Clinical Decision Support (CDS) Connect Work Group (WG)

Meeting Summary

April 21, 2022

3:00 – 4:00 pm ET

Attendees: 31 people, including 6 phone dial-ins

Organization	Attendees
AHRQ Sponsors	Edwin Lomatan, Mario Teran, Roland Gamache (3)
WG Members	Alex Goel, Alison Kemp, Jeremy Michel, Jerry Osheroff, Laura Marcial, Lisa Lang, Maria Michaels, Michelle Dardis, Nitu Kashyap, Paul Seville, Preston Lee, Raajiv Ravi, Randolph Barrows, Ryan Mullins (14)
MITRE CDS Connect Members	Allie Rabinowitz, Chris Moesel, Julia Afeltra, Michelle Lenox, Robert Truhn, Sam Carrillo (6)
WG Presenters	Amy Price, Danny Van Leeuwen (2)

MEETING OBJECTIVES

- Welcome; brief review of meeting objectives and agenda
- Roundtable and discussion on partnering experience
- Prioritize next steps in patient partnering
- Review recent developments with CDS Connect
- Close

ACTION ITEMS

- None

MEETING SUMMARY

Following an introduction and review of the agenda, two patient-partnering experts led a discussion on the purpose, benefit, and future of including patient and caregiver perspectives in the development and implementation of CDS. The WG next weighed in on identifying and prioritizing next steps to make the most impact on those efforts. MITRE concluded the meeting with an overview of the updates and improvements made to CDS Connect within the past month.

Welcome

MITRE started the meeting by welcoming participants and reviewing the names of WG members participating in the call. Maria Michaels then reviewed the agenda and facilitated the rest of the discussion.

Roundtable and Discussion on Partnering Experience

Michelle Lenox (MITRE) reviewed the CDS Connect WG's past work in efforts to further partnering with patients and caregivers in developing and implementing CDS. These actions included updating the CDS Connect website to be inclusive of patient and caregiver voices, hosting a panel to learn where the community currently stands and identify next steps, developing materials for a "One More Step" campaign to encourage taking the next step of partnering, and reviewing MITRE's work on ACTIVATE (an effort to co-produce interventions with patients).

Ms. Lenox introduced Danny Van Leeuwen (HealthHats) and Amy Price (Stanford), passionate patient and caregiver advocates deeply engrained in the patient advocate community.

Dr. Price entered the world of patient advocacy when she underwent treatment for a brain trauma injury. She had multiple questions throughout her medical journey and found that many other patients also wanted more information. This experience inspired her to pursue a Ph.D. in Evidence Based Health Care and has since worked in patient partnering and advocacy. Dr. Price is currently a researcher at Stanford and a patient editor at BMJ.

Mr. Van Leeuwen has been involved with patient engagement in research for more than 30 years. He finds his career rewarding, noting one memorable experience when working with an organization supporting individuals with disabilities (including mental illness). That organization's board included several members representing the individuals the organization served.

Dr. Price and Mr. Van Leeuwen reviewed a series of related topics. The first discussion point explored whether the complexity of partnership is "worth it." Mr. Van Leeuwen acknowledged that partnering with patients and caregivers is an added effort and can, at times, be difficult; nevertheless, he firmly believes it is necessary to include every voice for the product to be useful. Dr. Price agreed that complexity is a feature of such partnerships but emphasized the opportunities it presents to expand the impact of the work when the community is willing to change its perspective about patient partnering from one of "hard work" to viewing it as "a passionate relationship." This process can, in fact, be a fun and supportive journey.

The WG then discussed how "belonging" can be defined. WG members offered a variety of recommendations, such as offering a voice and embodying inclusivity as a principle.

Dr. Price and Mr. Van Leeuwen next reviewed exemplary onboarding practices that they had experienced, noting that a patient partner needs to feel supported in joining the conversation. Mr. Van Leeuwen highlighted his experience of being connected with a peer mentor for a 30-day timeframe to experience the content and nature of the work; after that period, his onboarding

officially began. Every person deserves a thoughtful onboarding and mentoring experience when joining a new team, and patient partners are no exception. The CDS community must recognize and establish onboarding—especially for patient partners—as an integral part of the culture of its research.

A WG member noted that patient outcomes often seem to be directly related to the efforts and level of trust established in the patient and caregiver partnering relationship. Dr. Price asserted that establishing trust is grounded in feeling valued. As a patient, she noticed that people talked about her to others, yet never addressed her as an equal. The first time a physician approached her as an individual brought her to tears; throughout her experience, she was seen as a patient, and not a person first. Onboarding patients as people is critical in understanding what really matters to the individual receiving treatment. Best practices include making patient partners feel comfortable and involved. Dr. Price suggested assigning patient partners specific tasks to ensure they are included and that their voices are heard in the work.

Mr. Van Leeuwen highlighted his experience serving at the National Quality Forum (NQF) as a patient advocate. The organization clearly defined his purpose on the committee; he is not expected to understand the statistics or scientific aspects of the conversation, but instead to focus on his frame of reference as a patient and caregiver. This exemplar structure is centered on senior staff clarifying his role and expectations upfront.

Dr. Price seconded the importance of setting expectations for patient partnering, noting that BMJ directly solicits perspectives from her life experiences. Because patient partners are not expected to understand biostatistics and epidemiology, these expectations should be clearly communicated.

The panel next questioned the appropriate amount of compensation for patient partners. Patient partners should be treated as equals in the research team; if it is inappropriate for a statistician to be reimbursed with a gift card, then the same outlook should be taken for a patient partner. On the other hand, Dr. Price is aware of work where patient partners are paid a higher hourly rate than that of the statistician. Excuses that patients might not have as much financial security are not valid; a statistician might also have monetary security issues to consider, such as maintaining grant funding. It is important to compensate all members of the research team in ways that are fair, being aware of implicit biases that might impact such decisions.

Dr. Price disagreed with the concept that compensating patient partners will unduly influence their input. Patient partnerships are jobs that involve work. These positions are not the subject of the research, nor do they impact research results in the way that a participant of the study might. Dr. Price and Mr. Van Leeuwen agreed on the need to establish standards for determining compensation that are fair and affordable. Mr. Van Leeuwen stated that compensation may look different depending on individual circumstances and needs. For example, “respite care” may better support caregivers who need to rely on external help when leaving the ones they care for in order to participate in research activities.

The WG also found consensus about the importance of having patients involved in the development of guidelines as well as throughout the entire healthcare process.

Prioritizing Next Steps in Patient Partnering

Allie Rabinowitz (MITRE) asked the WG to provide input on best practices for patient involvement in CDS development. Previously discussed approaches included disseminating Patient Partnering Panel content using the CDS Connect website or other methods of circulation; inviting presenters from outside the WG to discuss their experiences with patient partnering; and suggesting methods or venues to circulate the WG's efforts more broadly (e.g., conferences, publication opportunities).

A WG member recommended including a reference in an artifact's metadata to indicate whether a patient partner was included in the artifact development. Another WG member expanded on the idea by suggesting a handful of possible items to include based on artifact type. For example, an artifact discussing the translation of a guideline into CDS could include a "patient engagement" field in the metadata to indicate when patient partnering was used in the development of the guideline and/or of the artifact itself. WG members supported including information in the *CDS Connect User Guide* as well as creating a Frequently Asked Question (FAQ) resource about partnering with patients. The WG hopes that this concept will be expanded upon to document multifaceted approaches to patient and caregiver partnerships (e.g., methods of patient recruitment, number of patients consulted, different types of input, and how the input resulted in impact).

Ms. Rabinowitz next asked WG members to highlight currently available patient partnering resources that they find most useful in the pursuit of partnering with patients. Previously suggested items included toolkits and frameworks for partnering; connecting with organizations recruiting patients and advocates; accessing resources to help communicate with organizational leadership on the values of patient partnering; locating tools to support patient partnering within one's own institution; establishing funding for patient partnering within research funding announcements, as well as other financial support; understanding ways to communicate with patient partners about CDS; learning lessons from organizations excelling at patient partnering; and unearthing examples of how to transform "just in time" partnering into tong-term partnerships.

The WG believes that this broader discussion needs to continue so that CDS can actualize the best results for patients. Patient and caregiver input should be prioritized along the development process, from the drafting of guidelines through the ultimate creation and implementation of CDS.

What's New with CDS Connect

MITRE provided an overview of the ongoing updates to the Authoring Tool, Repository, and CDS Connect artifacts.

The Authoring Tool now requires users to accept its terms and conditions upon logging into their account. MITRE continues to prepare for the migration of the Authoring Tool to a new server environment, in addition to the refactoring of features that will improve maintainability and reusability.

The Repository has undergone Drupal 9 security updates and an upgrade to the server memory. MITRE continues to restore MeSH taxonomy browsing within the Repository, as well as create an alert system that informs administrators when an author has requested a review of their artifact. MITRE also continues to finalize the CDS Connect User Guide and to coordinate with NORC on the development and deployment of the Clinical Decision Support Innovation Collaborative (CDSiC) website.

In addition to reviewing new and updated artifacts in the Repository from external contributors, MITRE has also updated Implementation Guides (IG) and Clinical Quality Language (CQL) it stewards to capture updates to the source information and align the artifacts more closely with FHIR Clinical Guidelines CQL guidance.

Closing