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

Meeting Summary

December 16, 2021

3:00 – 4:00 pm ET

Attendees: 39 people, including 5 phone dial-ins

Organization	Attendees
AHRQ Sponsors	Chris Dymek, Edward Lomotan, Mario Teran, James Swiger (4)
WG Members	Alison Kemp, Andrey Soares, Anthony Gerardi, Chris d'Autremont, Dan Malone, Danny van Leeuwen, Dave Carlson, Edna Boone, Janice Tufte, Jerry Osheroff, Kerri Patterson, Maya Gerstein, Melanie Combs-Dyer, Michael Wittie, Neeraj Ojha, Peter Muir, Randolph Barrows, Ryan Mullins, Tien Thai, Zeynep Behjet (20)
MITRE CDS Connect Members	Allie Rabinowitz, Chris Mosel, Matt Coarr, Michelle Lenox, Noranda Brown, Sam Carillo, Susan Haas (7)
AHRQ Grantees	Chris Harle, David Dorr, Patricia Dykes (3)

MEETING OBJECTIVES

- Welcome; Brief Review of Meeting Objectives and Agenda
- Patient Partnering Efforts Review: "One More Step" Campaign
- Roundtable Discussion with AHRQ Grantees
- What's New with CDS Connect
- Close

ACTION ITEMS

- AHRQ will continue working with MITRE and WG members to develop concepts for patient partnering in ongoing CDS development.
- WG members are asked to consider a current or future "One More Step" patient partnering opportunity within their own work.

MEETING SUMMARY

Following a brief introduction, Michelle Lenox (MITRE) reviewed the current efforts of the CDS Patient Partnering Panel. Danny van Leeuwen (HealthHats; CDS Connect Patient Advocate) next introduced three AHRQ grantees and facilitated a roundtable discussion on efforts, lessons learned, and areas to explore in patient partnering in CDS development. The meeting concluded with a brief overview of updates to the CDS Connect website.

Welcome

MITRE opened the meeting by welcoming WG members participating in the call. Ms. Lenox then introduced the agenda and facilitated the discussion.

Patient Partnering Efforts Review: "One More Step" Campaign

After thanking the panel members for their participation, Ms. Lenox summarized the efforts of the CDS Patient Partnering Panel which had met over the summer months. A subset of WG members investigated where patient partnering is occurring in practice and why that effort is important. Panel discussions produced further questions on what defines patient and caregiver partnering, identified a need to hear more lessons learned, and examined resources that are currently available. The panel's next steps include spearheading a "One More Step" campaign, in which the CDS Connect project will solicit input from WG members on their efforts involving patients and caregivers in the various stages of CDS development. The intent is to encourage WG members to extend their patient partnering activities "one more step" – to find opportunities for incremental progress in incorporating patients and caregivers into their current work wherever they are working within the CDS development lifecycle.

Roundtable with AHRQ Grantees

In this context, Mr. van Leeuwen invited three AHRQ grantees to share their experiences in addressing challenges and realizing opportunities for patient partnering.

Chris Harle (University of Florida) began the exchange with his efforts to involve patients in CDS related to chronic pain, especially for musculoskeletal conditions. Dr. Harle has led a variety of patient partnering efforts in the development of relevant tools. One obstacle he found was identifying and accessing patient partners who are representative of the population and can contribute to the desired diversity of patient attributes. He also noted past success when consulting patients at early stages of the design and adaptation phases. Nevertheless, the CDS community has room for improving the balance between patient input and the input of clinicians and developers so that the patient voice is heard throughout the design and development phases.

David Dorr (Oregon Health and Science University) discussed his focus on patient-facing factors in addressing blood pressure monitoring and management. Dr. Dorr's work includes conducting interviews and online surveys to understand acceptable social norms, as well as identifying factors

that support trust of a clinical care team. Those findings shaped his understanding about the importance of messaging, as well as how options in CDS should reflect social norms and social trust. One of his successes involved the practice of connecting with every participant for feedback as soon as possible after using a CDS tool; his study team continues to explore ways to sustain this important feedback loop. Dr. Dorr identified the lack of diversity in the research population, as well as the "digital divide's" effect on the uptake and use of digital tools within personal health records.

Patricia Dykes (Harvard Medical School and Brigham and Women's Hospital) next described her work on developing CDS for evidence-based fall prevention. Dr. Dykes has conducted patient interviews to ascertain why fall-prevention efforts are not regularly undertaken in primary care settings, especially in populations of older adults. Implementation efforts underway in Boston and Florida feature patient interviews at the conclusion of a clinical visit about the CDS tools incorporated during that exchange. She uses feedback from patient councils to refine CDS to be more patient- and family-friendly. Dr. Dykes also mentioned lessons learned in working in diverse urban and rural populations, namely the need to account for very different resources and perspectives. She underscored the importance of designing an intervention that is generalizable, looking at what is common among the target populations and identifying resources that can be useful across settings. Dr. Dykes highlighted the challenges of receiving patient feedback during the COVID-19 lockdown and social distancing periods; flexibility was critical in receiving patient feedback when circumstances disrupted previously planned protocols. Finally, she noted the heterogeneity of patient preferences and the resultant need to tailor interventions to the individual's technologic capabilities (e.g., a hardcopy printout, video, or internet-based interactive platform).

Open Discussion

Mr. van Leeuwen opened the discussion for questions, inviting the panelists to respond to the observations and challenges in patient partnering.

Dr. Harle noted the importance of identifying diverse and representative patient partners. The OneFlorida Clinical Research Consortium has been helpful in his work to partner with relevant individuals in the design and evaluation of CDS technology, and he highlighted that building out these networks of networks may increase diversity. Dr. Harle recognized the difficulty in recruiting – with a limited pool of citizen scientists, it was challenging to also find a match on the required patient experience. A larger and more diverse network of patients is needed to better identify the right people to partner in CDS design and evaluation.

Dr. Dorr's current CDS topic of interest—blood pressure management—is a relatively common health issue with many interested patients willing to use CDS tools and contribute feedback. He found the timing of involving patient partners can change the impact; integrating patient partners from the onset of the project and in a supportive way is important for long-term success. He also suggested a potential role for an interested, qualified, and willing patient serving as a co-investigator.

Dr. Dykes's experience confirmed that routine involvement of patients and care partners in early phases of CDS development helps ensure the tools are meeting user requirements. She related the

challenges imposed by COVID-19 to these approaches. Previously, observation of the clinician-patient workflow and in-person interviews were possible, but the feasibility of these methods had been challenging in the present-day ongoing pandemic. That said, adaptations to these methods (e.g., holding interviews sessions over Zoom, conducting contextual interviews using artificial patient data) have created opportunities for timely gathering of perspectives and the integration into development. Patient caregiver panels are an excellent source of feedback on software design during formative phases of the project. With those panels not meeting as regularly during the pandemic, conducting summative user testing and feedback gathering immediately after CDS use has been critical to continuing to account for the patient perspective.

Mr. van Leeuwen observed a common theme among the panelists: challenges attendant to identifying or recruiting a diverse and representative population of partners.

A WG member added that the language researchers, clinicians, and CDS developers use to describe their work often alienates potential patient partners. Even if the language is crafted to be at a fifth-grade comprehension level, a gap persists in characterizing CDS is in a way that describes its impact on the lives of patients and their families. The member advocated for improved framing and messaging to incite the interest in potential patient partners. A second WG member amplified that the issue involves not only the jargon and comprehension level, but also how to present the information in way that is not overwhelming. The industry must also enhance the way its members communicate with other stakeholders. Mr. van Leeuwen compared this dynamic to a meeting of participants from different countries who speak different languages; a translator is required after each person speaks in order to ensure comprehension and collaboration. Dr. Dykes echoed this sentiment, acknowledging that clinicians often forget that their day-to-day, expertise-laden "common" language may be foreign to patients, caregivers, or other stakeholders.

Another WG member advocated for current patient partners to continue mentoring and advising individuals embarking upon patient-advocacy efforts.

Mr. van Leeuwen raised a question about whether CDS researchers and developers are motivated to allocate time, money, and resources into patient-partnering efforts or similar initiatives. Dr. Harle responded that AHRQ and the Patient Centered Outcomes Research Institute (PCORI) alike hold investigators responsible for these endeavors, providing funding opportunities and requirements incentivizing this work.

Another WG member suggested looking at the impact of using CDS to support shared decision making and enhance patient-clinician communications. Over time, the regular use of these CDS could make the process of shared decision a more expected part of care. There are still challenges to address here regarding patient expectation of roles and ways to address information imbalance. Methods for visualizing the impact of care could be beneficial.

Clinician grantees shared they find it helpful for overall communication around this information imbalance to first have patients and families talk about their own stories. It is valuable overall to the

work, but it also helps facilitate conversations. A WG member agreed that hearing those stories is an important part of communicating effectively.

A WG member commented that CDS should incorporate individual needs or differences as much as possible. This WG member personally experienced challenges in care for a rare/less-common diseases whenthe coding for the condition occurred at the generic level, not the specific level, and the resulting treatment was problematic for more specific case. She recommended CDS design should strive to align with patient's individual circumstances; further, this individualized information should be accessible across systems to ensure availability of all evidence, regardless of care setting.

What's New with CDS Connect

The MITRE team discussed updates and features that were recently implemented or that remain in progress. When users download artifacts created using the Authoring Tool, the download will now include XML representations of the Expression Logical Model (ELM) content, thus allowing the CDS logic to be more easily integrated into systems that support XML. In addition, the Authoring Tool team improved the efficiency of building and running the CDS Authoring Tool using Docker. The team updated several of the technical tools and libraries upon which the Authoring Tool relies. MITRE will also continue to work on improving the maintainability and reusability of the Authoring Tool platform and products.

With regard to the Repository, MITRE completed an upgrade to version 9 of Drupal, and continues to address memory issues due to Medical Subject Headings (MeSH) taxonomy. Additional work will troubleshoot code limiting the number of artifacts returned by the REST API (web server requests to obtain information from the server). Finally, CDS Connect is beginning to work with AHRQ and NORC to develop plans for multiparty development to incorporate CDSiC content into the Drupal instance managed by the CDS Connect Repository team, as well as future AHRQ website content for the Center for Evidence and Practice Improvement (CEPI) Evidence Discovery And Retrieval (CEDAR) team. This includes determining how developers from multiple organizations will be able to work with the same resources and synchronize deployment plans.

Closing