Multiple Chronic Conditions (MCC) eCare Plan Federal Partners Meeting

February 1, 2024

Jenna Norton
Arlene Bierman
EMI Advisors
RTI International
Oregon Health & Science University

Welcome! Please say hello **in the chat** by sending everyone your **name** and **affiliation**.

AHRQ

DEPARTMENT OF HEALTH & HUMAN SERVICES · USA

NIH National Institute of Diabetes and Digestive and Kidney Diseases

Agenda

Topic	Time	Presenter(s)
Welcome and Introductions	5 min	Jenna Norton, NIDDK Arlene Bierman, AHRQ
MCC eCare Plan Project Overview and Progress Update	65 min	MCC eCare Project Team
Federal Projects Round Robin Update	30 min	Federal Partners
What's Next for the eCare Plan Project?	15 min	Jenna Norton, NIDDK Arlene Bierman, AHRQ
Closing Remarks	5 min	Karen Bertodatti, EMI

Contractor Introductions

Evelyn Gallego, MBA, MPH, CPHIMS

Program Director

Himali Saitwal, MS

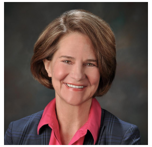
Terminology SME

Dave Carlson, PhD, MBA*

Solutions Architect

Karen Bertodatti, MPH, PMP

Project Manager



Gay Dolin, MSN, RN*

IG Developer/Clinical SME

Sean Muir*

App Developer

Savanah Mueller, MPH

Project Analyst

Bret Heale, PhD*

Biomedical Informaticist-SME

*subcontractor to EMI

Please say hello in the chat by stating your name and affiliation.

Contractor Introductions

Laura Marcial, PhD

Project Director

Jacqueline Ortiz, MS, MMCi

Associate Project Director

Joel Montavon, PharmD

Technical Integration Lead

David Dorr, MD, MS

Principal Investigator

Michelle Bobo, MS

Senior Research Assistant and Practice Facilitator

Please say hello in the chat by stating your name and affiliation.

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Housekeeping

- Live transcription is available.
- Use the hand raise feature when you'd like to speak.
- Use the chat to share feedback at any time.
- We are recording for note-taking purposes.

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Karen Bertodatti, MPH

Progress Summary

The Challenge of Multiple Chronic Conditions (MCC)

- **Disease-specific vs. person-centered approaches.** Disease-specific approach to care delivery and research is misaligned with the **whole person-centered needs** of patients and caregivers.
- **Interoperability obstacles in complex care.** People with MCC require care in multiple settings, from multiple providers. **Data do not easily move across settings of care**.
- **Health equity.** People from low-income backgrounds and under-represented racial or ethnic groups develop MCC at **higher rates and earlier ages**.

People with MCC account for:

64%	70%	83%	71%	93%
OF ALL **Clinician Visits**	OF ALL **In-Patient Stays**	OF ALL **Prescriptions**	OF ALL **Healthcare Spending**	OF ALL **Medicare Spending**

NEARLY

1 IN 3 & **4 IN 5**

American Adults — Medicare Beneficiaries

ARE LIVING WITH MCC, THE **MOST COMMON CHRONIC CONDITION**

CMS 2018: *https://www.cms.gov/data-research/statistics-trends-and-reports/chronic-conditions/chartbook-and-charts*;
AHRQ 2010: https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/prevention-chronic-care/decision/mcc/mccchartbook.pdf;
Quiñones, et al. Racial/ethnic differences in multimorbidity development and chronic disease accumulation for middle-aged adults. *PLoS One*, 2019;14(6), PMID: 31206556.

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. It **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.

Source: 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/

Norton JM, Ip A, Ruggiano N, Abidogun T, Camara DS, Fu H, Hose BZ, Miran S, Hsiao CJ, Wang J, Bierman AS. *Assessing Progress Toward the Vision of a Comprehensive, Shared Electronic Care Plan: Scoping Review*. J Med Internet Res. 2022 Jun 10;24(6):e36569. doi: 10.2196/36569. PMID: 35687382.

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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.

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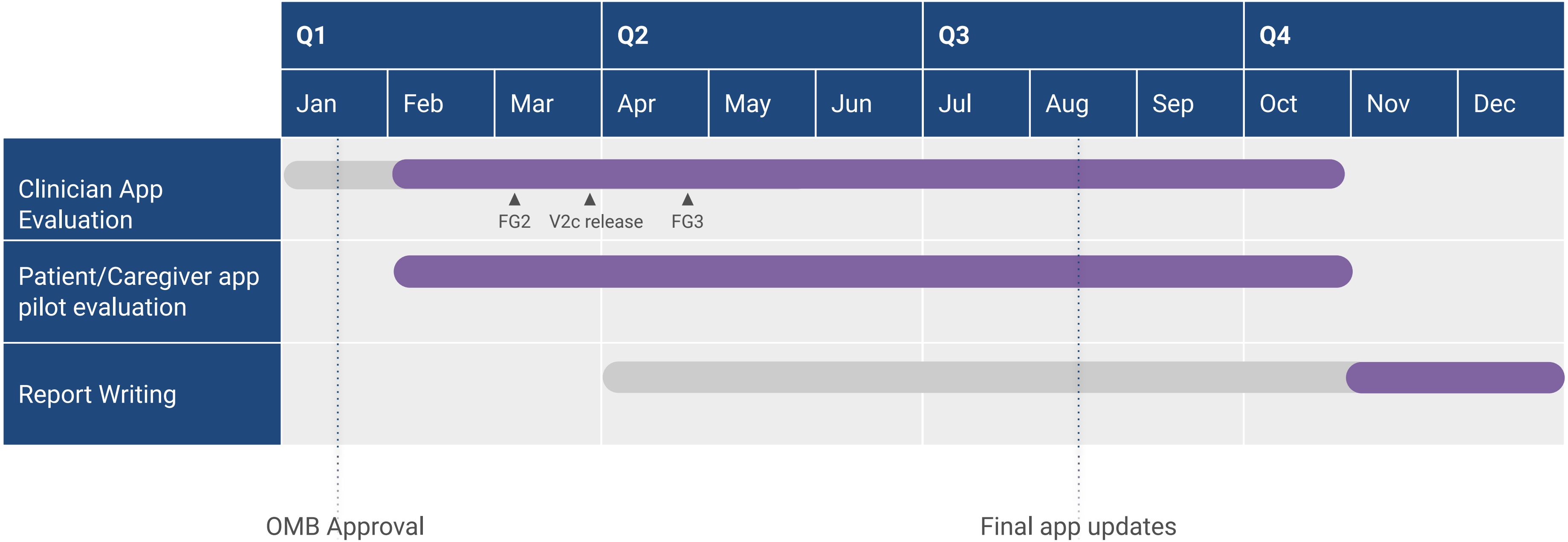
Overview of Work Year Over Year

		Year 1	Year 2	Year 3	Year 4	Year 5
1	**Data**	Defined **chronic kidney disease**, **cardiovascular disease**, **chronic pain**, and **diabetes** data concepts.		Defined **long COVID** and **caregiver** data concepts.		
2	**IG**	Developed **initial MCC FHIR IG**.	First round of real-world MCC FHIR IG **testing**.	Restructured **MCC FHIR IG** and built **value set library**.	Completed **for-comment HL7 ballot**.	Completed **STU1 HL7 ballot** and publishing **STU1 IG**
3	**Apps**	Developed **initial clinician** and **patient apps**.	First round of real-world app **testing**.	Redesigned and built **patient and caregiver** app.	Re-engineered **backend data services**.	**Agile, real-world testing & revision** to enhance both apps.

RTI International

Pilot Updates and Focus Group Feedback

Evaluation Timeline



Focus Group Methodology

Overall

- Objective: Formative feedback for clinician application development.
- Format:
    - Three rounds of focus groups (December 2023, March 2024, Spring 2024).
    - Virtual
    - Facilitated by OHSU, included notetakers
- Participant recruitment: Worked with OHSU clinician champions for the project to identify participants. Focus group 2 will include external providers,
    - Provider specialties included family medicine, internal medicine, geriatrics, cardiology and nephrology

First Round

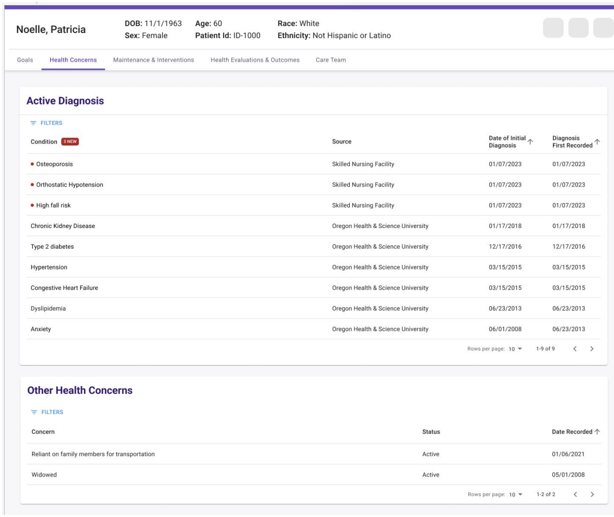
- Completed two 1-hour focus group sessions held on December 7, 2023.
- 9 participants of clinicians
- Qualitative analysis was conducted using a thematic analysis approach to identify priority areas for app enhancements

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

Focus Group 1 Findings: Diagnoses and Health Concerns

- 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.



Noelle, Patricia

DOB: 11/1/1963 **Sex:** Female **Age:** 60 **Patient Id:** ID-1000 **Race:** White **Ethnicity:** Not Hispanic or Latino

Active Diagnosis

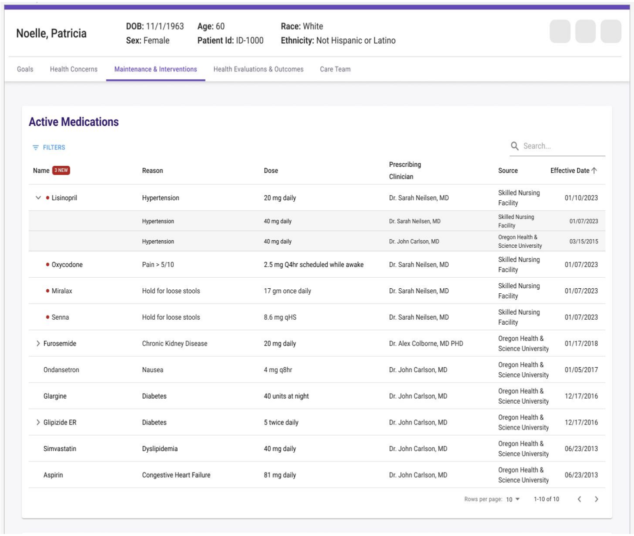
Condition	Source	Date of Initial Diagnosis	Diagnosis First Recorded
● Osteoporosis	Skilled Nursing Facility	01/07/2023	01/07/2023
● Orthostatic Hypotension	Skilled Nursing Facility	01/07/2023	01/07/2023
● High fall risk	Skilled Nursing Facility	01/07/2023	01/07/2023
Chronic Kidney Disease	Oregon Health & Science University	01/17/2018	01/17/2018
Type 2 diabetes	Oregon Health & Science University	12/17/2016	12/17/2016
Hypertension	Oregon Health & Science University	03/15/2015	03/15/2015
Congestive Heart Failure	Oregon Health & Science University	03/15/2015	03/15/2015
Dyslipidemia	Oregon Health & Science University	06/23/2013	06/23/2013
Anxiety	Oregon Health & Science University	06/01/2008	06/23/2013

Other Health Concerns

Concern	Status	Date Recorded
Reliant on family members for transportation	Active	01/06/2021
Widowed	Active	05/01/2008

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.



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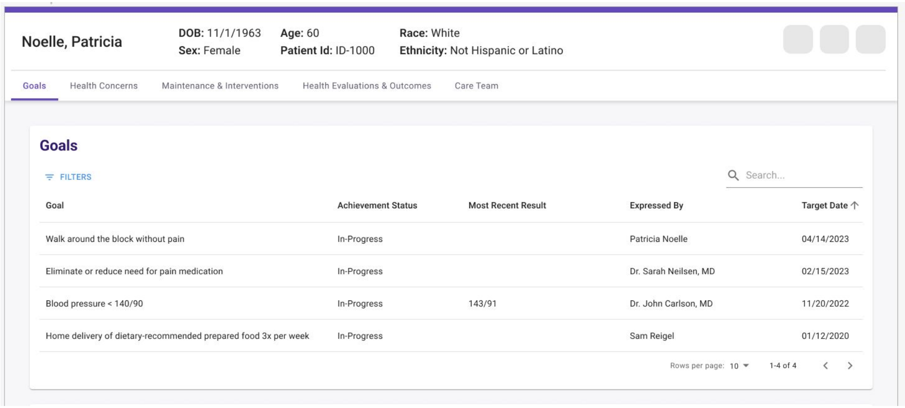
Active Medications

Name 3 NEW	Reason	Dose	Prescribing Clinician	Source	Effective Date ↑
● Lisinopril	Hypertension	20 mg daily	Dr. Sarah Neilsen, MD	Skilled Nursing Facility	01/10/2023
	Hypertension	40 mg daily	Dr. Sarah Neilsen, MD	Skilled Nursing Facility	01/07/2023
	Hypertension	40 mg daily	Dr. John Carlson, MD	Oregon Health & Science University	03/15/2015
● Oxycodone	Pain > 5/10	2.5 mg Q4hr scheduled while awake	Dr. Sarah Neilsen, MD	Skilled Nursing Facility	01/07/2023
● Miralax	Hold for loose stools	17 gm once daily	Dr. Sarah Neilsen, MD	Skilled Nursing Facility	01/07/2023
● Senna	Hold for loose stools	8.6 mg qHS	Dr. Sarah Neilsen, MD	Skilled Nursing Facility	01/07/2023
Furosemide	Chronic Kidney Disease	20 mg daily	Dr. Alex Colborne, MD PHD	Oregon Health & Science University	01/17/2018
Ondansetron	Nausea	4 mg q8hr	Dr. John Carlson, MD	Oregon Health & Science University	01/05/2017
Glargine	Diabetes	40 units at night	Dr. John Carlson, MD	Oregon Health & Science University	12/17/2016
Glipizide ER	Diabetes	5 twice daily	Dr. John Carlson, MD	Oregon Health & Science University	12/17/2016
Simvastatin	Dyslipidemia	40 mg daily	Dr. John Carlson, MD	Oregon Health & Science University	06/23/2013
Aspirin	Congestive Heart Failure	81 mg daily	Dr. John Carlson, MD	Oregon Health & Science University	06/23/2013

Rows per page: 10 1-10 of 10

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



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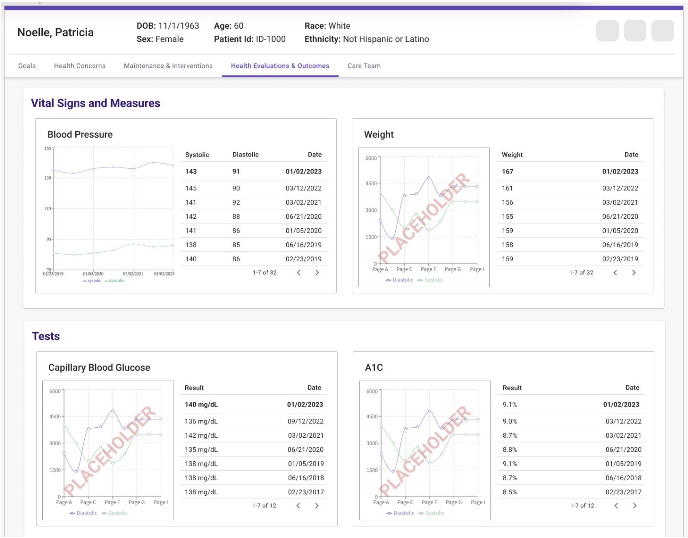
Goals

Goal	Achievement Status	Most Recent Result	Expressed By	Target Date ↑
Walk around the block without pain	In-Progress		Patricia Noelle	04/14/2023
Eliminate or reduce need for pain medication	In-Progress		Dr. Sarah Neilsen, MD	02/15/2023
Blood pressure < 140/90	In-Progress	143/91	Dr. John Carlson, MD	11/20/2022
Home delivery of dietary-recommended prepared food 3x per week	In-Progress		Sam Reigel	01/12/2020

Rows per page: 10 1-4 of 4

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



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Vital Signs and Measures

Blood Pressure

Systolic	Diastolic	Date
143	**91**	**01/02/2023**
145	90	03/12/2022
141	92	03/02/2021
142	88	06/21/2020
141	86	01/05/2020
138	85	06/16/2019
140	86	02/23/2019

Weight

Weight	Date
167	**01/02/2023**
161	03/12/2022
156	03/02/2021
155	06/21/2020
159	01/05/2020
158	06/16/2019
159	02/23/2019

Tests

Capillary Blood Glucose

Result	Date
140 mg/dL	**01/02/2023**
136 mg/dL	09/12/2022
142 mg/dL	03/02/2021
135 mg/dL	06/21/2020
138 mg/dL	01/05/2019
138 mg/dL	06/16/2018
138 mg/dL	02/23/2017

A1C

Result	Date
9.1%	**01/02/2023**
9.0%	03/12/2022
8.7%	03/02/2021
8.8%	06/21/2020
9.1%	01/05/2019
8.7%	06/16/2018
8.5%	02/23/2017

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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and Kidney Diseases

Gay Dolin, MSN

IG Walkthrough and STU Ballot

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.

HL7® FHIR®

Improve care coordination without increasing clinician burden

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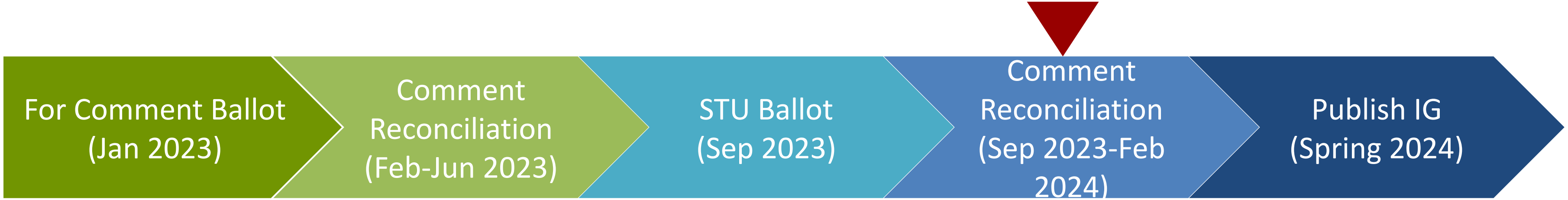
MCC eCare Plan FHIR IG Timeline

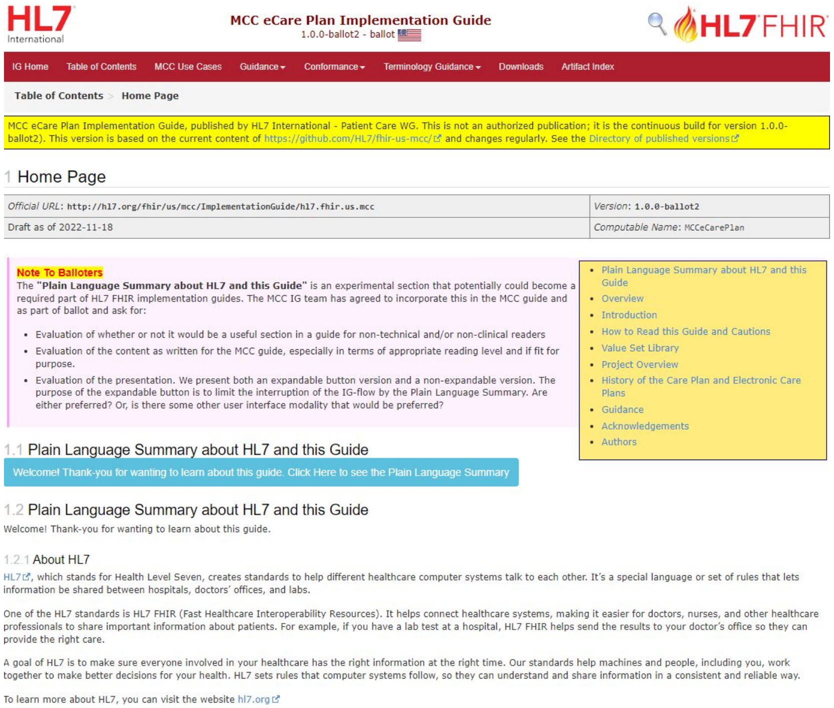
Balloting is a formal process used by HL7 to get feedback and comments on specifications prior to publication. There are different ballot levels: For Comment, Informative, Standard for Trial Use (STU), and Normative. Over the course of this project, the MCC eCare Plan IG will be matured through the For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



MCC eCare Plan Implementation Guide
1.0.0-ballot2 - ballot

MCC eCare Plan Implementation Guide, published by HL7 International - Patient Care WG. This is not an authorized publication; it is the continuous build for version 1.0.0-ballot2). This version is based on the current content of https://github.com/HL7/fhir-us-mcc/ and changes regularly. See the Directory of published versions

1 Home Page

Official URL: `http://hl7.org/fhir/us/mcc/ImplementationGuide/hl7.fhir.us.mcc`	*Version*: `1.0.0-ballot2`
Draft as of 2022-11-18	*Computable Name*: `MCCeCarePlan`

Note To Balloters
The **"Plain Language Summary about HL7 and this Guide"** is an experimental section that potentially could become a required part of HL7 FHIR implementation guides. The MCC IG team has agreed to incorporate this in the MCC guide and as part of ballot and ask for:

- Evaluation of whether or not it would be a useful section in a guide for non-technical and/or non-clinical readers
- Evaluation of the content as written for the MCC guide, especially in terms of appropriate reading level and if fit for purpose.
- Evaluation of the presentation. We present both an expandable button version and a non-expandable version. The purpose of the expandable button is to limit the interruption of the IG-flow by the Plain Language Summary. Are either preferred? Or, is there some other user interface modality that would be preferred?

1.1 Plain Language Summary about HL7 and this Guide

1.2 Plain Language Summary about HL7 and this Guide

Welcome! Thank-you for wanting to learn about this guide.

1.2.1 About HL7

HL7, which stands for Health Level Seven, creates standards to help different healthcare computer systems talk to each other. It’s a special language or set of rules that lets information be shared between hospitals, doctors’ offices, and labs.

One of the HL7 standards is HL7 FHIR (Fast Healthcare Interoperability Resources). It helps connect healthcare systems, making it easier for doctors, nurses, and other healthcare professionals to share important information about patients. For example, if you have a lab test at a hospital, HL7 FHIR helps send the results to your doctor’s office so they can provide the right care.

A goal of HL7 is to make sure everyone involved in your healthcare has the right information at the right time. Our standards help machines and people, including you, work together to make better decisions for your health. HL7 sets rules that computer systems follow, so they can understand and share information in a consistent and reliable way.

To learn more about HL7, you can visit the website hl7.org

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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

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

Care Team clarifications

- Simplified to support the MCC Care team within the Care Plan

Tech Edits - Complete

- Changes approved during PCWG block vote on November 7

Heath Concern clarification

- Proposal is to clarify the use of Health Concern in the eCare Plan in the guidance text and the diagrams

Next Steps

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

Dave Carlson, PhD, MBA

App Development Approach and Updates

Overview: SMART on FHIR Applications

Deliverable 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.

Year 5

Modify and enhance **Clinician and Patient/Caregiver Application** to support data aggregation and user-requested features.

Support for **pilot implementation** and **real-world testing.**

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 providers 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.

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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.

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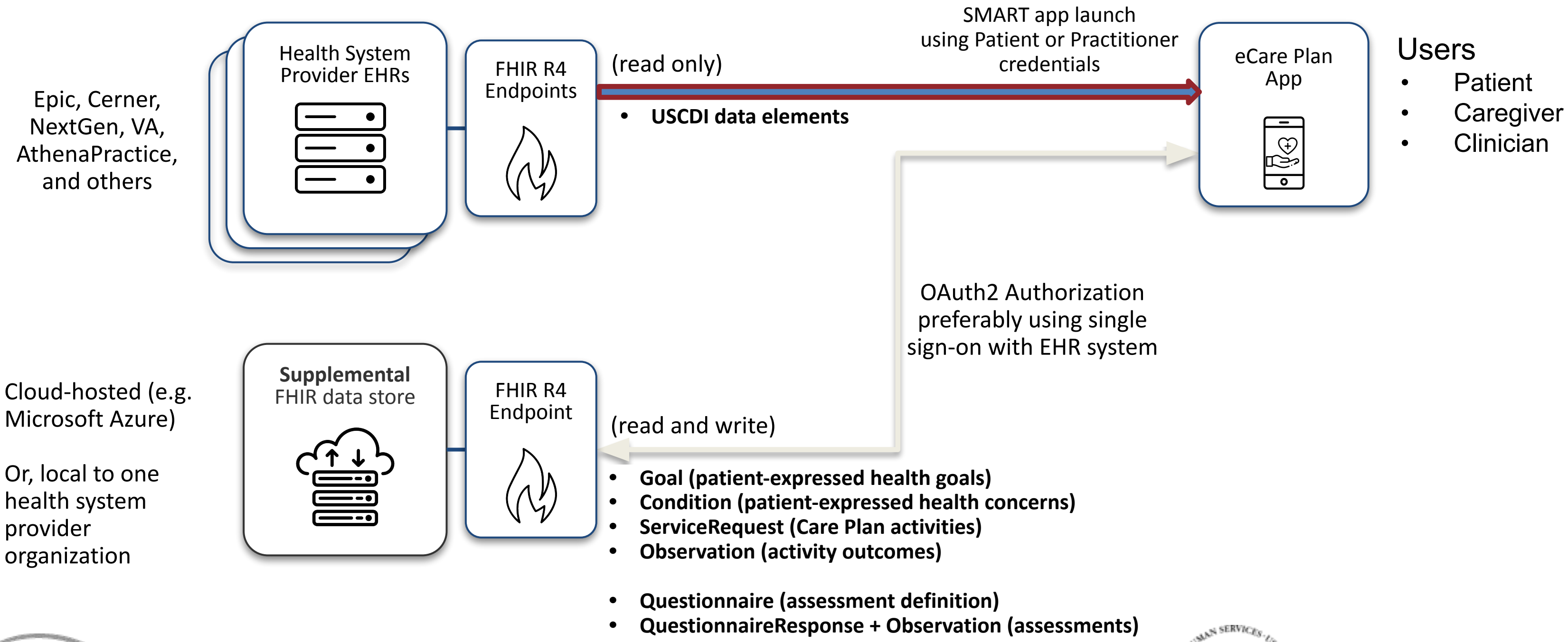
eCare Plan Applications Architecture - Supplemental Data



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

Health System Provider EHRs

FHIR R4 Endpoints

(read only)

SMART app launch using Patient or Practitioner credentials

- **USCDI data elements**

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

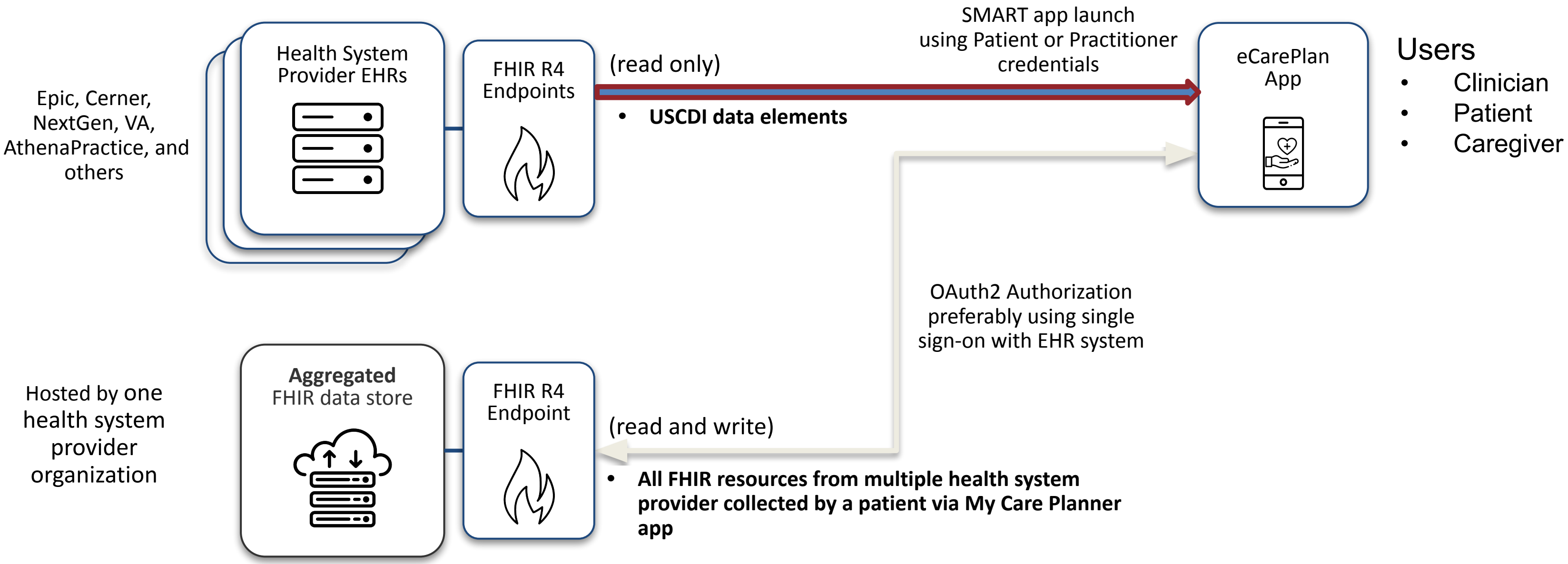
FHIR R4 Endpoint

(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)

SMART app launch using Patient or Practitioner credentials

- **USCDI data elements**

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

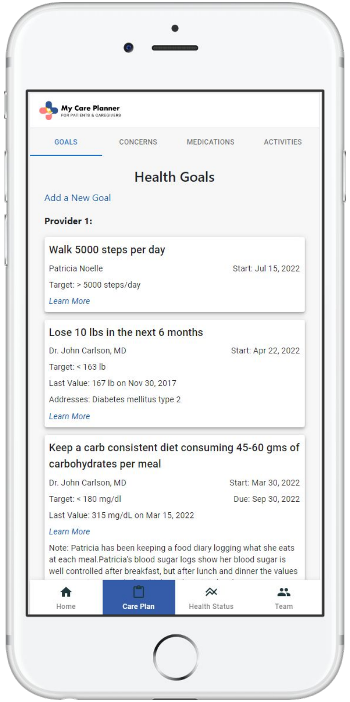
Patient/ Caregiver eCare Plan App

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)

Goal-Oriented Care Planning



Health Goals

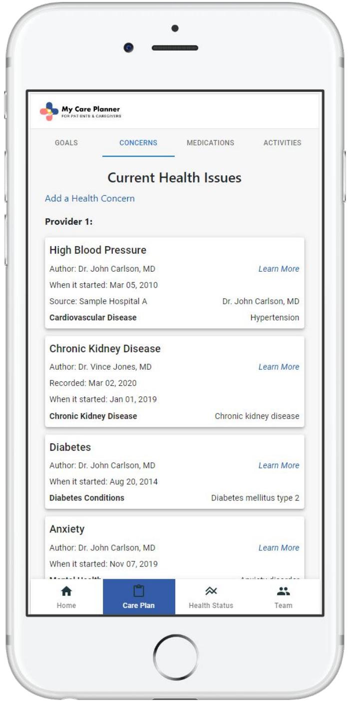
Add a New Goal

Provider 1:

Walk 5000 steps per day
Patricia Noelle — Start: Jul 15, 2022
Target: > 5000 steps/day
Learn More

Lose 10 lbs in the next 6 months
Dr. John Carlson, MD — Start: Apr 22, 2022
Target: < 163 lb
Last Value: 167 lb on Nov 30, 2017
Addresses: Diabetes mellitus type 2
Learn More

Keep a carb consistent diet consuming 45-60 gms of carbohydrates per meal
Dr. John Carlson, MD — Start: Mar 30, 2022
Target: < 180 mg/dl — Due: Sep 30, 2022
Last Value: 315 mg/dL on Mar 15, 2022
Learn More
Note: Patricia has been keeping a food diary logging what she eats at each meal.Patricia's blood sugar logs show her blood sugar is well controlled after breakfast, but after lunch and dinner the values



Current Health Issues

Add a Health Concern

Provider 1:

High Blood Pressure
Author: Dr. John Carlson, MD — *Learn More*
When it started: Mar 05, 2010
Source: Sample Hospital A — Dr. John Carlson, MD
Cardiovascular Disease — Hypertension

Chronic Kidney Disease
Author: Dr. Vince Jones, MD — *Learn More*
Recorded: Mar 02, 2020
When it started: Jan 01, 2019
Chronic Kidney Disease — Chronic kidney disease

Diabetes
Author: Dr. John Carlson, MD — *Learn More*
When it started: Aug 20, 2014
Diabetes Conditions — Diabetes mellitus type 2

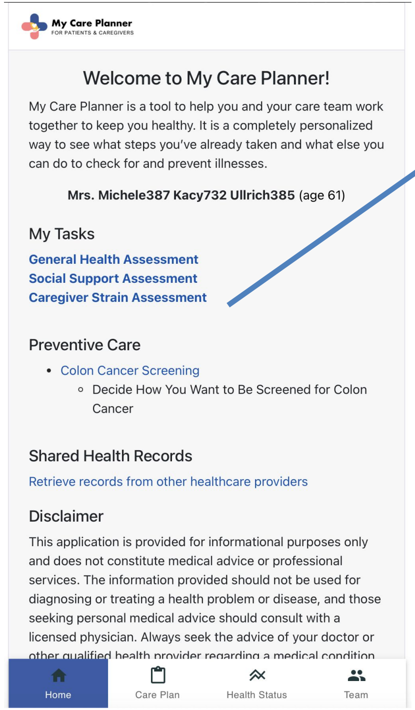
Anxiety
Author: Dr. John Carlson, MD — *Learn More*
When it started: Nov 07, 2019

- 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

AHRQ

National Institute of Diabetes and Digestive and Kidney Diseases

Caregiver and Patient Assessments



Welcome to My Care Planner!

My Care Planner is a tool to help you and your care team work together to keep you healthy. It is a completely personalized way to see what steps you've already taken and what else you can do to check for and prevent illnesses.

Mrs. Michele387 Kacy732 Ullrich385 (age 61)

My Tasks

General Health Assessment
Social Support Assessment
Caregiver Strain Assessment

Preventive Care

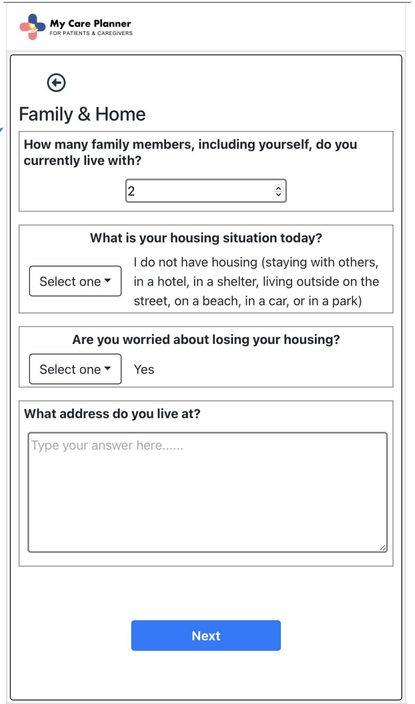
- Colon Cancer Screening
  - Decide How You Want to Be Screened for Colon Cancer

Shared Health Records

Retrieve records from other healthcare providers

Disclaimer

This application is provided for informational purposes only and does not constitute medical advice or professional services. The information provided should not be used for diagnosing or treating a health problem or disease, and those seeking personal medical advice should consult with a licensed physician. Always seek the advice of your doctor or other qualified health provider regarding a medical condition



Family & Home

How many family members, including yourself, do you currently live with?

2

What is your housing situation today?

Select one ▾ I do not have housing (staying with others, in a hotel, in a shelter, living outside on the street, on a beach, in a car, or in a park)

Are you worried about losing your housing?

Select one ▾ Yes

What address do you live at?

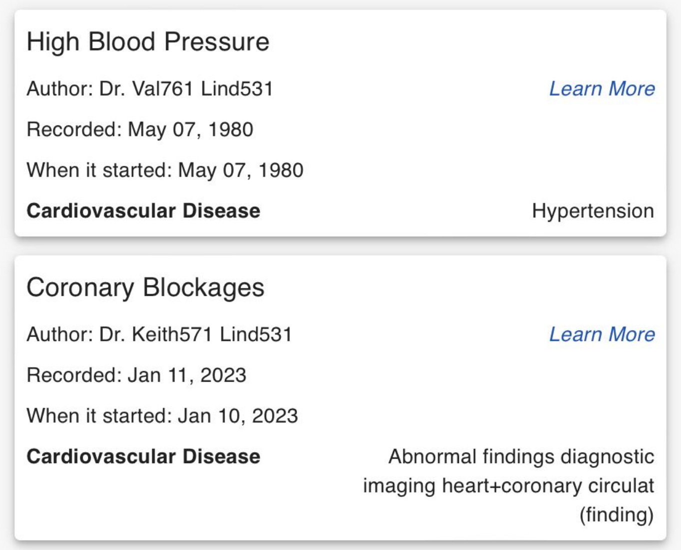
Type your answer here......

- FHIR Questionnaires generated by LOINC.org include terminology codes for all responses.
- Responses are saved in the Supplemental Data Store

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

CQL Classification and Display: Condition



High Blood Pressure

Author: Dr. Val761 Lind531

Recorded: May 07, 1980

When it started: May 07, 1980

Cardiovascular Disease Hypertension

Coronary Blockages

Author: Dr. Keith571 Lind531

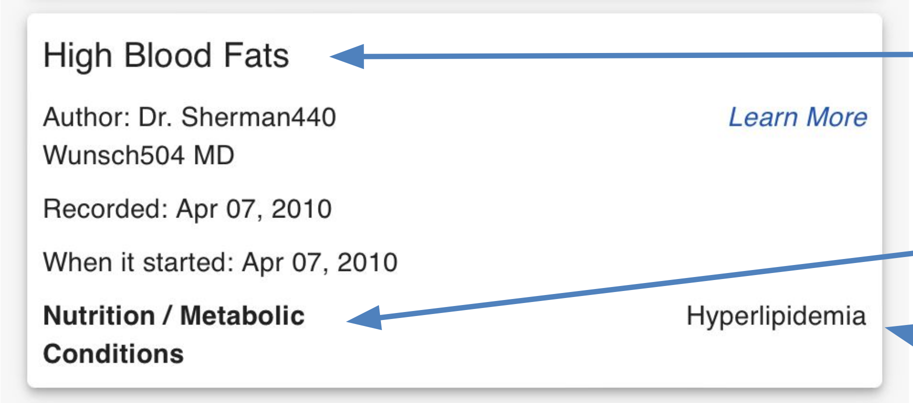
Recorded: Jan 11, 2023

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

Author: Dr. Sherman440 Wunsch504 MD

Recorded: Apr 07, 2010

When it started: Apr 07, 2010

Nutrition / Metabolic Conditions Hyperlipidemia

Patient-friendly name

Link to MedlinePlus (based on terminology codes)

Value set where this data item is classified

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

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.

AHRQ

NIH National Institute of Diabetes and Digestive and Kidney Diseases

Come Test With Us!

HL7 FHIR Connectathon 36

- May 18-19, 2024
- Dallas, TX

Ideas for eCare Track:

- Co-host with SPHR
- Testing with available EHR endpoints
- PACIO (round trip for Goals)
- MCC value sets classification

Agenda

Topic	Time	Presenter(s)
Welcome and Introductions	5 min	Jenna Norton, NIDDK Arlene Bierman, AHRQ
MCC eCare Plan Project Overview and Progress Update	65 min	MCC eCare Project Team
Federal Projects Round Robin Update	30 min	Federal Partners
What’s Next for the eCare Plan Project?	15 min	Jenna Norton, NIDDK Arlene Bierman, AHRQ
Closing Remarks	5 min	Karen Bertodatti, EMI

National Institute of Diabetes and Digestive and Kidney Diseases

Agency for Healthcare Research and Quality

The Clinical Decision Support Innovation Collaborative

National Institute of Diabetes and Digestive and Kidney Diseases

The Clinical Decision Support Innovation Collaborative (CDSiC)

MCC Round Robin update

February 1, 2023

James Swiger, MBE

Agency for Healthcare Research and Quality

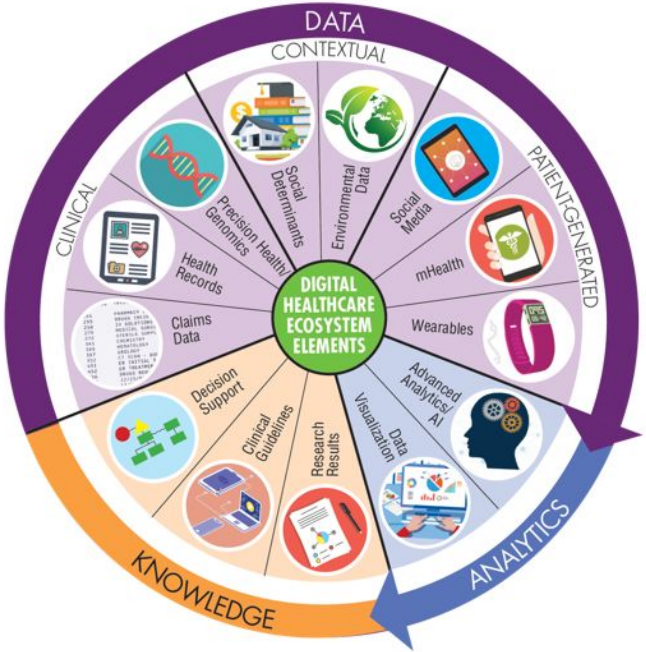
Agency for Healthcare Research and Quality (AHRQ)

AHRQ’s Mission:

- To produce evidence to make health care safer, higher quality, more accessible, equitable, and affordable, and to work within HHS and with other partners to make sure that the evidence is understood and used.

Division of Digital Healthcare Research’s (CEPI/DDHR) Mission:

- DDHR’s mission, within the Center for Evidence and Practice and Improvement, is to determine how the various components of the ever-evolving digital health care ecosystem can best come together to positively affect health care delivery and create value for patients and their families.
- http://digital.ahrq.gov



Clinical Decision Support in Legislation at AHRQ

Since 2016, DHR's Initiative has been based on patient-centered outcomes research and ACA legislative requirements (Sec 6301).

- (b) INCORPORATION OF RESEARCH FINDINGS – The Office [AHRQ], in consultation with relevant medical and clinical associations, shall assist users of health information technology focused on **clinical decision support** *to promote the timely incorporation of research findings* disseminated under subsection (a) into clinical practices and to promote the ease of use of such incorporation.

- (c) FEEDBACK – The Office shall establish a *process to receive feedback* from physicians, health care providers, **patients**, and vendors of health information technology focused on clinical decision support, appropriate professional associations, and Federal and private health plans about the value of the information disseminated and the assistance provided under this section.

- Re-authorized in 2019 for 10 years.

AHRQ’s PCOR CDS Initiative

Two Basic Goals: (1) To advance evidence into practice through CDS, and (2) to make CDS more shareable, standards-based, and publicly available.

1. Engaging a stakeholder community
2. Creating prototype infrastructure for sharing CDS and developing CDS
3. Advancing CDS through grant-funded research
4. Evaluating the overall initiative

Source: http://cds.ahrq.gov

AHRQ’s PCOR CDS Initiative

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4. Evaluating the overall initiative

Patient-Centered Clinical Decision Support Learning Network	CDS Connect
CDS Innovation Collaborative	CEDAR
 Grant	Evaluation: NORC at the UNIVERSITY of CHICAGO

CDS Innovation Collaborative (CDSiC): *Purpose and Aims*

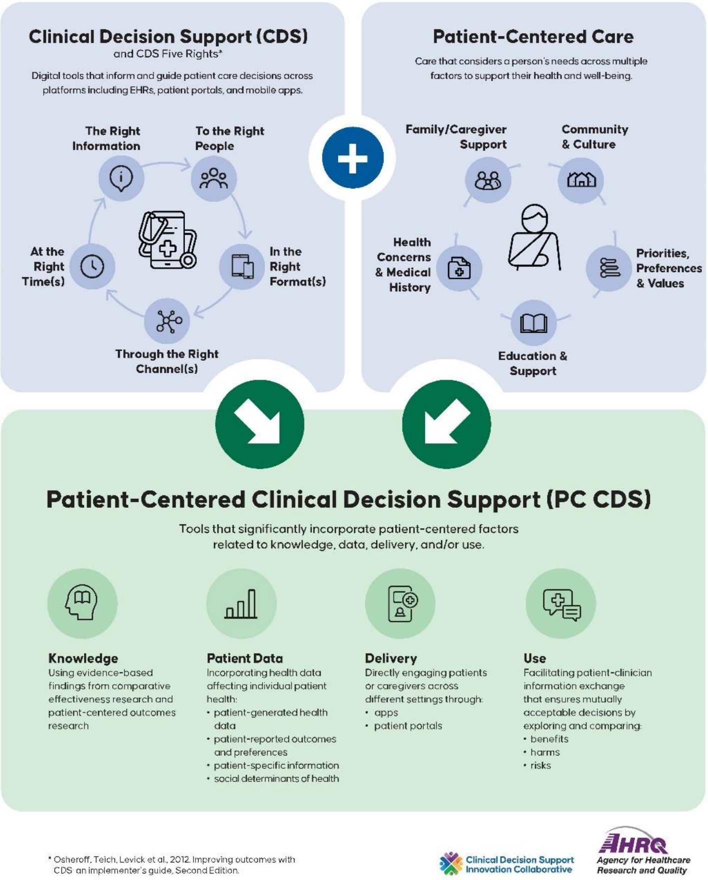
- **The CDSiC integrates diverse perspectives to produce resources and evidence to advance the field of patient-centered clinical decision support (PC CDS).**

- ***This project began in September 2023 and recently completed its first phase.***

- The CDSiC aims to support advancement of PC CDS by:
  - Creating a **learning community to share and advance the knowledge, resources, and methods** for developing, implementing, using, measuring and evaluating high-quality PC CDS.
  - **Promoting the practice and adoption of high-quality PC CDS** that considers patient/caregiver preferences & goals, clinician workflows, and shared-decision making values.
  - **Advancing standards-based CDS that can be shared and scaled** across the US health care ecosystem and result in measurable improvements in processes, experiences, and outcomes.

What is Patient-Centered Clinical Decision Support?

- “Traditional” CDS (and CDS Five Rights): digital tools that inform and guide patient care decisions across platforms including EHRs, patient portals, and mobile apps.
- Patient-Centered Care: Care that considers a person’s needs across multiple factors to support their health and well-being.



Clinical Decision Support (CDS)
and CDS Five Rights*

Digital tools that inform and guide patient care decisions across platforms including EHRs, patient portals, and mobile apps.

Patient-Centered Care

Care that considers a person’s needs across multiple factors to support their health and well-being.

Patient-Centered Clinical Decision Support (PC CDS)

Tools that significantly incorporate patient-centered factors related to knowledge, data, delivery, and/or use.

Knowledge
Using evidence-based findings from comparative effectiveness research and patient-centered outcomes research

Patient Data
Incorporating health data affecting individual patient health:
- patient-generated health data
- patient-reported outcomes and preferences
- patient-specific information
- social determinants of health

Delivery
Directly engaging patients or caregivers across different settings through:
- apps
- patient portals

Use
Facilitating patient-clinician information exchange that ensures mutually acceptable decisions by exploring and comparing:
- benefits
- harms
- risks

* Osheroff, Teich, Levick et al., 2012. Improving outcomes with CDS: an implementer’s guide, Second Edition.

Source: https://cdsic.ahrq.gov/cdsic/patient-centered-clinical-cds-infographic

Clinical Decision Support Innovation Collaborative

CDSiC Overview: *Three Unique Centers*

CDSiC Operations Center

Operational oversight that flows throughout CDSiC and strategic direction from Steering Committee

CDSiC Stakeholder Community & Outreach Center

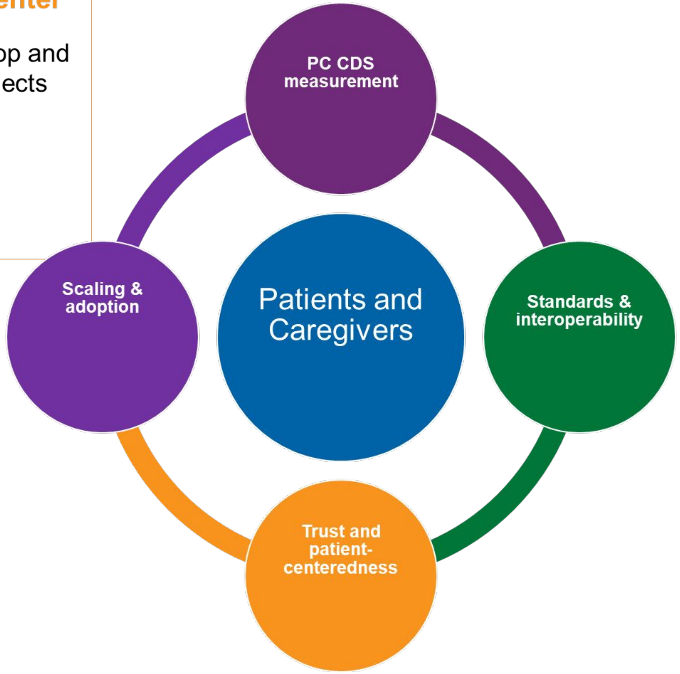
Thought leadership from four Workgroups that informs the Steering Committee and Innovation Center

CDSiC Innovation Center

Two cores that will develop and execute innovative projects

CDS Innovation Collaborative

http://cdsic.ahrq.gov



Stakeholder Center Workgroups: *Scope and Objectives*

CDS Outcomes and Objectives (O&O)

What is CDS (or CDSiC) trying to achieve and what outcomes do we need to measure to support this?

Standards and Regulatory Frameworks (SRF)

What is needed to advance the adoption and use of standards for the development of PC CDS?

Scaling, Measurement, and Dissemination (SMD)

How do we advance the implementation and use of CDS and ensure that we have standardized measures to track this?

Trust and Patient-Centeredness (TPC)

How do we foster trust and transparency in the processes of PC CDS design, development, testing, implementation, and use?

▸ **1st Phase Workgroups:**

- **Had a specific PC CDS focus area within the Stakeholder and Outreach Center.**
- **Developed three products that supported their focus area.**
- **Final products are available on the CDSiC website.**

CDSiC Innovation Center

The Innovation Center is the research hub for the CDSiC. It consists of two Cores that conduct innovative projects regarding real-world applications for patient-centered CDS. It also has a Planning Committee to provide strategic input and guidance.

Core 1: Measurement and Value of CDS

- Conducts projects to standardize the measurement of all aspects of CDS
- Reviews CDS implementations to evaluate utility

Core 2: Conducting and Coordinating CDS Projects

- Implements patient-centered clinical decision support projects in real-world settings
- Tests CDS design, development, monitoring, and evaluation strategies to identify best practices

First phase projects:

Project #1

Developed a comprehensive patient-centered CDS measurement framework; 3 phase lifecycle of PC CDS.

Project #2

Created a patient-centered CDS clinical performance dashboard.

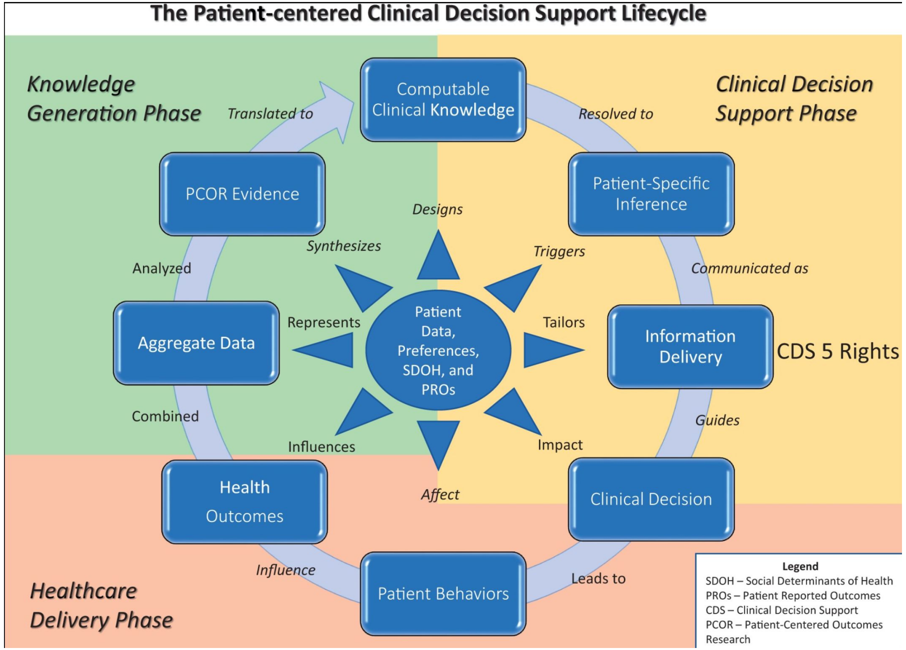
Code is available in Github.

Project #3

Created a prototype dashboard that shows best practices for presentation and analysis of selected PGHD.

Patient-Centered Clinical Decision Support Lifecycle

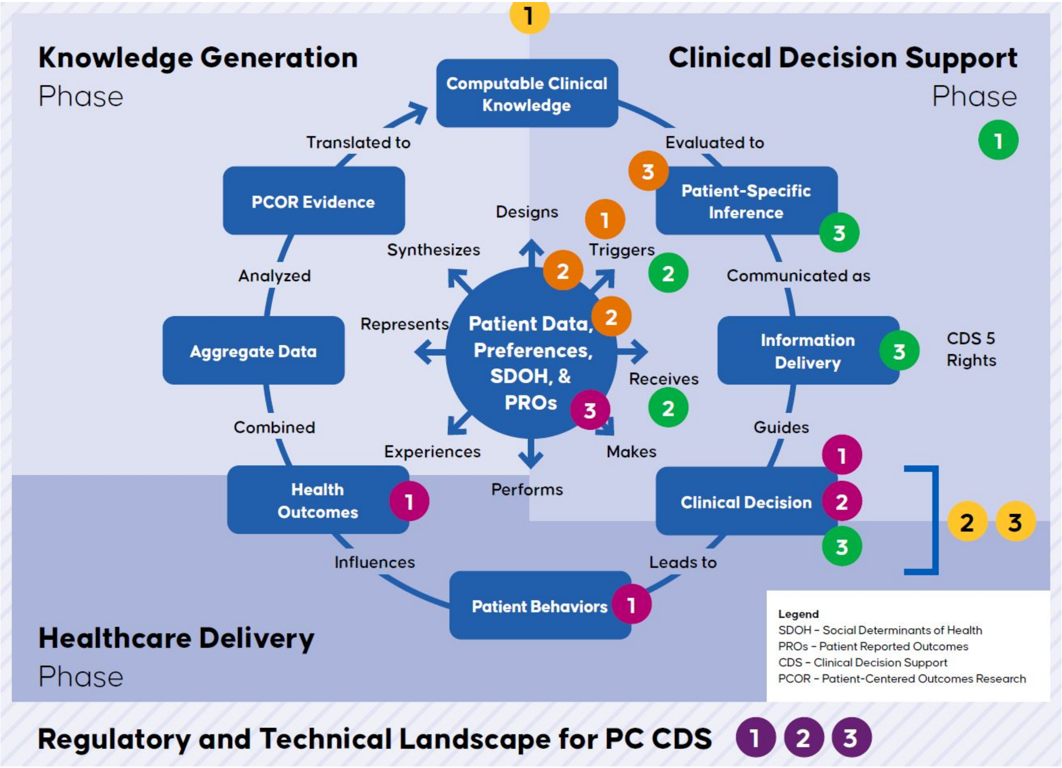
- Developed by the CDSiC Innovation Center and CDSiC team, this graphic[1] illustrates the eight stages necessary for realizing the benefits of patient-centered CDS.
- Published in the Journal of the American Medical Informatics Association (JAMIA).
- Describes the work that must be completed and data that must be collected, analyzed, or transmitted for healthcare stakeholders to implement and benefit from PC CDS.
- Identifies **opportunities for patient and/or caregiver participation** at each stage of the process.
- Used as a roadmap for stakeholder center product development.



[1] Citation: Sittig DF, Boxwala A, Wright A, Zott C, Desai P, Dhopeshwarkar RV, Swiger J, Lomotan EA, Dobes A, Dullabh P. A lifecycle framework illustrates eight stages necessary for realizing the benefits of patient-centered clinical decision support [published online ahead of print, 2023 Jul 6]. J Am Med Inform Assoc. 2023;ocad122. doi:10.1093/jamia/ocad122

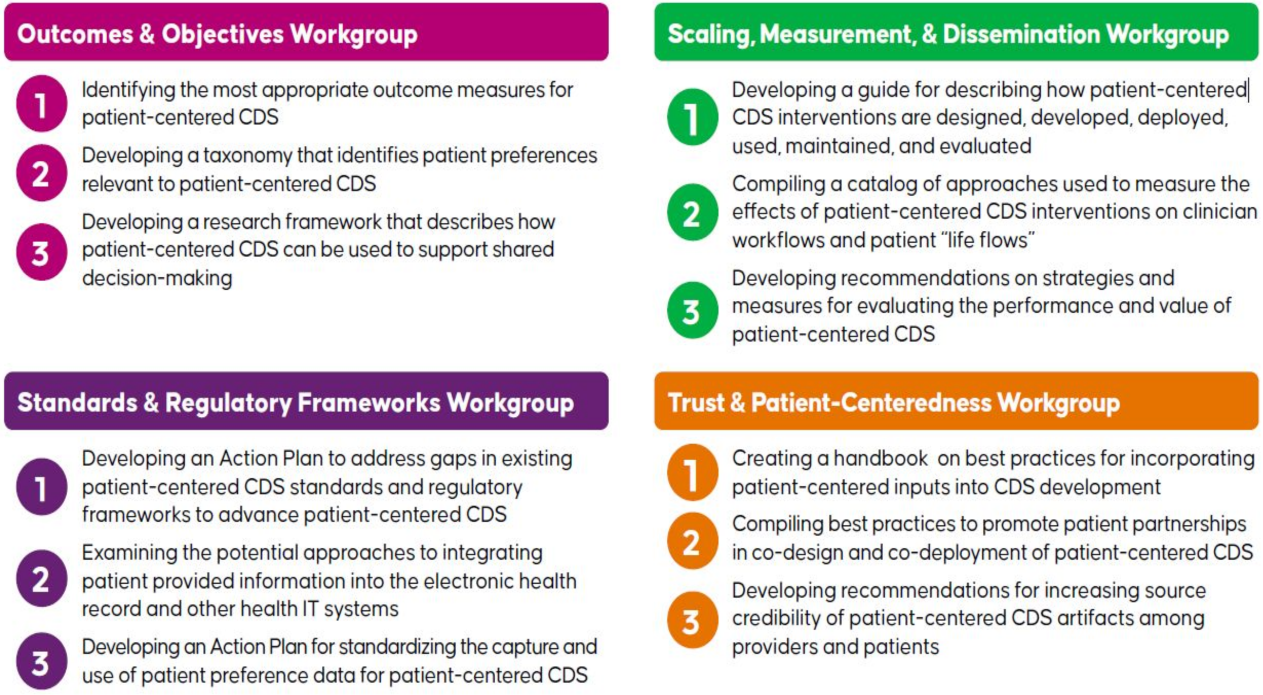
Patient-Centered CDS Lifecycle

In the project's first phase, each Workgroup developed three products that aligned with a key area of the PC CDS Lifecycle roadmap.



List of Completed Products from the WGs

- **All products from the first phase of the Collaborative are now complete and are available on the project website.**
- **CDSiC Stakeholder Center:**
- https://cdsic.ahrq.gov/cdsic/cdsic-stakeholder-community-outreach-center



Outcomes & Objectives Workgroup

1. Identifying the most appropriate outcome measures for patient-centered CDS
2. Developing a taxonomy that identifies patient preferences relevant to patient-centered CDS
3. Developing a research framework that describes how patient-centered CDS can be used to support shared decision-making

Scaling, Measurement, & Dissemination Workgroup

1. Developing a guide for describing how patient-centered CDS interventions are designed, developed, deployed, used, maintained, and evaluated
2. Compiling a catalog of approaches used to measure the effects of patient-centered CDS interventions on clinician workflows and patient "life flows"
3. Developing recommendations on strategies and measures for evaluating the performance and value of patient-centered CDS

Standards & Regulatory Frameworks Workgroup

1. Developing an Action Plan to address gaps in existing patient-centered CDS standards and regulatory frameworks to advance patient-centered CDS
2. Examining the potential approaches to integrating patient provided information into the electronic health record and other health IT systems
3. Developing an Action Plan for standardizing the capture and use of patient preference data for patient-centered CDS

Trust & Patient-Centeredness Workgroup

1. Creating a handbook on best practices for incorporating patient-centered inputs into CDS development
2. Compiling best practices to promote patient partnerships in co-design and co-deployment of patient-centered CDS
3. Developing recommendations for increasing source credibility of patient-centered CDS artifacts among providers and patients

CDSiC: A Look to the Future

- **The CDSiC has started its third year and looks forward to continued work in several areas:**

01 New Resources

02 Expand the Evidence base

03 Artificial Intelligence

04 Health Equity

05 Real-world Testing

06 Scalability

Want to get involved with the CDSiC?

Please submit your interest here:

https://cdsic.ahrq.gov/cdsic/contact-form

VA | U.S. Department of Veterans Affairs

CKD Care Transformation

National Institute of Diabetes and Digestive and Kidney Diseases

Chronic Kidney Disease Learning Community

- Foundation: AHRQ evidence-based Care Transformation Support (ACTS) Initiative
  - 2018-2021: developed vision, roadmap, concept demo for evidence-based care transformation / Learning Health Systems via an improved digital knowledge ecosystem.
- VA CKD Care Transformation Initiative: Goals/Activities (overview here)
  - Prevent veteran suffering and care team burnout, save VA money (e.g., spent on dialysis) through earlier CKD detection and evidence-based management.
  - Leverage Health Service Blueprint (seeded by ACTS) to guide development and implementation of people, process, and technology solutions to achieve goals.
  - Plan to establish a multi-stakeholder learning community to share strategies / tools, accelerate individual and shared progress
- Connecting the dots:
  - The planned CKD Learning Community can connect eCare Plan tools and learning to care transformation efforts by VA and others in ways that accelerate improvements in care delivery and outcomes.
- Contact Jerry Osheroff at josheroff@tmitconsulting for more information

National Institute of Diabetes and Digestive and Kidney Diseases

HRSA
Health Resources & Services Administration

Geriatrics Workforce Enhancement Program and Notice of Funding Opportunities

AHRQ

National Institute of Diabetes and Digestive and Kidney Diseases

NIH National Institute of Nursing Research

NIH/NINR NOFO on healthcare-community partnered social needs and SDOH interventions

AHRQ

NIH National Institute of Diabetes and Digestive and Kidney Diseases

Clinical-Community Linkages to Address Social Needs and Social Conditions to Advance Health Equity among Populations Experiencing Health Disparities

The Bridge-to-Care Initiative

RFA-NR-24-003

NIH National Institute of Nursing Research

Purpose: Bridge-to-Care Initiative

Advance research that leverages healthcare-community partnerships to address:

- Unmet health-related social needs among individuals and families
- Adverse social determinants of health (SDOH) within communities

Key Research Components

- ☐ <u>Intervention</u> or <u>evaluation</u> research that addresses health-related unmet social needs or adverse SDOH
- ☐ Improvements in health outcomes
- ☐ Focus on populations experiencing health disparities, including people with disabilities

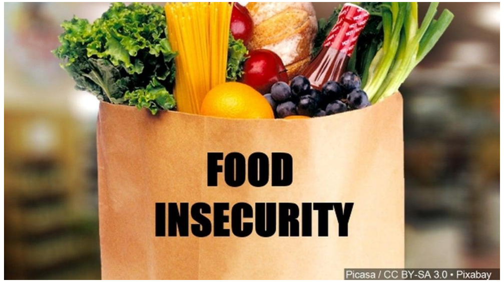
Partnerships

- Creation, expansion, and/or evaluation of healthcare-community partnerships
  - Community partners can include housing, transportation, food system, economic development, etc
- Effective partnerships do not serve simply as referral mechanisms and linkage to resources and services, but rather as mutually beneficial and equitable collaborations with shared goals

Study Types

Individual- or Family-Level Social Needs Interventions

Screen for patient or family health-related social needs and aim to address unmet patient or family social needs



Picasa / CC BY-SA 3.0 • Pixabay

Interventions to Address SDOH

Leverage healthcare-community partnerships to address adverse SDOH within communities

Evaluation of Interventions/Programs to Address Social Needs or SDOH

Evaluate existing or upcoming interventions/programs that leverage healthcare-community partnerships to address social needs or adverse SDOH

Please Share!

Contact:

Shalanda A. Bynum, PhD, MPH
Program Director, NINR
Shalanda.Bynum@nih.gov

The Office of the National Coordinator for Health Information Technology

ONC Projects

Office of the National Coordinator
for Health Information Technology

ONC Updates for MCC eCare Plan Project

- LEAP Project
- eLTSS FHIR IG and Implementation
- Draft USCDI v5
- HTI-1 Clinical Decision Support
- ONC Progress in Social Determinants of Health (SDOH) Information Exchange Activities
- TEFCA Overview and Updates

1/31/2024

eLTSS FHIR IG & Implementation and ONC LEAP Update

eLTSS FHIR Implementation Guide (IG) Update

- eLTSS standard for trial use 2 (STU2).
  - Included in the HL7 January 2024 ballot cycle.

- Updates to the eLTSS STU2 IG include:
  - Removal of CarePlan.activity.detail,
  - US CORE 3.1.1,
  - Addition of the pertains.ToGoal extension,
  - Addition of examples to support implementers (e.g. Task Guidance page),
  - And other changes from eLTSS standard for trial use 1 (STU1) pilot, and partner input.

eLTSS FHIR IG Implementers

- In September 2020, the Missouri Department of Mental Health, Division of Developmental Disabilities received an ONC Leading Edge Acceleration Project (LEAP) award to integrate health care and human services data to support improved outcomes.
- Missouri has advanced the work piloted during their LEAP award and plans to go-live with the eLTSS FHIR IG to exchange data.
  - Findings from the Missouri LEAP have been used to draft eLTSS STU2.
- Ongoing work includes collaboration across health information networks (HINs) in Missouri, vendors, the state, and more.

Draft USCDI Version 5

Draft USCDI Version 5

Allergies and Intolerances
- Substance (Medication)
- Substance (Drug Class)
- Substance (Non-Medication)
- Reaction

Care Team Members
- Care Team Member Name
- Care Team Member Identifier
- Care Team Member Role
- Care Team Member Location
- Care Team Member Telecom

Clinical Notes
- Consultation Note
- Discharge Summary Note
- Emergency Department Note
- History & Physical
- Operative Note
- Procedure Note
- Progress Note

Clinical Tests
- Clinical Test
- Clinical Test Result/Report

Diagnostic Imaging
- Diagnostic Imaging Test
- Diagnostic Imaging Report

Encounter Information
- Encounter Type
- Encounter Identifier

Facility Information
- Facility Identifier
- Facility Type
- Facility Name

Goals and Preferences
- Patient Goals
- SDOH Goals
- Treatment Intervention Preference
- Care Experience Preference

Health Insurance Information
- Coverage Status
- Coverage Type
- Relationship to Subscriber
- Member Identifier
- Subscriber Identifier
- Group Identifier
- Payer Identifier

Health Status Assessment
- Health Concerns
- Functional Status
- Disability Status
- Mental/Cognitive Status
- Pregnancy Status
- Alcohol Use
- Substance Use
- Physical Activity
- SDOH Assessment
- Smoking Status

Immunizations
- Immunizations
- Lot Number

Laboratory
- Tests
- Values/Results
- Specimen Type
- Result Status
- Result Unit of Measure
- Result Reference Range
- Test Kit Unique Device Identifier
- Result Interpretation
- Specimen Source Site
- Specimen Identifier
- Specimen Condition Acceptability

Medical Devices
- Unique Device Identifier - Implantable

Medications
- Medications
- Dose
- Dose Unit of Measure
- Route
- Indication
- Fill Status
- Medication Instructions
- Medication Adherence

Observations
- Advance Directive Observation
- Sex Parameter for Clinical Use

Orders
- Orders

Patient Demographics/ Information
- First Name
- Last Name
- Middle Name (Including middle initial)
- Name Suffix
- Previous Name
- Name to Use
- Pronoun
- Date of Birth
- Date of Death
- Race
- Ethnicity
- Tribal Affiliation
- Sex
- Sexual Orientation
- Gender Identity
- Preferred Language
- Interpreter Needed
- Current Address
- Previous Address
- Phone Number
- Phone Number Type
- Email Address
- Related Person’s Name
- Relationship Type
- Occupation
- Occupation Industry

Patient Summary and Plan
- Assessment and Plan of Treatment

Problems
- Problems
- SDOH Problems/Health Concerns
- Date of Diagnosis
- Date of Resolution

Procedures
- Procedures
- Performance Time
- SDOH Interventions
- Reason for Referral

Provenance
- Author
- Author Role
- Author Time Stamp
- Author Organization

Vital Signs
- Systolic Blood Pressure
- Diastolic Blood Pressure
- Average Blood Pressure
- Heart Rate
- Respiratory Rate
- Body Temperature
- Body Height
- Body Weight
- Pulse Oximetry
- Inhaled Oxygen Concentration
- BMI Percentile (2 - 20 years)
- Weight-for-length Percentile (Birth - 24 Months)
- Head Occipital-frontal Circumference Percentile (Birth- 36 Months)

Which additional Data Elements best serves the need for the eCare Plan Project?

To help identify patient generated data these 5 new data elements may be of use to Care Plan:

- Advance Directive Observation
- Orders
- Interpreter Needed
- Provenance - Author and Author Role

How can everyone help?

- Depending on what you are trying to get out of the Care Plan
  - Think about the 13 Data Elements that were included in Draft USCDI v5 and comment on them during this comment period

  - Comment on additional data elements we did not include or existing USCDI data elements (from previous versions)

USCDI Timeline

- January 18, 2024
  - Draft USCDI v5 publication
- January 18 -April 15, 2024
  - Public feedback period
  - ISWG Charges
  - April 15, 2024 11:59 ET deadline for comments and feedback
- July 2024
  - Anticipated final USCDI v5 publication
- July-September 2024
  - USCDI v6 submission and feedback period

Predictive DSIs in Healthcare

How Artificial Intelligence/Machine Learning can Improve Patients Care Plans

- It improves a patient’s care plan based on personalized analytics
  - Examples includes:
    - Isolating the impact of lifestyle changes
    - Restarting employment after surgery

- The merging of evidence-based care paths with historical utilization and outcomes

- Provider organizations are using social determinants of health combined with machine learning to offer clinically meaningful services
  - An example includes:
    - SDOH data – U.S. Census data – can point to access or other patient challenges and incorporate patient-reported data

Reference:

Siwicki, W. (2021). How machine learning can improve patients care plans Care Plan. https://www.healthcareitnews.com/news/how-machine-learning-can-improve patients-care-plans

ONC’s Progress in Social Determinants of Health (SDOH) Information Exchange Activities

Agenda

- SDOH Information Exchange Areas of Alignment
- ONC SDOH Information Exchange Resources and Activities
  - ONC SDOH Information Exchange Toolkit
  - ONC SDOH Information Exchange Learning Forums
- ONC SDOH Information Exchange Learning Forum Themes from the Community

SDOH Information Exchange Areas of Alignment

Examples of SDOH Information Exchange Alignment

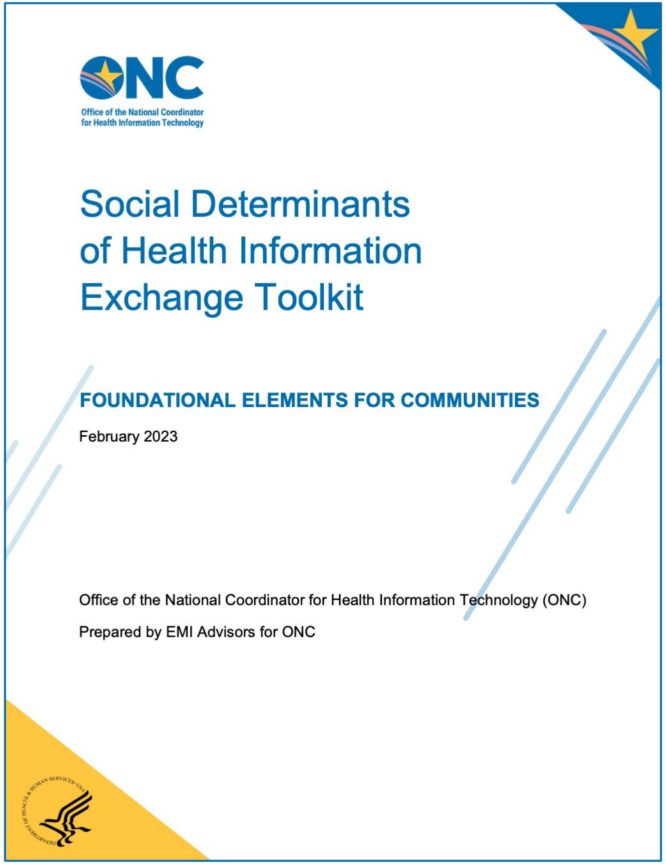
- **White House**
    - Executive Order 13985: Advancing Racial Equity and Support for Underserved Communities through the Federal Government
    - National Strategy on Gender Equity and Equality
    - White House Blueprint for Addressing the Maternal Health Crisis
    - Biden-Harris Administration National Strategy on Hunger, Nutrition and Health
  - The US SDOH Playbook to Address Social Determinants of Health
- **HHS**
  - 2020-2025 Federal Health IT Strategic Plan
  - Healthy People 2030 Framework
  - HHS's Strategic Approach to addressing SDOH to Advance Health Equity
  - Call to Action to Address Health Related Social Needs
- **CMS**
  - Framework for Health Equity 2022-2023
  - Medicare Managed Care Special Needs Plans
  - Medicaid and CHIP Health Related Social Needs Framework

ONC SDOH Information Exchange Activities

ONC SDOH Information Exchange Toolkit

Developed by ONC with support from EMI Advisors and a panel of technical experts convened in 2021.

- Provides information on the SDOH information exchange landscape to stakeholders of all experience levels.
- Identifies approaches to advance SDOH information exchange goals through the ‘foundational elements’ framework.
- Provides examples of common challenges and promising approaches.
- Shares guiding questions and resources to support implementers.
- Available here: [Social Determinants of Health (SDOH) Information Exchange Toolkit]()



ONC
Office of the National Coordinator
for Health Information Technology

Social Determinants
of Health Information
Exchange Toolkit

FOUNDATIONAL ELEMENTS FOR COMMUNITIES

February 2023

Office of the National Coordinator for Health Information Technology (ONC)

Prepared by EMI Advisors for ONC

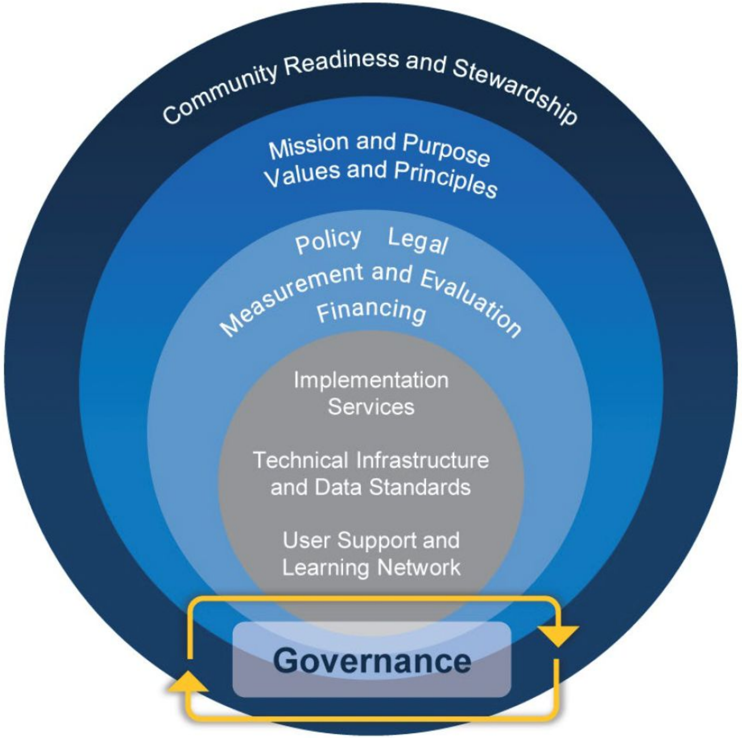
Purpose of the Toolkit

- The SDOH Information Exchange Toolkit is intended to be a practical guide that enables implementers of SDOH information exchange to learn more about the current landscape and identify key considerations and approaches to advance their goals through the consideration of important Foundational Elements.
- This Toolkit focuses on Foundational Elements for planning, implementing, and evaluating SDOH information exchange initiatives.

Intended Audience:

- Community resource referral initiatives
- Government agencies
- Health information exchanges (HIEs)
- Health care provider networks
- Human services providers
- IT platform developers and managers
- Networks of community-based organizations (CBOs)
- Payers
- Policymakers
- Other health and human services entities

Social Determinants of Health Information Exchange Foundational Elements



Learning Forum webinar series

DESCRIPTION	Meeting Date	Materials Link
Phase I Webinars		
Introduction to SDOH Information Exchange and the Learning Forum	March 2022	[View past meeting materials and recordings here]()
Vision, Purpose, and Community Engagement	April 2022	
Governance	May 2022	
Technical Infrastructure and Interoperability	June 2022	
Policy and Funding	July 2022	
Phase II Webinars		
Community-level Governance	February 2023	[View past meeting materials and recordings here]()
Values, Principles, and Privacy	March 2023	
Implementation, Measurement, and Evaluation	May 2023	
SDOH Information Exchange Learning Forum Summary	June 2023	

Learning Forum Themes from the Community

- Community stewardship and co-designed governance are critical and resource intensive
- Standards-based, vendor-agnostic approaches to SDOH information exchange will enable interoperability
- FHIR® awareness and readiness varies
- Limited awareness and understanding of policies for data sharing with non-HIPAA covered entities

Support Opportunities Identified by the Community

- **States:** have many SDOH information exchange activities that are considering or advancing the foundational elements framework (e.g., governance, vendor-agnostic approaches, leveraging federal funding).

- **Community-Based Organizations (CBO)/Social Care Stakeholders**: building capacity (technical, financial, human) and making technology decisions.

- **Data Service Provider (e.g. Health Information Exchanges (HIE)/Health Data Utilities (HDU)):** expand current capabilities and services to support SDOH information exchange needs.

- **Implementers:** technical support and funding for standards alignment, including implementation of Gravity Project standards.

- **Health Systems and Payers:** additional information and incentives for engaging and partnering with CBOs for bi-directional information exchange without increasing provider burden.

- **Federal Partners:** ongoing coordination to further disseminate and implement the SDOH Information Exchange Toolkit and provide technical support on health IT requirements in policies and programs.

TEFCA Overview and Updates

Agenda

- TEFCA Background
- TEFCA
  - Goals
  - Benefits
  - Exchange under TEFCA
  - Exchange purposes (XPs)
- TEFCA Updates

21st Century Cures Act - Section 4003(b)

“[T]he National Coordinator shall convene appropriate public and private stakeholders to ***develop or support*** *a* ***trusted exchange framework*** *for trust policies and practices and for a* ***common agreement*** *for exchange between health information networks.”*

[emphasis added]

TEFCA Goals

GOAL 1

Establish a universal policy and technical floor for nationwide interoperability

GOAL 2

Simplify connectivity for organizations to securely exchange information to improve patient care, enhance the welfare of populations, and generate health care value

GOAL 3

Enable individuals to gather their health care information

Benefits of TEFCA

Relevant, trusted information from nationwide sources for:

Individuals

Use an app to access their own records from TEFCA-connected sources located across the nation.

Providers and Health Systems

Improve care, coordination and population health by obtaining a more informed picture of care across settings through fewer connection points.

Public Health

Improve quality, reduce costs, and expand public health interoperability.

For more detail on the benefits of TEFCA for stakeholders, see factsheets at: https://rce.sequoiaproject.org/tefca-and-rce-resources/

Payers

Get and share data needed for care management, value-based care, payer-to-payer exchange, etc.

Health Information Networks

Enhance the value of network participation and lower the cost of connecting with other networks.

Technology Developers

Provide a scalable policy and technical ecosystem for innovation.

Researchers (Future)

Improve quality, reduce costs, and expand participation in clinical research.

Exchange Purposes (XPs)

- The Exchange purposes (XPs) identifies the reason for which information could be requested or shared through QHIN-to-QHIN exchange.
- Only these six XPs are authorized under the Common Agreement.
- A forthcoming final SOP will specify that Treatment, Individual Access Services (IAS), and Health Care Operations SubXP (FHIR only) require Responses.
- Eventually, the other XPs will require Responses in conformance with forthcoming implementation guides. These will be rolled out with adequate time for stakeholders to prepare.
- Additional XPs may be added over time, including whether they require Responses.

Permitted Exchange Purposes

- **Treatment**
- **Payment**
- **Health Care Operations**
- **Public Health**
- **Government Benefits Determination**
- **Individual Access Services**

TEFCA is Operational!

The following organizations were officially designated as Qualified Health Information Networks™ (QHINs™) on December 12, 2023 after completing the rigorous TEFCA onboarding process.

eHealth Exchange™

HEALTH GORILLA®

MedAllies

Epic Nexus

KONZA NATIONAL NETWORK

Once designated, these QHINs were able to immediately begin supporting the exchange of data under TEFCA's policies and technical requirements.

TEFCA Will Soon Require Support for FHIR-based Transactions!

- On December 11, 2023, ONC and the TEFCA Recognized Coordinating Entity® (RCE™), The Sequoia Project, released the Fast Healthcare Interoperability Resources (FHIR®) Roadmap for TEFCA℠ Exchange Version 2.
    - This version updates the previous roadmap and continues the momentum already established by providing more details and guidance for the future of FHIR in TEFCA.

- Common Agreement Version 2, which will include enhancements and updates to require support for Health Level Seven (HL7®) Fast Healthcare Interoperability Resources (FHIR®)-based transactions, is actively under development and scheduled to be adopted by the QHINs within the first quarter of 2024.

RCE Draft Timeline

2023

- Drafting process with RCE, ONC, and TEFCA Task Team of Common Agreement, QTF, SOPs, etc. (Applicant QHINs)

January 2024

- Documents for public feedback released on 1/19/2024

- Public webinars:
  - 1/23/2024 (recorded)
  - 1/30/2024
  - 2/2/2024

- Transitional Council kick-off

February 2024

- Public feedback period ends 2/5/2024

- Ongoing targeted partner input

March 2024

- Anticipated release of final Common Agreement Version 2.0, QTF Version 2.0, and SOPs end of Q1 2024

Future Work

- Additional Exchange Purpose (XP) Implementation SOPs

- Ongoing operations and change management

Documents for Feedback

The RCE has released a set of draft materials in support of FHIR adoption and other advancements. These build on the existing framework and include:

Common Agreement Version 2.0

QHIN Technical Framework Version 2.0

Participant/ Subparticipant Terms of Participation (ToP)

New Standard Operating Procedures (SOPs)

- Expectations for Cooperation
- Delegation of Authority
- Governance Approach
- XP Implementation SOP: Public Health (PH) SubXP-1
- RCE Directory Service Requirements Policy

Updated SOPs

- Exchange Purposes (XPs)
- XP Implementation SOP: Individual Access Services (IAS) Demographic Matched – *Updated from IAS Exchange Purpose Implementation*
- IAS Provider Requirements – *Updated from IAS Provider Privacy and Security Notice and Practices*
- XP Implementation SOP: Health Care Operations (HCO) SubXP-1 – *Updated from previously released draft*

New Explanatory Resources

- TEFCA Glossary
- TEFCA Cross Reference Resource

Feedback Process

- The RCE is seeking public input online through **Monday, February 5**. Interested parties can submit input via the **feedback form on our website**, **email feedback to rce@sequoiaproject.org**, or attend upcoming webinars.

- The RCE will thoroughly review all feedback received via the webinars and online feedback forms for each document.

- The community is encouraged to submit comments throughout the year on the RCE website's general feedback form.

https://rce.sequoiaproject.org/rce-draft-documents-for-feedback/

Office of the National Coordinator for Health Information Technology

Thank You

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Health IT Feedback Form: https://www.healthit.gov/form/healthit-feedback-form

Twitter: @onc_healthIT

LinkedIn: Office of the National Coordinator for Health Information Technology

Youtube: https://www.youtube.com/user/HHSONC

HealthIT.gov Subscribe to our weekly eblast at healthit.gov for the latest updates!

Appendix Slides for Draft USCDI Version 5

Core Principles

USCDI

- Core set of data needed for patient care and facilitate patient access and data exchange using health IT
- Establishes a consistent baseline of data for other use cases
- Expands over time via a predictable, transparent, and collaborative **public** process

Prioritization Criteria for New USCDI Data Elements

- Healthcare disparities and inequities
- Underserved communities
- Behavioral health
- Public health
- Key additions over past USCDI versions
- Modest burden for
  - Standards and implementation guide developers
  - Health IT developers
  - Providers and health systems implementing updates
- Aggregate lift for all new data elements

New Data Elements in Draft USCDI v5

Clinical Notes
- Emergency Department Note + ↑
- Operative Note + ↑ H

Immunizations
- Lot Number 🔍 + §

Laboratory
- Test Kit Unique Device Identifier 🔍 +

Medications
- Route +

New Data Class

Observations
- Advance Directive Observation ↑
- Sex Parameter for Clinical Use §

New Data Class

Orders
- Orders + §

Patient Demographics/Information
- Interpreter Needed = ↑
- Pronoun = ↑ §
- Name to Use = ↑ §

Provenance
- Author = ↑
- Author Role = ↑

= Equity Based ↑ Underserved 🔍 Public Health + Add'l USCDI Needs § ONC Cert

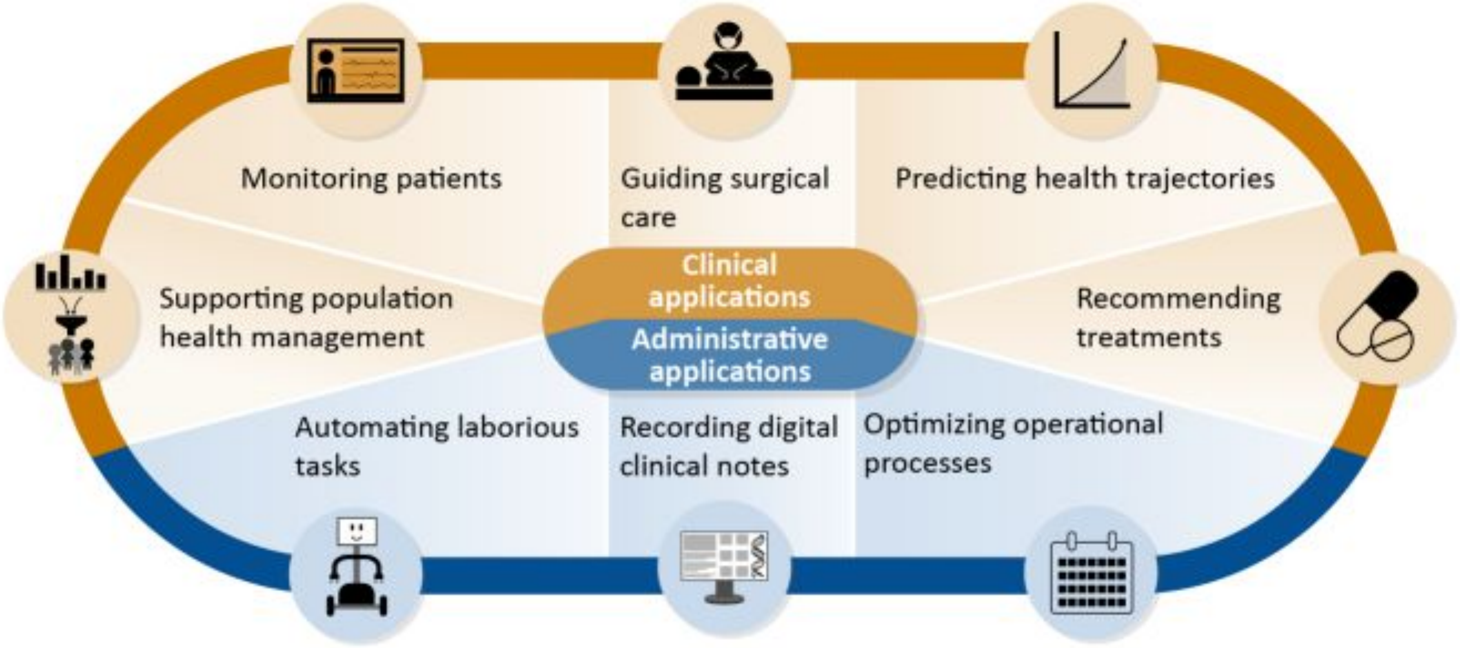
Appendix Slides for Predictive DSIs in Healthcare

Disclaimers and Public Comment Guidance

- The materials contained in this presentation about the "Health Data, Technology, and Interoperability: Certification Program Updates, Algorithm Transparency, and Information Sharing“ (HTI-1) Final Rule are based on the HHS-approved document that was posted on healthit.gov and will be submitted to the Office of the Federal Register for publication. The document has not yet been placed on public display or published in the Federal Register. The document posted on healthit.gov may vary slightly from the published document. The final rule that is published in the Federal Register is the official HHS-approved document, which amends provisions contained in 45 C.F.R. Parts 170 and 171. While every effort has been made to ensure the accuracy of this restatement of those provisions, this presentation is not a legal document. Please note that other Federal, state and local laws may also apply.

- This communication is produced and disseminated at U.S. taxpayer expense.

How can AI be used in healthcare?



GAO. | GAO-21-7SP

https://www.gao.gov/assets/gao-21-7sp.pdf

Transparency Is a Prerequisite for Trustworthy AI

Data Transparency + **Performance Transparency** + **Organizational Transparency** = **Trustworthy & High Quality Predictive DSIs (FAVES)**

Data Transparency

Requirements enable users to know when a DSI uses specific data elements relevant to health equity

Performance Transparency

Enable users to have consistent and routine electronic access to technical, and performance information on Predictive DSIs

Organizational Transparency

Requirement for Certified Health IT developers to apply intervention risk management for each Predictive DSI they supply as part of their Health IT Module

Predictive Decision Support Interventions

- ***Predictive Decision Support Intervention or Predictive DSI*** means technology that:
  1. Supports decision-making based on algorithms or models that
  2. Derive relationships from training data and then
  3. Produces an output that results in prediction, classification, recommendation, evaluation, or analysis

- The ONC Definition for Predictive DSI is
  - **Broad in scope:** includes a variety of techniques from algebraic equations to machine learning from relatively simple risk calculators (ASCVD or APACHE IV) to deep neural networks and LLMs
  - **Use case inclusive:** clinical, payer, research, administrative use cases
  - **Risk independent:** high-risk, low-risk, unknown risk
  - **Developer agnostic:** certified EHR company, health system, academic research lab, consumer technology firm

Policy Impact of DSI Certification Criterion

Improve Transparency	Regarding how a Predictive DSI is designed, developed, trained, evaluated, and should be used
Enhance Trustworthiness	Through transparency on how certified health IT developers manage potential risks and govern predictive DSIs that are supplied by the health IT developer as part of its Health IT Module
Foster an information ecosystem	Necessary to help healthcare organizations and users of these tools better determine whether their Predictive DSIs are fair, appropriate, valid, effective, and safe (FAVES)
Advance Health Equity by Design	By addressing bias and health disparities, potentially propagated by predictive DSIs, to expand the use of these technologies in safer, more appropriate, and more equitable ways for patients and individuals

Appendix ONC’s Progress in Social Determinants of Health (SDOH) Information Exchange Activities

Foundational Elements

Mission and Purpose: The intention of an initiative, ideally explicitly stated, that addresses the various value propositions of stakeholder groups, as well as the vision, scope of services, and expected benefits.

Community Readiness and Stewardship: Exploring the existing landscape in the geographic area and/or population of focus, assessing the capacity and willingness of the community to participate, and developing stakeholders' shared rights and responsibilities through the process of co-design, evaluation, and decision-making.

Values and Principles: Standards for establishing a framework for action, including ethical decision-making in pursuit of health equity.

Financing: Funding opportunities, sources, and plans for investments, ongoing costs, opportunities for blended approaches, and incentives for community adoption and use.

Implementation Services: Inclusive of technical services (e.g., defining requirements, standards specifications, and integration with existing infrastructure and services) and programmatic services (e.g., defining use cases, workflow design/redesign), as well as support for adoption and utilization by individuals and the community.

Foundational Elements (cont.)

Technical Infrastructure and Data Standards: Alignment of hardware, software, data, processes, and standards to enable scalable and interoperable data and IT systems.

Legal: Establishing the framework of processes and operations, along with rights and obligations, to support data use and sharing and to support compliance with Federal, state, local and tribal laws.

Policy: Consideration of federal, state, and local policy levers to advance the ability to collect, share, and use standardized SDOH data, as well as collaboration and alignment with other relevant efforts in the community, region, and/or state for collective impact and improved outcomes.

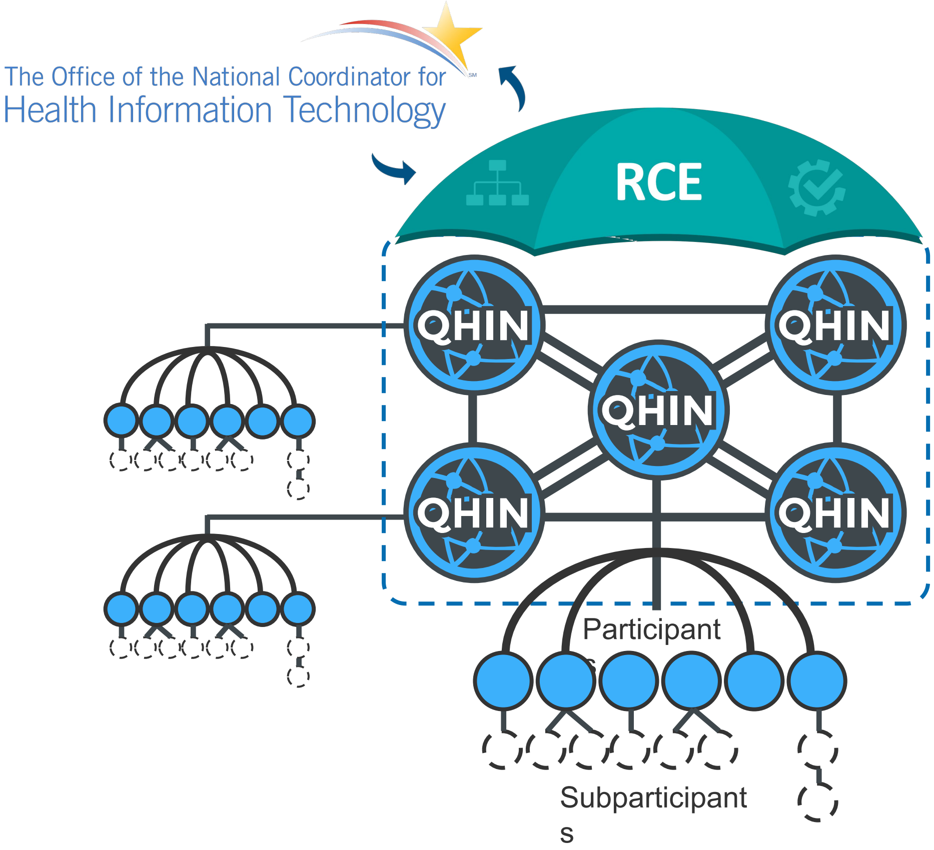
Measurement and Evaluation: Monitoring and evaluation of performance metrics, individual and population outcomes, program effectiveness, and quality management and improvement.

User Support and Learning Network: User support and learning network activities include assessment of community challenges and needs, education, communication, training, technical assistance, peer-to-peer learning, and identification of promising practices and lessons learned.

Governance: Decision-making processes and groups, including as relates to institutional, administrative, and data governance.

Appendix Slides for TEFCA Overview and Updates

How does exchange work under TEFCA?



ONC defines overall policy and certain governance requirements.

RCE provides oversight and governing approach for QHINs.

Qualified Health Information Networks (QHINs) connect directly to each other to facilitate nationwide interoperability.

Each QHIN connects Participants, which connect Subparticipants.

Educational Resources

Resources

https://rce.sequoiaproject.org/tefca-and-rce-resources/

- Includes:
    - Common Agreement v. 1.1
    - QHIN Technical Framework
    - FHIR® Roadmap for TEFCA
    - Standard Operating Procedures
    - QHIN Application
    - Communication Protocols
    - User’s Guide
    - Benefits of TEFCA by Stakeholder Factsheets
    - FAQs

Additional Resources: https://www.healthit.gov/tefca

All Events Registration and Recordings: https://rce.sequoiaproject.org/community-engagement/

Center for Medicare & Medicaid Innovation: Specialty Care Integration

Equity Consortium Plans

Other walk-on round robin updates

Agenda

Topic	Time	Presenter(s)
Welcome and Introductions	5 min	Jenna Norton, NIDDK Arlene Bierman, AHRQ
MCC eCare Plan Project Overview and Progress Update	65 min	MCC eCare Project Team
Federal Projects Round Robin Update	30 min	Federal Partners
What's Next for the eCare Plan Project?	15 min	Jenna Norton, NIDDK Arlene Bierman, AHRQ
Closing Remarks	5 min	Karen Bertodatti, EMI

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.

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National Institute of Diabetes and Digestive and Kidney Diseases

Thank You

National Institute of Diabetes and Digestive and Kidney Diseases

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Additional MCC eCare Plan Project Links

- AHRQ and NIDDK Confluence Page for MCC eCare: https://cmext.ahrq.gov/confluence/display/EC//
- HL7 Patient Care Work Group – MCC eCare Project Page: https://confluence.hl7.org/display/PC/Multiple+Chronic+Conditions+%28MCC%29+eCare+Plan