



National Institute of
Diabetes and Digestive
and Kidney Diseases

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: June 29, 2023

Meeting Time: 10:00 AM - 12:00 PM ET

Location: Virtual

Attendees

NIDDK	Federal Partners	Affiliation
Jenna Norton	Carmela Royba	AHRQ
	James Swinger	AHRQ
AHRQ	Karin Rhodes	AHRQ
Arlene Bierman	Annie Syed	AHRQ Fellow
Jaime Zimmerman	Deb Sanchez-Torres	CDC
Rachael Boicourt	Kailah Davis	CDC
	Maria Michaels	CDC
EMI	Pradeep Podila	CDC
Evelyn Gallego	Benjamin Picillo	CMMI
Himali Saitwal	Brian Waldersen	CMMI
Karen Bertodatti	Genevieve Kehoe	CMMI
Savanah Mueller	Mitchell Beers	CMMI
Dave Carlson (Clinical Cloud Solutions)	Rachel Roiland	CMMI
Gay Dolin (Namaste Informatics)	Ellen Blackwell	CMS
	Lorraine Wickiser	CMS
RTI	Puja Nair	CMS
Jacqueline Ortiz	Shari Ling	CMS
Laura Marcial	Janel Parham	HRSA
	Joan Weiss	HRSA
OHSU	Susy Postal	IHS
David Dorr	Ashley Wilder Smith	NCI/ORB
Michelle Bobo	Marcel Salive	NIA/NIH
	Shalanda A. Bynum	NINR
	Brenda Akinngbe	ONC
	JaWanna Henry	ONC
	Liz Turi	ONC
	Meley Gebresellassie	ONC
	Wanda Govan-Jenkins	ONC
	Martina Azar	VA

Agenda

- Welcome and Introductions
- MCC eCare Plan Project Progress Update
 - Overall Progress Summary
 - Pilot/Focus Group Feedback



National Institute of Diabetes and Digestive and Kidney Diseases

- IG Walkthrough and STU Ballot
- App development approach and updates
- Federal Projects Round Robin Update
 - AHRQ - CDS and CDSiC
 - HRSA - GWEPS and NOFO
 - NIH/NINR - NOFO on healthcare-community partnered social needs and SDOH interventions
 - ONC - LEAP, eLTSS FHIR IG and Implementation, Draft USCDI v5, HTI-1 Clinical Decision Support, ONC Progress in Social Determinants of Health (SDOH) Information Exchange Activities, TEFCA Overview and Updates
 - CMS CMMI - Specialty Care Integration
 - ASPE - Equity Consortium Plans
- What's Next for the eCare Plan Project?
- Concluding Thoughts & Next Steps

Discussion

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Welcome and Introductions	<ul style="list-style-type: none"> ● Jenna Norton (NIDDK) thanked attendees and highlighted the value of these federal partner meetings in fostering learning about developments in the field, often influencing the direction of their work and identifying avenues for collaboration. ● Arlene Bierman (AHRQ) described the importance of care planning and the necessity of integrating it into practice and workflow. She introduced an initiative by AHRQ through the ACTION 4 Network funding to increase the uptake and scale of person-centered care planning, with David Dorr (OHSU) serving as one of the investigators. <ul style="list-style-type: none"> ○ This project will include a stakeholder roundtable and a learning collaborative. She encouraged attendees to suggest individuals for participation in these initiatives, emphasizing the importance of gathering diverse perspectives.
MCC eCare Plan Project Progress Update	<ul style="list-style-type: none"> ● Overall Progress Summary <ul style="list-style-type: none"> ○ Karen Bertodatti (EMI), serving as the project manager for the NIDDK contract, acknowledged the project's collaborating contractors, EMI Advisors and RTI International, and the implementation and pilot partner, Oregon Health and Sciences University (OHSU). ○ Karen provided background for the project. This project focuses on individuals with multiple chronic conditions (MCCs) and the challenges they face within the healthcare system. These challenges include fragmented care delivery, data interoperability issues, and disparities in care among different demographic groups. ○ To address this, the project will develop three deliverables: <ul style="list-style-type: none"> ■ Identification of data elements for five initial chronic disease domains,

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	<ul style="list-style-type: none"> <ul style="list-style-type: none"> <ul style="list-style-type: none"> ■ Development of a Health Level 7 (HL7) Fast Healthcare Interoperability Resources (FHIR) implementation guide, and ■ Creation and pilot testing of clinician-, patient- and caregiver-facing care plan applications. ○ Karen shared that we are in year five of the project, and are currently developing and implementing the HL7 FHIR implementation guide and the SMART on FHIR apps. ● Pilot/Focus Group Feedback <ul style="list-style-type: none"> ○ Laura Marcial (RTI) highlighted the work done to date, including focus groups with clinicians, primarily led by OHSU. ○ Michelle Bobo (OHSU) discussed the timeline and objectives of the focus groups. <ul style="list-style-type: none"> ■ The focus groups aim to gather formative feedback from clinicians working with patients with multiple chronic conditions. The sessions are divided into three rounds to guide application development and evaluate the new version of the app. ○ Results of the first focus group identified priority areas for application enhancements and new feature development. <ul style="list-style-type: none"> ■ Key themes included the need for current, reliable, and actionable information, improved communication across the care team, better documentation and inclusion of all members of a patient's care team, and enhanced access to social concerns. ■ Feedback from clinicians highlighted the desire for more customization options, concerns about data accuracy, and the need for deeper information presentation in a minimalist interface. ■ Overall, providers valued having access to patient-reported information but expressed concerns about its trustworthiness. Data integration from multiple sources was seen as valuable as long as redundancy was minimized. ○ Ellen Blackwell asked for clarification on “Who is the caregiver?” She raised concerns about identifying the appropriate caregiver to grant access to patient information. <ul style="list-style-type: none"> ■ Michelle Bobo clarified that the focus in this setting is on patients who have designated a family member as a legal proxy to access their records. ■ Arlene Bierman added that pilot testing involves patients, caregivers, and clinicians to ensure that patients have control over who their caregiver is and what information they can access.

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	<ul style="list-style-type: none"> <ul style="list-style-type: none"> <ul style="list-style-type: none"> ■ Jenna added that the project is considering different levels of information access and caregiving roles among family members. While these considerations have been recognized, they have not yet been fully implemented in the current versions of the system. ○ Maria Michaels (CDC) recommended engagement with the HL7 working group focused on defining the care team, as they could offer valuable insights and help establish standards for broader use beyond the current project. <ul style="list-style-type: none"> ■ Karen added that the project incorporated caregiver perspectives from the Technical Expert Panel (TEP) convened in year three of the project. One recommendation was to include the Caregiver Strain Index, a questionnaire that measures strain on the caregiver, in the app. ● IG Walkthrough and STU Ballot <ul style="list-style-type: none"> ○ Gay Dolin (Namaste Informatics) provided an overview of HL7, emphasizing the development of a standard that leverages FHIR for data queries and retrieval. ○ This project created the MCC eCare Plan Implementation Guide, which is undergoing comment reconciliation and being prepared for publication. <ul style="list-style-type: none"> ■ The IG's use cases include upgrading and supporting specific care plans within clinical contexts and exposing shared e-care plans to clinical care teams, patients, or caregivers. ■ CareTeam exists within HL7 standards, but enhancements are being made to the care team domain analysis model. ○ Gay also showcased the home page of the implementation guide and discussed plans to incorporate plain language summaries into future guides, following experimentation and positive feedback. ○ Key updates made since the previous ballot include: <ul style="list-style-type: none"> ■ Updating to align with US Core 6.1, ■ Addressing concerns related to custodian identification, ■ Streamlining care team representations, ■ Addition of features like FHIR bundles for transmitting aggregated care plan information, and ■ Clarifications on including text in lieu of coded information. ○ Marcel Salive (NIA) asked for clarification on CareTeam.relatedPerson and why this replaced Caregiver.

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	<ul style="list-style-type: none"> <ul style="list-style-type: none"> <ul style="list-style-type: none"> ■ Dave, Gay, and Karen answered that “relatedPerson” is the name of the standard field in the FHIR specification to denote anyone who is not a practitioner and who is playing a role on the care team. These may include a spouse, relatives, friends, an attorney or guardian, and even a guide dog. Additionally, this is a term used only by developers and is not visible on the person-facing apps. ■ Supporting links: <ul style="list-style-type: none"> ● https://build.fhir.org/careteam.html ● https://hl7.org/fhir/R4/relatedperson.html ○ Gay extended an invitation for interested parties to join upcoming meetings of the HL7 Patient Care Work Group for continued discussion and refinement of the implementation guide. ● App development approach and updates <ul style="list-style-type: none"> ○ A primary emphasis of the apps is aggregating and displaying data from multiple providers. <ul style="list-style-type: none"> ■ The patient/caregiver and clinician apps are being pilot-tested at OHSU. This work involves patients and caregivers in expressing and providing content. ■ The app development aligns with the components of a comprehensive care plan, such as giving individuals direct access to health data, allowing patients and caregivers to contribute to shared care plans, and incorporating social determinants of health (SDOH) assessments. ○ Another focus is on clinicians’ and caregivers’ desires to better express goals for the patient and understand the patient’s health goals. ○ The third focus is on integrating SDOH assessments and pulling out outcome measures. ○ Out-of-scope elements for application development include recording corrections, scheduling appointments, secure messaging, and offering the apps in other languages. ○ The applications leverage the 21st Century Cures Act to enable giving patients direct access to their health data. ○ Challenges include: <ul style="list-style-type: none"> ■ Limitations in existing electronic health record (EHR) systems for capturing and representing goal-oriented care and ■ Constraints on patient-contributed content due to read-only access in EHR applications.

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	<ul style="list-style-type: none"> ○ The MCC care plan technical architecture involves the use of a supplemental data store to host patient-contributed content. ○ In the patient- and caregiver-facing application, patients and caregivers contribute to their care plans by creating health goals, adding health concerns, and completing questionnaires. This content is stored in a supplemental data store. <ul style="list-style-type: none"> ■ The supplemental data store hosts patient-contributed content, including health goals, concerns, and questionnaire responses related to SDOH and outcomes. ■ The application presents aggregated data in a meaningful and usable way. It includes features such as categorizing diagnoses based on extensive value sets using Clinical Quality Language (CQL). ○ Clinicians can access aggregated patient data from their institution, allowing them to view comprehensive health information collected from multiple providers. This includes data from patient-contributed content stored in the supplemental data store. ○ The current efforts of the team are focused on refining the CQL logic in the clinician and patient/caregiver apps and building on goal expression capabilities. ○ Dave invited federal partners to identify related projects to participate in upcoming Connectathons to foster collaboration in implementing FHIR standards. ○ Karen, Jenna, and Arlene provided more detail on The PACIO Project (Post Acute Care Interoperability), a CMS initiative that eCare has been able to build on.
<p>Federal Projects Round Robin Update</p>	<ul style="list-style-type: none"> ● AHRQ - CDSiC <ul style="list-style-type: none"> ○ James Swinger introduced himself. He has a background in biomedical engineering and supports AHRQ's clinical decision support (CDS) projects. ○ The Clinical Decision Support Innovation Collaborative (CDSiC) aims to incorporate research findings around CDS and ensure their usability and effectiveness in healthcare settings. ○ Under the Affordable Care Act, CDS is included as a means to promote the incorporation of research findings and receive feedback from the field to inform CDS. ○ To meet this legislative requirement, AHRQ's PCOR CDS Initiative consists of four pillars: <ul style="list-style-type: none"> ■ Engaging with stakeholders, ■ Creating prototype infrastructure for CDS development and sharing,

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	<ul style="list-style-type: none"> <ul style="list-style-type: none"> ■ Advancing CDS through grant-funded research, and ■ Evaluating the overall initiative to date. ○ The workgroups within these four pillars have produced various reports and resources accessible on the project website. Products include taxonomy, spreadsheets, and reports targeting different aspects of patient-centered CDS. ○ Future Work includes <ul style="list-style-type: none"> ■ Continued development of resources and expansion of the evidence base. ■ Incorporation of AI into patient chatbots for improved communication with clinicians. ■ Focus on health equity, real-world testing, and scalability of patient-centered CDS. ○ Jim invited stakeholders to participate in the project or provide feedback. ● VA CKD Care Transformation <ul style="list-style-type: none"> ○ Jerry Osheroff, a half-time VA employee, supports care transformation efforts based on prior work from the AHRQ's Evidence-Based Care Transformation Support (ACTS) initiative. ○ The VA is applying the Health Service Blueprint to expedite care transformation, especially in CKD management. <ul style="list-style-type: none"> ■ Planned solutions involve a unified dashboard for patient visits, targeting reduced suffering, healthcare costs, and care team burnout. ○ VA is creating a learning community to share strategies and tools for advancing CKD care transformation. ○ For more information or involvement, contact Jerry Osheroff. ● HRSA - Geriatrics Workforce Enhancement Program <ul style="list-style-type: none"> ○ Joan Weiss shared a notice of funding opportunity for geriatric workforce enhancement, and applications are due February 25. ○ The Geriatrics Workforce Enhancement Program (GWEP) aims to educate and train healthcare and supportive care workforces in caring for older adults. ○ Objectives include developing reciprocal relationships with academia, primary care sites, and community organizations; promoting interprofessional training; and establishing educational training sites in underserved areas. ○ With an expected budget of \$43 million, the GWEP plans to make 43 awards, each worth \$1 million annually, from July 2024 to June 2029.

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	<ul style="list-style-type: none"> ○ Requirements include training the workforce on care for individuals with multiple chronic conditions, including the e-care plan, and utilizing artificial intelligence, assistive technologies, and mobile health technologies for telehealth and in-person care delivery. ● NIH/ National Institute of Nursing Research (NINR) - NOFO on healthcare-community partnered social needs and SDOH interventions <ul style="list-style-type: none"> ○ Shalanda Bynum shared a new NOFO through NINR: RFA-NR-24-003: Clinical-Community Linkages to Address Unmet Social Needs and Adverse Social Determinants of Health to Advance Health Equity among Populations Experiencing Health Disparities: The Bridge-to-Care Initiative (R01 Clinical Trial Optional) (nih.gov). ○ The NINR is offering a funding opportunity called the Bridge to Care Initiative to improve care efficiency and effectiveness for underserved populations by leveraging healthcare and community partnerships. <ul style="list-style-type: none"> ■ The initiative seeks prospective intervention and evaluation proposals with a primary focus on health outcomes, combining health and social data to address adverse health outcomes in populations. ■ Key components include creating or expanding partnerships between healthcare and community organizations, aiming for mutually beneficial collaborations to address health and social needs holistically. ○ Research interests include interventions conducted in healthcare settings to address patient or family health-related social needs, expanding community-level resources, and evaluating interventions targeting social determinants of health. ● ONC <ul style="list-style-type: none"> ○ eLTSS FHIR IG <ul style="list-style-type: none"> ■ The Electronic Long Term Service and Support (ELTSS) Implementation Guide is derived from data sets used in CMS testing grants from 2014 to 2018. ■ eLTSS IG STU2 passed the HL7 January 2024 ballot but awaits reconciliation of pending issues. <ul style="list-style-type: none"> ● Updates include removing CarePlan.activity.detail (a deprecated data structure) and aligning with US Core 3.1 standards. ■ Missouri is conducting testing for eLTSS data exchange among three health information

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	<p>networks, with plans for live implementation in the spring.</p> <ul style="list-style-type: none"> ○ USCDI v5 draft <ul style="list-style-type: none"> ■ The USCDI v5 draft was released at the end of January, and of the 58 data elements recommended, 13 were adopted. Additionally, there are two new data classes: Observations and Orders. <ul style="list-style-type: none"> ● Please submit comments on the new data elements and classes for USCDI v5 by April 15, and identify any data elements that may have been missed. ● Of particular relevance to Care Plan are: (1) Advance Directive Observation (2) Orders, (3) Interpreter needed, (4) Provenance - Author, and (5) Provenance - Author role. ○ Predictive Decision Support Interventions (DSIs) in Healthcare <ul style="list-style-type: none"> ■ The Health Data, Technology, and Interoperability: Certification Program Updates, Algorithm Transparency, and Information Sharing (HTI-1) Final Rule was released. ○ SDOH Information Exchange alignment <ul style="list-style-type: none"> ■ The White House released an SDOH Playbook highlighting work taking place across agencies. ■ ONC published an SDOH toolkit. There are additional details included in the slides. ■ The learning forums have since ended, but ONC is taking a state-based approach for support of implementation with the first learning session starting next week. ○ TEFCA Overview and Updates <ul style="list-style-type: none"> ■ The background information on TEFCA can be found on the exchange purposes slide. There are forthcoming SOPs seeking feedback. ■ TEFCA is now live with five designated QHINs. ■ Please review the TEFCA Recognized Coordinating Entity® (RCE) batch of draft documents by February 5, online, via email, or during upcoming webinars. <ul style="list-style-type: none"> ● The Public Health SubXP-1, which includes details on electronic disease and care reporting, deadline has been extended to February 12. ● The FHIR roadmap v2 was just released. <ul style="list-style-type: none"> ● CMS - CMMI

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	<ul style="list-style-type: none"> ○ Mitchell Beers shared updates on the Making Care Primary (MCP) model, launching this July. ○ MCP targets comprehensive primary care for underrepresented patients across eight states. ○ The model prioritizes specialty care integration, mandating collaborative arrangements with specialists. ○ New model-specific codes incentivize collaboration between primary care and specialty providers. ● CDC - CPG-on-FHIR IG <ul style="list-style-type: none"> ○ Maria Michaels did not get a chance to share verbal updates but provided an update via the chat. ○ Clinical Practice Guidelines (CPG) FHIR IG, which has intersections with this eCare Plan work, was just balloted in the January 2024 cycle for STU2. ○ She recommended following the updates to the IG for any impacts to eCare Plans. ○ MedMorph, which is a reference architecture for automated data exchange, is resuming its technical expert panel to inform potential updates to the architecture and input on a variety of use cases. If you're interested in joining, please contact maria.michaels@cdc.gov. ● ASPE - Equity Consortium Plans <ul style="list-style-type: none"> ○ Jenna noted that the eCare project is funded through the ASPE Patient-Centered Outcome Research Trust Fund (PCOR TF). In the past, they had a more traditional funding process with written applications following group discussions. ○ They are moving into a new approach using consortiums to identify larger projects. Three consortia are running, one of which is focused on health equity. ○ The consortia will generate project ideas based on prior ASPE PCOR TF projects. ○ Jenna shared some current ideas under consideration: <ul style="list-style-type: none"> ■ Implementation of the eCare Plan in under-resourced settings potentially working with HRSA's community health centers. ■ Potential translation and cultural adaptation of the apps as well as some of the measures that are used to ascertain patient-reported data. ■ Using AHRQ's small-area SDOH database that could enable adding geolocation to the apps to and using that database to provide SDOH indicators. ○ Arlene added another prompt for the brainstorming to think about where we could use the eCare Plan applications such as FQHCs. ○ Arlene invited attendees to share ideas that build off of the eCare project in a larger context.

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	<ul style="list-style-type: none"> <ul style="list-style-type: none"> <ul style="list-style-type: none"> ■ Arlene also shared that the data standards exchange around care planning identified in the eCare project would benefit Mitchell's work at CMMI. The data standards can be used independently of the MCC eCare apps to share data more easily in primary care settings. ○ Marcel Salive commented that he was recently contacted by the GUIDE program for Alzheimer's care looking for evaluation measures. They are looking for caregiver strain and quality of life measures. <ul style="list-style-type: none"> ■ Marcel noted that since the MCC eCare Plan app includes administration of the PROMIS-29 and Caregiver Strain Index, that could be included in their evaluation strategy. ■ Arlene added that the app aims to collect data that isn't typically found in the medical record for purposes such as research. Arlene also added that we could incorporate other assessments in a standard way to be administered by the MCC eCare app if they required any more specific to Alzheimer's. ● NIA - Grant updates <ul style="list-style-type: none"> ○ Marcel shared that last year, the NIA issued new grants for the use of FHIR for clinical research. The MCC eCare Plan was referenced in the NOFO, and two of the awardees are using eCare Plan deliverables. One requirement is gathering interoperable data that might not be accessible to the researchers otherwise and using it to validate some of their outcome measurements. ○ MC COMPARE is led by David Dorr which involved two trials around hypertension and CKD. ○ The other project is at Brigham and Women's Hospital led by Anuj Dalal and Robert Rudin which is incorporating the Sync for Science program for managing consent as well. ○ These are three-year projects with investigator meetings to share learnings. ○ Jenna added that the MCC eCare team is meeting with Anuj Dalal's team in the coming weeks. The team is eager to learn more about their implementation questions. <ul style="list-style-type: none"> ■ Jenna noted that eCare was included in the NIA NOFO due to these federal partner meetings so this forum is a good place to discuss these types of mutually-beneficial collaborations. ○ Arlene appreciated that the two studies are very complementary. They cover different implementation settings where one is focused on care and safety for

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	<p>hospital-to-home transitions and the other is around chronic disease management in community settings.</p>
<p>What's Next for the eCare Plan Project?</p>	<ul style="list-style-type: none"> ● Jenna shared that the NIDDK NOFO around pilot interventions for social care advancing health equity received over 30 applications and the eCare plan was highlighted in this NOFO. ● Arlene discussed plans for an expert panel and leadership roundtable to address the support needed for care planning for the AHRQ Action project. They are seeking input from innovative health systems and practice networks as they aim to implement structural changes to facilitate care planning. ACTION 4 is launching a learning community to promote the adoption of care planning in routine practice, emphasizing accessibility and integration into healthcare delivery. ● Jenna added that there are new data elements in USCDI v4 relating to care planning that are focused on goals and preferences. ● The NIMHD recently funded a grant for clinical decision tools to facilitate social risk-informed care planning. Jenna connected with their team at the recent Academy Health Dissemination & Implementation Conference to explore synergy opportunities. Although clinical decision support was out of scope for the eCare Project, they discussed potential integration with their work to enhance eCare's collective impact. ● Jenna stated that if any of the federal partners are considering a project in the health IT space, NIDDK/AHRQ would be happy to support and collaborate.
<p>Concluding Thoughts & Next Steps</p>	<ul style="list-style-type: none"> ● Jenna and Arlene invited feedback from the group for ideas on future collaboration with eCare work. ● Karen shared that the slides will be posted after the meeting and the summary will be posted in 2 weeks.