



CDS (Clinical Decision Support) Connect Work Group

Meeting Summary

April 15, 2021

3:00 – 4:00 pm ET

Attendees: 44 people (41 attendees + 3 call-ins)

Organization	Attendee Names
AHRQ Members	Steve Bernstein, Roland Gamache, Ed Lomotan, Mary Nix, Mario Terán (5)
Work Group (WG) Members	Randolph Barrows, Edna Boone, Joe Bormel, Dave Carlson, Melanie Combs-Dyer, Chris d'Autremont, Priyanka Desai, Rina Dhopeswarker, India Duncan, Vojtech Huser, Sandra Zelman Lewis, Mario Macedo, Dan Malone, Laura Marcial, Russ Mardon, Maria Michaels, Peter Muir, Ryan Mullins, Neeraj Ojha, Mustafa Ozkaynak, Raajiv Ravi, Rhonda Schwartz, Max Alexander Sibilia, Julia Skapik, Andrey Soares, Jeff Solomon, Matt Storer, Danny van Leeuwen (28) Call-ins (3)
MITRE CDS Connect Members	Marisa Bellantonio, Noranda Brown, Matt Coarr, Lacy Fabian, Susan Haas, Michelle Lenox, Dylan Mahalingam (7)
Guests	Natalka Slabyj (1)

MEETING OBJECTIVES

- Second of two-part discussion on partnering with the patient/caregiver community; today's discussion explored issues of partnering based on the example of the *Person-First Safe Living in a Pandemic* initiative, which looked at questions and concerns from the general population seeking evidence during the emergence of the COVID-19 pandemic
- Share new CDS Connect features and available resources
- Discuss topics of interest to members relating to CDS Connect opportunities

ACTION ITEMS

- WG members should digest today's presentation materials and send any additional comments, ideas, or questions to the presenters and Ms. Michaels.

MEETING SUMMARY

Following roll call and review of the agenda, Dr. Laura Haak Marcial, PhD (a Health Informaticist at RTI) and Danny van Leeuwen, RN, MPH [of Health Hats, the Patient-Centered Outcomes Research Institute (PCORI) Board of Governors, and a patient-caregiver activist] presented on lessons learned around the *Person-First Safe Living in a Pandemic* initiative. This initiative was an effort to build and test methods and infrastructure to



increase the findability of evidence-informed guidance for regular people trying to live safely during the COVID-19 pandemic.

This presentation covered challenges in understanding how the general population seeks answers to questions around every day living during the pandemic, as well as varied approaches to finding and critically evaluating resources. The initiative resulted in a repository of health resources that will expand as new evidence is developed. The discussion concluded with ways the CDS Work Group might apply some of the lessons learned from this person-focused initiative, particularly around developing a continuously evolving, evidence-based repository and building trust.

Sharing Lessons Learned with CDS: Person-First Safe Living in a Pandemic

Dr. Marcial and Mr. van Leeuwen presented on lessons learned around understanding how people find relevant, trusted information that they can incorporate into their own day-to-day decisions around staying safe during the pandemic. They highlighted challenges for individuals, caregivers, and communities for finding evidence-informed guidance on safe living during the pandemic, and how computable decision science can help with determining the relevance of and findability for this information. CDS Connect faces many of these same challenges and the presenters discussed opportunities to draw parallels and best practices between the two initiatives.

The presenters described the need that individuals, caregivers, and communities have during the COVID-19 pandemic to find up-to-date, trusted, and evidence-informed information to guide daily living to limit or prevent exposure to the virus. Taking a person-first approach to the project, they started with asking “Who is the audience?” rather than “Where’s the evidence?” The team examined questions people posed during the pandemic, discussed their search for answers, and highlighted the intersections between patient-centered CDS and traditional CDS.

The presenters discussed the creation of personas for purposes of their study, as well as how they grouped people based on demographics, potential symptoms, job risk level, transportation access, general health, living and work density, and other factors. These personas allowed the presenters to understand the potential concerns of a variety of individuals. Quickly overwhelmed by the sheer volume of available information on the pandemic, they narrowed their focus to information related to being tested for COVID-19 infection.

The presenters struggled with the findability of person-relevant, useful information, leading to fresh perspectives about how to bring order to a disordered system. One search term (“COVID-19 Testing for ICU Nurses”) brought up widely divergent resources, with different levels of complexity, depending on the platform—web search engines (e.g., Google) and medical journal databases (e.g., PubMed) returned vastly different results. Presenters discovered that a wide gap had developed between the evidence-informed guidance and the questions people were really asking. As a result, they developed [Safe Living Resources](#), a repository highlighting various trusted resources that answered these commonly asked questions. This repository was developed on the Stacks platform, a library technology offered by EBSCO Information Services, a leading provider of research databases.

In addition, the presenters highlighted the importance of critical thinking during an emerging public health emergency. They developed a trust label, like the Nutrition Facts Label required on most packaged food, to



provide a way for people to critically assess potential resources. The trust label acts as a framework to help quickly evaluate one piece of information against another. The label consists of metadata to increase findability and self-awareness of trust. The presenters discussed how this Work Group might leverage CDS Connect standards expertise to evolve this metadata. AHRQ and other federal health agencies may consider collaborating with other organizations working in this area.

Finally, the presenters discussed ways to apply their findings to the CDS community. They focused on their end-user “triad” of patient, caregiver, and direct care clinician—personas representing the people making health decisions. They asked the CDS community to reflect on opportunities to build trust by partnering with these groups in their work. These actions include: listening to stakeholders; prioritizing standard development in language that the patient-caregiver community uses; having funding opportunities that include clear relationships with the patient-caregiver community; making patient-centered design a central feature; and including examples of how developers partnered with stakeholder communities when documenting the creation of CDS Connect datasets.

Discussion

A WG member asked whether the Safe Living Resources added to the EBSCO Stacks portal should be considered trustworthy, given that they have not gone through the official EBSCO vetting process. The presenters clarified that the EBSCO platform was only used to allow access to the collected and curated resources that the initiative had found.

A WG member, expressing their perspective as a patient in the pandemic, reflected on their own experience trying to be an informed consumer and offered that artificial intelligence and machine learning are other consumer-facing areas where a trust label might make sense. The presenters responded that Microsoft is funding an initiative around the topic called HealthGuard, which is a type of trust label that helps identify trustworthy sources of health news and information and is offered through the browser extension NewsGuard.

The presenters shared that they do not have the bandwidth to develop “consumer reports” of resources that are people-centered. Further, the resources that people trust diverge widely; the presenters recommend an approach focused instead on increasing self-awareness around trust.

Other WG members discussed the person-first focus of the approach. One member asked why the end user, meaning the person searching for information, should be assigned the relevant control to determine the veracity of health information, rather than going through a trusted third party. The presenter responded that patients already have this responsibility—for example, patients ultimately chose to fill a prescription and take a medicine, a choice which supersedes the physician’s expert advice— and, as a result, effort should focus on supporting them directly in that responsibility. The COVID-19 pandemic made clear that the current capacity of traditional trusted institutions to provide guidance and examine evidence does not align with the public’s need to receive that information in a timely manner during a public health emergency. The public at large needs the capacity and responsibility to interpret information into the context of their own circumstances.

The presenters shared the potential upside of investigating relevant funding opportunities, as well as strategies to increase inclusiveness within the CDS discipline itself. They solicited feedback and recommendations from WG members moving forward.



CDS Connect

What's New with CDS Connect

The MITRE team discussed updates and features that were recently implemented or remain in progress. They updated the CDS Authoring Tool's artifact list, implemented a new ability to duplicate artifacts, added new expression modifiers (First, Average Value), completed updates that support reusability and maintainability, and remodeled the user interface. About Prototype tools, the team released CQL testing 2.3.0 with support for FHIR 4.0.1, and continued work supporting Clinical Quality Language (CQL) 1.4 and 1.5. The team will continue updating CDS artifacts to support FHIR 4.0.1 and CQL to 1.5. In the Repository, the team completed an API update; CPG-on-FHIR work continues. The team is also continuing work on user-documentation updates, and software lifecycle changes, and improving technical support for Repository contributors.

Announcements/ Other Questions

AHRQ reminded WG members about an upcoming survey about CDS Connect from the National Opinion Research Center and suggested checking email spam folders in case the notification was sent there.

Ms. Michaels announced that Early Bird pricing for the HL7 Connectathon ends next Friday. Registration will close one week later.

Closing