Multiple Chronic Conditions (MCC) eCare Plan
Federal Partners Meeting

June 14, 2022

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**.

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Agenda

Topic	Time	Presenter(s)
Welcome and Introductions	5 min	Jenna Norton, NIDDK Arlene Bierman, AHRQ
MCC eCare Plan Project Overview and Progress Update	10 min	Jenna Norton, NIDDK Karen Bertodatti, EMI
MCC eCare Plan Topics and Agency Partner Feedback • eCare Planning v2 apps demo and real-world challenges • Update from RTI on pilot testing findings and recommendations	55 min	EMI Advisors RTI International
Federal Projects Round Robin Update	45 min	Federal Partners
Concluding Remarks	5 min	Jenna Norton, NIDDK Arlene Bierman, AHRQ

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Contractor Introductions

EMI ADVISORS

Evelyn Gallego, MBA, MPH, CPHIMS

Program Director

Karen Bertodatti, MPH

Project Manager

Savanah Mueller, MPH

Project Analyst

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IG Developer/Clinical SME

Himali Saitwal, MS

Terminology SME

Gay Dolin, MSN, RN*

IG Developer/Clinical SME

Dave Carlson, PhD, MBA*

Solutions Architect

Sean Muir*

App Developer

*subcontractor to EMI

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Contractor Introductions

Laura Marcial, PhD

Pilot Lead

Sara Armson

Clinical Terminologist

David Dorr, MD, MS

Principal Investigator

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Housekeeping

- Live transcription is available.
- Use the hand raising feature when you want to comment and kindly wait for a facilitator to call on you before speaking.
- Use the chat to share feedback at any time.
- We are recording for note-taking purposes.

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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.

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/

New! 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 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/

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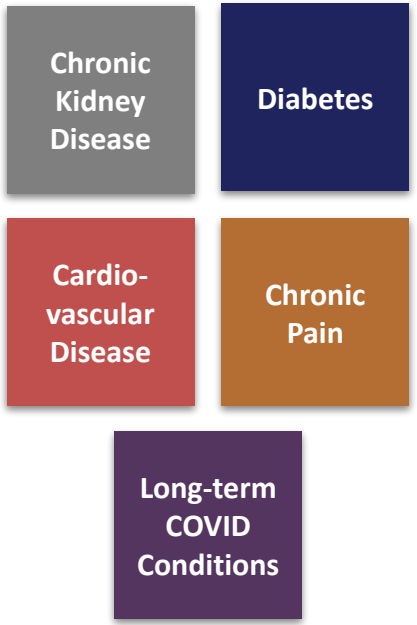
MCC eCare Project Deliverables*

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.



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

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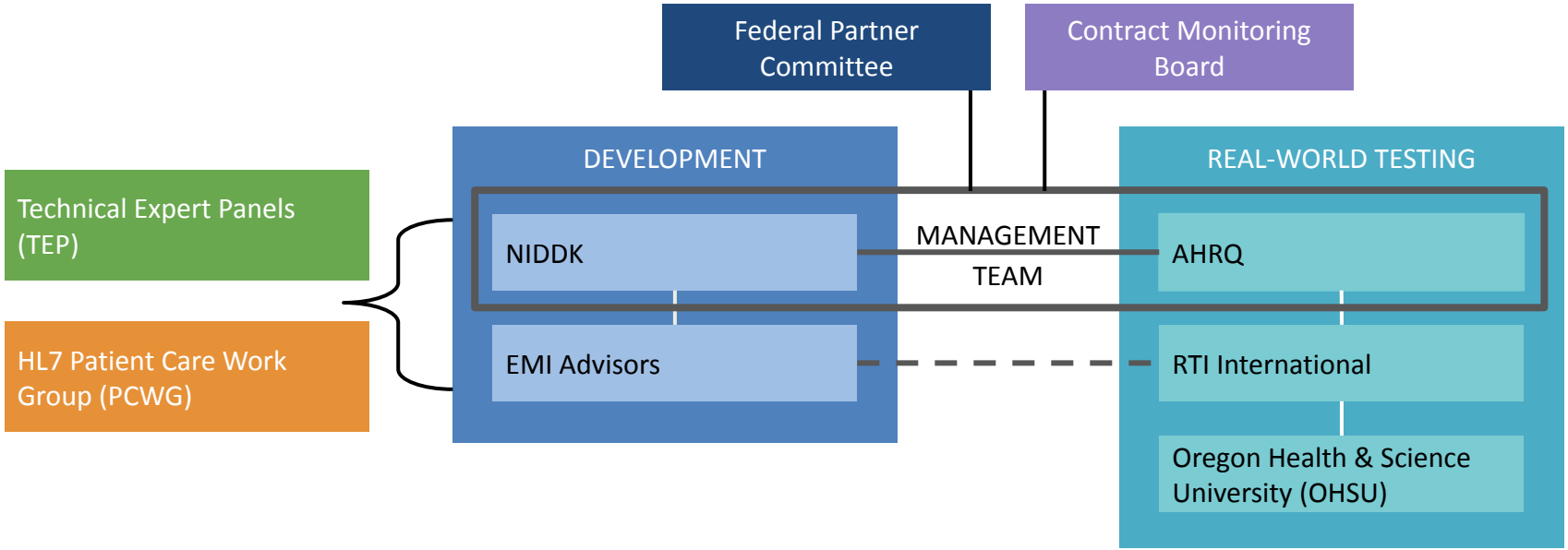
MCC eCare Plan Project Governance Model



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History of Federal Investment in Care Planning/Coordination

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

- **ONC**: 2015 Edition Care Planning Criterion
- **ONC/CMS**: electronic Long-Term Services and Supports (eLTSS)
- **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

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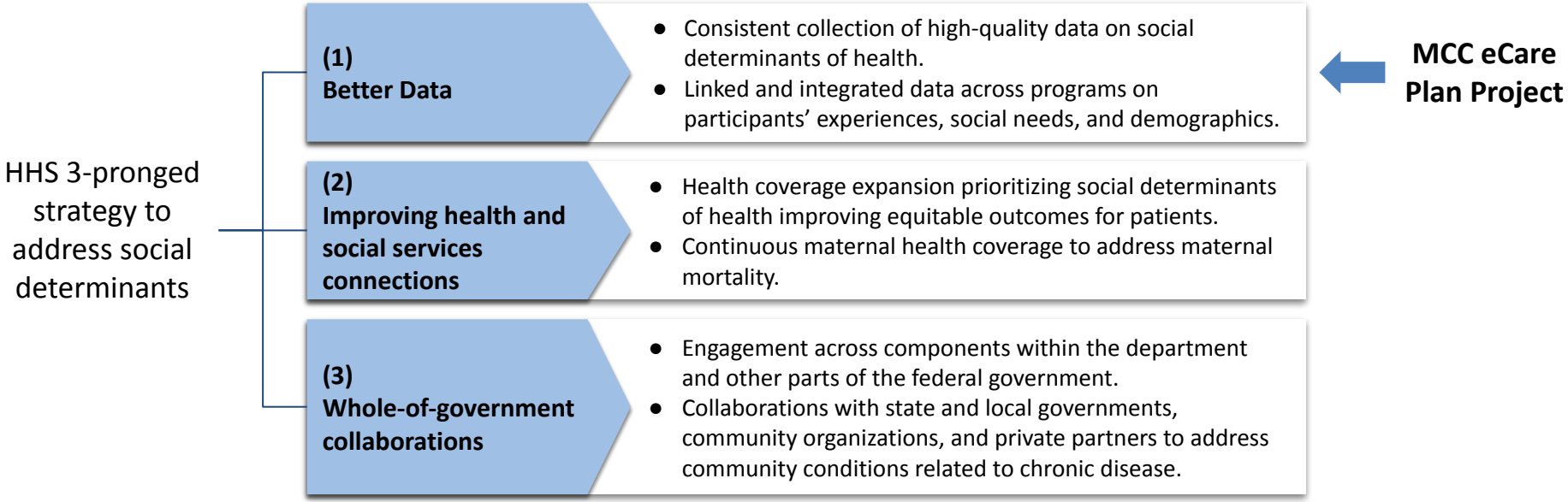
HHS: Advancing Health Equity

Integrating health services (both medical care and public health) with human services—and vice versa—is a **critical step to addressing social determinants of health and improving equitable outcomes**. This work is a major priority for the HHS.



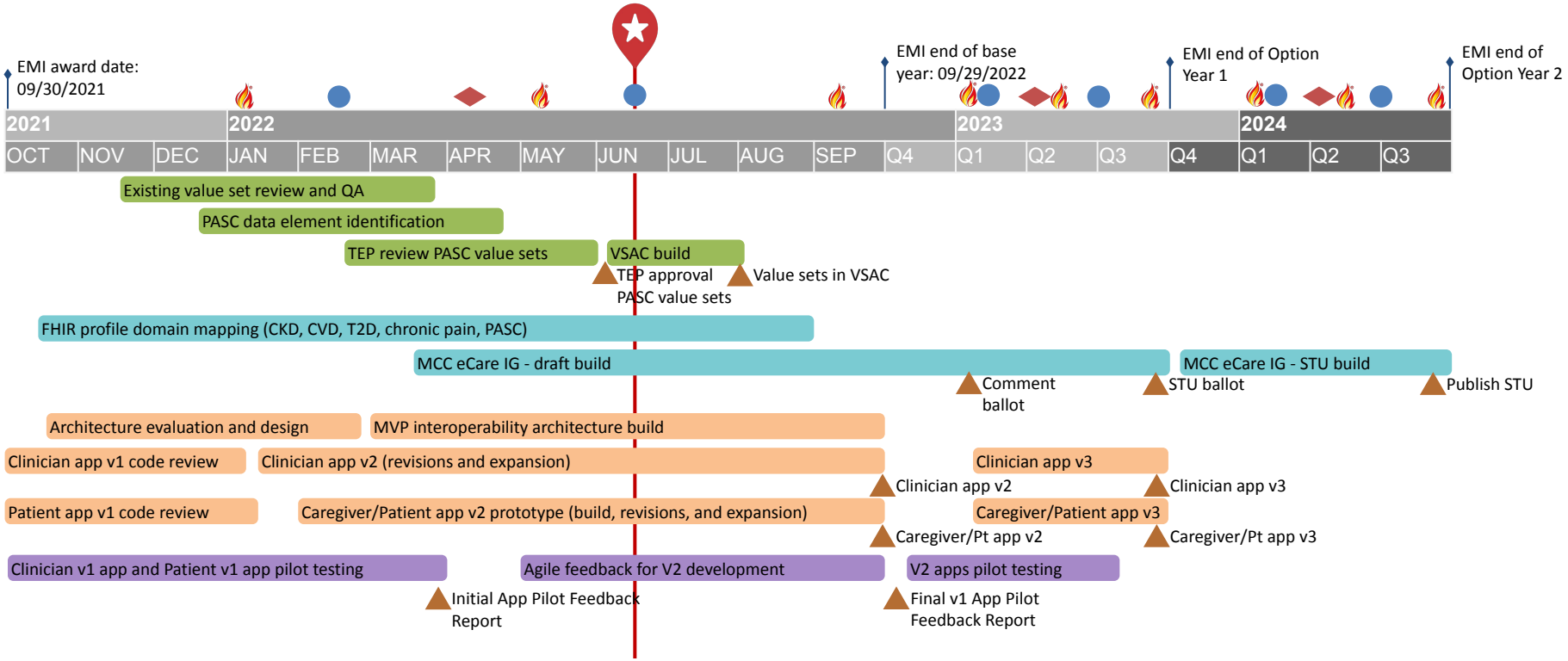
Source: https://jamanetwork.com/journals/jama-health-forum/fullarticle/2790811

MCC eCare Plan Project

Questions on any of the following?

- MCC eCare Plan Project
- Data elements and value sets for long COVID
- MCC eCare Plan FHIR Implementation Guide
- HL7 Connectathon 30: Care Planning Track
- Background on V1.0 Pilot Testing

Three Year Roadmap



Legend

- Contractor Deliverables
- Connectathon
- Contract dates
- Federal Partner Meeting
- Contract Monitoring Board
- Data/Value Sets
- MCC IG
- Apps dev.
- Apps testing

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eCare Plan v2 Applications

Demonstrating v2 Patient/Caregiver Application and Problem-Solving Real-World Interoperability Challenges

Dave Carlson, MBA, PhD, Clinical Cloud Solutions & EMI Advisors

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Overview: SMART on FHIR Applications

Deliverable **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.

Year 3

Expand and revise **Provider Application**.

Design and build **Patient/Caregiver Application**.

Design and build **interoperability architecture**.

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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.	→	There is no time restriction on when the app can be used.
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/

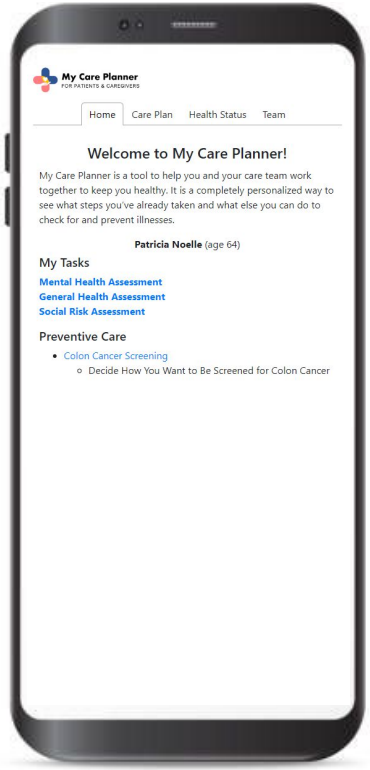
Provider App Vision

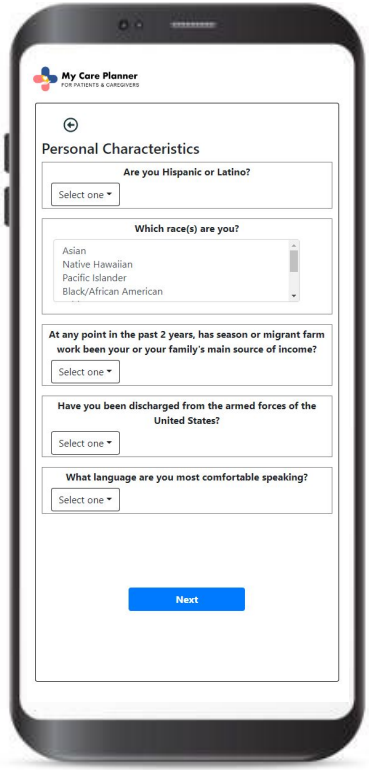
- A **standards-based application** platform for providers that supports them in patient-centered care planning and **care coordination** by surfacing key factors and data to improve outcomes for people with multiple chronic condition.
- Serves as a complementary app to an EHR system to:
  - **Improve provider productivity** and **reduce provider burden**, and
  - Bring together in a **single view** care planning data from multiple EHRs and patient-/caregiver-authored data not supported in EHRs.
- Serves as a companion app to the patient- and caregiver-facing app enabling **shared care planning** between all members of the care team.

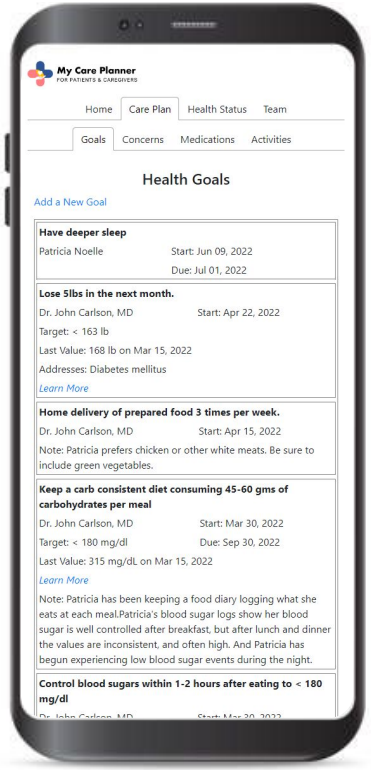
Patient/Caregiver App Vision

- A **standards-based application** platform for patients and caregivers to engage them in **participating in their care planning** for multiple chronic conditions.
- Allows patients and caregivers to **write information** into the app that can be shared with their providers.
- Allows patients and caregivers to see their health data from all of their providers in one place to fully enable **goal-oriented care planning**.
- Supports better care coordination due to **fully interoperable data exchange**.
- Serves as a companion app to the provider-facing app enabling **shared care planning** between all members of the care team.

Patient/Caregiver App v2.0 Demonstration and Feedback







Development Priorities for V2.0

Patient/Caregiver App

- Add/edit goal
- Detailed page for each goal
- Fill out a questionnaire
- Add/edit activity (what am I doing for my own health)
- Show care team (name and if available specialty/role, headshot)
- Add/edit member to care team
- Update Home Tab (i.e., upcoming activities such as the prompt to complete a questionnaire)
- When you write/edit something, the app should update/refresh

Provider App

- Add/edit goal
- Detailed page for each goal
- Reorganize Health Status page

Common Data Services Library (JavaScript)

- Configure and execute FHIR queries and CQL processing
- Make performance improvements (i.e., not block application use while query is underway)
- Demo prototype for second endpoint using supplemental data store for goals

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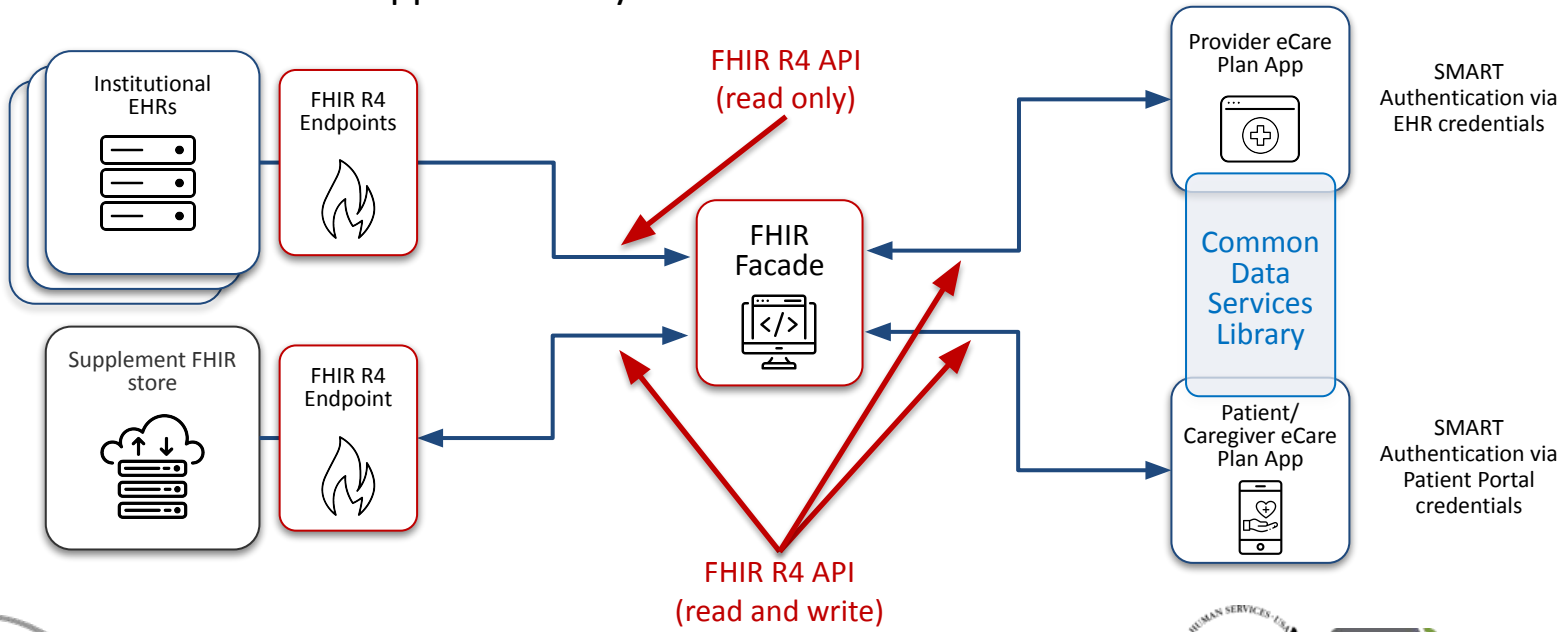
eCare Plan Applications Architecture

Plan: Expand application scope to include authoring and saving new content, including content that the EHR doesn't support natively.



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Real-World Challenges

- Accessing data from more than one provider.
  - Approach 1: Aggregated within FHIR facade server.
  - Approach 2: Patient directly logs into multiple portals.
- Saving patient/caregiver authored content.
  - Very limited ability to save directly into EHR systems.
  - Evaluating secure cloud-based or provider-specific shared storage.
- Limitations of Goal representation in Epic.
  - Only text description is supported at this time.
  - Goal data managed in supplemental FHIR store including measurable targets.

eCare Plan First Round Pilot Results

Key lessons learned and next steps to inform future development

Laura Haak Marcial, PhD, FAMIA (she/her/hers), RTI International
David Dorr, MD, MS, FACMI, FAMIA (he/his/him), Oregon Health Sciences University

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Tier 1: Development Considerations

Using the Right Language

- The right language can support the feeling that patients are **capable of managing their own care**
- Word choices should **meet the user where they are**
- Language should be value-neutral and **free of stigma**
- Avoid alienating patients with **overly technical language**
- Using **common terms**, such as “high blood pressure” instead of “hypertension”
- Language **choices also affect caregivers**

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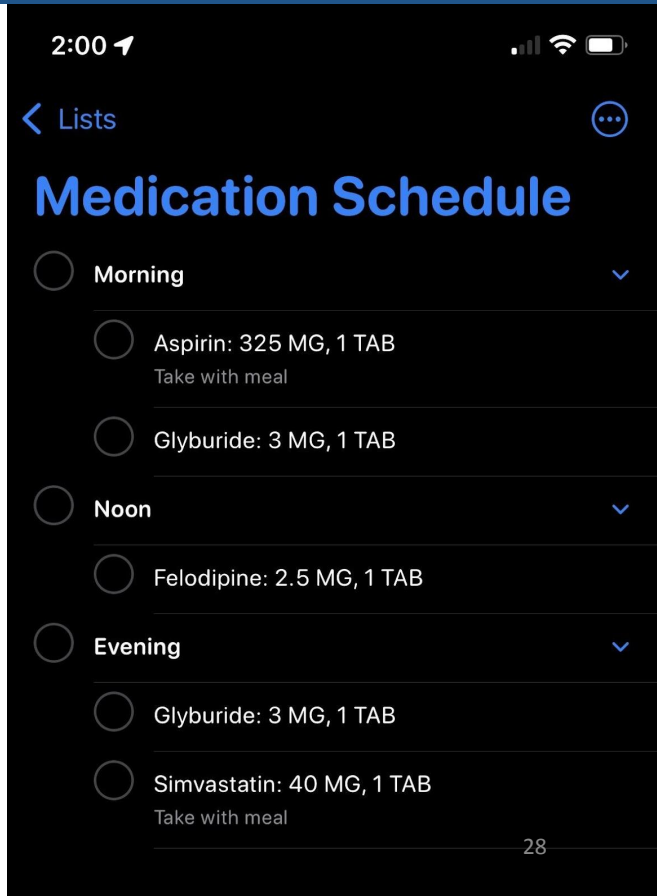
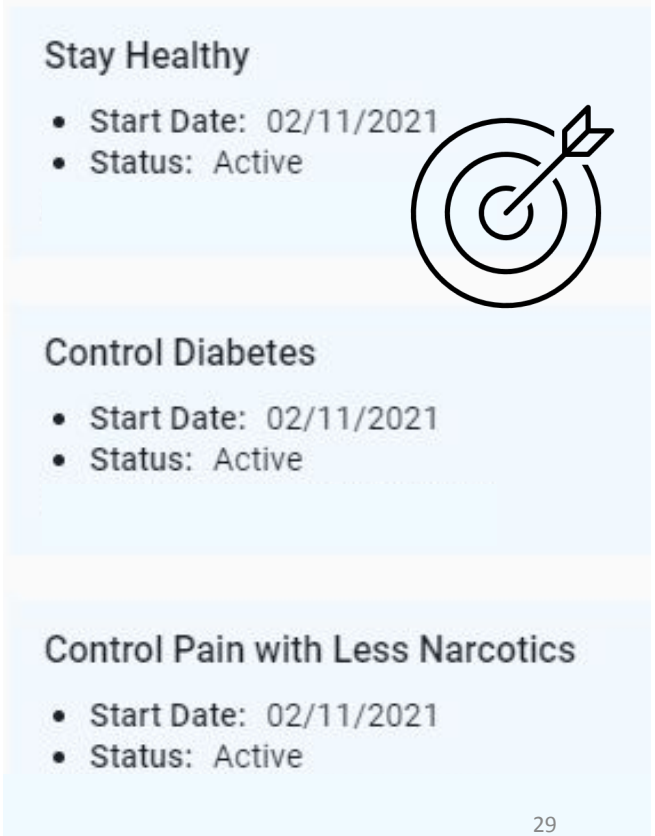
Improving Medication Display

- A **medication schedule could help patients keep track** of what to take and when
- When possible, parse and map prescriptions to a **daily schedule**
  - Provide a way to handle prescriptions that cannot easily be fit to a daily schedule
- Manage information about **over-the-counter medications**
- Where possible support updates and corrections as **annotations** to the record



Improving Goals

- Patients and providers **prefer SMART** to general goals like "stay healthy"
- Include **educational resources** for goal-setting
- Set **targets** together
- Patients and providers both see the potential for goals to be the **central focus**:
  - Support **integration** with graphs and labs
  - Locally **store** non-clinical goal-related data, (e.g., time spent with grandkids)
  - Enable patient **write-back** (see Interoperability Challenges in Real-World Setting)



Tier 2: Tackling Interoperability Challenges

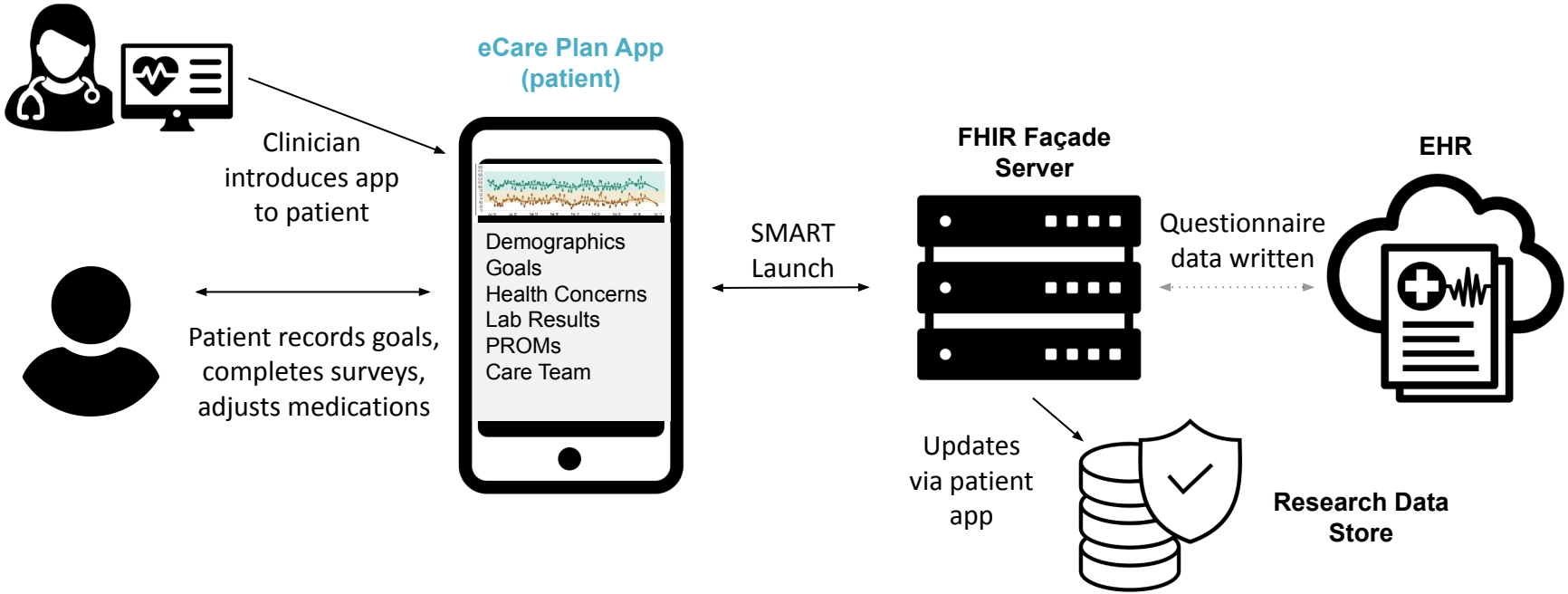
Write Back

- Patients and patient advocates **highly value** the ability for patients to supply information for the care plan
- Ideally this would include **writing this data back** to the EHR
- Activated patients take notes during and between visits, and write-back could **nudge other patients** towards more active involvement
- An interim step might be **storing the data locally**
- Write-back of goals could be easily **patient-controlled**
  - For example, home readings of blood pressure might add some value to readings taken in the clinic

Storing Patient Reported Data Locally

Trigger:

Patient with diagnosis of Chronic Kidney Disease or Long COVID



Tier 3: Future Work

Health Information Exchange

- ONC Final Rule places patients at the **epicenter** which both increases agency and adds burden
- **USCDI** is an important driver of interoperability and is still evolving
- Interoperability is not yet integral to EHR vendor **business models**
- Aggregation of data from multiple health systems and HIEs remains a **future state**
- Complicated by **access** to technology and health/data **literacy**
- Write-back increases provider burden in the form of **verifications, reconciliation and/or adjudication**

Agency Questions & Feedback

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Administration for Community Living

HCBS Quality Measures
NCQA Person Centered Outcome Measures

National Institute of Diabetes and Digestive and Kidney Diseases

ACL Social Care Referrals Challenge

MCC eCare Plan
Federal Partners Meeting
June 14, 2022

Administration for Community Living

Agenda

- Challenge Project Overview
- Challenge Technical Assistance Approach
- HL7 Human Service Resource & Provider Directories FHIR IG
- ACL and eCare Plan Alignment

ACL's Social Care Referrals Challenge seeks health IT solutions to support health care systems and community-based organizations in partnering to provide holistic health and social care for older adults and people with disabilities.

Administration for Community Living

ACL Challenge Project

- Launched in March 2020 as a competition for state and community stakeholders in the aging and disability network to work collaboratively on technical solutions for sharing standards-based social needs data and person-centered plans between health systems and social service providers.
- Promotes the use of open-source standards for service directories from **Open Referral** and for social referrals from the **Gravity Project**.
- Three competitive phases and bonus:
  - Phase 1: Concept & Design Submission (6 winners announced May 2021))
  - Phase 2: Proof of Concept & Demonstration (4 winners announced Dec. 2021)
  - Phase 3: Implementation & Testing (2 winners Q3 2022)
  - Bonus Phase:
    - Mapping Taxonomies (1 winner Q4 2022)
    - Directory Federation (1 winner Q1 2023)

Phase 3 Objectives

- Establish closed-loop referral functionalities that are inclusive of referral management across key stakeholders such as CBOs, health care providers, and health plans.
- Demonstrate use of Human Services Data Specification (HSDS) and related HSDS mapping to HL7 FHIR profiles for standardized, open resource directories that allow for lookup and retrieval of community resources by any state, CBO, or referral vendor.
- Demonstrate use of Gravity Project identified coded terminology (LOINC, SNOMED-CT, and ICD-10) and technical standards (HL7 FHIR) to represent and exchange SDOH data.
- Present data analytics and dashboard visuals that track service delivery and outcomes.

Bonus Phase: Mapping Taxonomies Objective

- To map different terminology codes to standardized codes (e.g., homegrown codes to standardized codes, medical terminology to social codes) for specific social domains and risk factors enabling standardized data within referral management. Incorporates:
  - **Service Taxonomy Mapping.** Mapping of business rules organizing community service organization details such as service type, supported benefits, specific population eligibility requirements.
  - **Coded Terminology Mapping.** Mapping standardized core clinical terminologies in EHRs and use of high-quality terminology maps that are accepted and used by payers, providers, and CBOs.

Bonus Phase: Directory Federation Objective

- To facilitate the ability of a system to identify, differentiate, branch, patch, pull, and push directory resource data.

Directory federation is defined as having the appropriate technical tools that address open-source components to enable transformation, matching, collaborative editing, and syncing of service directory information across multiple technology systems, (e.g., resource directories, community referral platforms, EHR platforms).

TA Deliverable: HL7 Human Service Resource & Provider Directories FHIR IG

- Describes the architectural considerations for accessing data from a directory of social services.
- Specifies methods of aligning FHIR resources that describe healthcare provider directory information (e.g., DaVinci PDEX, U.S. Core IG) with Open Referral's HSDS.
- Specifies RESTful methods for accessing data from HSDS-compliant directories, in alignment with the Human Service Data API protocols (HSDA).
- Target ballot as STU1 for January 2023.
- Project Info: https://confluence.hl7.org/display/HSS/Human+Service+Resource+and+Provider+Directories+FHIR+IG

ACL Challenge & MCC eCare Plan Crosswalk

Project	Use Case(s)	User Groups	Population	Target Systems	Standard(s)
ACL Challenge	Social Care Referral from Clinical to Social Service Provider	Clinical Provider, Health Plan, State Agency, CBO Provider	Older and IDD/DD Adults	EHRs, HIEs, SHARPs, CBO IR&A Systems	Vocabulary/ Terminology: • Gravity Coded Terminology for referrals (SNOMED-CT); 211 LA Taxonomy Content/ Transport: • HL7 Gravity FHIR IG • HL7 HSRPD FHIR IG • HL7 eLTSS FHIR IG • HL7 C-CDA • IHE 360x
MCC eCare Plan	eCare Plan generation and exchange including clinical and social care referrals	Clinical Provider, Patient/ Caregiver, CBO Provider	Chronic Disease Patients	EHRs, HIEs, SMART on FHIR Apps	Vocabulary/ Terminology: • Coded vocabularies for chronic domains and long COVID • Gravity coded terminologies for screening, diagnosis, goals, interventions Content/ Transport: • HL7 MCC eCare Plan FHIR IG

ACL Patient Story for Bonus Phase

- **Six older adults,** diagnosed with **food insecurity,** are discharged from the hospital.
- In each patient's EHR, a referral request is documented for **home-delivered meals program and medically tailored meal program**.
- Hospital EHR system currently integrates with two different Social Health Access Referral Platforms (SHARPs), each with differing resource directories with updated, validated community resource data used for directing referrals to appropriate resources based on defined criteria on population served.
- Referral request is coded using nationally recognized intervention codes (SNOMED-CT) and transferred electronically from the hospital EHR to the SHARP using nationally recognized format and transport standards (e.g., HL7 C-CDA and Direct, HL7 FHIR and REST).
- SHARPs route and track the referral requests to the CBOs incorporated in their respective directories.
- SHARPs track the referral responses and referral statuses using nationally recognized referral management standards (e.g., FHIR Service Request, IHE 360x).

ACL Bonus Phase Use Cases

Use Case 1: Mapping Taxonomies

- The SNOMED-CT coded home delivery meal program and medically tailored meal program referral request from the EHR does not match the taxonomy used by the CBO IR&A system nor the SHARP to represent these types of nutrition programs.
- Key transactions are mapping EHR terminology for meal delivery programs to taxonomies used by CBO IR&A system and SHARP and exchanging translated information across all three systems.

Use Case 2: Directory Federation

- One of the CBOs the SHARP integrates with has access to a home-delivered meals program managed within the CBO's own resource directory in their Information, Referral, and Assistance (IR&A) data tracking system.
- This service program is not identified in the SHARP resource directory.
- All three systems (CBO IR&A, SHARP, and EHR) need to exchange and track referral information for the referred patients. Key transactions are identifying and differentiating directory resource data.

Social Determinants of Health Data Exchange for Chronic Disease Prevention Initiative

June 14, 2022

Federal Partner Meeting Round Robin

Centers for Disease Control and Prevention
National Center for Chronic Disease Prevention and Health Promotion

Office of Informatics and Information Management

NCCDPHP's Core Team Members in our Efforts

Dr. Timothy Carney
Director, OIIRM

Dr. Jennifer Wiltz
Deputy Medical Director, NCCDPHP

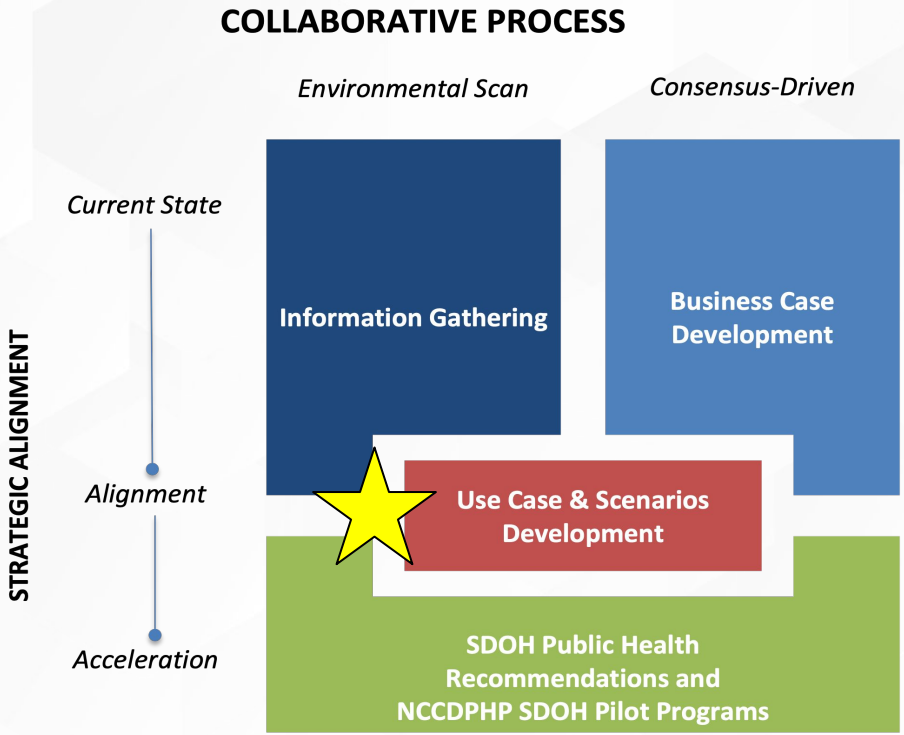
Dr. Pam Pagano
Deputy Director and Operations Team Lead, OIIRM

Dr. Jina Dcruz
Health Scientist (Informatics)

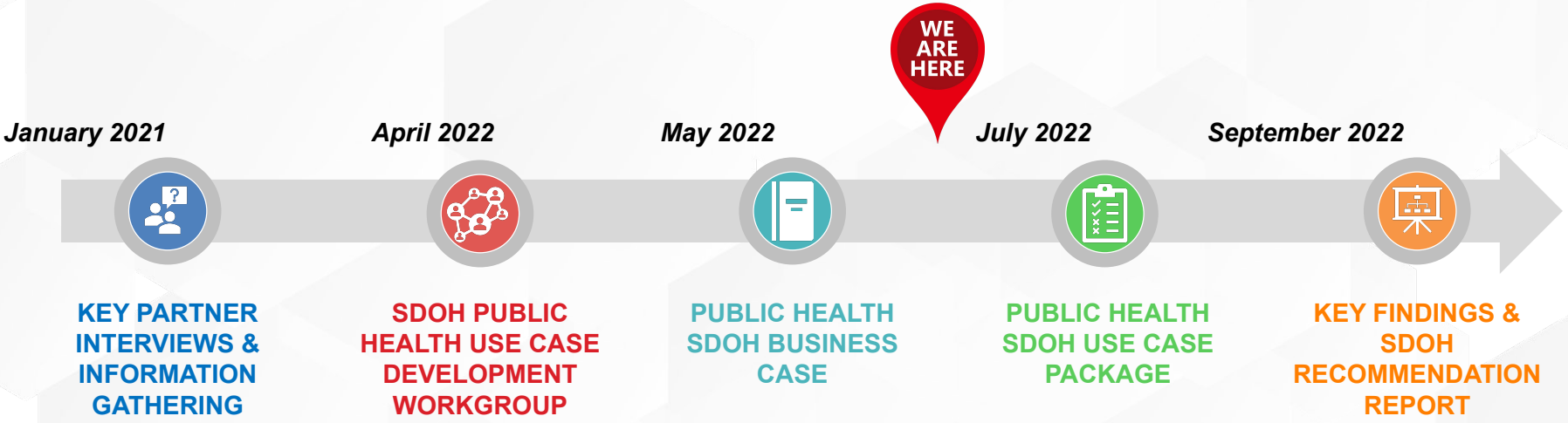
Dr. Kailah Davis
Informatics Science, Research and Evaluation Team Lead

Dr. Pradeep Podila
Health Scientist

Recap: CDC's Social Determinants of Health (SDOH) Data Exchange Initiative Approach



Timeline


WE ARE HERE
January 2021
April 2022
May 2022
July 2022
September 2022
KEY PARTNER INTERVIEWS & INFORMATION GATHERING
SDOH PUBLIC HEALTH USE CASE DEVELOPMENT WORKGROUP LAUNCH
PUBLIC HEALTH SDOH BUSINESS CASE
PUBLIC HEALTH SDOH USE CASE PACKAGE
KEY FINDINGS & SDOH RECOMMENDATION REPORT

Progress Updates

- Conducted 23 key partner interviews and 4 cross-sector listening sessions.
- Launched our Health Level Seven (HL7) Workgroup Confluence site under the Gravity Project.
- Facilitated CDC SDOH workgroup kickoff on April 20, 2022.
- Published the workgroup Project Charter.
- Finalized and presented the data infrastructure gap analysis.
- Gained over 200 participating members to date.
- Collaborated on a workgroup presentation with Clinical and Community Data Initiative (CODI) and the Colorado Health Observation Regional Data Service (CHORDS).
- Published the consensus-based SDOH Public Health Business Case.
- Created Use Case Personas and Story with support and input of workgroup members.

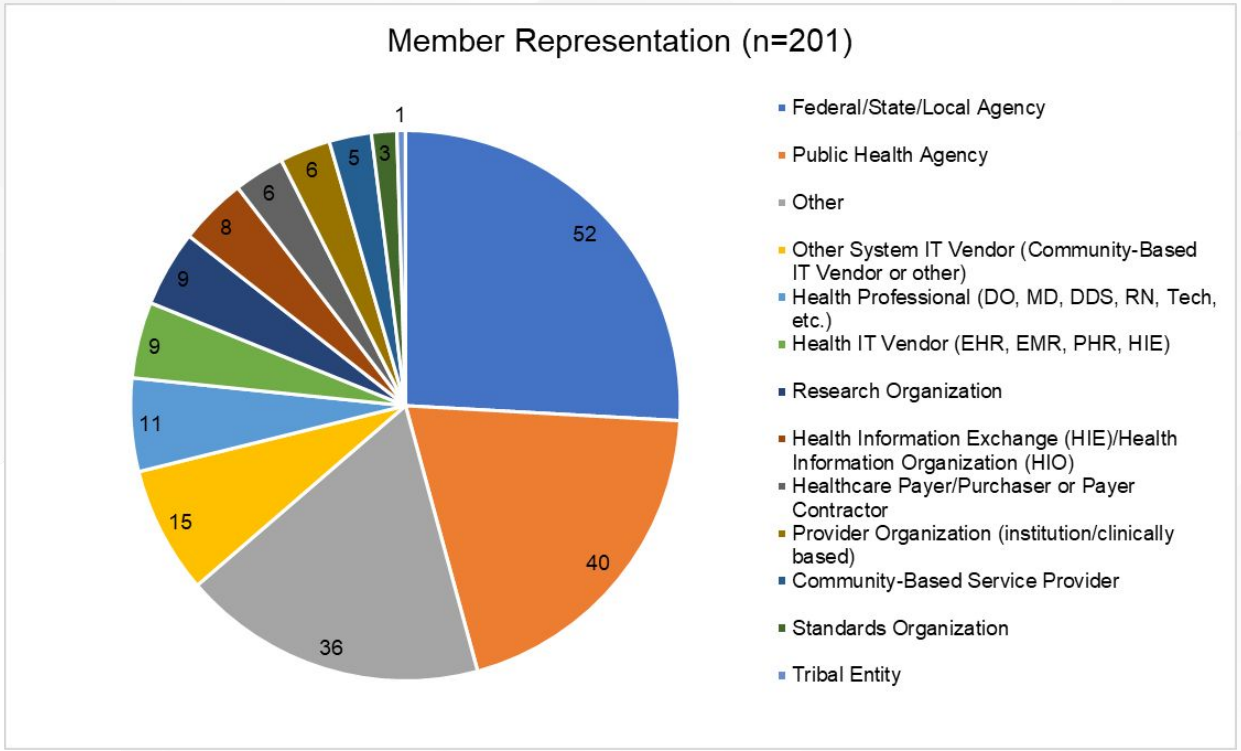
Workgroup Scope

- Develop an SDOH public health **business case and high-priority use cases** for chronic disease prevention and health promotion.
- Design and publish up to three high-priority public health-focused use cases that extend on those developed for clinical care by the Gravity Project.

Public health in the context of this SDOH initiative is defined as “the science of protecting and improving the health of people and their communities. This work is achieved by promoting healthy lifestyles, researching disease and injury prevention, and detecting, preventing, and responding to infectious diseases”[1] and chronic disease prevention and health promotion.

[1] https://www.cdcfoundation.org/what-public-health

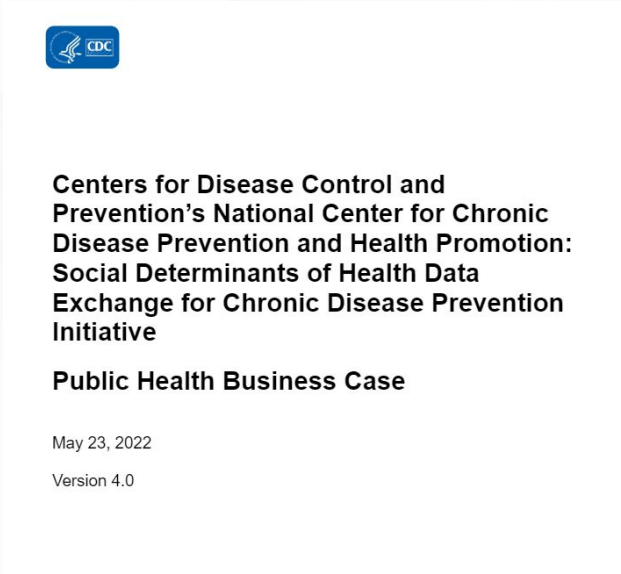
Workgroup Membership



Committed Members = 90
Other Interested Parties = 101

Public Health Business Case Sections

- Introduction
- Initiative Overview
- Public Health Business Need
- Background
- Initiative Goal
- Identified Benefits
- Significant Assumptions & Constraints
- Anticipated Return on Investment
- Initiative Risks and Mitigation Strategies
- Timeline
- Conclusion



URL:
https://confluence.hl7.org/pages/viewpage.action?pageId=90342116#Documents-CDCSDOHPublicHealthBusinessCaseFinalDeliverable

Summary of Consensus Building Comments

Initial Feedback
(April 20 - May 9)

- 24 workgroup members submitted comments on each section.
- General themes:
  - Reference tribal nations more explicitly
  - Expand workgroup member representation
  - Define chronic disease and scope
  - Adding downstream impact of COVID-19
  - Clarify alignment with other CDC and HHS data initiatives

Consensus Voting Period
(May 9 - May 16)

- 7 workgroup members submitted comments during the voting period. Feedback was successfully integrated into the final deliverable.
- General themes:
  - Tech/language edits
  - Gravity Project description adjustment
  - Relevant updates and resources

Next Steps

Workgroup

- Facilitate workgroup meetings 5-8.
- Incorporate workgroup feedback on Use Case 1 & 2 components.
- Develop Use Case 3 in collaboration with NCCDPHP Division of Diabetes Translation.
- Perform an end-to-end review of Use Cases.
- Launch consensus vote on Use Cases 1-3 and publish final deliverable.
- Conclude the workgroup at the end of July 2022.

Post Workgroup

- Continue to support infrastructure advancements at the state and federal level.
- Integration with Helios FHIR Accelerator work.
- Seek funding from Patient-Centered Outcomes Research (PCOR) Trust Fund to support advances data capture and capabilities.
- Inclusion of SDOH use cases for United States Core Data for Interoperability (USCDI)+.
- Ongoing collaboration with CDC's Data Modernization Initiative.

Join the Workgroup!

- If you are interested in participating, we invite you to officially join the workgroup here: https://confluence.hl7.org/display/GRAV/Public+Health+Use+Case+Workgroup+for+Chronic+Disease+Prevention+Home

- For additional Workgroup information, please contact us.
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  - Savanah Mueller at savanah.mueller@emiadvisors.net
  - CDC NCCDPHP Point of Contact: Kailah Davis at lui9@cdc.gov

Office of the National Coordinator for Health Information Technology

Gravity Project and Pilots

National Institute of
Diabetes and Digestive
and Kidney Diseases

Centers for Medicare & Medicaid Services

HL7 FHIR Connectathon - PACIO Integration of Post-Acute Care IGs

National Institute of Diabetes and Digestive and Kidney Diseases

Other Relevant Projects

Agenda

Topic	Time	Presenter(s)
Welcome and Introductions	5 min	Jenna Norton, NIDDK Arlene Bierman, AHRQ
MCC eCare Plan Project Overview and Progress Update	10 min	Jenna Norton, NIDDK Karen Bertodatti, EMI
MCC eCare Plan Topics and Agency Partner Feedback • eCare Planning v2 apps demo and real-world challenges • Update from RTI on pilot testing findings and recommendations	55 min	EMI Advisors RTI International
Federal Projects Round Robin Update	45 min	Federal Partners
Concluding Remarks	5 min	Jenna Norton, NIDDK Arlene Bierman, AHRQ

National Institute of Diabetes and Digestive and Kidney Diseases

Thank You

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Additional MCC eCare Plan Project Links

- AHRQ and NIDDK Confluence Page for MCC eCare: https://ecareplan.ahrq.gov/collaborate/display/EC/eCare+Plan+Home

- HL7 Patient Care Work Group – MCC eCare Project Page: https://confluence.hl7.org/display/PC/Multiple+Chronic+Conditions+%28MCC%29+eCare+Plan