Multiple Chronic Condition (MCC) eCare Plan Project

Pre-read material in preparation for the

Federal Partner Meeting on February 1, 2024

About This Pre-Read

To optimize our time during the Multiple Chronic Condition eCare Plan Federal Partners Meeting on February 1, 2024, we are presenting in this pre-read deck some background information and additional project updates that we may not have the time to go into fully during the meeting.

We plan to reserve some time during the meeting to answer questions regarding this material so we invite you to review this deck if time permits and bring your questions to our meeting on February 1.

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- **MCC eCare Plan Project progress summary**

- Pilot/focus group feedback

- IG walkthrough and STU ballot

- App development approach and updates

- eCare projects in practice

NIDDK/AHRQ eCare Plan for Multiple Chronic Conditions (MCC) Project

Build 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*

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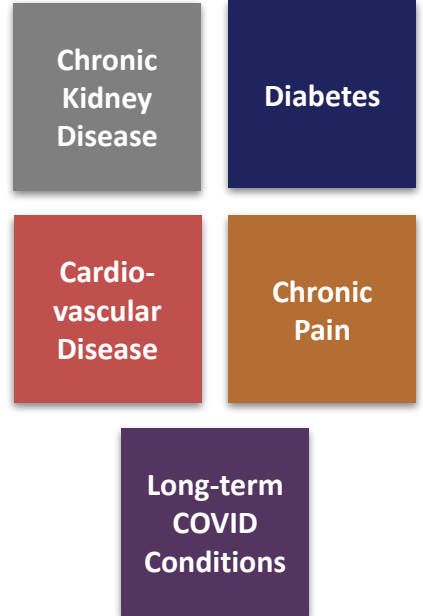
*All deliverables will be open-source and freely available.

National Institute of Diabetes and Digestive and Kidney Diseases

Overview of Work Year Over Year

	Year 1 (Fall 2019-Fall 2020)	Year 2 (Fall 2020-Fall 2021)	Year 3 (Fall 2021-Fall 2022)	Year 4 (Fall 2022-Fall 2023)	Year 5 (Fall 2023-Fall 2024)
Data elements, value sets, and FHIR mappings	• HL7 project approval. • MCC use case development. • Built CKD and other prioritized value sets in NLM VSAC and mapped to FHIR constructs. • Facilitated TEP.	• Completed identification of 1,100+ data elements for CVD, chronic pain, and T2D. • Facilitated TEP. • Developed data standards approaches for person/plan details, health concerns, and social concerns.	• Conducted quality assurance and review of existing value sets. • Identified long COVID data elements and facilitated TEP. • Built additional, new value sets in VSAC. • Mapped new/revised data elements to FHIR.	• Revised and finalized new value set libraries and tables. • Updated use cases. • Built and updated new profiles.	• Perform value set maintenance. • Test value sets with real-world data.
HL7 FHIR IG	• Conceptualization and design of the MCC eCare Plan FHIR IG.	• Developed draft MCC eCare Plan FHIR IG.	• Developed high-level mapping and design approach for the MCC eCare Plan FHIR IG. • Restructured the IG to include new guidance and library of value sets. • Expanded to incorporate value sets for all five clinical domains.	• Revised, updated, and submitted IG for comment HL7 ballot in Jan 2023 cycle. • Integrated ballot comments and perform reconciliation. • Prepare and submit FHIR IG for STU ballot in Sep 2023 cycle.	• Integrate ballot comments and perform reconciliation. • Submit IG for STU publication.
Patient/ Caregiver and Clinician eCare applications		• Developed v1.0 application for patients. • Developed v1.0 application for clinicians. • Facilitated configuration of apps at	• Built patient/caregiver app v2.0. • Developed features to support goal-oriented shared care planning. • Conducted iterative user feedback sessions.	• Developed and revised a common data services library. • Allowed for multiple, simultaneous logins in the patient/caregiver app. • Patient/caregiver UI redesign. • Modified backend of both apps to	• Facilitate display of aggregated data from multiple health system EHRs in both apps. • OHSU pilot support. • UI and app logic updates based on clinician and patient/caregiver dyad focus

Three Year Roadmap

Legend
🔥 HL7 Connectathon
🔵 Federal Partner Meeting
🔶 Contract Monitoring Board

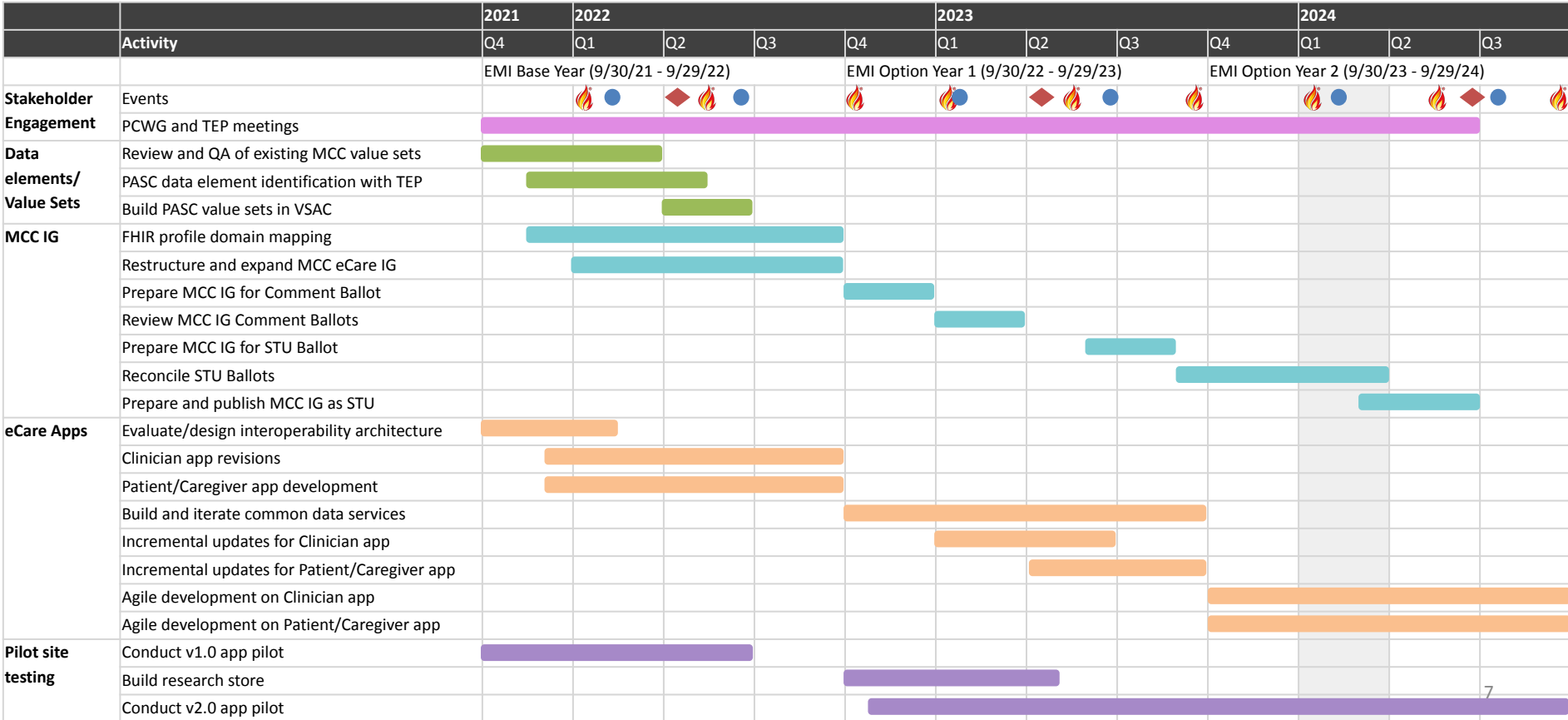|	Activity	2021 Q4	2022 Q1	Q2	Q3	Q4	2023 Q1	Q2	Q3	Q4	2024 Q1	Q2	Q3
		EMI Base Year (9/30/21 - 9/29/22)				EMI Option Year 1 (9/30/22 - 9/29/23)				EMI Option Year 2 (9/30/23 - 9/29/24)			
Stakeholder Engagement	Events												
	PCWG and TEP meetings												
Data elements/ Value Sets	Review and QA of existing MCC value sets												
	PASC data element identification with TEP												
	Build PASC value sets in VSAC												
MCC IG	FHIR profile domain mapping												
	Restructure and expand MCC eCare IG												
	Prepare MCC IG for Comment Ballot												
	Review MCC IG Comment Ballots												
	Prepare MCC IG for STU Ballot												
	Reconcile STU Ballots												
	Prepare and publish MCC IG as STU												
eCare Apps	Evaluate/design interoperability architecture												
	Clinician app revisions												
	Patient/Caregiver app development												
	Build and iterate common data services												
	Incremental updates for Clinician app												
	Incremental updates for Patient/Caregiver app												
	Agile development on Clinician app												
	Agile development on Patient/Caregiver app												
Pilot site testing	Conduct v1.0 app pilot												
	Build research store												
	Conduct v2.0 app pilot												

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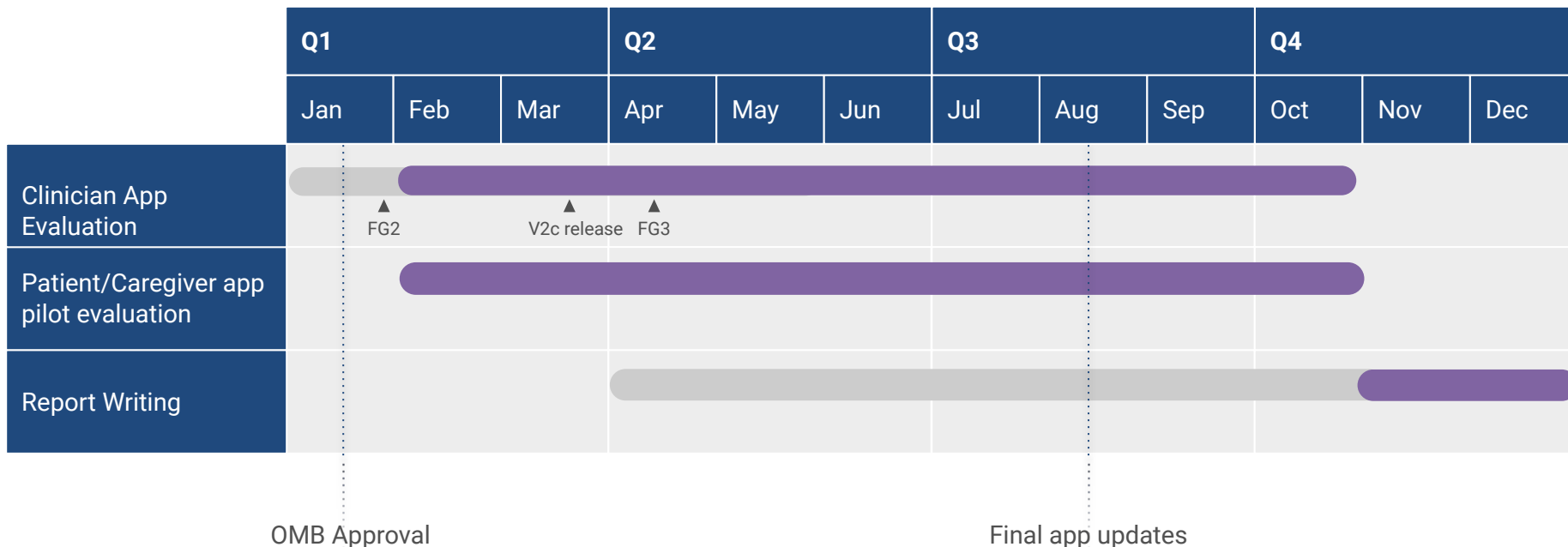
- eCare projects in practice

RTI International

Pilot Updates and Focus Group Feedback

Evaluation Timeline

	Q1			Q2			Q3			Q4		
	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
Clinician App Evaluation												
Patient/Caregiver app pilot evaluation												
Report Writing												

FG2   V2c release   FG3

OMB Approval   Final app updates

Focus Group Methodology

Overall
- Objective: Formative feedback for clinician application development.
- Format:
  - Three rounds of focus groups (Early December 2023, February 2024, Sprint 2024).
  - Virtual
  - Facilitated by OHSU, included notetakers
- Participant recruitment: Worked with clinician champions for the project to identify participants. Focus group 2 will include external providers.

First Round
- Completed two 1-hour focus group sessions held on December 7, 2023.
- 9 participants of clinicians
- Qualitative analysis was conducted using a thematic analysis approach to identify priority areas for app enhancements

Focus Group 1 Findings: Overall Takeaways

- Top priority: Clinicians want current, reliable and actionable information.
  - Medications, labs, vitals, problem list
  - Ability to highlight the most important elements
- Communication is key
  - Information from external care organizations is incomplete and challenging
  - Primary care and specialty clinicians may review different elements
  - All want a way to share goals
- Social components are important
  - Provide centralized place to find social needs such as transportation or finances
  - Family caregivers are important to track
- Team-based care
  - Care teams include care coordinators, social workers, primary care, specialists, transitional care, skilled nursing facilities – all need access and input

- Priority: Articulate how this improves on current Epic problem list
  - Issues of data accuracy persist, e.g., diagnosis date is always challenging
- The clean design is appealing and easy to follow
  - Helpful to know who/which team is managing each problem.
- Modify view for clinician preferences
  - Allow a problem list that can be prioritized to quickly identify high-risk issues
  - The Source column appeals to some but not others.
- More information for diagnoses
  - Link to related information, e.g., most recent DEXA scan for patient with osteoporosis
  - Allow updated information for chronic conditions, e.g., CHF II now CHF III.

Focus Group 1 Findings: Active Medications

- Allow organization
    - Allow user to sort alphabetically or by date for each column header
    - Show medications stopped in the last 30 days
- Medication reason is important
    - Display prescriber name, date, dose and reason
    - Indicate recent dose changes (e.g., reductions)
    - Link to get more information for dose reduction (who, when)
- Prescribed doses can be complex
    - Design should allow for skipped days or different doses on the same day
- Care transitions can lead to prescribing challenges
    - Some care settings can record how many are taken and who administered. This information is useful in SNF settings.

Focus Group 1 Findings: Goals

- Dropdown with additional narrative about goals
  - Who reviewed the goal
  - Record a discussion about the goal
  - Current achievement level and evolution
  - Important to incorporate challenges (e.g., social needs)
- Allow organization
  - Prioritize the list
  - Sort by achievement, active date
- Support coordinated care
  - Encourage communication from clinicians
 - Support flagging conflicting goals

Focus Group 1 Findings: Vitals and Measures

- Ability to tailor the dashboard to each patient
  - Which measures/values are most important to monitor?
- Clean, easy to look at
  - Visual representation of things like medication changes
  - How do we make it better than what Epic offers?
- Desire for ability to fluidly communicate with other providers about measures
  - One click phone dialing; clinician phone numbers are loaded/pulled in
  - Could clinicians add notes? Hover and see notes?
- AI that uses metrics to re-prioritize problem list based on current values
  - Notification when values do not coincide with patient goals
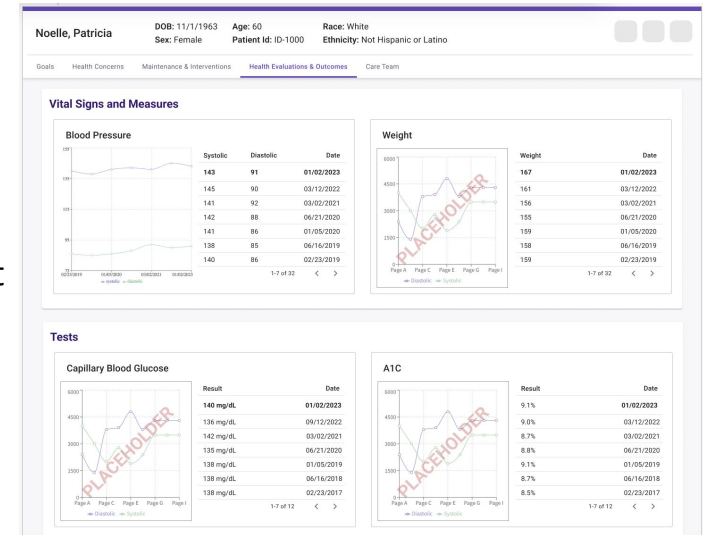
Focus Group 1 Findings: Final Thoughts

- Snapshot view, meaningful conglomeration of information
    - Information either needs to be prioritized or prioritizable
    - Information needs to be trustworthy
    - Ability to hover and gather subsequent information
- Patient reported information needs to be visually distinct from clinical information
    - Patient-reported data isn't always trustworthy
    - Perhaps, clinician can verify all patient-reported data? Then it can show when patient-reported data have been verified?
- Integrate from multiple sources in meaningful ways
    - How can data be integrated in ways that is not just placing similar information together?
    - How can duplicates be avoided?

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A Primer on FHIR Implementation Guides

What is a FHIR implementation guide?

A FHIR implementation guide (IG) is a set of rules about *how FHIR resources are used (or should be used) to solve a particular problem*. It contains associated documentation to support and clarify the usage.

Who uses them and for what purpose?

- **Architects and developers of healthcare information technology (HIT) systems** - Follow guidance for developing implementations.
- **Business analysts** - Assist developers in understanding system implementation requirements.
- **Project managers** - Gain understanding of how to manage or prioritize implementation.
- **Clinical informaticists** - Interpret clinical implications and provide feedback.
- **Policymakers** - Understand the IG and encourage implementation once deemed valuable for the industry.

MCC eCare Plan FHIR Implementation Guide (IG)

The HL7® MCC eCare Plan FHIR Implementation Guide (IG) defines FHIR R4 profiles, structures, extensions, transactions, and value sets needed to represent, query for, and exchange Care Plan information to support care planning for people with multiple chronic conditions (MCC).

The IG supports the following use cases:

1. Generate and update comprehensive e-care plan in clinical setting.
2. Expose (Share) e-care plan to clinical care team, patient, or caregiver.
3. Identify care team members.

**Improve care coordination without increasing clinician burden**

Reusing and Constraining the FHIR Care Plan Resource

The MCC eCare Plan FHIR Implementation Guide is built on the FHIR Care Plan Resource framework.

Each layer in the cake diagram demonstrates how the FHIR Care Plan Resource is reused and constrained for the MCC Care Plan use cases.

*The MCC IG adds additional items or guidance beyond what is available in US Core or FHIR resources but it cannot loosen existing rules from what is constrained.

MCC Care Plan Profile*

US Core Care Plan

Care Plan Resource

FHIR R4 + Standard

🔥 HL7 FHIR®
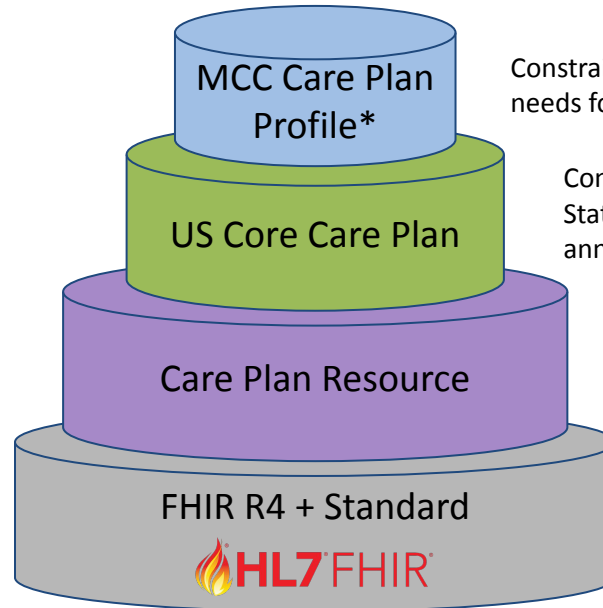
Constrains the US Core FHIR Care Plan Resource to meet the needs for multiple chronic conditions (MCC) care planning.

Constrains the Care Plan Resource for use in the United States. US Core incorporates USCDI data elements annually and according to HL7 ballot cycles.

Describes the intention of how one or more practitioners intend to deliver care for a particular patient, group, or community for a period of time.

FHIR is a standard for health care data exchange, published by HL7®.

Reusing and Constraining: Value Set Library

Process

Constrained Profile

FHIR Profile

FHIR Resource

FHIR Standard

Example

MCC Condition Profile

US Core Condition Profile

Condition Resource

FHIR R4 Standard

Added constraints for MCC eCare Plan:
- Goal.extension:resource-pertainsToGoal (Must support)
- Condition.onset (Must Support)
- Condition.recordedDate (Must Support)

Use with:

Value Set Library

Added constraints for USA

Basic Structure – All Realms

What is "The eCare Plan MCC Value Set Library"?

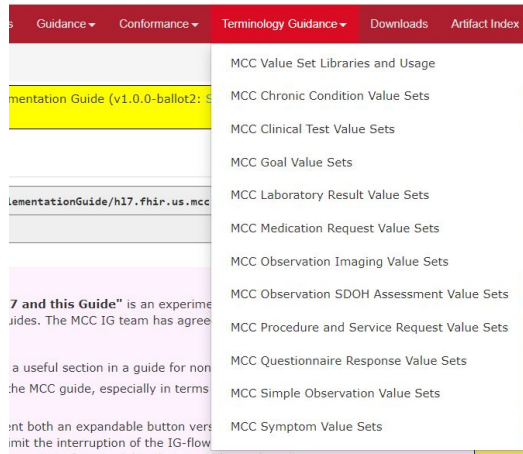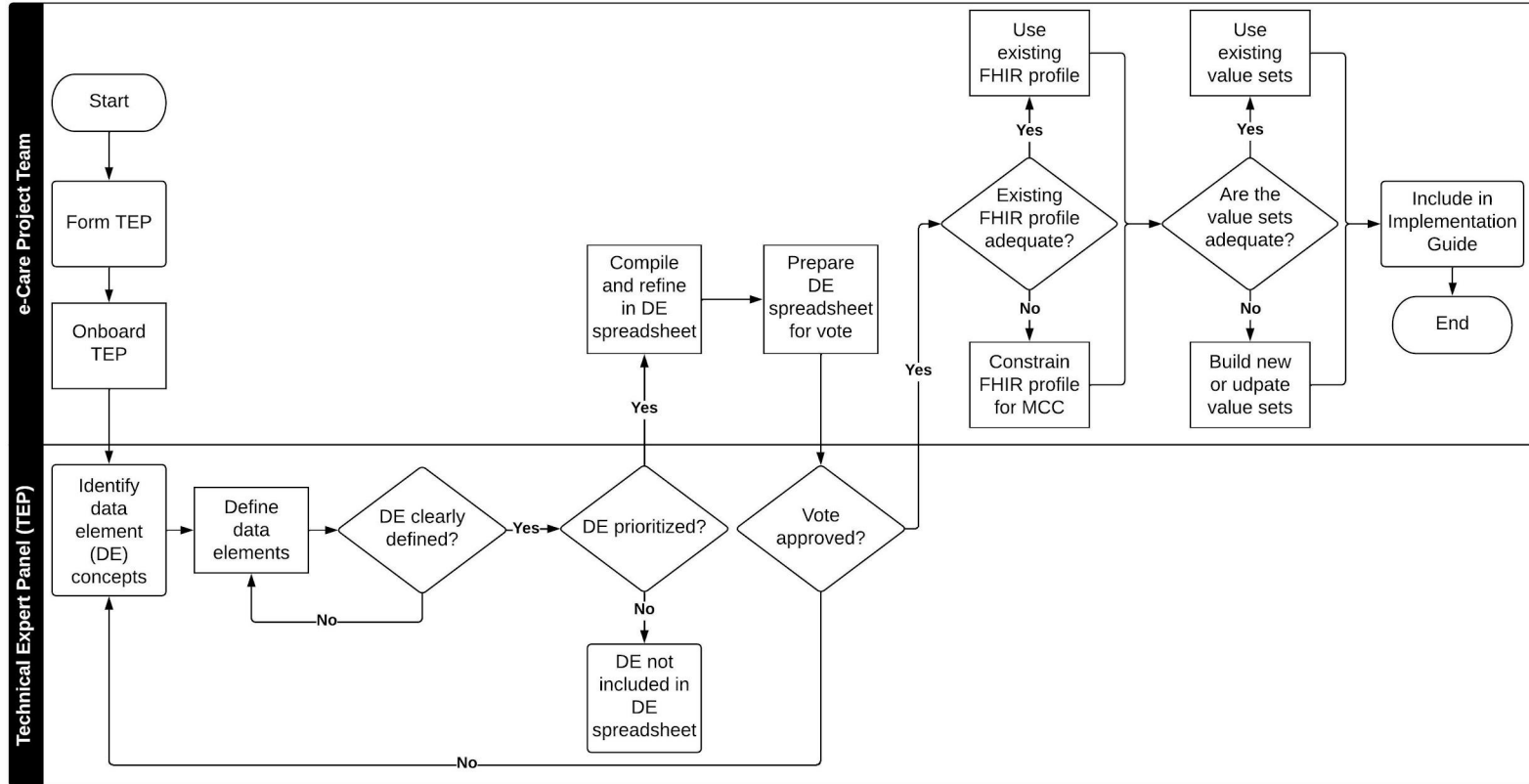Similar to the Dewey Decimal System of old, the MCC Value Set Library:

- Organizes the value sets based on their subject.
- Identifies the profiles that the value sets can be used in and where within the profile they can be used.
- Provides links to the Profile from each library (and vice versa).

Data Element Identification Process

Long COVID Diagnosis and Comorbidities Value Set Status - Complete (SNOMED CT, ICD-10-CM, Grouped)

Long COVID Diagnosis

- Long Covid Diagnosis
- Acute Covid Diagnosis

Long COVID Comorbidities (Newly Built Value Sets)

- Acute renal failure
- Asthma
- Bronchiectasis
- Chronic obstructive pulmonary disease (COPD)
- Chronic Tension-type headache
- Cognitive disorder
- Complications due to Diabetes Mellitus
- Coronary Revascularization History
- Ehlers Danlos syndrome (EDS)

- Fibromyalgia
- Functional disorder of gastrointestinal tract
- Herpes zoster reactivation
- Hypertension
- Interstitial lung disease
- Low back pain
- Lymphadenopathy
- Malnutrition
- Mast Cell Activation Syndrome (MCAS)
- Metabolic syndrome
- Migraine
- Multisystem Inflammatory Syndrome in Adults (MIS-A)

- Myalgic Encephalomyelitis_Chronic Fatigue Syndrome (ME_CFS)
- Narcolepsy
- Neuropathy
- Persistent hypertension
- Pink eye
- Postural tachycardia syndrome (POTS)
- Pulmonary embolism
- Pulmonary hypertension
- Small Fiber Neuropathy
- Valvular Heart Disease

Long COVID Comorbidities (Existing Value Sets)

- Cerebrovascular Disease Stroke or TIA
- Chronic kidney disease
- Congestive heart failure
- Dementia
- Diabetes mellitus
- Multiple Sclerosis
- Obesity
- Posttraumatic stress disorder (PTSD)
- Sleep Disorders
- Tuberculosis

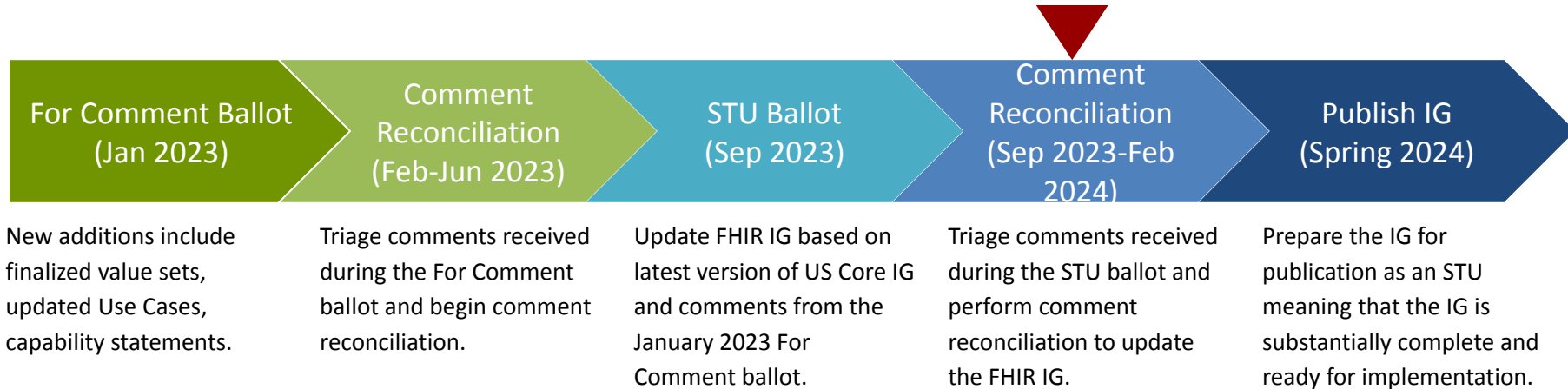National Institute of Diabetes and Digestive and Kidney Diseases

Long COVID Symptoms Value Set Status - Complete (SNOMED CT)

- Abdominal Pain
- Anxiety
- Arthralgia
- Autonomic dysfunction
- Back Pain
- Bleeding
- Brain Fog
- Chest Pain
- Chills
- Chronic Pain
- Constipation
- Cough
- Covid Toes
- Debility or Frailty
- Depression Symptoms

- Diarrhea
- Difficulty swallowing
- Disability Severity
- Dizziness
- Dyspnea
- Edema
- Fatigue
- Fever
- Functional and Mobility Impairment
- Gastroesophageal reflux
- Grief and Suffering
- Hair Loss
- Headache
- Hypercoagulability
- Immunologic Changes
- Impaired Hearing
- Impaired Sense of Smell

- Impaired Sense of Taste
- Insomnia and other sleep difficulties
- Itching
- Language and Speech Problems
- Lightheadedness
- Loss of Appetite
- Lower Urinary Tract Symptoms
- Menstrual Cycle Irregularities
- Mood Swings
- Myalgia
- Nausea
- Neurogenic Pain
- Orthostatic Intolerance
- Pain
- Pain in Extremities
- Pain in Throat

- Palpitations
- Paresthesia
- Parkinsonia Like Symptoms
- Post-exertional Malaise (PEM)
- Rash
- Respiratory Distress
- Sinonasal Congestion
- Stress
- Tachycardia
- Tinnitus
- Urinary Incontinence
- Visual Changes
- Vomiting
- Weight Changes
- Wheezing

MCC eCare Plan FHIR IG Timeline

Balloting is a formal process used by HL7 to get feedback and comments on specifications prior to publication. There are different ballot levels: For Comment, Informative, Standard for Trial Use (STU), and Normative. Over the course of this project, the MCC eCare Plan IG will be matured through the For Comment ballot and the STU ballot. Below is a timeline for the development of the IG:

For Comment Ballot (Jan 2023)	Comment Reconciliation (Feb-Jun 2023)	STU Ballot (Sep 2023)	Comment Reconciliation (Sep 2023-Feb 2024)	Publish IG (Spring 2024)
New additions include finalized value sets, updated Use Cases, capability statements.	Triage comments received during the For Comment ballot and begin comment reconciliation.	Update FHIR IG based on latest version of US Core IG and comments from the January 2023 For Comment ballot.	Triage comments received during the STU ballot and perform comment reconciliation to update the FHIR IG.	Prepare the IG for publication as an STU meaning that the IG is substantially complete and ready for implementation.

Significant Changes to the IG for September Ballot

- **Plain Language Summary**
  - Beta testing for HL7.
  - Summary of HL7 and the implementation guide.
  - Designed to be a "patient friendly" summary.

Significant Changes to the IG for September Ballot

- Updated and aligned to US Core 6.1.

- Replaced care plan resource "author" with "custodian."

- Updated the Care Team to remove the specialized Caregiver. The Care Team now references CareTeam.relatedPerson* to represent the Caregiver.

- Included guidance on transmitting aggregated information.

- Added clarification on describing how text outcomes can be represented codableConcept.text and how the patient/caregiver condition status is a self-assessment.

September 2023 Ballot Results

- 40 Overall Votes (voters) (Mix of Government/University, Pharma, General Interest, Provider):
    - 38 Affirmative (above threshold for publication)
    - 2 Negative

- [Ballot Dashboard](#)
    - 32 Actual Comments
        - Plain Language
        - Care Team clarifications
        - Tech Edits
        - Value set application questions/suggestions
        - Heath Concern clarification

IG Requested Changes -Status

Plain Language - **In Progress**

- Most were comments of approval, which were acknowledged.
- Finalizing the dropdown format presentation.

Care Team clarifications - **In Progress**

- Continued discussions with PCWG, 3 of 4 addressed

Tech Edits - **Complete**

- Changes approved during PCWG block vote on November 7

Value set application questions/suggestions - **Planned**

- Requires continued discussions with PCWG

Heath Concern clarification - **Planned**

- Requires continued discussions with PCWG

National Institute of Diabetes and Digestive and Kidney Diseases

Next Steps

- Bi-weekly calls during the Patient Care Work Group session on Wednesdays, 5-6 PM ET
- Discuss, vote and implement comment resolution.

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Agile Approach

The Agile methodology is a project management approach that involves breaking the project into phases, such as planning, designing, developing, testing, deploying and reviewing. It emphasizes continuous collaboration and improvement.

Agile can increase development speed, expand collaboration, and foster the ability to better respond to market trends (clinician or patient/caregiver needs).

Sources: https://www.atlassian.com/agile, https://asana.com/resources/agile-methodology

Agile User Stories

When feedback is received by the evaluation team, it is turned into user stories. These user stories are translated into tasks that guide the app development team in developing new features.

As a <role>
I want <goal>
so that <benefit>

Acceptance criteria:
(Conditions of Satisfaction)

...

...

As an Account Manager
I want a sales report of my account
to be sent to my inbox daily
So that I can monitor the sales
progress of my customer portfolio

Acceptance criteria:
1. The report is sent daily to my inbox
2. The report contains the following sales details: ...
3. The report is in csv format.

These features are then prioritized and feasibility is determined to guide implementation.

MoSCoW prioritization

MUST HAVE — All the requirements that are necessary for the successful completion of the project.

SHOULD HAVE — Requirements that are important for project completion but not necessary.

COULD HAVE — Requirements that are nice to have, but have a much smaller impact when left out of the project.

WILL NOT HAVE — All the requirements that have been recognized as not a priority for the project's timeframe.

eCare Apps Support Comprehensive Shared Care Planning

	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 clinicians to coordinate and plan care.

*U.S. Department of Health and Human Services 2015 Stakeholder Panel | Baker, et al. Making the Comprehensive Shared Care Plan a Reality. *NEJM Catalyst*. 2016: https://catalyst.nejm.org/making-the-comprehensive-shared-care-plan-a-reality/

Context Setting

Project Objective: Build data capacity for pragmatic 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 MCC.

eCare App Focus

Proof of concept for an interoperable platform that enables standardized data exchange for data elements critical to care planning.
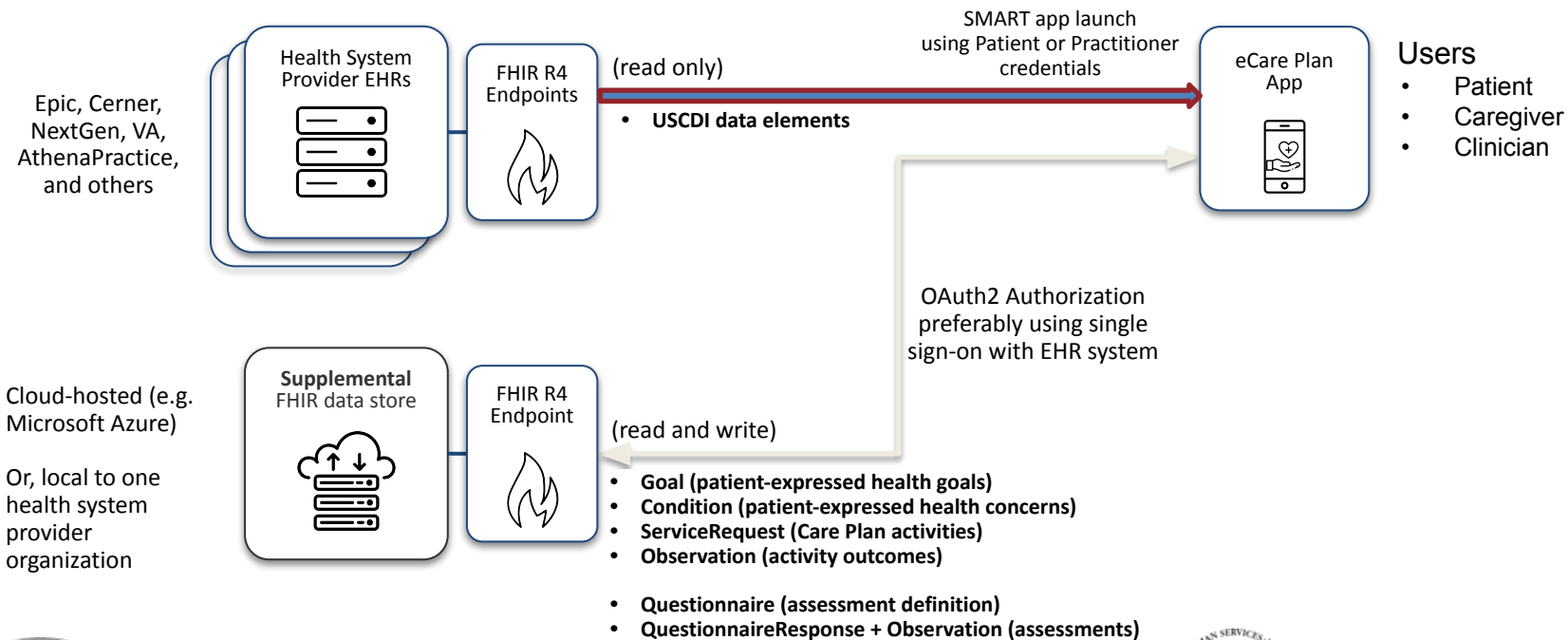
Limitations/Challenges

- Limited EHR support for capturing data relevant to goal-oriented care planning
- Very limited write access to EHR systems via FHIR.
- Challenge of where/how to store supplemental data that health systems would be comfortable with for contributions by patients/caregivers or not supported by EHRs.

Future Scopes/Out of Scope Now

- Features that enable greater accessibility (i.e., multiple languages).
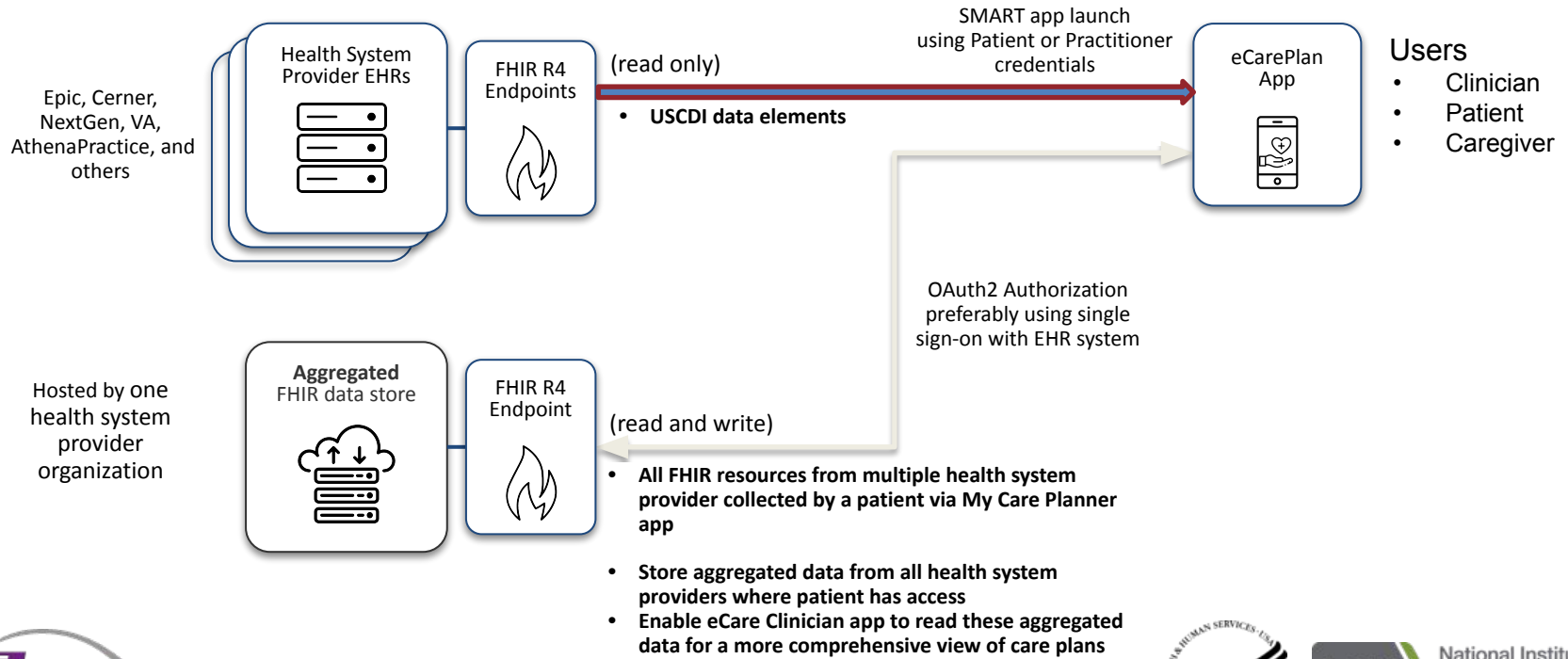- Robust user features that provide a more full care planning experience (i.e., med reconciliation, corrections, scheduling, alerts, secure messaging).
- Clinical decision support.
- Aggregated data for data analytics research.
- Full integration with social care and care providers who don't use EHR systems.
- End-to-end shared decision-making workflow support.

eCare Plan Applications Architecture - Supplemental Data

Health System Provider EHRs

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

FHIR R4 Endpoints

(read only)

- **USCDI data elements**

SMART app launch using Patient or Practitioner credentials

eCare Plan App

Users
- Patient
- Caregiver
- Clinician

OAuth2 Authorization preferably using single sign-on with EHR system

Cloud-hosted (e.g. Microsoft Azure)

Or, local to one health system provider organization

Supplemental FHIR data store

FHIR R4 Endpoint

(read and write)

- **Goal (patient-expressed health goals)**
- **Condition (patient-expressed health concerns)**
- **ServiceRequest (Care Plan activities)**
- **Observation (activity outcomes)**

- **Questionnaire (assessment definition)**
- **QuestionnaireResponse + Observation (assessments)**

eCare Plan Applications Architecture - Aggregated Data

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

Health System Provider EHRs

FHIR R4 Endpoints

(read only)

- **USCDI data elements**

SMART app launch using Patient or Practitioner credentials

eCarePlan App

Users
- Clinician
- Patient
- Caregiver

OAuth2 Authorization preferably using single sign-on with EHR system

Hosted by one health system provider organization

Aggregated FHIR data store

FHIR R4 Endpoint

(read and write)

- **All FHIR resources from multiple health system provider collected by a patient via My Care Planner app**

- **Store aggregated data from all health system providers where patient has access**
- **Enable eCare Clinician app to read these aggregated data for a more comprehensive view of care plans**

National Institute of Diabetes and Digestive and Kidney Diseases

Patient/Caregiver App Vision

Patient/ Caregiver
eCare Plan App

Supplemental
Data Store

Clinician eCare Plan
App

- Leverage the 21st Century Cures Act to enable patients to **read FHIR data** from **multiple health system organizations** where they receive care.
- Synthesize and share a comprehensive care plan from all collected health system provider data.
- Enable **patients and caregivers to contribute to their shared care plan** through self-reporting of:
  - Goals
  - Health Concerns
  - Patient-initiated activities
- **Integrate FHIR Questionnaires** to present and collect standardized assessments, including:
  - PROMIS-29 (General health assessment and symptoms for Long COVID research)
  - PRAPARE (SDoH Data Elements)
  - Caregiver Strain Index (Assessment of caregiver burden)

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Diabetes and Digestive
and Kidney Diseases

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Goal-Oriented Care Planning
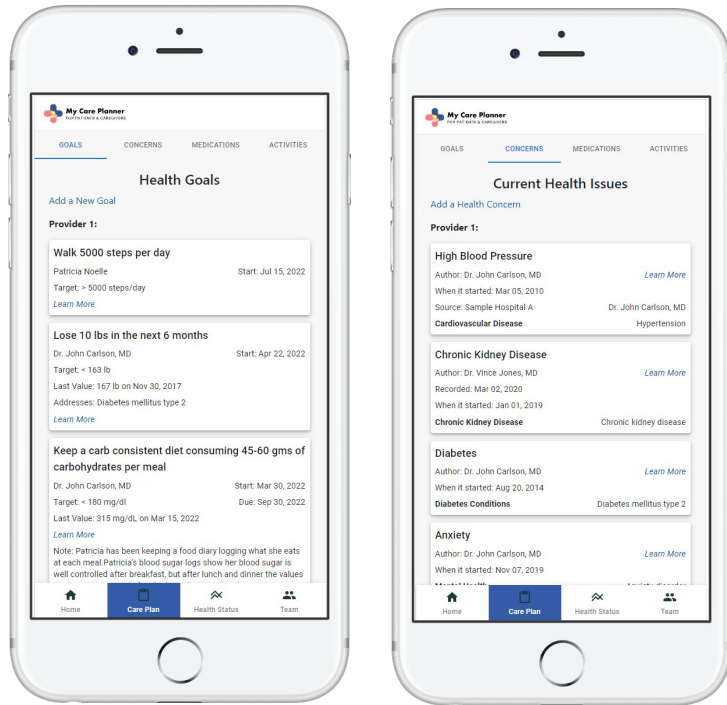
- Place a person's goals at the center of decision-making
- Cross-platform web application
  - JavaScript React app
  - Formatted for mobile device browsers
- Current integration in pilot:
  - Epic, Cerner, VA, NextGen, AthenaPractice

Caregiver and Patient Assessments

- FHIR Questionnaires generated by LOINC.org include terminology codes for all responses.

- Responses are saved in the Supplemental Data Store

Supplemental Data Store

Patient/ Caregiver eCare Plan App

Supplemental Data Store

Clinician eCare Plan App

- A FHIR Supplemental Data Store (SDS) is required to support patient-centered, goal-oriented shared care planning:

  - 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

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

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

Using CQL to Filter & Classify FHIR Data

- MyCarePlanner uses Clinical Quality Language (CQL) to interpret and summarize aggregated data from multiple FHIR data sources.

- CQL applies the MCC FHIR 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 (out of scope for this project).

- The CQL Execution Framework is a set of JavaScript libraries that can execute CQL artifacts expressed as JSON ELM, embedded in a browser.

https://github.com/cqframework/cql-execution

National Institute of
Diabetes and Digestive
and Kidney Diseases

CQL Classification and Display: Condition

High Blood Pressure

Author: Dr. Val761 Lind531

Learn More

Recorded: May 07, 1980

When it started: May 07, 1980

Cardiovascular Disease   Hypertension

Coronary Blockages

Author: Dr. Keith571 Lind531

Learn More

Recorded: Jan 11, 2023
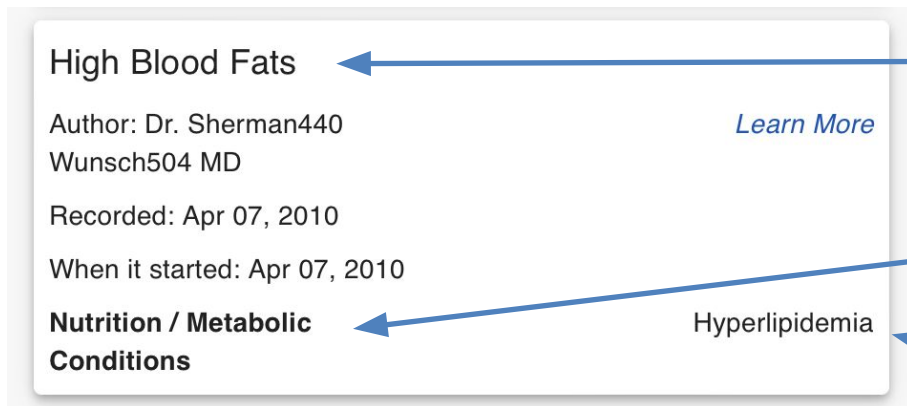
When it started: Jan 10, 2023

Cardiovascular Disease   Abnormal findings diagnostic imaging heart+coronary circulat (finding)

- Classify / group data using MCC FHIR IG value sets
  - Related problem list items from multiple health systems
  - Patient-friendly name assigned to each value set
- Examples from VA FHIR sandbox with synthetic data for Veterans

CQL Classification and Display: Condition (cont.)

High Blood Fats → Patient-friendly name

Learn More → Link to MedlinePlus (based on terminology codes)

Nutrition / Metabolic Conditions → Value set where this data item is classified

Hyperlipidemia → Condition.code display name from terminology (often not patient-friendly)

Clinician App Vision

Patient/ Caregiver eCare Plan App

Supplemental Data Store

Clinician eCare Plan App

- A **standards-based application** platform for clinicians 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 clinician productivity** and **reduce clinician 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.

Current Efforts

Patient/Caregiver App: "MyCarePlanner"

- Saving patient authored data, such as goals, and aggregated patient data from multiple health sources to the Supplemental Data Store.
- Implementing a sort and filter display for medications and health concerns.
- Display the health system source (provider or health system name) for all resource types.
- Exploring additional goal documentation functionalities including tracking, priority, and confidence.

Clinician App: "eCarePlanner"

- User experience (UX) and user interface (UI) design updates with wireframes.
- Application enhancements including display of aggregated patient data and health system resource display.
- Grouping and displaying medications by associated diagnosis.
- Supporting clinician focus group facilitation and discovery based to identify and implement new features and design of the clinician app.

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- MCC eCare Plan Project progress summary

- Pilot/focus group feedback

- IG walkthrough and STU ballot

- App development approach and updates

- **eCare projects in practice**

eCare Project in Practice

- **NIA NOFO - [Demonstration Projects to Promote Use of Interoperable Health Records in Clinical Research](#)** [10/18/2022]: Develop best practices for collecting and harmonizing medical information from EHRs of older adults and analyzing health conditions through informatics methods.

- **[Multiple Chronic COnditions: MultiPle dAta SouRcEs (MC COMPARE)](#) - Oregon Health & Science University** **David Dorr and Lipika Samal** High blood pressure can lead to heart attacks, strokes, and kidney failure, amongst other outcomes, but lowering blood pressure too much leads to bad outcomes. This study will help understand how more information about certain people, especially those with multiple chronic conditions and older adults, can help balance the risks and benefits.

- **[Demonstrating the potential for electronic health record interoperability to improve patient safety research](#) [of older adults over the acute episode of care](#) - Brigham and Women's Hospital** **Anuj Dalal and Robert Rudin** We will partner with two patient safety studies of older hospitalized adults to design, develop, implement, and evaluate methods for empowering patients to locate, collect, and share their electronic health records for research. This work will enhance our existing digital infrastructure by leveraging two open-source projects that have developed core infrastructural building blocks. Our results will provide critical lessons that demonstrate the value of using interoperable standards for empowering patients to share their data for research, and how the combined data can create new knowledge about patient safety risks in older adults who are hospitalized.

eCare Project in Practice (cont.)

- **NIDDK NOFO - [Pilot Interventions to Integrate Social Care and Medical Care to Improve Health Equity](#)** [10/19/2023]
  - Develop pragmatic approaches that can be used in health care settings to reduce health disparities in diseases within the mission of NIDDK and achieve health equity, especially among individuals from racial and ethnic minority groups, rural populations, sexual and gender minority groups, and other socioeconomically disadvantaged and medically underserved communities.
- **AHRQ [ACTION Network RFTO](#)**
  - The project will identify innovative and feasible models and digital solutions for person-centered care planning and develop strategies and recommendations to advance AHRQ's mission of implementing person-centered care planning as routine practice for persons with MCC.
- **NEW Care Plan Data Elements in [ONC USDCI v4](#)**
  - Two new data elements have been added to the data class Goals and Preferences: Treatment Intervention Preference; and Care Experience Preference.
- **NEW [Clinical Decision Tools to Facilitate Social Risk-Informed Care Planning](#)**
  - NIMHD funded study to develop EHR based CDS tools to facilitate social risk informed care plan adjustments in community health centers.

MCC eCare Team Project Contacts

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History of Federal Investment in Care Planning/Coordination

Over a decade of federal investment in advancing the development and use of standards for care planning and related care coordination activities:

- **ONC**: 2015 Edition Care Planning Criterion
- **ONC/CMS**: electronic Long-Term Services and Supports (eLTSS)
- **SAMHSA:** Omnibus Care Plan
- **CMS**: PACIO Project
- **NIDDK/AHRQ**: MCC eCare Plan
- **ONC/AHRQ/ACL/CMS**: Gravity Project
- **ACL**: Social Referral Challenge Program
- **ONC**: LEAP Grant Program
- **CDC**: MedMorph
- **CDC**: Clinical Practice Guidelines (CPG) on FHIR
- **ACF**: Human Services Interoperability Innovations Grant
- **CDC**: SDOH Use Case for Chronic Disease Prevention

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.

National Institute of Diabetes and Digestive and Kidney Diseases

MCC eCare Plan Project Governance Model

Federal Partner Committee

Contract Monitoring Board

DEVELOPMENT

REAL-WORLD TESTING

Technical Expert Panels (TEP)

HL7 Patient Care Work Group (PCWG)

NIDDK

EMI Advisors

MANAGEMENT TEAM

AHRQ

RTI International

Oregon Health & Science University (OHSU)