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**CDS (Clinical Decision Support) Connect Work Group  
Meeting Summary  
March 18, 2021  
3:00 – 4:00 pm ET**

**Attendees: 49 people (43 attendees + 6 call-ins)**

<b>Organization</b>	<b>Attendee Names</b>
<b>AHRQ Members</b>	Steve Bernstein, Roland Gamache, Ed Lomotan, Mary Nix, Mario Terán (5)
<b>Work Group (WG) Members</b>	Max Alexander, Noam Arzt (HLN), Randolph Barrows, Chandra Bondugula, Edna Boone, Joe Bormel, Richard David Boyce, Matthew Burton, Dave Carlson, Chris d’Autremont, Rina Dhopeswarkar, Dwayne Hoelscher, Ronilda Lacson, Preston Lee, Mario Macedo, Dan Malone, Maria Michaels, Ryan Mullins, Neeraj Ojha, Jerry Osheroff, Raajiv Ravi, Joshua Richardson, Marc Sainvil, Rhonda Schwartz, Andrey Soares, Julia Skapik, Danny van Leeuwen, Michael Wittie, Sandra Zelman Lewis (29)  Call-ins (6)
<b>MITRE CDS Connect Members</b>	Noranda Brown, Matt Coarr, Lacy Fabian, Susan Haas, Michelle Lenox, Dylan Mahalingam, Nichole Sweeney, Jacob Thomas, Chris Moesel (9)

## **MEETING OBJECTIVES**

- Discuss with WG members the concept of partnering with the patient and caregiver community and gather feedback on related website updates
- Share new CDS Connect features and available resources
- Discuss topics of interest to members relating to CDS Connect opportunities

## **ACTION ITEMS**

- Next month’s presenters ask that members listen to or read a [three-part podcast series](#) prior to April’s meeting in preparation for the follow-up discussion about partnering with the patient and caregiver community.



## MEETING SUMMARY

Following roll call and review of the agenda, the MITRE team presented information about partnering with the patient and caregiver community to develop CDS. This presentation generated significant active discussion from the WG about the importance of this topic, as well as potential ways to engage with patients and caregivers more effectively.

### **Partnering with the Patient and Caregiver Community to Develop CDS (MITRE)**

The MITRE team provided the first of a two-part discussion on partnering with the patient/caregiver community for CDS development (the second part, to be based on a COVID-19 use case, is scheduled for the April meeting). The team's goal was to gather WG member perspectives about the issue, while also priming the members for the second discussion. Danny van Leeuwen, the CDS Connect patient/caregiver advocate, shared his experience in a CDS technical expert panel on CMS quality measures development, to illustrate the importance of this partnering work, and how it differs from patient engagement.

Ms. Lenox (MITRE) described how potential updates to the website would show an expansion of the CDS community by explicitly including patients and caregivers. Referring to the current CDS lifecycle graphic, Ms. Lenox prompted WG members for their thoughts on what it might mean for them, as CDS developers and informaticians, to partner with the patient and caregiver community. WG members shared their current experiences with partnering, after which Ms. Lenox demonstrated the updates to graphics and the website itself that potentially will cue developers to partner with these communities. Ms. Lenox concluded her discussion by soliciting WG feedback about changing artifacts and their metadata in ways that might encourage and deepen CDS developer's partnership with patients and caregivers.

### **Discussion**

A WG group member found this type of partnership to be relevant to their work (having produced a patient-facing artifact). They hoped for future conversation exploring stewardship and equity.

Two WG members shared information about current development efforts that actively engage patients and caregiver groups in CDS testing. The first WG member—currently developing a CDS to prevent harmful drug interactions—is looking for the patient and caregiver community to evaluate the tool in a simulated environment. The second WG member—developing a pricing tool for patients to evaluate providers and services—plans to test this tool with patients and to engage further with hospitals.

A WG member asked how patients might engage with a CDS artifact after it had been posted to CDS Connect, and what responsibility a development organization might have to maintain its artifacts at the conclusion of their project life. In general, they were interested in seeing more patient-facing CDS tools.

A WG member noted that the American Association of Retired Persons (AARP) may have an initiative to gather and share feedback from their community members for these purposes. They suggested reaching out to see if AARP still maintains this initiative.

A WG member joined Ms. Michaels in posing questions about gathering patient/caregiver community input early in the development cycle to direct which artifacts and tools are developed. Mr. van Leeuwen mentioned



# CDS Connect

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that in his experience, unless relationships have already been established with these groups with prior efforts, these discussions could be difficult.

A WG member, currently working on improving the quality of telehealth in Portugal, mentioned that this topic could be interesting to discuss in that context. They added that the CDS Connect lifecycle might be useful for telehealth standards development.

A WG member agreed that updating the graphics on the welcome page to reflect the involvement of patients and caregivers would be good. They suggested illustrating the bidirectionality of the partnering relationship, as discussed by Mr. van Leeuwen.

Mr. van Leeuwen and a WG member mentioned the challenges in explaining to patients and caregivers what CDS development is, along with the impact that health data standards have on care. There was agreement between the two on the importance of engaging with patients and caregivers on those topics. A WG member mentioned that, in many discussions they have taken part in, at least one patient or caregiver is included, with the goal of having them add to the conversation.

Ms. Michaels posed a follow-up question: Is it better to have the patient on calls where the discussion may be very technical, or should a parallel call be held instead where the topic in question is discussed from the perspective of patient engagement? In the first option, involving patients in technical calls that are largely not relevant to them might lead patients to not being as actively engaged in the discussion as they would hope to be— or stop attending calls.

A WG member noted the impact that distrust among the patient community towards the medical community; for example, some patients are reluctant to be vaccinated for COVID-19. They opined that trust might be built by having patients involved in discussions that shape vaccination communications, drawing a parallel to increasing trust in artifacts by partnering on CDS development.

A WG member pointed out that some members of the patient and caregiver community might be more technically proficient than those who currently choose to be involved in the CDS development community. Technically savvy patients/caregivers would have valuable contributions to make in partnership discussions.

Shifting to the patient perspective, various WG members identified site-related features that might be important to the patient and caregiver community. These included the ease of finding the CDS Connect site, adding a plain-language explanation about how a patient may benefit from clinical language and artifacts, how one might raise the topic of CDS with their provider, and the need to add data use and data security assurances to app-related artifacts. On the point of assurances, one WG member cautioned against using the concept of “endorsement”; that term is regulated by the Federal Trade Commission (FTC) rather than the Food and Drug Administration (FDA).

A WG member questioned whether the intended goal of CDS Connect is to serve as a resource for patients to find clinical guideline information. Mr. van Leeuwen said that the idea that everyday patients and clinicians would flock to CDS Connect is unrealistic. Further, it is important to make the distinction between “patients and caregivers” and “the patient and caregiver community;” those *representing* the community are likely to be more actively involved.

Ms. Michaels joined a WG member to ask whether artifacts should include specific information about feedback from patients and providers about Implementation Guides.

The discussion concluded with Mr. van Leeuwen suggesting pre-work in advance of the April WG meeting.



# CDS Connect

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## **What's New with CDS Connect**

The MITRE team discussed updates and features that were recently implemented or remain in progress. Authoring Tool (AT) updates continue to support reusability and maintainability. Work continues on support for Clinical Quality Language (CQL) 1.5 in the Prototype Tools. Further, a new version of the CQL Testing Framework has been released. In addition, the Repository team continues to complete software updates and security patches along with the CPG-on-FHIR® work. Technical support for Repository contributors continues.

AHRQ reminded WG members about an upcoming survey from the National Opinion Research Center about CDS Connect. WG members who had not previously opted out of the survey are invited to provide feedback.

## **Announcements/Other Questions**

Ms. Michaels announced a panel to be held at the American Medical Informatics Association (AMIA) 2021 Virtual Clinical Informatics Conference, called "Nothing for Me, Without Me: Co-Design of Clinical Decision Support," on Wednesday, May 19, from 2:30 p.m. to 3:30 p.m. AHRQ and MITRE team members will discuss patient partnerships during that event.

## **Closing**