National Institute of Diabetes and Digestive and Kidney Diseases

MCC e-Care Plan Project | PASC & Caregiver Technical Expert Panel (TEP) Monthly Meeting Summary

Meeting Date and Time: October 3, 2023, 2:00 pm - 3:30 pm ET
Meeting Location: Virtual (Zoom)

The PASC & Caregiver TEP convenes on a biannual basis to inform the work of the MCC e-Care Plan Project which is led by NIDDK and AHRQ. More information about the PASC & Caregiver TEP can be found on the Confluence page here. For this TEP meeting, we have also invited the previous TEPs that have been convened for the MCC project over the years. More information on these TEPs can be found here.

Attendance

Present	Absent
MCC e-Care Team ● Arlene Bierman, AHRQ ● Dave Carlson, Clinical Cloud Solutions ● Evelyn Gallego, EMI Advisors ● Gay Dolin, Namaste Informatics ● Himali Saitwal, EMI Advisors ● Jacqueline Bagwell, RTI International ● Jenna Norton, NIDDK ● Joel Montavon, RTI International ● Karen Bertodatti, EMI Advisors ● Keegan Barnes, RTI International ● Kevin Abbott, NIDDK ● Laura Marcial, RTI International ● Neha Shah, NIDDK ● Rachael Boicourt, AHRQ ● Savanah Mueller, EMI Advisors ● Sean Muir, JKM Software TEP members ● Aluko Hope, OHSU ● Anuj Dalal, Brigham and Women's Hospital ● Audie Atienza, NIH/NCATS ● Carla Rodriguez-Watson, Reagan-Udall Foundation for the FDA ● Diana Berrent Guthe, Survivor Corps ● Emily Taylor, Solve M.E. ● Hector S. Izurieta, FDA	MCC e-Care Team ● Jaime Zimmerman, AHRQ TEP Members ● Alex Spyropoulous, Northwell Health ● Allan Levey, Emory ● Andrea Lerner, NIH/NIAID ● Barrett Bowling, Duke ● Ben Abramoff, Penn Medicine ● Bill Adams, Boston Medical Center ● Caroline Blaum, NCQA ● Catherine Des Roches, Harvard University ● Charisse Madlock-Brown, University of Tennessee Health Science Center ● Claire Ashton-James, University of Sydney ● Danielle Peereboom, Johns Hopkins Bloomberg School of Public Health ● David Dorr, OHSU-Oregon ● David Graham, FDA ● Elizabeth Unger, CDC ● Esther Oh, Johns Hopkins University ● Glenna Brewster Glasgow, Emory ● Jeff Sparks, Brigham and Women's Hospital ● Jennifer Wolff, Johns Hopkins University ● Karen Rose, Ohio State University

National Institute of Diabetes and Digestive and Kidney Diseases

• Henry Parkman, Temple University • Ivonne H. Schulman, NIDDK • Jerry Osheroff, TMIT Consulting • Jerry Suls, Northwell Health • Kailah Davis, CDC • Katie Brandt, Massachusetts General Hospital • Pradeep Podila, CDC • Rachel L Garfield, University of Vermont Medicine Previous TEP members • Joseph Vassalotti, NKF • Kam Kalantar-Zadeh, UCLA • Manisha Jhamb, University of Pittsburgh • Mary Lynn McPherson, University of Maryland • Miguel Vazquez • Nancy Kusmaul, University of Maryland, Baltimore • Raquel Greer, NIDDK Guests • Emily Ann Meyer, HHS/OASH • Jamie Green, Geisinger • Josh Richardson, RTI International • Karin Rhodes, AHRQ • Sean Bruna, AHRQ • Tim Carney, CDC-NCCDPHP-OIIRM • Vonetta Dotson, AHRQ	• Kevin Bozic, UT Austin • Laura Plantinga, Emory • Loretta Christensen, IHS • Marcel Salive, NIA • Marlis Gonzalez Fernandez, Johns Hopkins University • Patricia Dykes, Harvard University • Safana Siddique, CDC • Shelly Spiro, Pharmacy HIT CollaborativeAlecia Clary, The Reagan-Udall Foundation for the FDA

Agenda

- Welcome (5 min) - Karen Bertodatti
- Project updates (15 min) - Karen Bertodatti
- MCC eCare FHIR IG (25 min) - Gay Dolin
- Value set updates/maintenance (20 min) - Himali Saitwal
- eCare Project in Practice (10 min) - Jenna Norton and Arlene Bierman
- TEP round robin updates (10 min) - Discussion
- Next steps (5 min) - Karen Bertodatti

Discussion

National Institute of Diabetes and Digestive and Kidney Diseases

Meeting Notes	Feedback, Decisions, and Actions
Welcome	● Karen welcomed and introduced attendees. These included all of the TEP members and guests that have informed this project. ● Karen reviewed the agenda and introduced the NIDDK and AHRQ project leads, and EMI contractors. ● Karen thanked the Technical Expert Panels for their contributions to this project.
Project Updates	● The objective of the MCC eCare Plan project is to build capacity for pragmatic, patient-centered outcomes research by developing an interoperable electronic care plan to facilitate the aggregation and sharing of critical patient-centered data. ● The three deliverables to support the development portion of this project include the identification of data elements, value sets, and FHIR mappings for five chronic conditions, the development of an HL7 FHIR Implementation Guide, and pilot-tested SMART on FHIR apps. ○ For more information on the apps, please email Karen at karen.bertodatti@emiadvisors.net. ● The project is co-led by NIDDK and AHRQ. NIDDK supports the development side while AHRQ supports the real-world testing work. The development work is informed by the technical expert panels and the HL7 Patient Care Work Group. The entire project is overseen by a federal partner committee and contract monitoring board. ● The EMI Advisors team took over the project work as the prime contractor during year three with a focus on updating the clinician and patient/caregiver app, identifying Long COVID data elements, and balloting and publishing the IG. ● The focus for this contract year is reviewing IG ballot comments to update and publish the IG, attending Connectathons to get implementation feedback, iterating on the apps to improve care planning for people with MCC, and performing real-world testing of the value sets.

MCC eCare FHIR IG	● Gay prefaced that a FHIR IG takes the FHIR standard and puts together rules and constrains resources to be used for a particular use case.
	  ○ The MCC eCare Implementation Guide uses the framework of the FHIR care plan resource and builds it together for three use cases.
	  ○ One goal is to take advantage of what is already in the EHR to support care planning, rather than be a source of duplicate documentation.
	● Gay recapped how the MCC IG is designed, reusing and constraining the US Core Care Plan. The additions the team made were to Goal.extension:resource-pertainsToGoal, Condition.onset,

Meeting Notes	Feedback, Decisions, and Actions
	and Condition.recordedDate. ○ Resource-pertainsToGoal links conditions to goals and interventions to outcomes. ● Gay explained that the IG development and terminology team created libraries of value sets that can be used with the MCC profiles, rather than creating over 500 profiles. ○ The value sets libraries are organized on condition category, describing what context the value sets would be used in. ● The team has balloted the IG twice, once for-comment and once for Standard for Trial Use (STU) ballot. ○ The comments during the second ballot revolve around the plain language summary, clarifications around Care Team, tech edits, value set application, and clarification on health concerns' relationship to condition. ● Gay reviewed the significant changes in the IG during this second round of balloting. ○ Most notable is the addition of the plain language summary. Gay is also the HL7 US realm program manager; in this role, she emphasized that a goal within HL7 is to include non-tech user-friendly summaries in the IGs. ○ The MCC IG is the first to implement this. There are two viewing methods in the IG: one is embedded on the home page while the other is a drop-down. ○ Gay invited TEP members to review and comment on the plain language summary. ■ Emily Taylor shared that they call their plain language summaries "Energy Saving Summaries" which patients with energy-limiting disabilities have appreciated. ○ Other major changes include: ■ Alignment to US Core 6.1, which provides the design for USCDI v3. ■ The author resource was replaced with custodian through the preadoption of the FHIR R5 custodian extension. ■ Added guidance on how to transmit aggregated health data from multiple sources. ■ Clarified text outcome representation for patient-reported items. ○ Any questions on the IG can be directed to karen.bertodatti@emiadvisors.net and gdolin@namasteinformatics.com. ● Karen reviewed the timeline for balloting and publishing of the IG. The team is working on reconciling the ballot comments from the September 2023 ballot. The team aims to publish the IG in early

Meeting Notes	Feedback, Decisions, and Actions
	2024.
Value set updates/ maintenance	● Himali reviewed the framework of how the TEP members informed the identification of data elements. ○ TEP members identified data concepts, which the terminologists would assess, build value sets, and determine which FHIR profiles were best to represent them. If no existing FHIR profile was suitable, then they would create a new one. ○ The PASC TEP focused on Long COVID and Caregiver data elements. This was facilitated through global literature reviews, personal experiences of TEP members, and ongoing research. ● Himali shared the process of maintaining and updating the MCC value sets. She added that this was the first time we were able to successfully update the value sets. ○ She mentioned the importance of maintenance, especially for Long COVID, as it is still being actively researched. ○ Himali first tagged the ICD-10 and SNOMED grouper value sets in the Value Set Authority Center (VSAC) that are in the IG to differentiate from all the value sets sponsored by the HL7 Patient Care Work Group. ○ With these tagged value sets, she generated the MCC eCare Dashboard from the collaboration management feature on VSAC. ○ The dashboard creates a report of outdated codes which can then be updated with replacement codes. ○ The next update will be at the end of July 2024. ○ Any questions can be directed to himali.saitwal@emiadvisors.net. ● Karen shared that the list of value sets can be viewed in the MCC IG. The links in the IG are connected to VSAC. ● Hector Izureta asked about the adaptability of the long COVID conditions value set as this research is still a work in progress. ○ Gay responded that the intention is not to re-ballot annually until people are implementing. Instead, the team has been discussing having another webpage on the NIH project collaboration page to house the updated value sets reflecting recent research. This webpage can be updated without going through the entire HL7 balloting process. ○ Jenna added that these data elements are not definitional of Long COVID but rather the symptoms that have been coming up. These value sets will support future research in this space to understand a long COVID case definition. The value set library approach allows people to add additional

Meeting Notes	Feedback, Decisions, and Actions
	value sets as we learn more and shape these moving forward. ○ Jenna invited attendees to share any instances of implementation of these value sets. ■ Himali added that these value sets are being used in a machine learning project funded by ONC that uses real-world HIE data to answer research questions about COVID-19 and related conditions. ○ Arlene added that this work was designed to build capacity to do real world research on people with multiple chronic conditions.
eCare Project in Practice	● Jenna shared that the National Institute on Aging (NIA) announced during a recent Federal Partner Meeting a new project to promote the use of interoperable health records in clinical research. The eCare plan was able to include some language acknowledging the foundation of the eCare project in the NOFO. ○ Two projects have since been funded at the end of the 2023 fiscal year as a result, and they will leverage the eCare application or implementation guide. ○ MC COMPARE led by David Dorr and Lipika Samal at OHSU is evaluating how to manage high blood pressure through the use of additional aggregated data. ○ Demonstrating the potential for electronic health record interoperability to improve patient safety research of older adults over the acute episode of care is another study led by Anuj Dalal and Robert Rudin at Brigham and Women's Hospital. It will empower patients to locate, collect, and share their EHR data for research. ● NIDDK released a new project supporting pilot interventions to integrate social care and medical care to improve health equity. This project is looking at approaches to implement screening for social risks and address them through closed-loop referrals. ● Arlene shared that the eCare plan is a tool to support integrated care planning for patients with MCC, but there is still a ways to go before care plans are regularly implemented. AHRQ is trying to expedite this through the ACTION Network RFTO. This will include TEPs, stakeholder panels of health system leadership and payers, and a learning community. It will start in 2024. For more information, please reach out to arlene.bierman@ahrq.hhs.gov. ○ The request for information that was sent out during planning produced 59 responses. ● Jenna highlighted that USCDI v4 is implementing Care Planning data elements.

National Institute of Diabetes and Digestive and Kidney Diseases

Meeting Notes	Feedback, Decisions, and Actions
	● Jenna shared that there is a newly funded study to facilitate social risk-informed care plans using clinical decision support. Evelyn added that is it focused on two chronic conditions, hypertension and type 2 diabetes. The data elements we have included can support this new work.
TEP round robin updates	● Karen shared an update from Emily Taylor (Solve M.E.). Solve M.E. is a nonprofit organization that serves as a catalyst for critical research related to diagnostics, treatments, and cures for Myalgic encephalomyelitis, long COVID, and other post-infection diseases. ○ They released a new platform called Solve Together which is a dynamic, patient-centered platform that integrates multiple data sources designed to speed up the discovery of treatments and cures. ○ They make data on post-infectious diseases accessible to researchers, expediting the identification of diagnostic and therapeutic targets. Patients can create reports for their doctors, sync health-tracking wearables, and discern their distinct symptom and health trends. ○ For more information, please reach out to ETaylor@solvecfs.org. ● Jerry Osheroff shared work following the AHRQ Evidenced Based Care Transformation Support initiative which led learning health systems in achieving the quintuple aim. One of the focuses is on identifying care gaps for patients with chronic kidney disease pain management with opioid use. This work explores how to use EHR tools in a vendor-agnostic way to identify care gaps. They are considering using the MCC value sets and IG to support this work. ○ Jerry shared a link to learn more about the LHS Collaborative initiative.
Next steps	● Karen invited TEP members to follow the Confluence page for updates on the project. ○ In particular, she invited any TEP members who are using or planning to use the MCC value sets or open-source care planning applications to let us know at karen.bertodatti@emiadvisors.net. NIDDK and AHRQ are eager to learn how these project deliverables hold up in real world settings. ● Jenna thanked the TEP for their participation and support.