



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 14, 2022

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

**Location:** Virtual

#### Attendees

<b>NIDDK</b>	<b>Federal Partners</b>	<b>Affiliation</b>
Jenna Norton	Kenneth Salyards	ACF
Kevin Abbott	Ami Patel	ACL
	Shawn Terrell	ACL
<b>AHRQ</b>	Kailah Davis	CDC
Arlene Bierman	Maria Michaels	CDC
Neha Shah	Pradeep Podila	CDC
Janey Hsiao	Tim Carney	CDC
Stephanie Leppry	Beth Connor	CMS
	Ellen Blackwell	CMS
<b>EMI</b>	Joel Andress	CMS
Savanah Mueller	Lorraine Wickiser	CMS, DCPAC
Demri Toop	Samantha Meklir	HHS, ONC
Karen Bertodatti	Susy Postal	IHS
Emma Jones	Ashley Wilder Smith	NIH, NCI
Dave Carlson	Brenda Akinngbe	ONC
Evelyn Gallego	Carmela Couderc	ONC
Himali Saitwal	Susan Crowley	VHA
<b>RTI</b>		
Laura Marcial		
Sara Armson		
<b>OHSU</b>		
Dave Dorr		
<b>HL7 Patient Care Work Group Guests</b>		
Laura Heermann		

#### Agenda

- Welcome and Introductions - Jenna Norton, NIDDK and Arlene Bierman, AHRQ
- MCC eCare Plan Project Overview and Progress Update - Jenna Norton, NIDDK and 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
- Federal Projects Round Robin Update



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- ACL - HCBS Quality Measures, Shawn Terrell
- ACL - NCQA Person-Centered Outcome Measures, Shawn Terrell
- ACL - Social Care Referrals Challenge, Ami Patel
- CDC - SDOH Data Exchange for Chronic Disease Prevention Initiative, Kailah Davis
- CMS - HL7 FHIR Connectathon - PACIO Integration of Post-Acute Care IGs, Lorraine Wickiser
- ONC - Gravity Project and Pilots, Sam Meklir
- Concluding Thoughts and Next Steps - Jenna Norton, NIDDK and Arlene Bierman, AHRQ

## Discussion

Agenda Topic	Discussion
Welcome and Introductions	<ul style="list-style-type: none"> <li>● Karen, Jenna, and Arlene welcomed attendees and reviewed the agenda. Project support includes EMI Advisors for NIDDK and RTI International and OHSU for AHRQ.</li> </ul>
MCC eCare Plan Project Overview and Progress Update	<ul style="list-style-type: none"> <li>● The project is working toward supporting a comprehensive shared care plan as defined by a 2015 HHS Stakeholder panel.</li> <li>● This project has 3 primary deliverables: (1) data elements, value sets, clinical information models, and FHIR mappings, (2) HL7 FHIR Implementation Guide, (3) Pilot tested patient-, clinician-, and caregiver-facing eCare plan applications.               <ul style="list-style-type: none"> <li>○ In our current year, year 3, we are wrapping up the identification of long-term COVID conditions data elements.</li> <li>○ The IG is inclusive of the aforementioned data elements.</li> <li>○ The third deliverable includes two SMART on FHIR applications, one for providers and one for patient/caregivers.</li> </ul> </li> <li>● Jenna and team recently published the <a href="#">eCare plan scoping review</a>.</li> <li>● Karen shared how the MCC eCare Project contributes to the <a href="#">HHS 3-pronged strategy</a> to advance health equity.               <ul style="list-style-type: none"> <li>○ The MCC eCare plan primarily addresses the first prong around supporting better data through consistent collection of high-quality SDOH data. We are doing this through the development of data standards related to chronic domains which includes a focus on SDOH.</li> <li>○ There may be opportunities for expansion and collaboration for the MCC eCare Project to help address the other 2 prongs in the future.</li> </ul> </li> <li>● No questions were asked about the pre-read materials.</li> </ul>
MCC eCare Plan Topics and Agency Partner Feedback	<p><b>eCare planning v2 apps demo</b></p> <ul style="list-style-type: none"> <li>● Dave reviewed the objective of the third deliverable to develop SMART on FHIR applications (provider- and patient/caregiver-facing) that use FHIR r4 and meet the requirements of the 21st Century Cures Act.</li> <li>● In the analysis of this project, we determined that only two applications were required, merging patients and caregivers into a</li> </ul>

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	<p>single application, built to differentiate functionality where appropriate.</p> <ul style="list-style-type: none"> <li>○ The role of the caregiver varies over time as patient needs may change.</li> <li>● In year 3 of the project, we are revising the provider-facing application based on pilot feedback from OHSU and building the patient/caregiver application with an emphasis on understanding the requirements for the caregiver portion of the application. A final piece of our work in year 3 is designing and building the interoperability architecture needed to support integration across multiple providers.</li> <li>● The applications are designed to support care planning as defined by the 2015 HHS stakeholder panel.             <ul style="list-style-type: none"> <li>○ The apps provide direct access to health data for patient/caregiver engagement through FHIR R4, queries, and APIs to access EHR systems.</li> <li>○ Documentation of progress towards goals has been a primary focus to incorporate patient and caregiver voices in the care planning and shared decision making processes.</li> <li>○ We are also supporting documentation of both clinical and nonclinical data.</li> </ul> </li> <li>● The provider app has received the most testing to date and aims to work as a companion app to support team coordination through a consolidated view of care planning data.</li> <li>● The patient/caregiver app enables a multi-condition focus. A primary effort in year 3 is to allow patients and caregivers to write information from the app that can be shared with the provider.</li> <li>● Dave Carlson performed a live demonstration of the patient/caregiver web-based application.             <ul style="list-style-type: none"> <li>○ The web-based application allows for maximum dissemination across numerous mobile platforms.</li> <li>○ Key features include four tabs: home, care plan, health status, and team.                 <ul style="list-style-type: none"> <li>■ The home tab features risk assessments as FHIR questionnaires to evaluate patient symptoms linking to a LOINC panel. The three embedded assessments demoed include PROMIS-29, PRAPARE, and the Caregiver Strain Index.</li> <li>■ The care plan tab details goals, active problem list, medications, and activities (interventions).</li> <li>■ The app uses LOINC, ICD-10, and SNOMED codes to provide patients with a Medline plus page relevant to medications, conditions, and goals data so they can learn more.</li> <li>■ The health status tab retrieves information about tests, vitals, and immunizations.</li> <li>■ The team tab is still in progress.</li> </ul> </li> </ul> </li> </ul>

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	<ul style="list-style-type: none"> <li>● Ellen Blackwell requested clarification on the definition of a caregiver.               <ul style="list-style-type: none"> <li>○ Dave C. responded that our definition for caregivers do not have any additional constraints at this time and we are thinking about it mostly from the context of a family caregiver. Caregivers may access the ecare patient/caregiver app using a proxy login through the patient’s primary EHR system. We are working on consent management.</li> <li>○ Ellen shared in the chat that there is a code payable in Medicare: 96161, “Administration of caregiver-focused health risk assessment instrument (e.g., depression inventory) for the benefit of the patient, with scoring and documentation, per standardized instrument.”                   <ul style="list-style-type: none"> <li>■ Emma will take this information into consideration in her work with HL7.</li> </ul> </li> <li>○ Dave Dorr shared that proxy access is the topic of a John A. Hartford project he is working on. It will create a learning collaborative to enhance access. We can fold in eCare Plan access as time goes on. Proxy access is improving.</li> </ul> </li> <li>● Dave reviewed development priorities for v2 of the apps, which include goal editing and authoring, care team details, and extracting common logic between the apps into a shared library for FHIR queries and CQL processing.</li> <li>● We aim to support the widespread dissemination of this work for other users in multiple EHR systems and vendors.               <ul style="list-style-type: none"> <li>○ To support the ability to aggregate content across multiple EHR systems, we are working to develop a FHIR façade through work with RTI and OHSU.</li> </ul> </li> </ul> <p><b>Real-world challenges</b></p> <ul style="list-style-type: none"> <li>● Three primary challenges include:               <ul style="list-style-type: none"> <li>○ Accessing data from more than one provider.                   <ul style="list-style-type: none"> <li>■ We are looking towards TEFCA and other regulatory and technical infrastructure underway to support this.</li> <li>■ Maria recommended logging into a portal that connects multiple EHR systems, such as an HIE or My Patient Link.                       <ul style="list-style-type: none"> <li>● Dave C asked if the Cures Act requires HIEs to allow for patient direct access.</li> <li>● The application is designed to require only a FHIR R4 compliant endpoint that supports SMART on FHIR authentication and to date, HIEs do not yet support FHIR endpoint access in this manner.</li> </ul> </li> </ul> </li> <li>○ Saving patient/caregiver authored content.                   <ul style="list-style-type: none"> <li>■ There is limited ability to use FHIR standards to write data.</li> </ul> </li> </ul> </li> </ul>

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	<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>■ Laura added that write-back is a universal issue in EHRs.</li> <li>■ Dave D responded that the major issue in write-back is where the EHR puts the data. Where it is possible, like PROs, it is left to the implementing site to build a workflow and match the data to the data storage locations.</li> <li>○ Limitations of Goal representation in Epic.               <ul style="list-style-type: none"> <li>■ We are looking towards supplemental storage to expand data around goals.</li> </ul> </li> </ul> </li> <li>● Shawn asked if it is possible to add quality measures when available?       <ul style="list-style-type: none"> <li>○ Dave C explained that it is not an immediate goal to support clinical decision logic, but we are anticipating executing CQL logic to provide analysis of value sets and classify data.</li> <li>○ Dave C further added that a core objective is to collect and aggregate interoperable data, including patient/caregiver assessment and outcomes and save those to a FHIR server for population health and research analytics. eCQMs could be evaluated on those collected data.</li> </ul> </li> <li>● Shawn asked if this can be used by a participant-centered care team without the integration function? What is the level of adoption of the apps, such as with case manager agencies?       <ul style="list-style-type: none"> <li>○ Dave C shared that the FHIR façade is not required, but a value-add. This allows us to test against any patient portal the patient may have, but they may not be able to write and save any data at this time.</li> <li>○ Dave Dorr responded with a <a href="#">video link</a> about accessing the eCare Plan.</li> </ul> </li> <li>● Shawn asked if a geo-mapping function can be integrated into the application?       <ul style="list-style-type: none"> <li>○ Dave C responded that this is not available at this time as it is a web-based application but may be an opportunity moving forward. In the meantime, we may be able to implement a Zip Code function.</li> </ul> </li> <li>● Ashley asked for clarification in the chat: While some information would be pre-populated from the EHR presumably, would other information need to be collected de novo from the app (e.g., symptom information)? What happens to respond to high symptoms via this app? How do you ensure that the symptoms are appropriately attributed if people have MCCs? How does an intervention get to the right provider?       <ul style="list-style-type: none"> <li>○ Ashley added that she is involved in a research consortium that is testing pragmatic, cluster-randomized trials of cancer symptom management/control via the EHR. They use PROMIS and PRO-CTCAE (along with other tools) to capture symptoms, and interventions are CDS-based.</li> </ul> </li> </ul>

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	<ul style="list-style-type: none"> <li>○ Dave C responded to the chat stating that the first objective for the patient/caregiver app is to retrieve and summarize all relevant information from existing health records, from multiple providers, and, as much as possible, display it in a consumer-friendly expression. The second is to enable patients and caregivers to supplement existing data with information about what they are actually doing, including their goals, health concerns, and activities. As well as progress and outcomes to help them and the clinical team to evaluate and adjust personalized goals.</li> <li>○ Ashley responded in the chat: I am still curious about how the responses are intended to occur. Additionally, for you and others working on this, we at NCI/NIH have been learning a lot about limitations related to collecting and acting on symptom data via patient portals. The app developed here would clearly augment that, but there are shared challenges that it might be worth having an offline discussion about to potentially share with you all some pitfalls based on our experiences and if there are any workarounds you might consider.</li> <li>○ Dave D said he would be interested in continuing this conversation with Ashley.</li> </ul> <p><b>Update from RTI on pilot testing findings and recommendations</b></p> <ul style="list-style-type: none"> <li>● Laura described the testing process of the applications with OHSU.             <ul style="list-style-type: none"> <li>○ Phase one entailed having providers interact with test profiles in a test environment for both the patient and provider applications.</li> <li>○ Phase two entailed having patients interact with their own data in the production environment. The focus was on usability.</li> <li>○ Multiple components of evaluation informed this work, including stakeholder sessions with wireframes, pilot testing, and follow-up interviews.</li> <li>○ Three tiers of responses were assembled.</li> </ul> </li> <li>● Tier 1: Development considerations were items that could be integrated immediately.             <ul style="list-style-type: none"> <li>○ This included altering the language to be more inclusive and in common terms.</li> <li>○ Additional feedback focused on medication display and recommending integrating a medication schedule function and allowing for support of updates and corrections to medications.                 <ul style="list-style-type: none"> <li>■ Maria asked if a similar function was available for immunizations.</li> </ul> </li> <li>○ Improving goal display, targets, and documenting progress through write-back is another high-priority item for both providers and patients.</li> </ul> </li> </ul>

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	<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>■ Dave D added that goals are often not entered in a structured way. We are hoping to be able to facilitate the entry and processing of goals in a meaningful way into the app.</li> </ul> </li> <li>● Tier 2: Tackling Interoperability Challenges is an item that may take more effort but can be a future focus for v2 or v3 of the applications.               <ul style="list-style-type: none"> <li>○ Write back allows for the integration of patient voice in care planning and could support more active engagement from patients during and between visits. A challenge lies in getting this write-back information into the right place in the EHR.                   <ul style="list-style-type: none"> <li>■ Dave D shared an example from another AHRQ-funded project, Collaboration-Oriented Approach to Controlling High Blood Pressure (COACH) for a short-term solution. The patient can write data to be stored locally until the EHR is ready to receive it.</li> </ul> </li> </ul> </li> <li>● Tier 3: Future work can be done beyond the initial piloting and dissemination of the apps.               <ul style="list-style-type: none"> <li>○ There is a lot of variation in the extent to which EHRs have implemented the rules for the 21<sup>st</sup> Century Cures Act in terms of the ability to pull in data from different places and adjudicate effectively.</li> <li>○ There are still issues for write back and native functions of reconciliation.</li> </ul> </li> <li>● Agency Questions and Feedback               <ul style="list-style-type: none"> <li>○ Maria inquired about reducing the provider burden for verification, reconciliation, and/or adjudication if a patient or caregiver provides information through the app or HIE.                   <ul style="list-style-type: none"> <li>■ Dave D responded that his approach is to just put the information into the chart, but there is a challenge of where to put it in EHR and ensure that it will be seen by the provider.</li> <li>■ Dave D added that there are some limitations around goals, prioritizations, and immunizations. Ultimately, reconciliation needs to be done by a provider on some level, which is a barrier. This will need to be done through changing workflows, shared understanding, safeguards, and education.</li> <li>■ Maria asked if it is possible to verify through an immunization information system vs. manually.                       <ul style="list-style-type: none"> <li>● Dave D noted that there is a state-based immunization information system that gets verified through reconciliation, but there is a concern with database corruption.</li> </ul> </li> <li>■ Dave C added that there is a Smart Health Card that provides a digitally signed, verified record.</li> </ul> </li> </ul> </li> </ul> </li></ul>

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	<ul style="list-style-type: none"> <li>■ Emma added that a key part of the medication reconciliation process is having a trusted source and the ability to recognize variances, but this can be supported through codified data. To drive workflow, there needs to be a visual indication that items have been added and signed off.</li> </ul>
<p>Federal Partners Round Robin Updates</p>	<p>ACL – NCQA Person-Centered Outcome Measures, Shawn Terrell</p> <ul style="list-style-type: none"> <li>● There are three measures that are starting a testing project through a learning collaborative.               <ul style="list-style-type: none"> <li>○ 1. Assessment of a complex care need with a person-driven documented plan for achieving it.</li> <li>○ 2. Follow up on the outcome within 180 days.</li> <li>○ 3. Assessment of the degree to which the goal was achieved.</li> </ul> </li> <li>● These measures are done through goal attainment scaling.</li> <li>● The learning collaborative starts in July and runs through August with a Senior Center Council on Aging in Ohio and a Managed Care Organization for people with disabilities and older adults.</li> <li>● Results should be shared by early next year.</li> <li>● Shawn shared an NCQA person-driven outcome measures overview and <a href="#">link</a> to a webinar.</li> </ul> <p>ACL – Home and Community-Based Services (HCBS) Quality Measures, Shawn Terrell</p> <ul style="list-style-type: none"> <li>● Eight to twelve specific measures are assessed, including measuring abuse, neglect, exploitation, employment, choice and control, social connectivity, transportation, and person-centered outcome with goal attainment scaling.</li> <li>● This work is based on the NQF project, culminating in 2018.</li> <li>● An objective of this project is to assess the goals related to the 11 domains.</li> <li>● Evelyn inquired if this is a public collaborative for alignment with Gravity SDOH goal development.               <ul style="list-style-type: none"> <li>○ Shawn confirmed that this is a closed learning collaborative.</li> </ul> </li> <li>● Shawn shared a recent <a href="#">ACL webinar</a> on HCBS Outcomes.</li> </ul> <p>ACL - Social Care Referrals Challenge, Ami Patel</p> <ul style="list-style-type: none"> <li>● The Social Care Referrals Challenge is focused on reducing silos around the interoperability of health care and social services through standardization of referrals.</li> <li>● The technical focus is on the adoption of open APIs.</li> <li>● The project is currently in phase 3: implementation and testing.               <ul style="list-style-type: none"> <li>○ This will be followed by two bonus phases: mapping taxonomies and directory federation.</li> </ul> </li> <li>● EMI and FEI Systems are supporting additional mapping approaches for aligning FHIR resources that describe healthcare provider directory information with Open Referral's HSDS through the development of an IG.</li> <li>● The Use Cases included in the ACL challenge aligns with MCC eCare plan.</li> </ul>

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	<ul style="list-style-type: none"> <li>● You can learn more about the Challenge teams <a href="#">here</a>.</li> <li>● Maria Michaels recommended a bidirectional e-referrals IG that might be helpful in this work and will share a link offline.</li> <li>● Evelyn added that Gravity is in the process of working within HL7 to align on key similarities and differences across the Gravity closed-loop referral use case as well as 360X and BSeR.</li> <li>● Carmela Couderc asked what “SHARP” means.             <ul style="list-style-type: none"> <li>○ Ami responded that this is an acronym used to refer to platforms like Unite Us or Aunt Bertha (Find Help). SHARP stands for Social Health Access Referral Platform.</li> </ul> </li> </ul> <p>CDC - SDOH Data Exchange for Chronic Disease Prevention Initiative, Kailah Davis</p> <ul style="list-style-type: none"> <li>● The initial project to develop a use case and business case using a collaborative process to support public health for chronic conditions. This can be expanded in the future.</li> <li>● Since the last presentation in February, the project has published an internal environmental scan and completed a data infrastructure gap analysis which is being circulated internally within CDC. Work is now focused on developing the use cases through the launch of the workgroup.</li> <li>● Over 200 members are participating in the workgroup, the majority representing federal, state, local, and public health agencies.</li> <li>● Early feedback from the workgroup during the consensus-building process included having tribal nation representation, expanding workgroup participation, and refining the scope to specify chronic disease and a downstream impact of COVID-19.</li> <li>● Upcoming work includes finalizing the use cases and concluding the workgroup at the end of July. Future work will be around collaborating with Helios, advising on infrastructure, and including recommendation language in CDC NOFOs.</li> </ul> <p>ONC - Gravity Project and Pilots, Sam Meklir</p> <ul style="list-style-type: none"> <li>● Three pilots are working with Gravity for pilot testing the HL7 SDOH Clinical Care FHIR IG.             <ul style="list-style-type: none"> <li>○ These are supported through the ONC-HL7 Cooperative Agreement to develop, advance, and harmonize SDOH data standards using FHIR APIs.</li> <li>○ Two pilots include the Alliance of Chicago and OCHIN, a health center control network.</li> <li>○ UT Austin, through LEAP, is developing a closed-loop referral system called FHIR to SHIP (social and health information platform) as a patient engagement app. They are also developing a toolkit, which will be available next year.                 <ul style="list-style-type: none"> <li>■ Their Use Case is based on the Gravity Project to allow sharing of information between the clinical staff, the client, the patient, and the community-based organization.</li> </ul> </li> </ul> </li> <li>● A pilot affinity group will begin soon to support the pilot engagement.</li> </ul>

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	<ul style="list-style-type: none"> <li>○ Evelyn shared in the chat that the Gravity Pilots Affinity Group will also serve as a platform to showcase the progress of ONC and ACL-funded pilots and projects testing the Gravity standards.</li> </ul> <p>CMS - HL7 FHIR Connectathon - PACIO Integration of Post-Acute Care IGs, Lorraine Wickiser</p> <ul style="list-style-type: none"> <li>● Karen shared that the MCC team coordinated with PACIO at the last Connectathon to integrate MCC data into one of their scenes.</li> <li>● Lorraine shared via Jenna in the chat that before the Connectathon, the PACIO team collaborated with the MCC eCare Plan team to integrate MCC eCare Plan data into the scene. Betsy uses the provided transportation to attend an office visit with her PCP. The PCP examines her, and they discuss her diabetes control (along with the status of other chronic conditions like her blood pressure since her stroke). The PCP retrieves the prior MCC eCare Plan focused on her diabetes and kidney function and makes appropriate updates to reflect her recent history and the modified care plan.</li> </ul> <p>CPG on FHIR, Maria Michaels</p> <ul style="list-style-type: none"> <li>● CPG on FHIR is part of an initiative called Adapting Clinical Guidelines for the Digital Age.</li> <li>● This project takes downstream perspectives of implementers and brings them into knowledge development that includes computable components.</li> <li>● Dave C requested clarification on the CPG on FHIR expansion.             <ul style="list-style-type: none"> <li>○ Maria explained that this is a journal supplement. The updates would include guidelines on linking the integrations process with the technical side.                 <ul style="list-style-type: none"> <li>■ For more in-depth discussions on the technical updates, Maria recommended attending discussions through the CDS workgroup.</li> </ul> </li> <li>○ There is also an evaluation framework of the computable knowledge product.</li> <li>○ CPG on FHIR is a foundation for sharable clinical knowledge.                 <ul style="list-style-type: none"> <li>■ This provides a way for a guideline developer who wants to use CPG on FHIR but is not technical to understand the process of creating computable guidelines.</li> <li>■ The co-developing allows those developing the computable guidelines to work directly with those that are writing the guidelines, making it clearer before it is published.</li> </ul> </li> </ul> </li> </ul> <p>MedMorph, Maria Michaels</p> <ul style="list-style-type: none"> <li>● MedMorph is a reference architecture decoupled from content, which means that it can be applied to multiple use cases.</li> <li>● Three public health use cases are in the works, including chronic Hepatitis C surveillance, cancer reporting, and health care surveys.</li> </ul>



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	<ul style="list-style-type: none"><li>Partners at HRSA are working on using the MedMorph architecture for UDS reporting.</li><li>There is an area of exploration of patient-reported blood pressure data through collaborative work with CardX.</li></ul> <p>New Projects</p> <ul style="list-style-type: none"><li>Evelyn described in the chat that the HL7 Patient Care Work Group has approved a new project to develop data standards for physical activity (PA). The project is sponsored by the American Heart Association and will incorporate the addition of PA data elements in care planning and social referrals.</li></ul>
Concluding Thoughts and Next Steps	<ul style="list-style-type: none"><li>Jenna and Arlene thanked the attendees and encouraged them to reach out via email with any questions.</li></ul>