Meeting Summary

Multiple Chronic Conditions (MCC) eCare Plan Federal Partners Meeting

Hosted by: National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and Agency for Healthcare Research and Quality (AHRQ)

Meeting Date: February 22, 2022

Meeting Time: 2:00 PM - 4:00 PM ET

Location: Virtual

Attendees

NIDDK	Federal Partners	Affiliation
Jenna Norton	Kenneth Salyards	ACF
Kevin Abbott	Kailah Davis	CDC
	Maria Michaels	CDC
AHRQ	Pradeep Podila	CDC
Arlene Bierman	Tim Carney	CDC
Djibril Camara	Ellen Blackwell	CMS
Janey Hsiao	Joel Andress	CMS
	Shari Ling	CMS
EMI	Lorraine Wickiser	CMS
Savanah Mueller	Hector Izurieta	FDA
Gay Dolin	Susy Postal	IHS
Karen Bertodatti	Ashley Smith	NCI
Emma Jones	Marcel Salive	NIA
Dave Carlson	Brittney Boakye	ONC
Evelyn Gallego	Carmela Couderc	ONC
	JaWanna Henry	ONC
HL7 Patient Care Work Group Guests	Samantha Meklir	ONC
Laura Heermann	Stephanie Garcia	ONC
Michael Padula		
Stephen Chu		

Agenda

- Welcome and Introductions (10 minutes) - Jenna Norton, NIDDK and Arlene Bierman, AHRQ
- MCC eCare Plan Project Update and Partner Feedback (75 minutes) - EMI team
    - Overall Project Status
    - Data Element Identification, Value Sets & Implementation Guide
    - SMART on FHIR eCare Plan Application Interoperability Infrastructure
    - HL7 Connectathon 29 Care Planning Track Report Out
    - Agency Partner Feedback
- Federal Projects Round Robin Update (30 minutes)
    - ACF, Case Management/HL7 Human Social Services Work Group
    - ACL, Social Referral Challenge Program
    - CDC, SDOH Use Case and Business Case
    - CDC, MedMorph

  - CDC, CPG on FHIR
  - CMS, PACIO Project
  - ONC, Gravity Project Pilots and LEAP
  - ONC, Long-Term and Post-Acute Care
  - NIA, Demonstration Project for Interoperable Health Records in Clinical Research
- Concluding Thoughts and Next Steps (5 minutes) - Jenna Norton, NIDDK and Arlene Bierman, AHRQ

Action Register **Status Key:** P = planned, IP = in progress, C = completed

Task	Owner	Due Date	Status
Share the current list of social elements identified from the MCC project with Ellen Blackwell.	Jenna Norton	n/a	C
Invite the MCC team to CPG-on-FHIR calls to coordinate for the upcoming May HL7 Connectathon.	Maria Michaels	March 1, 2022	C
Add increased and altered need for insulin to the long COVID data element list, as recommended by Hector Izurieta.	Emma Jones	March 4, 2022	C
Connect Jenna Norton and MCC team with mCARD work contact.	Maria Michaels	n/a	C

Discussion

Agenda Topic	Discussion
Welcome and Introductions	● Jenna welcomed attendees and reviewed the agenda. Project support includes EMI Advisors for NIDDK and RTI International for AHRQ.
MCC eCare Plan Project Update and Partner Feedback	**Overall Project Status** ● Karen reviewed the background of the MCC eCare plan project with details on the following points: ○ There has been over a decade of federal funding to improve care coordination and care planning through standards development. ○ The MCC eCare project is modeled after using the comprehensive shared plan definition established by ONC in 2015 as the north star. ○ The purpose of the MCC eCare project is to develop an interoperable electronic care plan to facilitate aggregation and exchange of patient-centered data across multiple settings for people with MCC. ○ The three deliverables for the project are: ▪ data elements and value sets in key domain areas to enable standardized transfer of data, ▪ provider-, caregiver-, and patient-facing electronic care plan applications, and ▪ a FHIR Implementation Guide (IG).

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MCC eCare Plan Project Update and Partner Feedback	○ The governance model for the project demonstrates executive management from the NIDDK and AHRQ co-leads with work organized into development and real-world testing activities. **Data Element Identification, Value Set, and Implementation Guide** ● Gay recapped a summary of the work for the data elements and value sets deliverable accomplished during Year 1 and Year 2 of the project. ● Now, in the current year three, the project team is working on: ○ revisiting the existing value sets, ○ identifying data elements for long COVID, ○ building and updating value sets in the Value Set Authority Center (VSAC), and ○ revising the structure and approach for the IG design. ● Gay presented on the proposed IG design with the following key points: ○ If we are to include the 1,100+ data elements identified in Years 1 and 2 into the IG using the current design style, it would add 600+ new profiles to the IG and cause profile proliferation. ○ The team recommends creating MCC "Foundation" profiles and reference value sets using a value set "library"; the library will be a page with lists of value sets housed in VSAC organized by profile type. "Foundation" MCC eCare profiles could include a "Condition" Profile, a "Procedure" Profile, a "Goal" Profile, and a "Lab" Profile. ● Emma gave an overview of the data element gathering process the project team has been using with the Long COVID/Caregiver Technical Expert Panel (TEP). ○ The data element gathering process uses the same care planning framework to organize the collection of the data elements in four main areas: health concerns, goals, interventions, and outcomes. ○ The team is using a live spreadsheet in Google Drive to collect and organize the identified data elements. ● Ellen Blackwell requested additional information on social issues related to long COVID. ○ Emma responded saying these data elements are being gathered from the current TEP members; in addition, the team will align this list with social elements defined by the Gravity Project, such as homelessness, joblessness and food insecurity. ○ Ellen requested a list of social factors. ○ **Action:** Jenna will share the current list of social elements identified from the MCC context. ○ Stephen Chu added that there are two aspects for social factors: social risk factors for the condition and social factors modifiable by condition based on the severity of disease i.e., sequelae.

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MCC eCare Plan Project Update and Partner Feedback	○ The HL7 Patient Care Work Group meeting information can be found here; this is a good forum to continue discussion around the data elements, value sets, and IG design for the MCC eCare Project. **SMART on FHIR eCare Plan Application and Interoperability Infrastructure** ● Dave gave an update on the work for the SMART on FHIR patient-, provider-, and caregiver-facing apps. ● The work accomplished in Year 3 included evaluating the inherited interoperability infrastructure and app designs, developing a proposed infrastructure architecture strawman, building a prototype for the patient/caregiver app v2.0, setting up a testing environment, and establishing an agile development and testing process with RTI International. ● The provider app is undergoing usability testing and iterative improvements based on initial feedback. ● The project team developed a prototype for the patient/caregiver app which builds on the v1.0 patient app and combines functionality for the caregiver role. ○ Other intentional design features of this prototype include adding the ability to communicate directly with any FHIR endpoint and making it easily configurable for real-world testing. ○ The next steps for the patient/caregiver app include exploring the use of value sets to classify and present data, building the feature for authoring patient goals, and identifying minimum viable product (MVP) features list for the caregiver perspective. ● Dave shared the key finding from the team's evaluation of the inherited interoperability architecture which is that the inherited architecture does not yet support aggregation of data across multiple provider organizations; this aggregation across multiple organizations is a key component for developing a comprehensive shared care plan. ● The team proposed a new MCC eCare Plan architecture which will support authoring and saving new content in both the provider and patient/caregiver applications that isn't natively supported in EHRs; this would be done through a FHIR façade and a supplemental data store. ● Dave summarized the presentation with a list of in scope capabilities for the MCC eCare Project applications which include shared goal management between patients and the rest of the care team, exploring the relationship of goals to interventions and outcome measures, and authoring and monitoring of progress toward goals. ● Some opportunities for collaboration with other projects that would be useful for the goal of comprehensive shared care planning include patient corrections, preventative care recommendations, design and

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MCC eCare Plan Project Update and Partner Feedback	implementation for a FHIR façade server and potential collaboration with a Trusted Exchange Framework and Common Agreement (TEFCA) pilot.
	
	HL7 FHIR Connectathon 29 Care Planning Track Report Out
	● Dave and Emma provided a recap from the HL7 FHIR Connectathon that took place in January 2022.
	● The Care Planning track during the Connectathon focused on discussion around the usefulness of goals and conditions.
	● Major accomplishments include a demo transforming a C-CDA document into FHIR, shared interest in the use of CQL logic for patient-centered goal management, and goal identification and documentation within the clinical workflow.
	● The Care Planning track discovered two key issues:
	  ○ There is no guidance on how to capture and share a patient's barriers/risks as well as protective factors that impact progress on a goal, and
	  ○ The need to be able to capture and share prioritization ordering of goals in terms of a specific sequence in addition to capturing whether the goal is of high/medium/low priority.
	● The upcoming FHIR Connectathon in May 2022 will discuss and test goals and relationships between goals and interventions and outcomes.
	  ○ The team requested feedback from the federal partners on opportunities to collaborate or co-host sessions.
	  ○ Maria Michaels recommended the MCC project team to join the CPG-on-FHIR calls before the May Connectathon to discuss collaboration.
	  ○ **Action:** Maria to connect MCC team with the CPG-on-FHIR work group contact to join an upcoming work group call.
	  ○ Dave acknowledged this connection and added that there are plans to collaborate with Bryn Rhodes, HL7 Clinical Decision Support co-chair, already.
	
	Agency Questions and Feedback
	● Hector Izurieta recommended the inclusion of increased/altered need for insulin with long COVID.
	  ○ Jenna and Emma indicated identification of these data elements is an iterative process with the TEP and encouraged feedback and recommendations during the TEP calls.
	  ○ **Action**: Emma to include increased/altered need for insulin in the long COVID data element spreadsheet.
	● Laura Heerman requested clarification surrounding labs.

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MCC eCare Plan Project Update and Partner Feedback	○ Dave responded the prioritization of labs would be necessary in knowing which labs to present in the apps across multiple conditions. ○ Laura recommended connecting with Dr. Nathan Davis and Dr. Nathan Davis, Intermountain Healthcare, and Dr. Stan Huff, University of Utah School of Medicine, to inform this work. ○ Jenna noted that patients and physicians of different specialties may have different priorities for which labs would be most important to display. ○ Dave commented this work may tie nicely into the CPG-on-FHIR work.
Federal Partners Round Robin Updates	● Ken Salyards provided an update from the Administration for Children and Families (ACF). ○ A new work group within HL7 has been created called the HL7 Human and Social Services Work Group (HSS WG). The HSS WG has been working on several items associated with projects that ACF is looking to advance. ○ Projects include consent management, closed-loop referral, and case management. The current work is on defining these projects and pushing for implementation from an HSS WG and FHIR perspective. ○ ACF currently has infrastructure built on FHIR R4 which enables implementation of the FHIR care plan. ○ Dave invited ACF to coordinate participation for the May Connectathon. ● Evelyn Gallego provided an update on the Administration for Community Living (ACL) Social Care Referral Challenge Program. ○ The EMI team provides technical assistance to the ACL Social Care Referral Challenge Program. The Program recently awarded Phase 2 funding to four entities. ○ The Program is currently working through the criteria for Phase 3 funding and a Bonus Phase. ○ The Bonus Phase is designed to address two areas of opportunity. Entities will be able to apply for support to address two goals: ▪ The first goal is to create a federated directory which would address current challenge in the market of having multiple provider directories in use without a federated model. The is a lot of work underway e.g., clinical side there is the DaVinci work on the Validated Healthcare Directory (VHDir) FHIR IG. There is a proliferation of directories, many of them using the open referral standard, Human Services Data Specifications (HSDS).

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Federal Partners Round Robin Updates	▪ Goal two focuses on terminology and better aligning medical taxonomy (e.g., what Gravity uses to standardize taxonomy in clinical settings) and community-based referral taxonomies (e.g., AIRS taxonomy which is used by many of the 211 taxonomies). ○ Phase 3 addresses capacity building and implementation in the field at the local level. ● Tim Carney gave an overview of the new CDC project for Social Determinants of Health (SDOH) Data Exchange for Chronic Disease Prevention Initiative. ○ The work began in September 2021 and builds off of the work from Gravity Project. It aims to improve population health activity around clinical-community connectivity through the creation of a data strategy that underlines SDOH and health equity. ○ The CDC is approaching this work through the lenses of eight CDC divisions which include the Division of Cancer Prevention and Control, the Division of Diabetes Translation, and the Division of Heart Disease and Stroke Prevention, to name a few. ○ High level target areas include food insecurity, social connectedness, community-clinical linkages, tobacco-free policy, and built environment. ○ Tim highlighted three core SDOH data challenges and summarized existing efforts the National Center for Chronic Disease and Public Health Promotion (NCCDPHP) is working on. ○ The CDC SDOH Data Exchange for Chronic Disease Prevention Initiative aims to advance 10 essential public health services, expand the collection, sharing, and use of data, accelerate SDOH pilot efforts, and align SDOH across sectors. ○ The work of building a better use case is important for identifying opportunities for acceleration of this work, raising of this work among federal partners, supporting CDC priorities, and supporting federal health IT priorities. ○ The use case that will be developed through this work will build off of the clinical documentation that already exists through Gravity Project and add in non-clinical and administrative data sources to understand what public health decision makers and program managers need. ○ This work includes a collaborative and consensus-driven process to develop the business case and will include a call for participation for the working group to define the actual use cases starting in Spring of 2022.

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Federal Partners Round Robin Updates	○ Evelyn added this project is a sub-project under the Gravity Project and is the first to focus on a public health use case. ● Maria Michaels provided an update on MedMorph. ○ MedMorph stands for Making EHR Data More Available for Research and Public Health. ○ This project is relevant to MCC eCare project because it will be the method for how to exchange data from an EHR to the care plan application and to wherever it needs to go on FHIR. ○ The MedMorph team is still working on publishing version 1 of the reference IG. ● Maria Michaels shared progress on Clinical Practice Guidelines (CPG) on FHIR. ○ The project is focused on developing computable clinical knowledge which could include decision support and quality measures. ○ Version 1 of the CPG-on-FHIR IG has a section on care plan and was published in 2021. ○ The CPG on FHIR team would be interested in enhancing the work around prioritization of labs or including care planning for multiple domains. While the IG is content agnostic, the team would welcome the opportunity to tweak the IG to allow for additional use of these frameworks. ● No representative was available to provide the PACIO project update. ● JaWanna Henry provided an update on the Gravity Project Pilots. ○ Under ONC's cooperative agreement with HL7, ONC is providing support to accelerate the shift to FHIR-based exchange and providing incentives to community-based organizations to participate standards-based data exchange for clinical systems. ○ Working on finalizing two pilot sites to test different FHIR resources referenced in the SDOH Clinical Care IG through two phases of the project which end in January 2023. ○ JaWanna also provided an update on the Leading Edge Acceleration Projects (LEAP). They are working with the University of Texas in Austin, and the project focuses on developing applications to advance health IT standards and tools to exchange SDOH data. LEAP stakeholders include work with EMI Advisors, Unite Us, and FindHelp (Aunt Bertha). ○ Evelyn added that the Gravity Pilots will be a new work group under the Gravity Project and there will be a public call for participation. The two ONC-funded Gravity Pilot sites will be invited, along with the LEAP awardee and the ACL Challenge

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Federal Partners Round Robin Updates	Awardees. All other entities with a desire to test the Gravity IG are invited to attend the public work group calls. ● No representative was available to provide the ONC Long-Term and Post-Acute Care update. ● Marcel Salive shared an update from the National Institute on Aging (NIA). ○ The National Advisory Council on Aging (NACA) just approved a concept for "Demonstration Projects to Promote Use of Interoperable Health Records in Clinical Research." ○ This concept is designed to address fragmentation of medical records for research purposes with a focus on multiple chronic conditions. ○ This concept is expected to turn into a funding opportunity sometime in the summer. ○ Arlene proposed sharing the MCC standardized data elements for potential applicants to build upon when the NIA makes the funding announcement. ▪ Marcel commented that they will do the funding announcement first and then provide a few webinars for people to understand what this work is about. ▪ Jenna requested to be informed when the webinars are relevant. ○ Maria identified one of the MedMorph content implementation guides on research exchange as a resource that may be relevant for this work. ● Maria mentioned the new mCARD project through the CodeX FHIR Accelerator; this model may be relevant for chronic conditions. ○ **Action:** Jenna asked Maria to provide a contact for the MCC team to learn more about mCARD. ○ JaWanna shared in the chat the meeting registration link for the CodeX Community of Practice February 2022 Meeting.
Concluding Thoughts and Next Steps	● Karen noted the next Federal Partners meeting will take place in June. ● Attendees will receive the summary, and people who could not attend will receive the meeting recording. ● Jenna thanked the Federal Partners for updates, and Arlene invited them to share feedback and updates between meetings, as necessary.