Multiple Chronic Condition (MCC) eCare Plan Project

Pre-read material in preparation for the

Federal Partner Meeting on June 14, 2022

About This Pre-Read

To optimize our time during the Multiple Chronic Condition eCare Plan Federal Partners Meeting on June 14, 2022, 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 June 14.

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- **Project Background and High-Level Update**
- Data Elements, Value Sets, Clinical Information Models, and FHIR Mappings
- HL7® Fast Healthcare Interoperability Resource (FHIR®) Implementation Guide (IG)
- HL7® Connectathon 30: Care Planning Track
- V1.0 Pilot Testing

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)
- **SAMSHA:** 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

National Institute of Diabetes and Digestive and Kidney Diseases

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**. Clinicians 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.

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/

NIDDK/AHRQ e-Care 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, clinical information models, 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 patient-, clinician-, and 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	
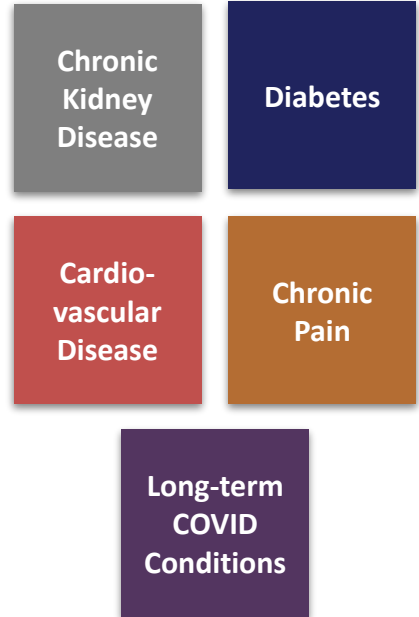
*All deliverables will be open-source and freely available.

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Overview of Work Year Over Year

	Year 1 (FALL 2019-FALL 2020)	Year 2 (FALL 2020-FALL 2021)	Year 3 (FALL 2021-FALL 2022)
Data elements, value sets, clinical information models, 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. • Began identification of data elements for CVD, chronic pain, and T2D. • 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.	• Conduct quality assurance and review of existing value sets. • Identify long COVID data elements and facilitate TEP. • Build additional, new value sets in VSAC. • Map new/revised data elements to FHIR.
HL7 FHIR IG	• Conceptualization and design of the MCC eCare Plan FHIR IG.	• Developed draft MCC eCare Plan FHIR IG.	• Develop high-level mapping and design approach for the MCC eCare Plan FHIR IG. • Restructure the IG to include new guidance and library of value sets. • Expand to incorporate value sets for all five clinical domains (CKD, CVD, chronic pain, T2D, and long COVID). • Prepare IG for comment ballot in Jan 2023.
Patient/Caregiver and Provider eCare applications		• Developed v1 application for patients. • Developed v1 application for providers. • Facilitated configuration of apps at OHSU site for pilot testing.	• Built prototype for patient/caregiver app v2. • Develop features and functionality to support goal-oriented shared care planning. • Set up sandbox environment on Azure cloud for demonstration and testing. • Form an agile team with RTI/OHSU to support development and pilot design. • Conduct iterative user feedback sessions.

Three Year Roadmap
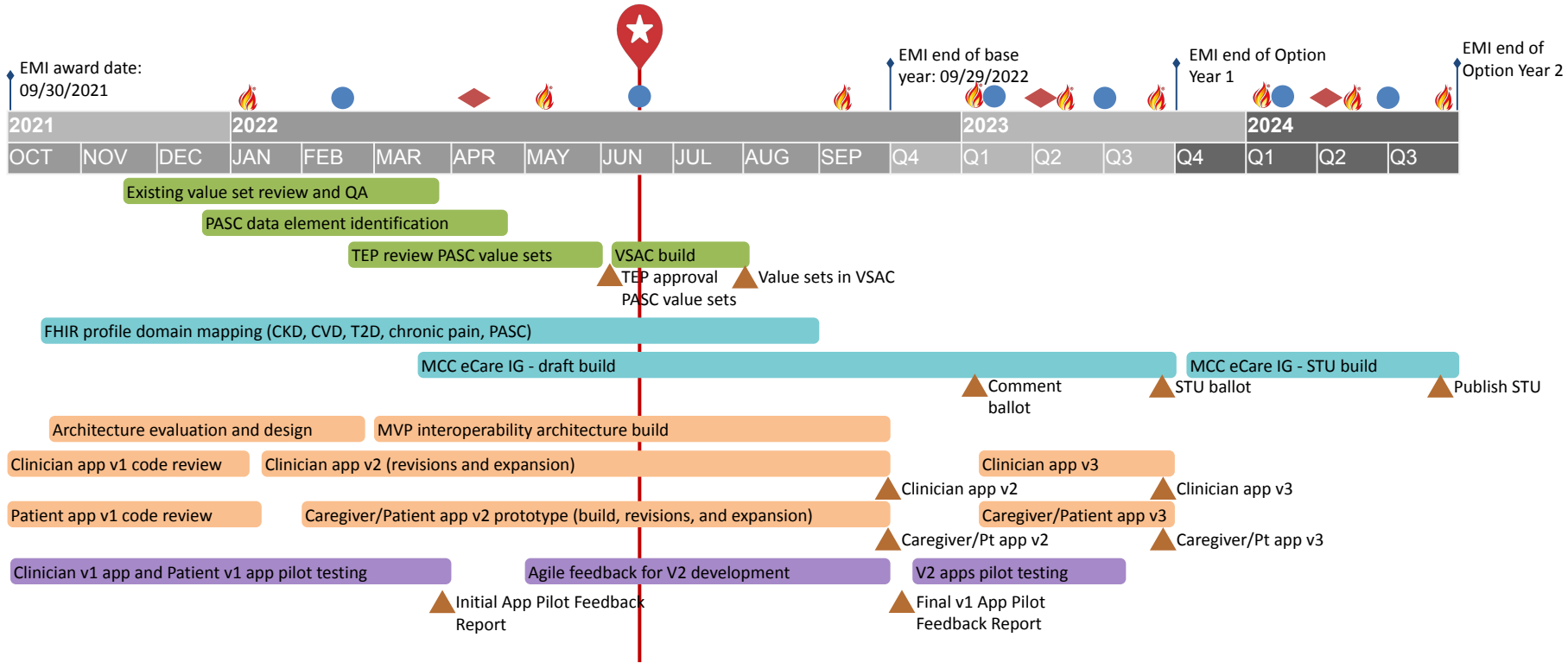
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Technical Expert Panels (TEP)

The MCC eCare Project is informed by various TEPs that provide domain-specific expertise to identify data elements and validate value set approach. TEPs have informed the following domains:

- Chronic Kidney Disease
- Cardiovascular Disease
- Type 2 Diabetes
- Chronic Pain
- **Long COVID/PASC** *
- **Caregiver Considerations**

Current TEP

100+ PARTICIPANTS

Social risks · Pulmonary medicine · Health IT · Health policy · Public health · Pharmacy · Social work · Nursing · Psychology · Geriatrics · Addiction medicine · Pain medicine · Cardiology · Nephrology · Internal med/Primary care · Patients · Caregivers · Developers/Vendors · Long COVID · Cognitive function · Neurology · Behavioral health · GI · Equity

Long COVID/PASC and Caregiver TEP Members

Alecia Clary, Ph.D., MSW

Alex Spyropoulous, MD

Allan Levey, MD, PhD

Aluko Hope, MD

Andrea Lerner, MD, MS

Anuj Dalal, MD

Audie Atienza, PhD

Barrett Bowling, MD

Bill Adams, MD

C. Grace Whiting, JD

Carla Rodriguez-Watson, PhD

Carole White, PhD, RN

Caroline Blaum, MD, MS

Carolyn Clevenger, DNP, RN

Catherine DesRoches, DrPH

Charisse Madlock-Brown, PhD, MLS

Claire Ashton-James, PhD

David Dorr, MD

David Graham, MD

Diana Berrent

Elizabeth Unger, MD, PhD

Emily Taylor

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Jerry Suls, PhD

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Rachel Garfield, PhD, MHS

Safana Siddique, MBBS, MPH

Shelly Spiro, RPh, FASCP

Suzanne Pincus

Tim Carney, PhD, MPH, MBA

Vanessa Diaz, MD

Expertise represented across 45 TEP members include:

- COVID-19
- PASC/ Long COVID
- Caregivers
- Patient advocacy
- Clinical decision making
- Chronic conditions
- SMART on FHIR apps
- *and more!*

Why it is important to Standardize Data Elements?

HL7 data standards provide the common language that lets different digital systems work together so everyone can securely access and use the right health information when and where they need it.

HL7 data standards (e.g., CDA, FHIR) marry predefined **structures** with **semantics** to standardize information that goes across the wire.

- **Structures** = FHIR Resources and Profiles or CDA Templates
- **Semantics** = Code Systems/Vocabularies or Value Sets of code system concept codes

As a result, receivers can understand the data that was sent.

"Well, then," said Milo, not understanding why each one said the same thing in a slightly different way, "wouldn't it be simpler to use just one? It certainly would make more sense."

The Phantom Tollbooth
Norton Juster

National Institute of Diabetes and Digestive and Kidney Diseases

Care Planning Components for Standards Development

Person & Plan	Health Concerns	Goals	Interventions	Outcomes
Defining information for the care plan itself, the person/ patient, and other members of the care team, including unpaid caregivers.	Health states or social risks that may require attention, intervention, or management and are of interest/ importance to the patient, family, or health care provider.	A defined outcome or condition achieved in the process of patient care as: patient- defined, caregiver-defined, or clinical.	Actions taken toward achieving goals of care, including removal of barriers to success.	Observations on the outcome of care from the interventions used to treat the patient.

Care Coordination

The deliberate organization of patient care activities between two or more participants (including the patient) involved in patient care to facilitate and ensure that the delivery of healthcare services is appropriate, safe, and efficient. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities, and often is managed by the exchange of information among participants responsible for different aspects of care.

HL7 FHIR

NIH National Library of Medicine
Value Set Authority Center

See the MCC eCare Plan Implementation Guide - Structure and Design Considerations (working draft) for more information on FHIR mappings.

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NIH National Institute of Diabetes and Digestive and Kidney Diseases

Process for Identifying a New Clinical Domain

The process for identifying and standardizing a new clinical domain is an iterative process which includes the following steps:

- The TEP determines and prioritizes data element concepts.

- The TEP provides clinical definitions.

- The TEP and EMI Standards and Terminology Experts determine if the data concept needs a value set or should be represented with FHIR constructs.

  - If a value set is needed, the EMI Terminologists will work with the TEP to develop text definitions for the clinical focus, scope, and inclusion and exclusion statements. The EMI Terminologists will reuse or build a new value set and the TEP will review.

  - If the data concept can be represented with FHIR constructs, the EMI Standards Experts will map them using the FHIR specification.

Long COVID Data Elements Identification

Data Element Gathering Spreadsheet
Interactive spreadsheet for TEP to contribute input on long COVID symptoms and interventions.

Long COVID Analysis Spreadsheet
Working spreadsheet for EMI Standards and Terminology Experts to analyze data element/concept inputs from the TEP to inform value set and FHIR profile design.

Value Set build and FHIR Profile development

Building Long COVID-Associated Value Sets

- Defined data elements and concepts inform the development of value sets.

- **Value sets** are lists of codes with their terms, from standard clinical vocabularies (e.g., SNOMED CT®, RxNorm, LOINC®), that define clinical concepts.

- We use value sets with FHIR structures to **support EHR-querying** and **interoperable exchange** of health information for an eCare plan.

- We use value sets to **display and filter** health information within the eCare plan application.

- Value sets are housed in the **Value Set Authority Center (VSAC)**, a public repository that provides users with tools to search existing value sets, create new value sets, and maintain value set content consistent with current versions of the terminologies they use. https://ecqi.healthit.gov/tool/vsac | https://vsac.nlm.nih.gov

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Long COVID Diagnosis

- Long Covid Diagnosis

Long COVID Comorbidities (Newly Built Value Sets)

- Bronchiectasis
- Chronic obstructive pulmonary disease (COPD)
- Interstitial lung disease
- Asthma
- Fibromyalgia
- Herpes zoster reactivation
- Pulmonary embolism
- Pulmonary hypertension
- Lymphadenopathy
- Pink eye

Long COVID Comorbidities (Existing Value Sets)

- Diabetes mellitus
- Chronic kidney disease
- Congestive heart failure
- Tuberculosis
- Obesity
- Posttraumatic stress disorder (PTSD)
- Dementia

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

- Abdominal Pain
- Anxiety
- Arthralgia
- Back Pain
- Bleeding
- Brain Fog
- Chest Pain
- Chills
- Chronic Pain
- Constipation
- Cough
- Covid Toes
- 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

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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** - Guidance for developing implementations.
- **Business analysts** - Assist developers in understanding system implementation requirements.
- **Project managers** - 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 *(work in progress)*:

1. Query for patient data across providers and compile into a consolidated care plan representation.
2. Encourage capture of and communication of a patient's health concerns and related goals, interventions, and outcomes.
3. Gather and aggregate patient data for uses beyond the point of care (e.g., public health, population health, quality measurement, risk adjustment, quality improvement, and research).

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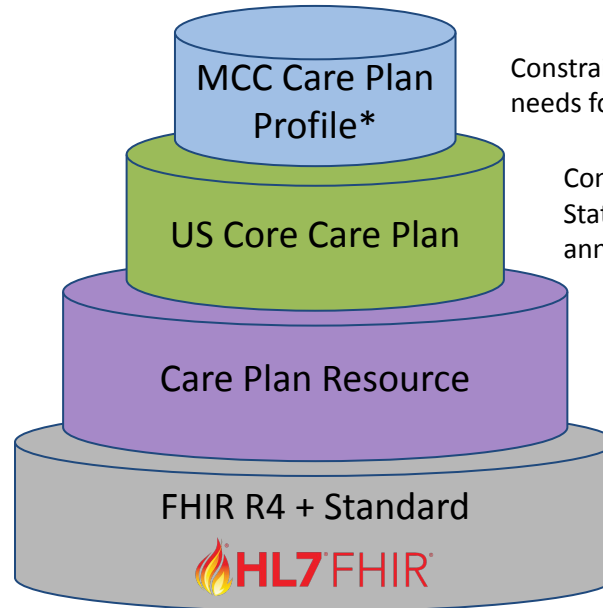
Constrains the US Core FHIR Care Plan Resource to meet the needs for multiple chronic conditions (MCC) care planning.

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®.

The Need for a New Implementation Guide Design

- The first draft of the MCC eCare Plan Implementation Guide (IG) developed in Project Year 2 incorporates considerations primarily for CKD.
- During Project Years 1 and 2, **1100+ data elements** were identified for CVD, T2D, and chronic pain, and most are associated with value sets.
- If we continue to use the same design approach from the first draft of IG, it will **add 600+ new profiles** (FHIR artifacts) to the IG when we add the data elements for the additional domains (CVD, T2D, chronic pain, long COVID/PASC).


It started out as a simple analysis, but piled up to information overload.

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Approach to Update MCC eCare Plan IG

- During Year 3, we are using the following tactics to **redesign the IG and mitigate profile proliferation**:
  - Create MCC "Foundation" profiles and value set "library".
  - Revisit US Core annually after January ballots and examine corresponding USCDI updates.
  - Provide guidance (but not further specifying) in the MCC FHIR IG, including:
    - FHIR Plan Definition,
    - FHIR Clinical Guidelines, and
    - Clinical Quality Language.

Reusing and Constraining: Value Set Library
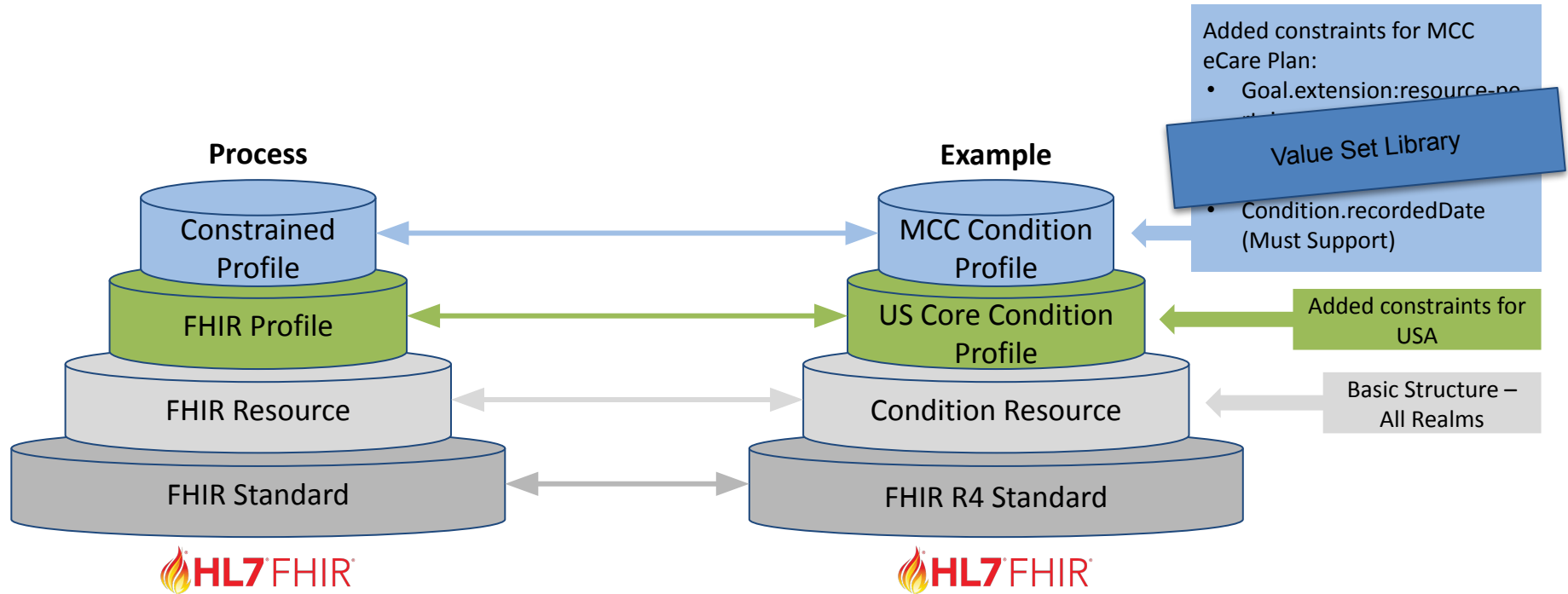
What is "The eCare Plan MCC Value Set Library"?

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

- Organizes the value sets based on their subject
- Allows addition or removal of value sets from their subject area
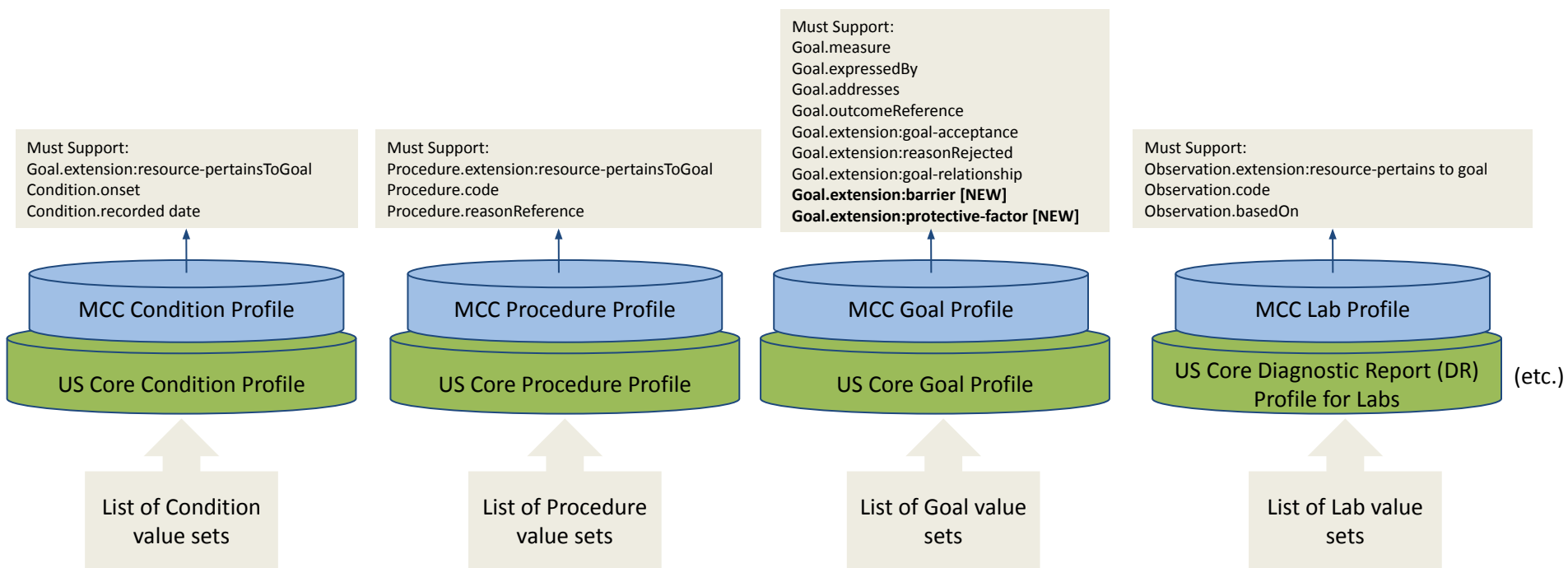- Within the subject area, more granularly classifies the value set

The eCare MCC Value Set Library - Condition *Example*

FHIR Profile Element	Value Set Name and Link	Value Set Clinical Focus
Condition.code	Chronic Kidney Disease All Stages (1 through 5)	This set of values contains diagnosis terms representing All Stages (1 or 2 or 3 or 4 or 5) of chronic kidney disease.
Condition.code	Long Covid Diagnosis	This set of values contains diagnosis terms representing Post Acute Sequelae of Sars-Cov-2 infection (PASC) (Long Covid) disease.
Condition.code	Bronchiectasis Diagnosis	This set of values contains diagnosis terms representing Bronchiectasis disease.
Condition.code	Small Fiber Neuropathy Diagnosis	This set of values contains diagnosis terms representing Small Fiber Neuropathy.

The eCare MCC Value Set Library - Symptom *Example*

FHIR Profile Element	Value Set Name and Link	Value Set Clinical Focus
Observation.value	Brain Fog	This set of values reflect patients feeling of being sluggish, fuzzy, and not sharp.
Observation.value	Impaired Sense of Smell	This set of values reflect patients with impaired sense of smell including anosmia, hyposmia, and dysosmia.
Observation.value	Insomnia and Other Sleep Difficulties	This set of values reflect patients with insomnia and other symptoms of sleep difficulties.
Observation.value	Mood Swings	This set of values reflect patients with rapidly and intensely fluctuating emotions.

Foundation MCC eCare Plan Profiles

Must Support:
Goal.measure
Goal.expressedBy
Goal.addresses
Goal.outcomeReference
Goal.extension:goal-acceptance
Goal.extension:reasonRejected
Goal.extension:goal-relationship
Goal.extension:barrier [NEW]
Goal.extension:protective-factor [NEW]

Must Support:
Goal.extension:resource-pertainsToGoal
Condition.onset
Condition.recorded date

Must Support:
Procedure.extension:resource-pertainsToGoal
Procedure.code
Procedure.reasonReference

Must Support:
Observation.extension:resource-pertains to goal
Observation.code
Observation.basedOn

MCC Condition Profile

US Core Condition Profile

MCC Procedure Profile

US Core Procedure Profile

MCC Goal Profile

US Core Goal Profile

MCC Lab Profile

US Core Diagnostic Report (DR) Profile for Labs

(etc.)

List of Condition value sets

List of Procedure value sets

List of Goal value sets

List of Lab value sets

The IG will contain a page with lists of VSAC-housed value sets organized by profile type.

MCC eCare Plan FHIR IG: Draft and Milestones

- In progress draft IG: https://build.fhir.org/ig/HL7/fhir-us-mcc/
- Target milestones:
  - For comment ballot in January 2023.
  - STU ballot in September 2023.
  - STU publication in September 2024.

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Connectathon 30 – Care Planning Track

- **58** track participants
- **18** participants attended both days

- Clients/Servers:
  - Servers: FHIR sandboxes on MELD and Logica.
  - Clients: Patient/Caregiver and Provider MCC SMART-on-FHIR Apps

PROJECTS
- PACIO Project
- gravity PROJECT
- HL7 FHIR ARGONAUT PROJECT

GOVERNMENT
- The Office of the National Coordinator for Health Information Technology
- ACF
- Washington State Department of Health
- CMS Centers for Medicare & Medicaid Services
- Dubai Health Authority

HEALTH CARE COMPANIES
- CVS Health
- aetna
- BlueCross BlueShield
- Cigna
- GE Healthcare
- HIGHMARK
- EVERNORTH

HEALTH IT STANDARDS & SOLUTIONS
- MITRE
- GREEN ROOM TECHNOLOGIES
- INITIATE GOVERNMENT SOLUTIONS BUILDING SOLID FOUNDATIONS
- RTI INTERNATIONAL
- OPEN CITY LABS
- Lantana CONSULTING GROUP
- Juniper CDS
- newwave
- Goldbelt Frontier
- Pura Juniper
- Alphora
- PHILIPS
- Microsoft
- Vitamin Software
- Chickasaw NATION INDUSTRIES SERVICE WITHOUT RESERVATION
- MaxMD
- firely
- HealthLX
- Telligen
- Health Intersections
- Next Level HEALTH INNOVATIONS
- LINDEN TECH ADVISORS
- A|D Vault

VENDORS
- Epic
- Allscripts
- PatientCentricSolutions

ASSOCIATIONS
- eat right Academy of Nutrition and Dietetics
- AMA

ACADEMIA
- MUSC MEDICAL UNIVERSITY of SOUTH CAROLINA
- Yale University School of Medicine
- CENTER FOR OUTCOMES RESEARCH AND EVALUATION CORE

Track Description

- Hosted by the Multiple Chronic Conditions (MCC) eCare Plan [project](#).
- Continue testing of the **MCC** eCare plan FHIR IG, SMART on FHIR Apps (clinician- and patient/caregiver-facing) and value sets defined for MCC clinical domains.
- Supports the development and exchange of FHIR-based care plans and applying evidence-based clinical practice guidelines at the point of care to create and share person-centered care plans and to manage their ongoing care.
- For more information please visit: [2020-05 Care Coordination Track](#)

Track Goals

- **Demonstrate** the purpose of using goals in care planning, where goals may be created by any member of the care team, including patients and caregivers.
- **Explore**:
  - How care goals in practice can be **clinically useful and interoperable**.
  - **Relationships** between a goal and the following:
    - Conditions and/or assessment observations that goals address
    - Outcome observations that document goal progress
    - Other goals
    - Associated interventions
    - Associated "notes" about goals
  - The **clinical workflow feasibility** for creating FHIR Goal.description using coded terminology vs. free text.
  - **Clinical workflow and challenges** with creating measurable goals that reference specific codes, e.g., lab or vital sign LOINC code.
- **Evaluate**:
  - The use of **FHIR Goal** to capture and track SMART goals, i.e., Specific, Measurable, Achievable, Relevant, and Time-Bound.
  - **Recommended updates** to existing **US Core Goal Search Parameters**.

Notable Achievements

- Demonstrated execution of CQL logic embedded in the Patient/Caregiver eCare SMART on FHIR app to classify and summarize patient data, and also used to create a URL to query and display Medline Plus Connect information for patients/caregivers looking to learn more about conditions, lab results and medications.

Notable Achievements

- Performed demonstration to show patient or caregiver-authored goals shared in an interoperable way with the Provider eCare SMART on FHIR app.

Discovered Issues / Questions

Goal Resource
- Can CQL logic be used to evaluate progress on Goal.target measure?
- Goal should have an "end date" at the root level (as well as the goal.target due date.)

Relationships between goals
- Should the Goal point to the Procedure or should the Procedure point to the Goal? A similar question was discussed for relationships between Goal and other resource types.
- How do we capture progress against Goals? Is Goal note sufficient? Discussed example in nutrition and the use of ClinicalImpression to capture progress.
    - Nutrition example: NutritionIntake is used for food dairies, diet-related data from myFitnessPal, data to assist malnourished patients. However, NutritionIntake is a new resource in R5 and not available for use in our R4 test environments.

Care planning interoperability
- Can CDA documents contain sufficient discrete data to support transformation and use by FHIR applications providing care management/case management solutions?
- Responsibility for resolving references in FHIR Bundles when exchanging data between organizations. Who could/should/would resolve bundle content to limit duplications?

Moving Forward

To discuss at Patient Care Work Group

- Add Goal.endDate as well as keeping target.due element on Goal.
- Use of ClinicalImpression resource as one of the referenced resources for the Goal.addresses element to capture progress on a Goal.
- Applications for the FHIR principle around "the thing that comes second references the thing that came first" for Goal relationships (i.e., Goal references Procedure or Procedure references Goal)

To discuss with Learning Health Systems Work Group

- Provide ability to capture the status of the care team member roles (e.g., Is the cardiologist active? Is meals-on-wheels inactive (not providing services)?, etc.).

Topics with ongoing discussion

- Identify how to exchange comprehensive care plans for MCC across organizations when part of the care responsibility and clinical records are shared. Specifically, determine how to reconcile and minimize duplication of patient data.
- Integration of more decision-support logic into care planning and care management.
- Look ahead for R5 changes that will be beneficial when available (i.e., NutritionIntake)

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Pre-Pilot Stakeholder Working Groups

eCare Plan Stakeholders

- Patients/ Caregivers
- Healthcare Clinicians
- IT Staff
- Providers/ Leaders

Phase I: Understanding the Problem

Phase II: Requirement Gathering and Feedback

Phase III: Input on the Application Design/Usability and Implementation Considerations
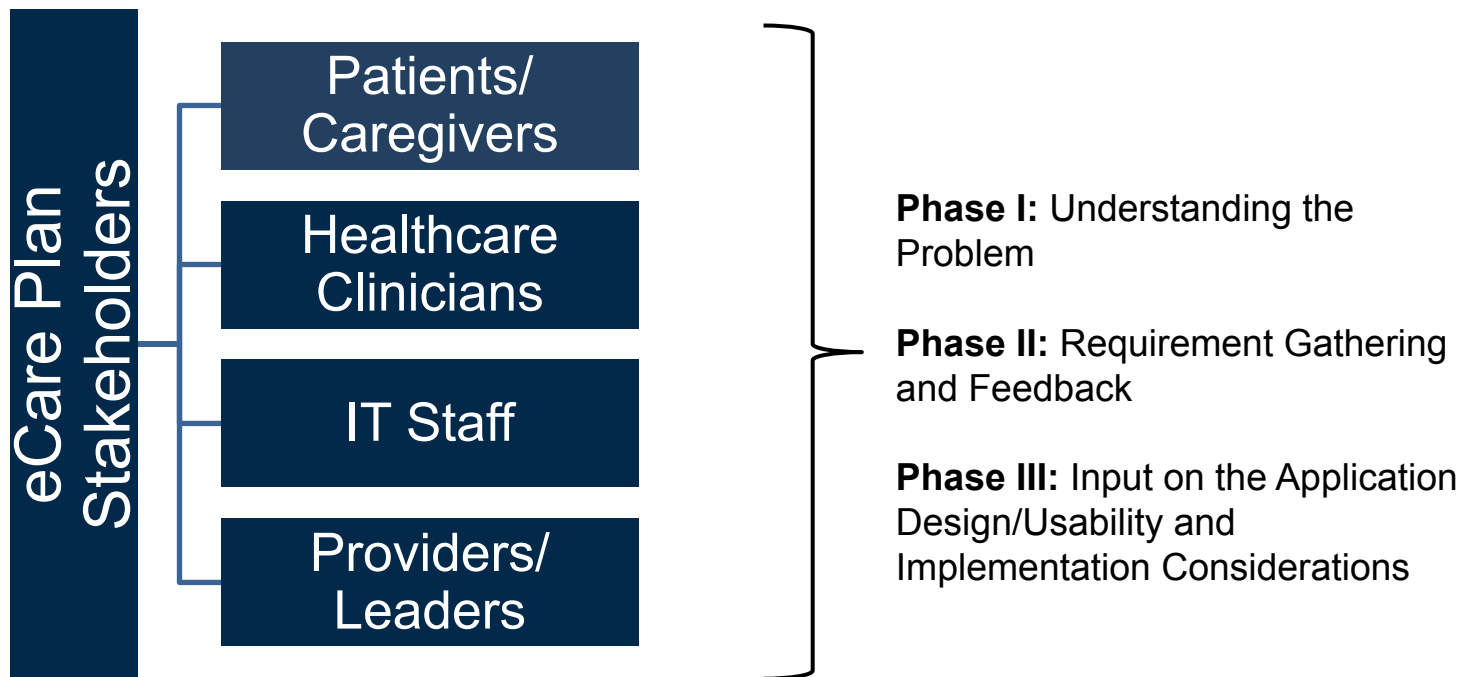
Stakeholder discussions were augmented with application wireframes and Patricia Noelle persona and scenarios

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Persona: Patricia Noelle

- **Meet Patricia Noelle**
- **65 years old**
- **Clinical Health Concern: CKD, Diabetes, CHF, Chronic Low Back Pain, Depression**
- **Social risks: food insecurity, transportation**
- **1 child (Rose who is her care giver)**
- **Springfield, IL**

About Patricia

- Patricia is a retired schoolteacher.
- Her husband passed away a few years ago, and she currently lives with her daughter, Rose.
- Patricia feels nervous and overwhelmed managing her MCCs. This also impacts her depression.
- Patricia relies on Rose to drive her to the doctor and thereby can only schedule appointments when Rose is not working.

Patricia's Typical Routine & Interactions

- Patricia spends her days: watching TV, walking around the house, sometimes having a meal with friends.
- She finds certain activities like reading more difficult now due to decreased vision.
- Currently she follows a carbohydrate controlled, heart healthy diet.

Wireframes: Provider App

Patient Name:	Betsy Johnson	Patient ID	XXXXXXXXXX
Document Title:	Test Document	Document ID:	XXXXXXXXXX
Date of Birth:	03/29/1942	Date Last Revised:	02/13/2017

See More Information [5]

Health & Social Concerns	Goals [1]	Health Maintenance & Interventions [2]	Health Status Eval & Outcomes [3]

Diagnoses

	Condition		Date of Initial Diagnosis
☐	Chronic Kidney Disease	Rx [6] [7]	04/26/2015
☐	Diabetes	Rx	12/13/2014
☐	Hypertension	Rx	07/22/2003
☐	Depression	Rx	01/15/2009
☐	Congestive Heart Failure	Rx	05/21/2007
☐	Peripheral Neuropathy	Rx	04/06/2005
☐	Retinopathy	Rx	11/11/2003
☐	Obesity	Rx	Initial Diagnosis 01/22/1997 Subsequent Diagnosis 10/22/2014
☐	Hyperlipidemia	Rx	05/16/1993
☐	Hypothyroid	Rx	04/06/1992

Mark as Inactive [4]

Inactive Diagnoses

	Condition	Date Marked Inactive
☐	Chronic Kidney Disease	04/26/2015
☐	Diabetes	12/13/2014
☐	Hypertension	07/22/2013
☐	Depression	01/15/2009
☐	Congestive Heart Failure	05/21/2007

Mark as Active

Social Concerns

Food Security	
Transportation Access	Relies on Daughter
Housing Stability	
Primary Language	English
Health Insurance Status/Type	Medicare
History of Abuse	
Smoking Status	Non-smoker
Health Literacy	
Computer/Phone Access	
Alcohol Abuse	
Substance Abuse	
Caregiver Characteristics	
Characteristics of Home Environment	
Employment Status	Retired
Education Level	College Graduate
Environmental Conditions	

Patient Name:	Betsy Johnson	Patient ID	XXXXXXXXXX
Document Title:	Test Document	Document ID:	XXXXXXXXXX
Date of Birth:	03/29/1942	Date Last Revised:	02/13/2017

See More Information [4]

Health & Social Concerns [1]	Goals [2]	Health Maintenance & Interventions [3]	Health Status Eval & Outcomes

Sort by: Clinical Tests [7] Weight

Clinical Test Results

Weight	185	02/13/2017

Change in Weight over Time

Date	Result
05/21/2017	185 lbs
04/23/2017	178 lbs
03/11/2017	174 lbs
02/11/2017	174 lbs
01/10/2017	180 lbs
12/12/2016	185 lbs
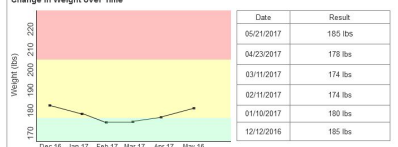
Systolic Blood Pressure	155	02/05/2017
Diastolic Blood Pressure	92	02/05/2017

Change in Blood Pressure over Time

Date	Systolic	Diastolic
05/21/2017	155	92
04/23/2017	150	89
03/11/2017	145	90
02/11/2017	145	89
01/10/2017	147	91
12/12/2016	150	91
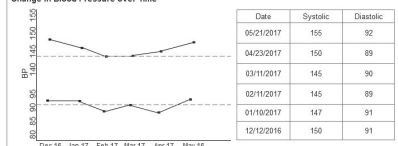
Dialysis Access Status	[Usable/Not Usable] Type of Access: XXXX Anatomic Subtype: XXXX Location: XXXX Bruit: XXX Thrill: XXX AVF Diameter: XXX AVF Depth: XXX AVF Length: XXX History: XXXXXXX	XX/XX/XX (Date of Most Recent Exam) XX/XX/XX (Date of Vascular Surgery)
Depression	PHQ-2: XXX PHQ-9: XXX	XX/XX/XXXX XX/XX/XXXX
Cognitive Health	XXX	XX/XX/XXXX
Fatigue	XXX	XX/XX/XXXX
Pain	XXX	XX/XX/XXXX
Functional Status	XXX	XX/XX/XXXX
Quality of Life	XXX	XX/XX/XXXX
Activities of Daily Living	XXX	XX/XX/XXXX

Laboratory Test Results

Test	Result	Date
eGFR	28 mL/min/1.73m [2]	05/21/2017

Change in eGFR over Time [5]

Date	Result
05/21/2017	28 ml/min/1.73m2
04/23/2017	31 ml/min/1.73m [2]
03/11/2017	35 ml/min/1.73m [2]
02/11/2017	35 ml/min/1.73m [2]
01/10/2017	42 ml/min/1.73m [2]
12/12/2016	46 ml/min/1.73m [2]
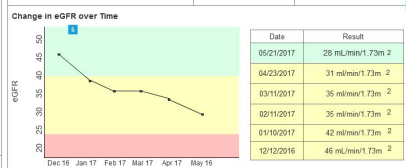
Serum Creatinine	1.9 mg/dL	02/05/2017
Urine Albumin-to-Creatinine Ratio (UACR)	1345 mg/g	02/05/2017

Change in UACR over Time

Date	Result
05/21/2017	1345 mg/g
04/23/2017	1320 mg/g
03/11/2017	1310 mg/g
02/11/2017	1310 mg/g
01/10/2017	1325 mg/g
12/12/2016	1345 mg/g
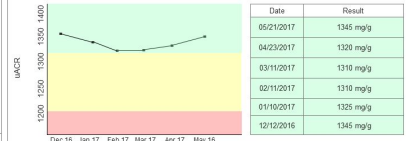
Hemoglobin	12	02/05/2017
A1C	11.2	02/05/2017
Serum Potassium	4.8	02/05/2017
Corrected Calcium	10.1	02/05/2017
Serum Phosphorus	4.3	02/05/2017
Serum Albumin	3.9	02/05/2017
Transferrin Saturation	22	02/05/2017
Ferritin	103	02/05/2017
Blood Urea Nitrogen	XXX	02/05/2017
LDL	120	02/05/2017
HDL	33	02/05/2017
Triglycerides	331	02/05/2017
Total Cholesterol	242	02/05/2017
Vitamin D	18	02/05/2017
KT/V	XXX	02/05/2017
Intact Parathyroid Hormone	80	02/05/2017
Serum Bicarbonate	23	02/05/2017
Sodium	XXX	02/05/2017
Chloride	XXX	02/05/2017

Wireframes: Patient App
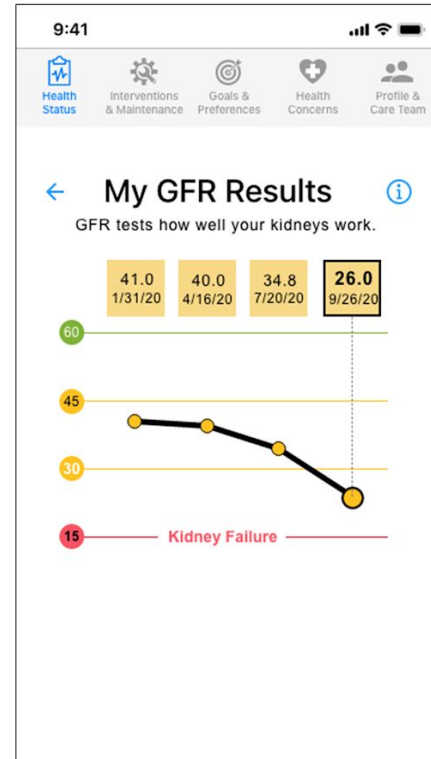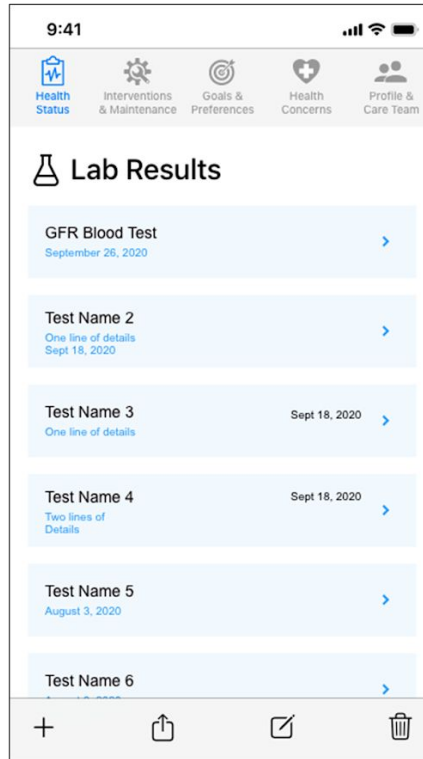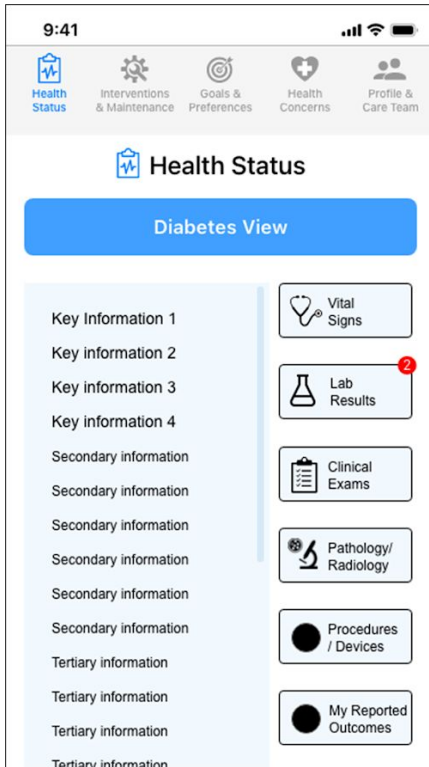
Pilot: eCare Plan Usability Testing

What is Usability Testing?

Evaluating a product or service by testing it with representative users.

Phase 1- Provider Testing
- Providers will be asked by a facilitator to review patient information in the eCare Plan Provider App while interacting with the facilitator as the patient.
- If time allows, providers will also be asked to preview the eCare Plan Patient App.

Core Elements of Usability Testing

Facilitator
Guides the participant through the test process

Tasks
Realistic activities that the participant might actually perform in real life

Participant
Realistic user of the product or service being studied

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Phase 2- Provider/Patient Testing
- Providers will be asked to select patients and their caregivers to use the eCare Plan Patient App while they use the eCare Plan Provider App to interact with the patient.

eCare Plan App Usability Testing

Phase I

| Login to the **Provider-facing App** in test | Navigating through the **Provider-facing App** | Brief **Patient-facing App** review* | Usability Questions |

*Usability testing with providers included a preview of the patient-facing app using the Patricia Noelle persona

Phase II

| Brief review of goals of testing | Login to the **Patient-facing App** | Navigating through the **Patient-facing App** | Usability Questions |

Pilot Evaluation Questions

1. What are the key issues for *designing* (using a UCD approach with a patient-centered focus) interoperable and publicly shareable MCC care coordination tools for patients and clinicians, and how did the project address those issues?

2. What are the key issues for *developing* interoperable and publicly shareable MCC care coordination tools for patients and clinicians, and how did the project address those issues?

3. What are the key issues for *implementing* interoperable and publicly shareable MCC care coordination tools for patients and clinicians, and how did the project address those issues?

4. What *effects (or outcomes)* do MCC care coordination tools have on management of multiple chronic conditions across settings?

5. What *lessons learned* arise from the project's experiences with developing and implementing interoperable and publicly shareable MCC care coordination tools for patients and clinicians?

eCare Plan Framework
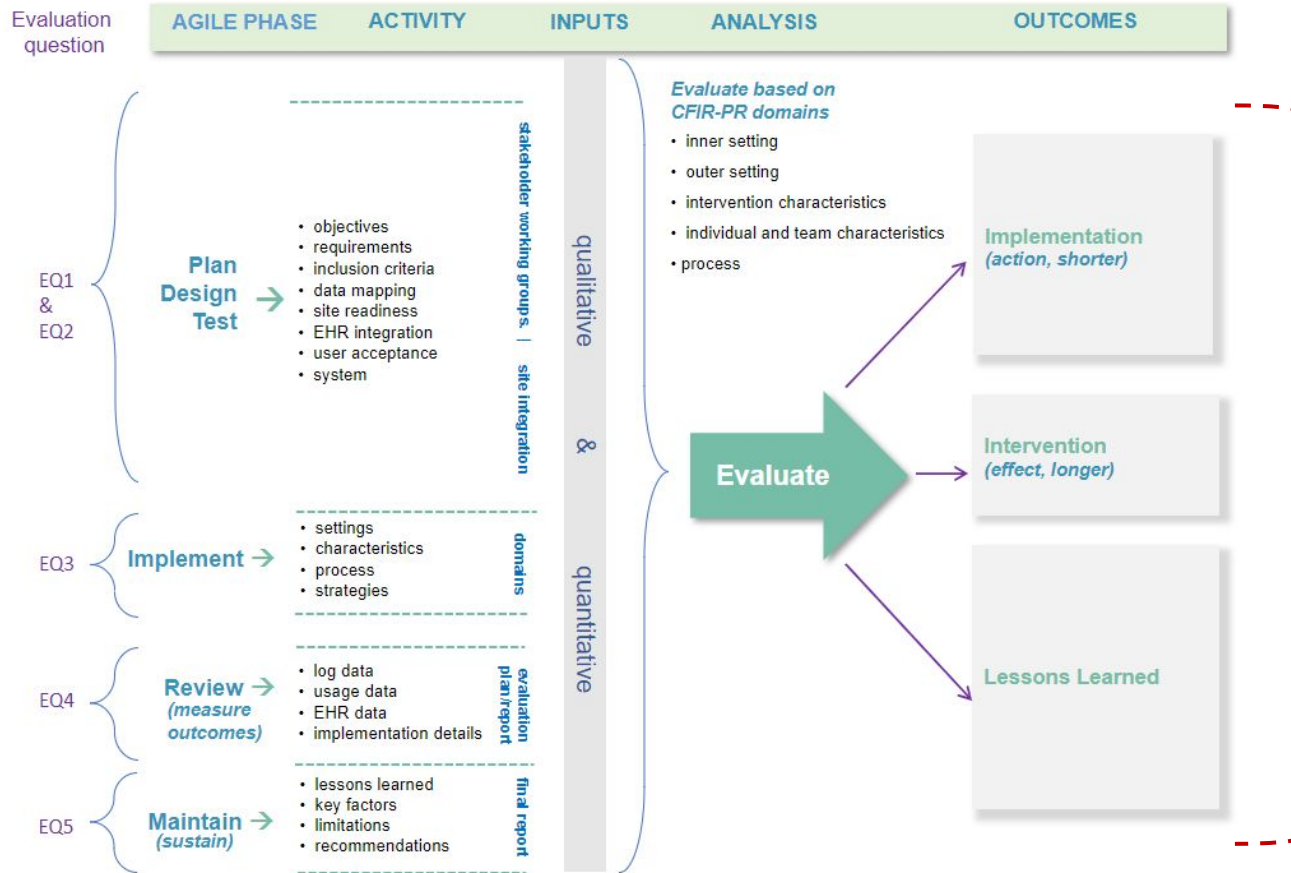
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