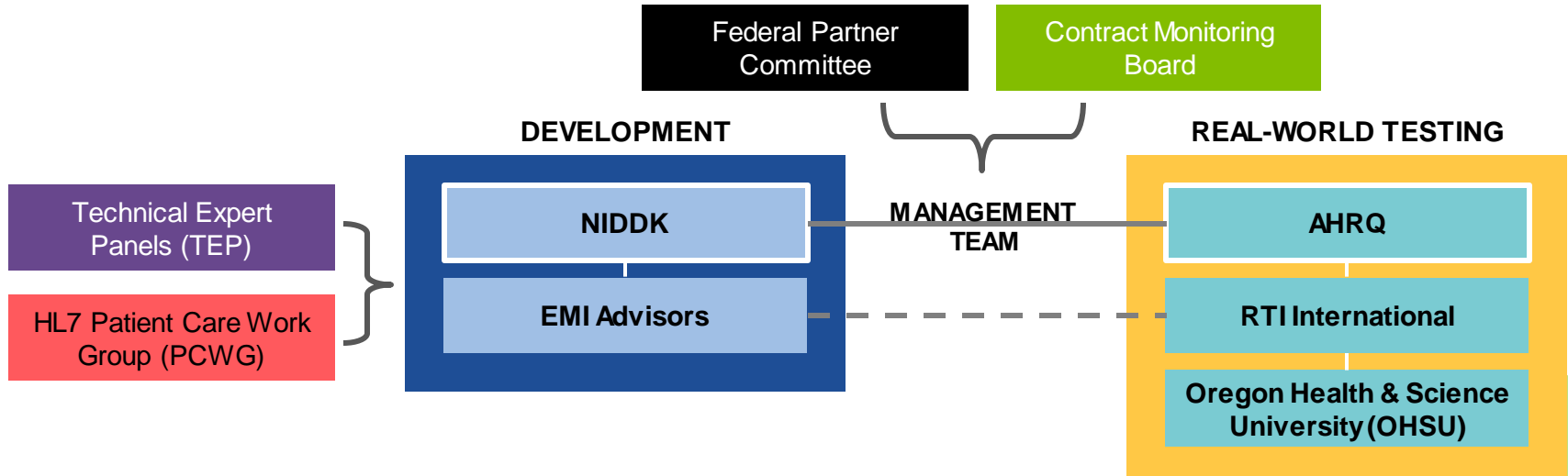
ASPE
OFFICE OF THE ASSISTANT SECRETARY
FOR PLANNING AND EVALUATION

OS PCOR TF
OFFICE OF THE SECRETARY
PATIENT-CENTERED OUTCOMES RESEARCH TRUST FUND

Project Governance

Project Overview

Role of Health IT Standards for Care Planning

- Standards provide the fundamental **definitions for** and **structures of** the data that can be communicated electronically across a wide variety of healthcare use cases.

- Interoperable care planning involves standardization across three layers:
  - ➤ how care plan information is sent and received (transport),
  - ➤ the structure and format of the information (syntax), and
  - ➤ the terms or meaning of the information within the care plan (semantics).

STANDARDS EXIST TO SUPPORT ALL THREE LAYERS

Two Fundamental Standards

HL7 CDA

Clinical Document Architecture (CDA)

HL7 FHIR

Fast Health Interoperability Resource (FHIR)

What is FHIR?

- <u>HL7 FHIR® (Fast Healthcare Interoperability Resources)</u> is a robust data model for describing health, administrative, and social care data.

  ➢ *Supports technical, syntactic, and semantic interoperability*.

- It is a **RESTful API** for interacting with that data using JSON or XML.

- It is a set of **open-source tools** to implement and test FHIR applications.

- It is a collection of **FHIR Servers** around the world that you can interact with.

- But most importantly… it is a **community** of implementers working together to support the seamless exchange of patient-level data.

Comprehensive Shared Care Plan Definition

1. Gives the person **direct access to health data**
2. Puts the **person's goals at the center** of decision-making
3. Is holistic, including **clinical and nonclinical data** (e.g., home- and community-based and social determinants needs and services)
4. **Follows the person** through both high-need episodes (i.e., acute illness) and periods of health improvement and maintenance
5. Allows **care team coordination;** the care team is able to: 1) view information relevant to their role, 2) identify which clinician is doing what, and 3) update other members of an interdisciplinary team
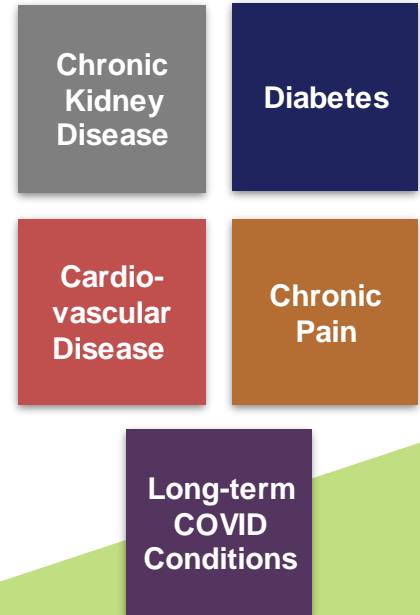
MCC eCare Plan Project

Build data capacity for pragmatic, patient-centered outcomes research (PCOR) by developing an **interoperable electronic care plan** to facilitate aggregation and **sharing of critical patient-centered data** across **home-**, **community-**, **clinic-**, and **research- based** settings for people with **multiple chronic conditions** (MCC).

https://ecareplan.ahrq.gov/collaborate/

MCC eCare Project Deliverables (EMI Team)

1 **Data elements, value sets, and FHIR mappings** to enable standardized transfer of data across health and research settings for kidney disease, diabetes, cardiovascular disease, chronic pain, and long-term COVID

2 **HL7® Fast Health Interoperability Resource (FHIR®) Implementation Guide** based on defined use cases and standardized MCC data elements, balloted for trial use

3 **Pilot testable eCarePlanner (provider-facing) and MyCarePlanner (patient/caregiver-facing) e-care plan applications** that integrate with the EHR to pull, share, and display key patient data

Chronic Kidney Disease

Diabetes

Cardio-vascular Disease

Chronic Pain

Long-term COVID Conditions

*All deliverables will be open-source and freely available.

MCC eCare Project Deliverables (RTI/OHSU Team)

(4) **Standards Development Plan** to chart a course for the future as the MCC context evolves and USCDI-based FHIR resource support grows

(5) **Evaluation Plan** to guide testing and add to the science by incorporating an agile development process and pilot of the SMART on FHIR apps in a clinical environment

(6) **Report** to capture findings from the evaluation to assess impact on shared care planning and chart a path for future research

MyCarePlanner

Supplemental Data Store
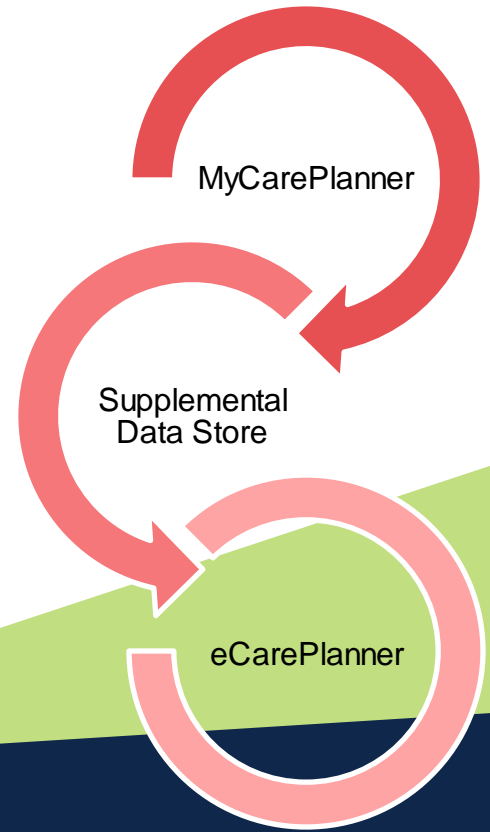
eCarePlanner

Shared Care Planning Challenges & App Development

SMART on FHIR Applications

- Patient and caregiver engagement

  ➢ Access and display combined clinical content from multiple provider organizations and EHR systems

  ➢ Support patient/caregiver contributed data, including assessments, goals, health concerns, and outcomes

  ➢ Include support for social needs, goals, and social care referrals

- Healthcare provider clinical care team

  ➢ Supplement EHR capabilities with eCare Plan content and features

  ➢ SMART on FHIR app embedded within EHR workflow to minimize impact on clinician burden

SMART on FHIR Applications

Comprehensive Shared Care Plan Definition*		MCC eCare Plan Applications
1	Gives the person **direct access to health data**	Apps query EHR and other FHIR endpoints
2	Puts the **person's goals at the center** of decision-making	Apps designed around the process of goal-oriented shared decision-making
3	Is holistic, including **clinical and nonclinical data**	Apps supports SDOH data and patient/caregiver-reported data
4	**Follows the person** through both acute and chronic care	Apps can be used anytime and support transfer of data between acute and primary care contexts
5	Allows **care team coordination**	Apps allow caregiver (proxy), patient, and all providers to coordinate and plan care

SMART on FHIR Applications
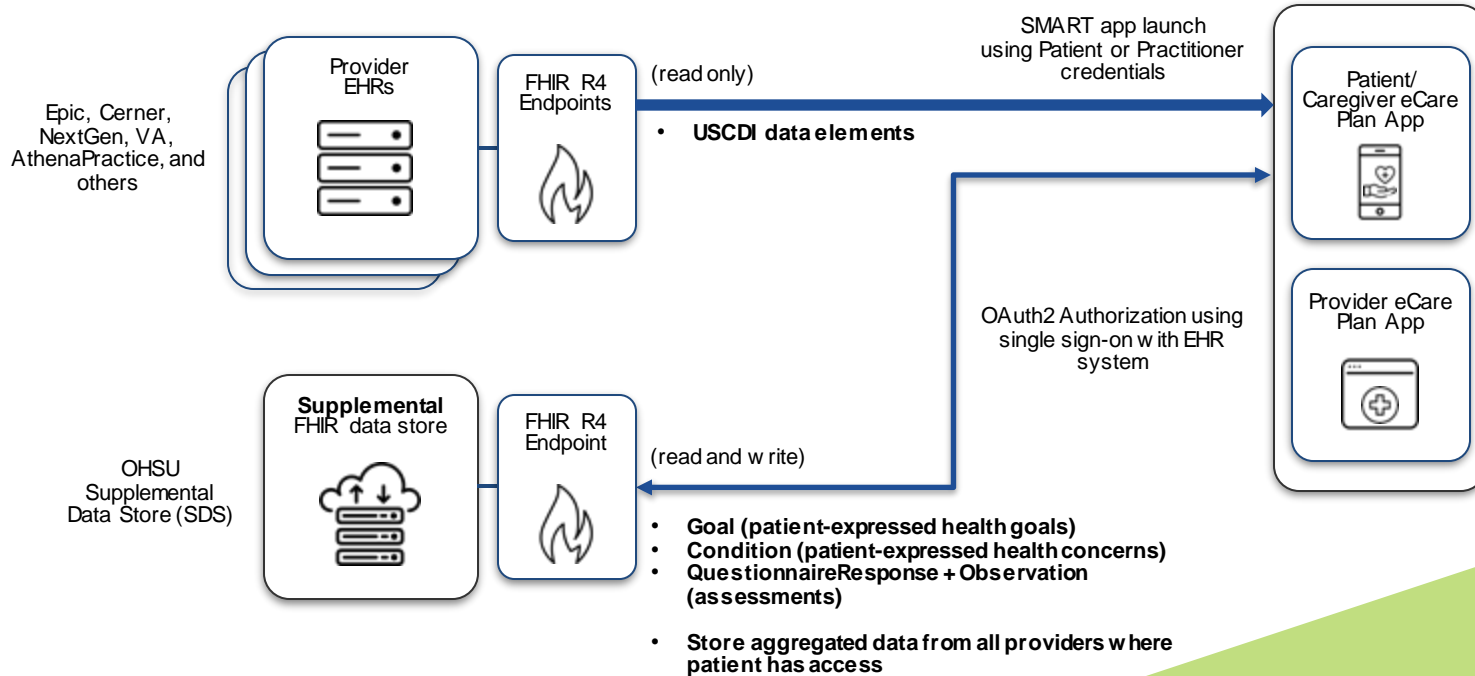
Provider App Vision

- A **standards-based application** platform for providers that supports them in patient-centered care planning and **care coordination** by surfacing key factors and data to improve outcomes for people with multiple chronic condition

- Serves as a complementary app to an EHR system to:
  - ➢ **Improve provider productivity** and **reduce provider burden**, and
  - ➢ Bring together in a **single view** care planning data from multiple EHRs and patient-/caregiver-authored data not supported in EHRs

- Serves as a companion app to the patient/caregiver app enabling **shared care planning** between all members of the care team

Patient/Caregiver App Vision

Patient/Caregiver eCare Plan App

**Common Data Services Library**

Provider eCare Plan App

- A **standards-based application** platform for patients and caregivers to engage them in **participating in their care planning** for MCC

- Allows patients and caregivers to **write information** into the app that can be shared with their providers

- Allows patients and caregivers to see their health data from all of their providers in one place to fully enable **goal-oriented care planning**

- Supports better care coordination through **interoperable data exchange**

- Serves as a companion app to the provider-facing app enabling **shared care planning** between all members of the care team

Implementation & Testing

MyCarePlanner Screenshots
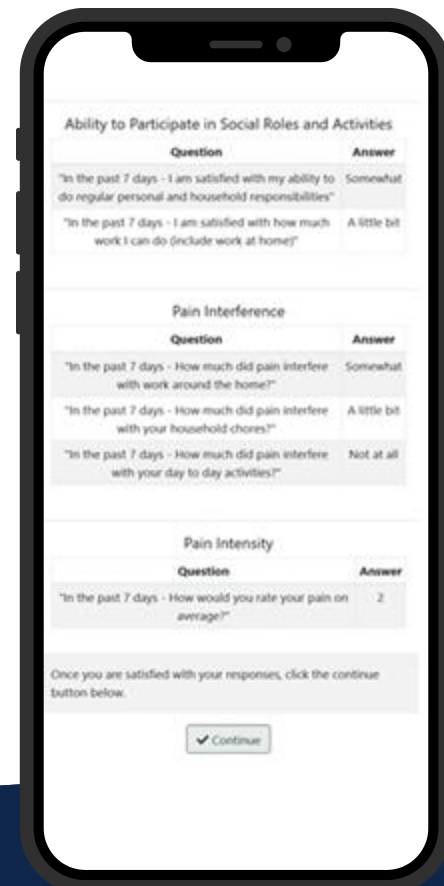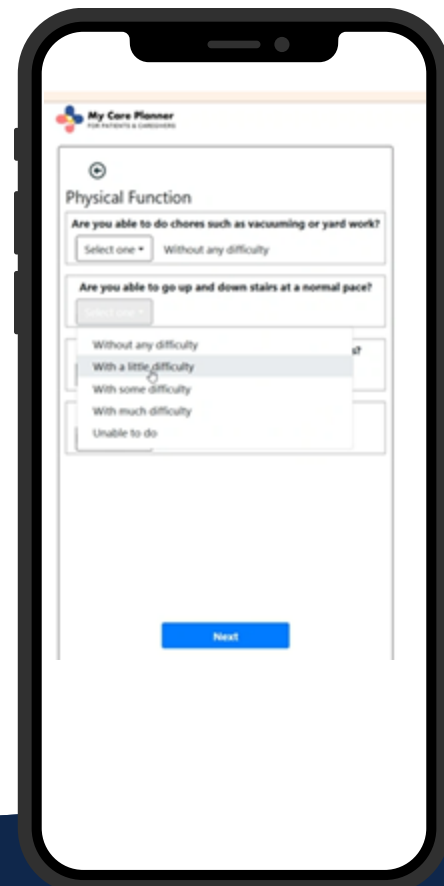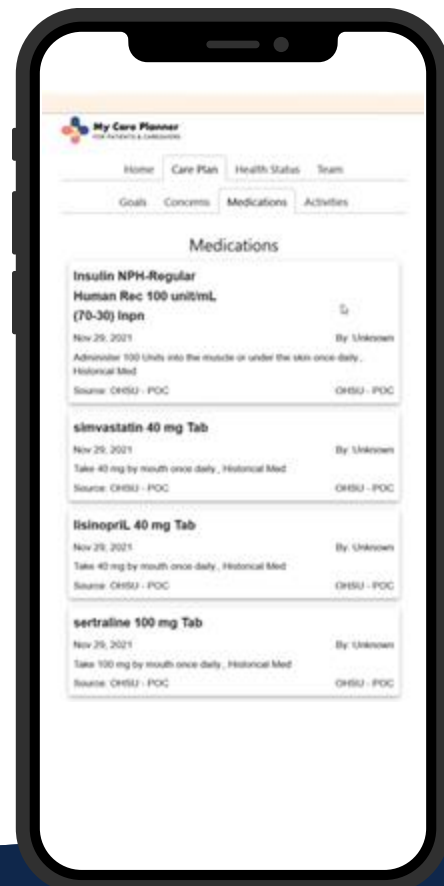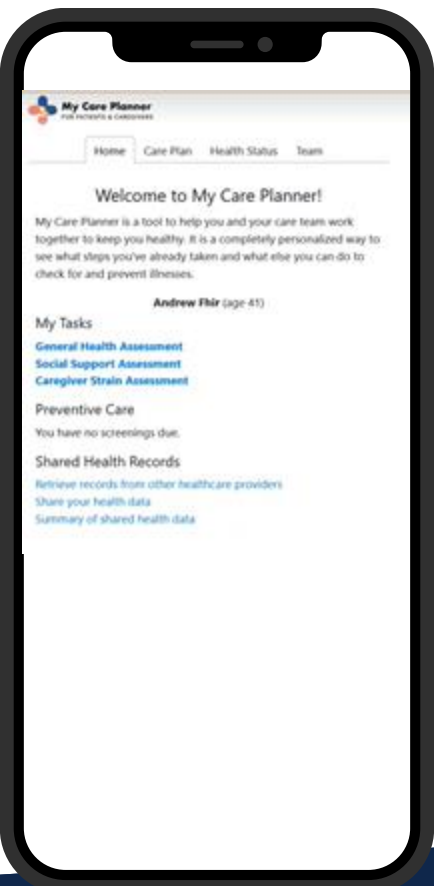
Pilot Phases

Soft go-live	Phase I	Phase II	Phase III

Unit and Performance Testing of System Components

Clinician Requirements Gathering

MyCarePlanner (Patient-facing Application) Testing

eCarePlanner (Clinician-facing Application) Testing

eCare Plan Testing Activities
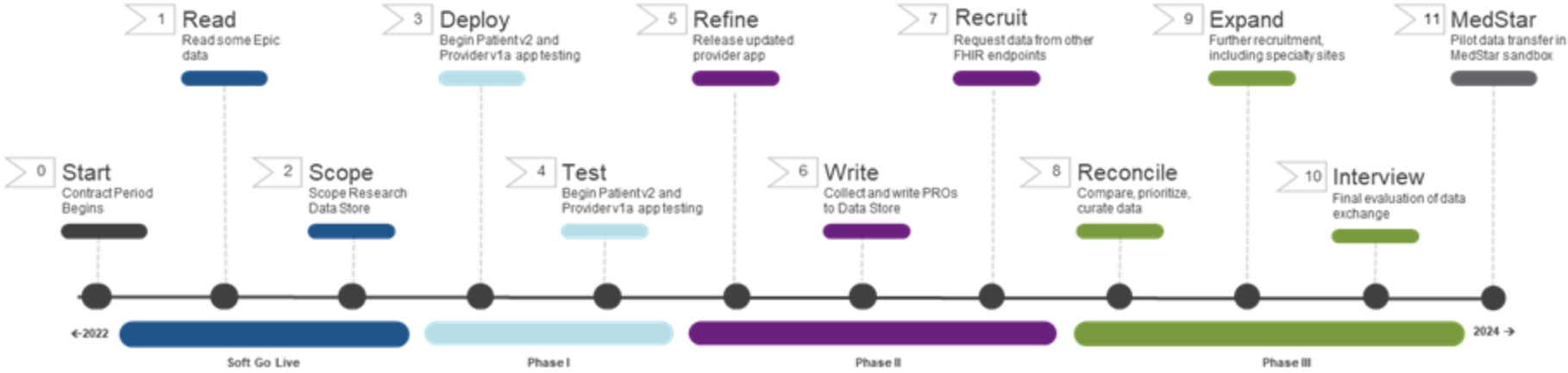
OHSU Site-based Implementation

- OHSU primary and specialty ambulatory care practices and other clinical partner providers to participate in pilot

- Pilot will include reaching out to other FHIR endpoints to collect patient data
  - ➢ Recruit up to 100 patients and at least 10 providers
  - ➢ Other Epic environments: Providence, Legacy, and OCHIN
  - ➢ Facilities served by EHR vendors other than Epic
    - o VA Vista system
    - o NextGen

eCare Plan Evaluation Timeline

Evaluation Activities	Timing of Activities 2023–2025															
	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan
Clinician app evaluation	■	■	■	■	■	■	■	■	■	■	■	■	■			
Patient/caregiver app pilot		■	■	■	■	■	■	■	■	■	■	■	■			
Report writing							■	■	■	■	■	■	■	■	■	■
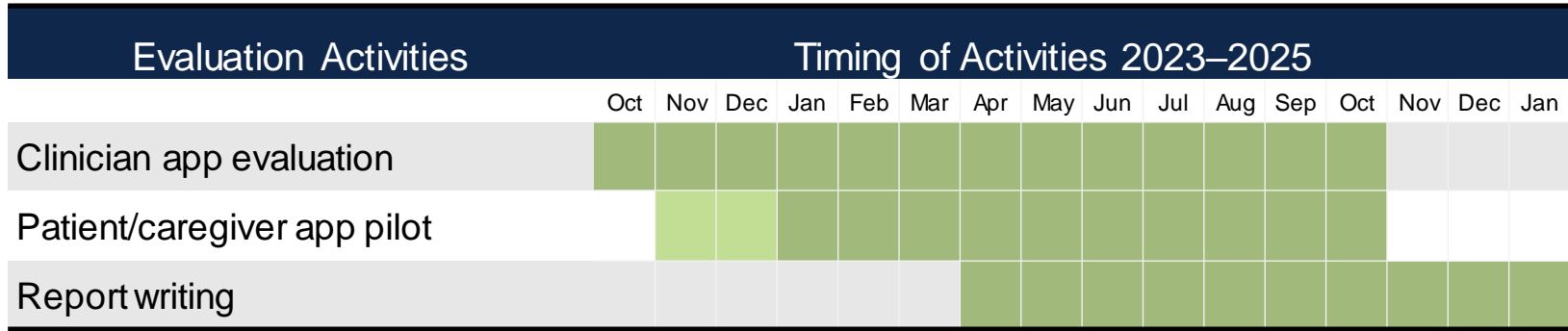
What's Next

- Continued development of the **supplemental data store** at OHSU
  - ➢ Developing multiple login functionality to aggregate data
  - ➢ Repository to save shared aggregated data
- Exploring efforts to support patients in **getting access to their data**
  - ➢ Including personal health devices and wearables to be used for care planning
    - o HL7 FHIR IG for Standard Personal Health Record (SPHR)
- Continue development of the **Common Data Services Library**

Questions?

LIGHTNING TALKS

Lightning Talk

Michelle Dougherty

Include Me! The Power of the Patient Voice in Their Care Plan

Our approach

Met with individuals who managed multiple chronic conditions or were a caregiver (or both)

Conducted 3 interviews in 6 months

Focused on needs, feedback on app design, and clinical scenarios
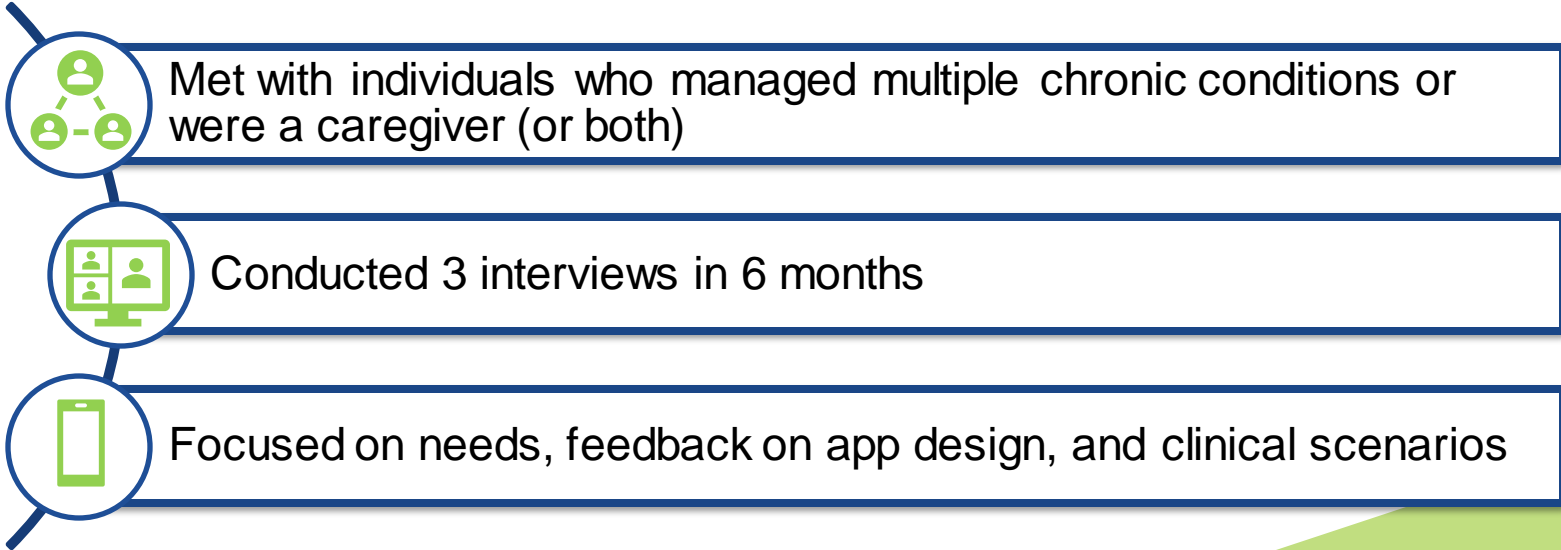
What is Most Important and Why

- Value an application that brings an individual together with their care team, specialists, services, caregivers, and others they designate.

- Frustration with the challenges of accessing, compiling and sharing their information.

- Desire a care plan application that is dynamic, updated in real time and available for them and their care team.

- Use a personalized plan with goals that are action oriented and reflect their priorities.

- Ability to provide updates, include relevant information and share.

How It Should Work

Engagement with the Care Plan App

- Ability share notes and preferences (e.g., religious)
- Inclusion of important legal information (advance care plan, POA, etc.)
- Ability to filter, search, upload, look at history

Care Coordination Across Care Teams

- Importance of including the extended care team (a lot of care happens away from the provider)
- Importance of coordinating changes across their care team

eCare Plan Application

Interoperability & Information Sharing

- Difficult getting a comprehensive care plan
- Multiple portals & logins
- Still compiling paper records and faxing

Personalization & Privacy

- Reflects their priorities
- Input on who has access – have some control
- Ability to share

Lightning Talk

Dave Carlson

SMART on FHIR Apps & Real-World Integration

eCare Plan Supplemental Data Store (FHIR)

Epic, Cerner, NextGen, VA, AthenaPractice, and others

Provider EHRs

FHIR R4 Endpoints

(read only)

- **USCDI data elements**

SMART app launch using Patient or Practitioner credentials

Patient/ Caregiver eCare Plan App

Provider eCare Plan App

OAuth2 Authorization using single sign-on with EHR system

OHSU Supplemental Data Store (SDS)

Supplemental FHIR data store

FHIR R4 Endpoint

(read and write)

- **Goal (patient-expressed health goals)**
- **Condition (patient-expressed health concerns)**
- **QuestionnaireResponse + Observation (assessments)**

- **Store aggregated data from all providers where patient has access**

eCare Plan Supplemental Data Store (FHIR)

- Include features that supplement or complement EHR system content and capabilities, without duplicating EHR clinical content and workflow.

- Care coordination spanning multiple healthcare providers, plus patient/caregiver access and contributions.

- Extend EHR systems to include unsupported content and FHIR APIs:
  - ➢ Patient/caregiver authored goals, health concerns and action plans: FHIR Goal, Condition, and ServiceRequest, both read and write
  - ➢ Assessments and outcomes: FHIR Questionnaire, QuestionnaireResponse, and extracted Observations

HL7 MCC eCare Plan FHIR IG

Improve care coordination without increasing clinician burden

Value Set Libraries

- MCC Clinical Test
- MCC Goal
- MCC Laboratory Result
- MCC Medication Request
- MCC Observation Imaging
- MCC Observation SDOH Assessment

- MCC Procedure and Service Request
- MCC Questionnaire Response
- MCC Simple Observation
- MCC Symptom

➢ More than 200 value sets defined for conditions
➢ More than 550 value sets defined across all data element domains

The HL7® MCC eCare Plan FHIR Implementation Guide (IG) defines FHIR R4 profiles deriving from FHIR US Core 6.1.0 Profiles

Use CQL to Filter & Classify FHIR Data

- eCare applications use Clinical Quality Language (CQL) to interpret and summarize aggregated data from multiple FHIR data sources.

- CQL applies the IG value sets to classify conditions, laboratory results, goals, and other data elements to create meaningful summaries for patients and their care providers.

- CQL expression libraries also may be used to represent and execute patient-centered CDS for preventive care screening and care recommendations.

Real-World Challenges

- Gap between EHR certification requirements (currently ONC US Core for Data Interoperability USCDI version 1) and current development based on USCDI v5. Certification support has limited requirement for Goal representation, and no requirement for ServiceRequest orders or assessment observations, including SDoH data elements.
- Saving and sharing patient/caregiver authored content.
  - ➢ Very limited EHR vendor support to save/update data
  - ➢ Provider organizations are reluctant to embrace a general supplemental data store separate from the EHR system.
  - ➢ Strong resistance to cloud-hosted supplemental content shared by patients and multiple providers.
- Aggregation of data across multiple providers.
  - ➢ Exploratory use of local supplemental data store for the pilot, limited to use by the research team.
  - ➢ Managing patient consent or withdrawal of consent and ensuring privacy of PHI.
  - ➢ Longer-term goal to use TEFCA, HIEs, or cloud-hosted PHRs.

Lightning Talk
Matt Storer

SDS: A HAPI-FHIR® Based Supplemental Data Store for Centralized Caching of Resources for Multiple Endpoints and Storage of In-App Patient-Generated Assets

Presenter Info

- Matthew Storer (he/him)
- BS in Computer Science, University of Vermont (2001)
- Involved in research informatics since 2012
- Research Engineer at OHSU since 2016
- Certified HL7® FHIR® Proficient (R4)
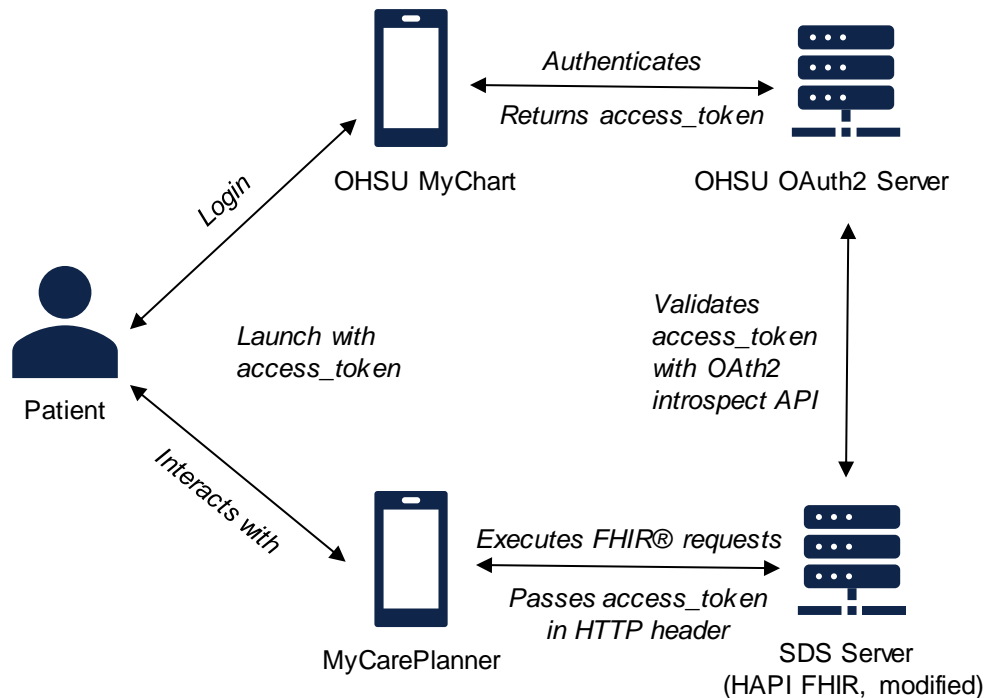- 2023 AMIA/HL7® FHIR® Applications Competition Coach

What is the SDS?

- A HAPI FHIR-based system, hard-forked and modified to "piggyback" authentication and access using a provided OAuth2 access token, ensuring a seamless and secure user experience

- Capable of storing FHIR® resources for a given user from multiple sources, with access secured via FHIR patient compartment infrastructure

- Employs namespace partitioning to ensure resources from different sources are segregated (improved organization, negates potential for collisions, etc.)

Authorization Access

- The SDS enforces access rules by requiring all requests to include a valid OAuth2 access token passed to it in an HTTP header.
- The SDS independently validates the access token by passing it to a predefined OAuth2 server's *introspect* API.
- A valid response independently provides the FHIR® Patient ID associated with it, which the SDS uses to enforce internal access rules to FHIR resources via patient compartments.
- An invalid response immediately returns HTTP 401 Unauthorized to the client.

Authenticates

Returns access_token

OHSU MyChart

OHSU OAuth2 Server

Login

Launch with access_token

Patient

Validates access_token with OAth2 introspect API

Interacts with

Executes FHIR® requests

Passes access_token in HTTP header

MyCarePlanner

SDS Server
(HAPI FHIR, modified)

Resource Organization and Linkage

- Resources stored in the SDS are segregated into partitions based on where they originated.

- Two special resources—Local Patient and Local Linkage—are created and maintained by the SDS to facilitate these connections.

- The Patient ID associated with the authenticated OAuth2 access token must match a third-party Patient ID referenced in a Local Linkage resource, which itself is used to grant access by way of patient compartments.
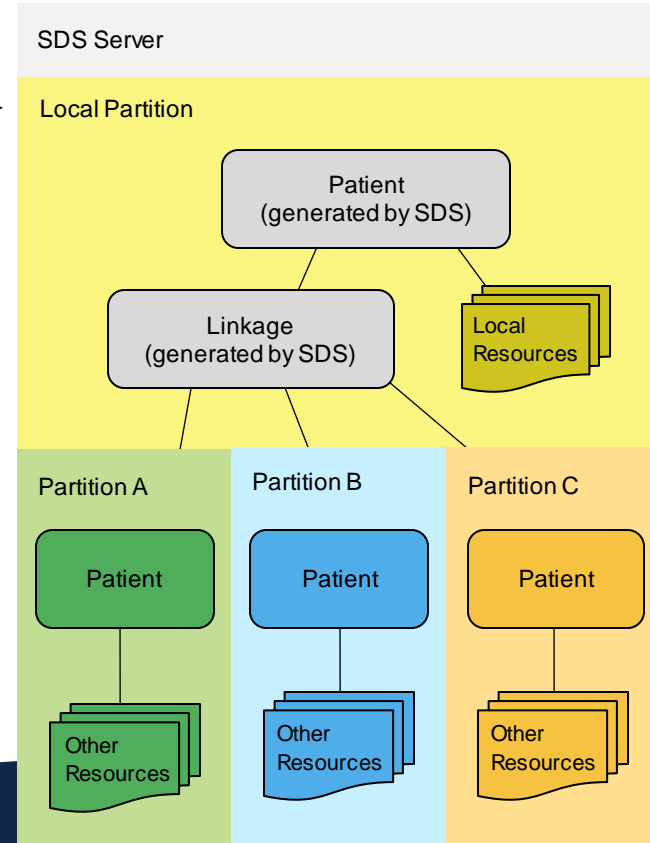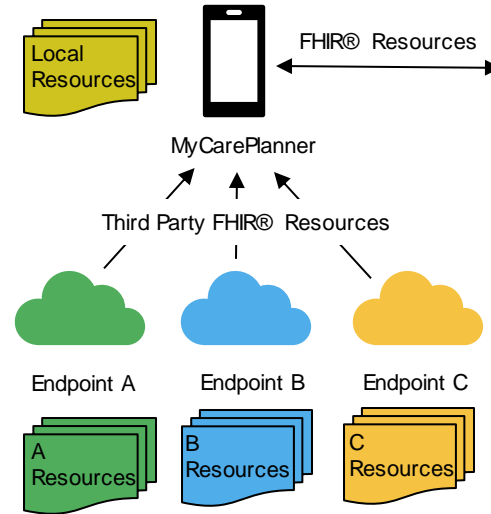
Lessons Learned

- Smart Governance
  - ➤ Housing a patient's entire medical history across multiple sources raises the stakes with respect to the security process; while standing an SDS or SDS-like system up in a particular environment might not be technical infeasible, care should be taken to build out a secure system that extends beyond the SDS to institutional processes

- Multiple Value Add
  - ➤ Data persistence for ease of patient access (coaching for rapid availability)
  - ➤ Write ability to retain goals, questionnaire responses, and patient reported outcomes
  - ➤ Enables provider access to broader sets of patient data

Lightning Talk

Josh Richardson
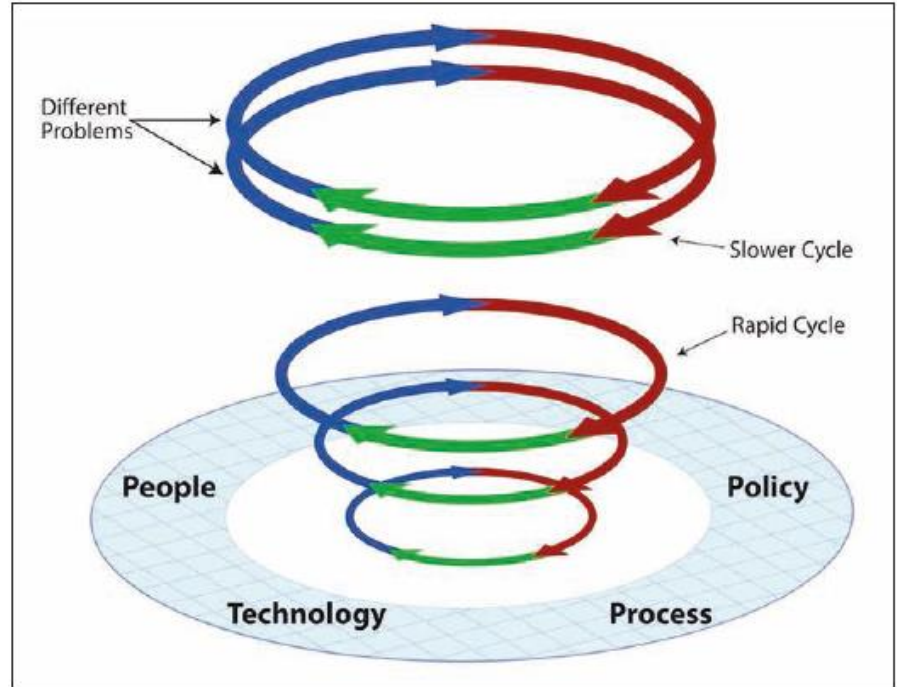

Learning Health Systems

Learning Health System Aims

- Generate and apply the best evidence for the collaborative healthcare choices of each patient and provider
- Drive the process of discovery as a natural outgrowth of patient care
- Ensure innovation, quality, safety, and value in health care

Cycles of Learning and Improvement

Friedman CP, Rubin JC, Sullivan KJ. Toward an Information Infrastructure for Global Health Improvement. Yearb Med Inform. 2017 Aug;26(1):16-23. doi: 10.15265/IY-2017-004. Epub 2017 Sep 11. PMID: 28480469; PMCID: PMC6239237.
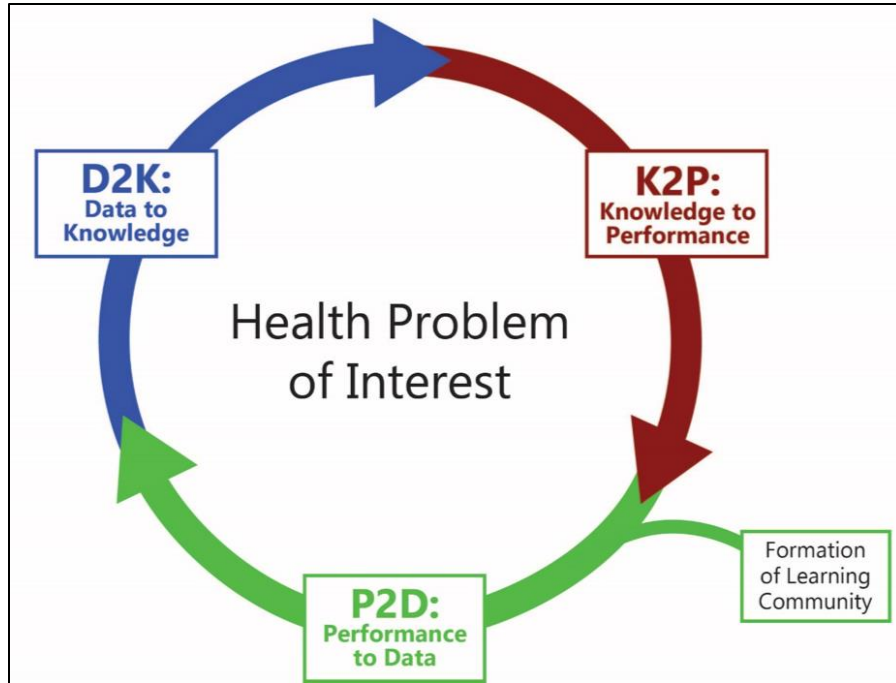
CDO Infrastructure Services for LHS Maturity

7. Merge and Interpret Internal and External Knowledge

6. Access and Evaluate Results of External Knowledge-Generation Efforts

8. Codify and Persist New Knowledge in Human Readable and Computable Forms
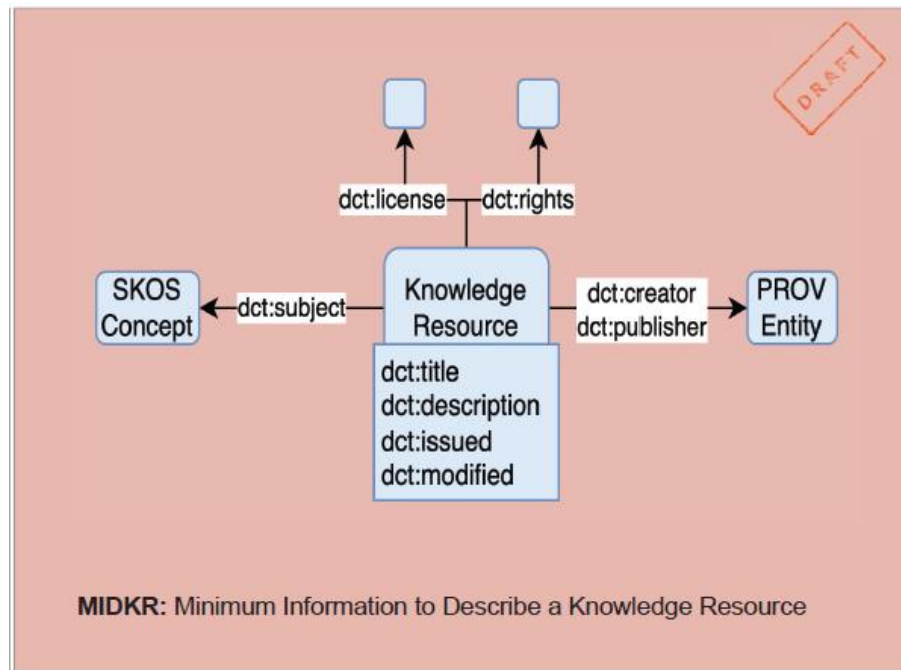
5. Share and Analyze Data Into New Internal Local Knowledge

9. Enable Delivery of Knowledge-Derived Interventions

4. Provide and Govern Access to and Use of Data

10. Promote and Support Performance Changes

3. Represent Health Information as Analyzable Data

2. Develop and Apply Tools to Measure Performance and Performance Changes

1. Organize, Start, Maintain, and Support Learning Communities

D2K: Data to Knowledge
K2P: Knowledge to Performance
P2D: Performance to Data

Minimum Metadata for Mobilizing Computable Biomedical Knowledge (MCBK)

- Developing a metadata model for FAIR+T knowledge in partnership with key stakeholders
- Addressing key constituencies from knowledge creators to knowledge users
- Leveraging existing standards and systems, e.g. RDF, Dublin Core, MeSH

MIDKR: Minimum Information to Describe a Knowledge Resource

Richardson JE, Eldredge C, Sottara D, Richesson RL, McCusker J. Enabling Rapid Application and Management in Learning Health Systems: The Computable Biomedical Knowledge Metadata Model (CBK-MM) Initiative. 2023 AMIA Annual Symposium; 2023 Nov 13; New Orleans, LA.
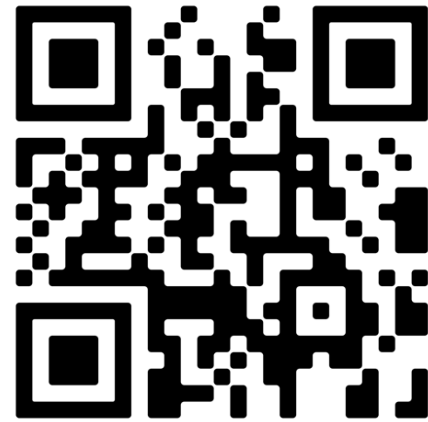
HL7 LHS WG Inventorying Standards Communities

Enter to win a **free registration** to the AMIA 2024 Annual Symposium!

Scan the QR code below for more information and to enter.

A winner will be notified via email after the conference.