STAKEHOLDER CENTER PROGRESS REPORT
MARCH 2024

CDSiC Stakeholder Community and Outreach Center:
Quarterly Report

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Agency for Healthcare Research and Quality

Clinical Decision Support Innovation Collaborative

PURPOSE

The Clinical Decision Support Innovation Collaborative (CDSiC) Stakeholder Community and Outreach Center prepares a publicly available quarterly progress report to provide a summary of the status of all projects and activities being conducted within the CDSiC Stakeholder Center's four Workgroups and Planning Committee during the reporting period.

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PUBLIC DOMAIN NOTICE

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Introduction

NORC at the University of Chicago (NORC) is pleased to submit the seventh quarterly report to the Agency for Healthcare Research and Quality (AHRQ) on the Clinical Decision Support Innovation Collaborative (CDSiC) Stakeholder Community and Outreach Center (Stakeholder Center). This quarterly report provides a summary of the status of all projects and activities being conducted within the CDSiC Stakeholder Center in the first quarter of 2024.

The CDSiC aims to advance the design, development, dissemination, implementation, use, measurement, and evaluation, of evidence-based, shareable, interoperable, and publicly available patient-centered clinical decision support (PC CDS) to improve health outcomes of all patients by creating a proving ground of innovation. Products put forth by the CDSiC will provide innovative solutions that promote the adoption of PC CDS to facilitate whole-person, evidence-based care and improve patients' health and care experience. Ultimately, the CDSiC aims to create a world where patients, caregivers, and clinicians have the information needed to make decisions that improve the health and well-being of all individuals.

Through its Workgroups, the CDSiC Stakeholder Center provides the project's thought leadership—developing products that advance CDS for the broader community, informing the overall work of the CDSiC (in partnership with the CDSiC Operations Center Steering Committee), and offering input on projects the CDSiC Innovation Center develops. Critically, the Stakeholder Center has engaged diverse stakeholders in CDSiC activities, consistent with the mandate established by Section 6301 of the Affordable Care Act for AHRQ to engage and obtain feedback from diverse stakeholders. The Stakeholder Center consists of a Planning Committee and four Workgroups, 1) Measurement and Outcomes, 2) CDS Standards and Regulatory Frameworks, 3) Implementation, Adoption, and Scaling, and 4) Trust and Patient-Centeredness. Together, these Workgroups will produce 11 products by September 2024.

The following sections provide a summary of the status of all projects and activities conducted within the CDSiC Stakeholder Center from January 2024 through March 2024.

Status Report

Planning Committee

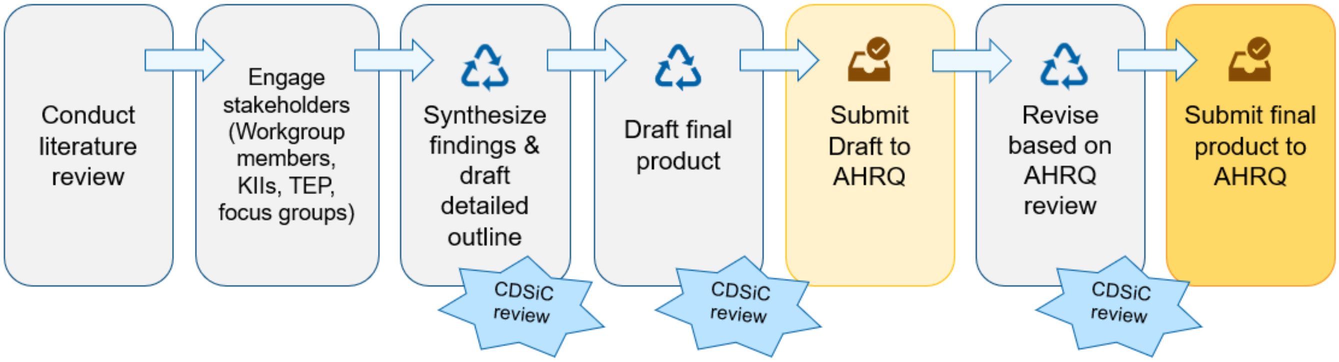
The Stakeholder Center Planning Committee is comprised of the Stakeholder Center Lead, AHRQ project officers, the CDSiC Primary Investigator and Co-Investigators, and Workgroup Co-leads. In the first quarter of 2024, the Committee met monthly to discuss product development activities across Workgroups, focusing on how Workgroup products are addressing topics relevant to PC CDS. These topics included artificial intelligence, patient preferences, return on investment, CDS override reasons, and patient journey health measures. These discussions raised considerations for current products under development as well as potential areas to probe in future CDSiC work. The Committee will reconvene in June 2024.

Stakeholder Center Workgroups

Across the four Workgroups, the Stakeholder Center will produce 11 products that advance the CDS field in 2024. The products vary in terms of the expected length of time to complete based on scope, falling into one of three levels. This year, the Workgroups will produce 11 products at the Level 2 and Level 3 effort. Level 2 projects involve a medium amount of effort. Level 3 projects are shorter-term activities. Three Workgroups (Implementation, Adoption, and Scaling, Measurement and Outcomes, and Trust and Patient-Centeredness) will produce three products each, including one Level 2 product and two Level 3 products. The Standards and Regulatory Frameworks Workgroup will produce two Level 2 products.

Product development is supported by 12 Workgroup support staff with direction from the Stakeholder Center lead and the CDSiC leadership team. The product development process varies across each product, but generally involves targeted literature searches, stakeholder input and feedback (e.g., through Workgroup engagement), qualitative data collection (e.g., key informant interviews [KIIs], focus groups, patient panels, technical expert panels [TEPs]), and analysis and synthesis (Exhibit 1). In addition, product development activities involve bi-weekly meetings between Workgroup Leads and support teams. Each Workgroup product goes through a rigorous internal review process by the Stakeholder Center and NORC leadership team at the outline and draft stages to ensure that the products are high-quality written deliverables that provide substantive contributions to the CDS field.

Exhibit 1. Workgroup Product Development Process



Workgroups continued to meet bi-monthly through the reporting period, using meetings to update Workgroup members on product progress and solicit their input on product scope and activities. In March 2024, three Workgroups submitted draft products to AHRQ for review. All remaining products are under development. See below for more information and development updates on each product.

Implementation, Adoption, and Scaling Workgroup

Landscape Assessment on the Use of Artificial Intelligence to Scale PC CDS (Level 3)

In seeking to identify how to address barriers to the wide adoption and impact of PC CDS, a promising approach is to leverage the increasing capabilities of artificial intelligence (AI), including large language models such as ChatGPT. This product aims to support the PC CDS field in understanding how they can leverage AI in their work. Under this product, the Workgroup support team conducted a landscape assessment and KIIs to understand key opportunities and considerations for the use of AI to scale PC CDS and CDS. The product maps findings from real-world implementations of AI with CDS to five dimensions where AI can scale PC CDS: 1) automate processes, 2) facilitate technical development and support of PC CDS, 3) complement direct/immediate clinician interaction, 4) facilitate sharing and replication of PC CDS, and 5) support cognitive processes and decision making. Recommendations on how AI can be used to scale PC CDS in a patient-centered way are also provided. To develop this product, the Workgroup support team synthesized findings from peer-reviewed and grey literature and conducted 11 KIIs with electronic health record (EHR) developers, CDS developers, researchers, patient representatives, and health system leaders

Case Studies of PC CDS Implementations to Identify Challenges, Opportunities, and Recommendations for the Implementation, Adopting, and Scaling of PC CDS (Level 3)

Case studies offer an opportunity to identify insights that only become apparent when delving into specific use cases. This product will describe case studies of real-life PC CDS implementations, with a particular focus on those implementations supported by AHRQ, and derive more detailed insights into the key challenges, opportunities, and recommendations for the implementation, adoption, and scaling of PC CDS.

During the reporting period, the Workgroup identified nine prior AHRQ grantees as case study candidates. These prior grantees who received AHRQ funding to implement PC CDS interventions in their clinical settings. The Workgroup support team reviewed documents and reports from the PC CDS implementation projects and invited nine prior grantees to participate in KIIs. As of March 2024, the Workgroup has conducted six interviews.

Examine Return on Investment for PC CDS (Level 2)

Favorable return on investment (ROI) is critical to the widespread implementation, adoption, and scaling of any healthcare intervention. However, there is limited literature on ROI for PC CDS, which is a significant barrier to widespread dissemination of PC CDS. This product will catalog opportunities and approaches for PC CDS to provide a favorable ROI based on a focused literature review and KIIs. The ROI examination used in this product will focus primarily on documenting approaches to measuring profit and cost savings of safe and effective PC CDS. Secondary outcome measures include proxy measures that impact value such as clinician and patient satisfaction, CDS use, alert fatigue, reputation, market share, and infrastructure development, among others. The final deliverable will be a report summarizing the opportunities, methodologies, and resources needed to demonstrate ROI for PC CDS. During the reporting period, the Workgroup support team conducted a targeted literature review, synthesizing initial findings from 26 articles. The team also conducted nine KIIs. The Workgroup plans to conduct a prioritization activity as part of the product development process.

Measurement and Outcomes Workgroup

Inventory of Measurement Tools to Assess Patient Preferences for PC CDS (Level 3)

In 2023, the CDSiC developed the Taxonomy of Patient Preferences, which identified and described six domains of patient preferences relevant to PC CDS, as well as considerations for capturing, implementing, and using patient preferences in care. This product builds on the foundation work of the prior report to 1) identify existing instruments/tools to collect and assess patient preferences that fall within the Taxonomy of Patient Preferences, 2) aggregate and describe available measures/instruments in a filterable inventory, and 3) describe considerations relevant to using the tools in the inventory and for measuring patient preferences more broadly as well as current gaps in the measurement of patient preferences.

To develop this product, the Workgroup support team conducted a scoping review of the peer-reviewed and grey literature to identify patient preference measurement tools/instruments and identify gaps in the current practice of eliciting patient preferences directly from patients. The final inventory includes 43 instruments/tools for capturing patient preferences within the clinical context and provides information about the tool that will help users understand if the tool is right for their setting. The inventory and draft report were reviewed and refined by Workgroup members. The draft product was submitted to AHRQ in March 2024.

Prioritizing Patient-Centered Measure Areas for PC CDS (Level 3)

The Workgroup will create a prioritized list of measurement areas that can inform what should be considered standard in measuring patient health journey for PC CDS. Using 15 patient health journey measurement areas identified previously by the CDSiC, this product summarizes findings from a multi-step prioritization activity performed by patient advocates.

During the reporting period, the Workgroup developed a form for participants to rate the importance of the 15 measures. Nine patient advocates and representatives completed the form. Eight patient advocates and representatives then participated in a panel in early March, to review and discuss the results of the rating activity. Following the panel, participants were asked to asynchronously complete a final ranking of the measurement areas in order of importance. The final deliverable will take the form of a report that summarizes the panel methods and findings as well as a prioritized list of measurement areas.

PC CDS Reporting Tool (Level 2)

In 2023, the CDSiC developed the PC CDS Planning, Implementation, and Reporting Tool to support consistent reporting of PC CDS interventions in the literature. This year, the Measurement and Outcomes Workgroup is working to refine the tool for improved usability, which will enable broader adoption of the tool.

During the reporting period, the Workgroup support team completed three usability testing sessions with external experts to further refine the formatting, organization, and framing of the reporting tool. The refined reporting tool was then sent to four CDS experts and five novices to field test the tool using a CDS intervention that they have worked on. Participants completed an initial feedback form, which were used to guide focus group discussions with the experts and novices. The Workgroup support team conducted one focus group in March, and remaining focus groups will be held in early April.

Standards and Regulatory Frameworks Workgroup

Taxonomy of Override Reasons for PC CDS Recommendations (Level 2)

The Workgroup will develop a written taxonomy of PC CDS override reasons, encompassing override reasons for both clinicians as well as patients/caregivers. The taxonomy will serve as a foundation for creating standard override terminology, which will support advancement in analysis of PC CDS overrides. The Workgroup support team identified an initial list of almost 200 override reasons currently in use through a limited review of the relevant literature and a review of override reasons in EHR systems obtained from healthcare organizations, as well as by engaging with experts and clinicians in the field.

To refine the taxonomy, the Workgroup developed and completed a card sort activity in which override reasons were grouped under the taxonomy domains and evaluated for their alignment between draft taxonomy domains and real-world override reasons, The Workgroup then conducted KIIs with four experts in fields relevant to PC CDS to further revise the taxonomy based on expert opinion. To validate and finalize the taxonomy, the Workgroup conducted an additional four KIIs with an informatician, CDS developer, patient representative, and patient-centeredness researcher. The Workgroup support team is currently drafting the product report, which will be submitted to AHRQ in April 2024.

Prioritizing Patient Preferences for Standardization to Support PC CDS (Level 2)

The current standards landscape for patient preferences indicates that some domains of patient preferences are more routinely collected and have standardized codes for representing these data in PC CDS tools compared to others. The Workgroup will explore the prioritization of patient-centric data for PC CDS, including prioritizing patient preference domains/sub-domains for standardization, through a multi-stakeholder roundtable. The final report will provide actionable next steps for the standards development community to move patient preferences standardization forward.

In late March, the Workgroup hosted the roundtable with ten individuals, representing patient, informatician, EHR developer, researcher, and standards developer perspectives. The roundtable participants reviewed background on patient preferences and the importance of standardization, and through a guided conversation, discussed which patient preferences should be routinely collected for PC CDS and what preference information in primed for standardization to create a prioritization of patient preferences for standardization.

Trust and Patient-Centeredness Workgroup

Patient and Caregiver Perspectives on AI in PC CDS Tools (Level 3)

With healthcare on the cusp of an AI revolution, this product aims to describe patient and caregiver views on the use of AI for CDS to better understand how the use of AI in PC CDS may impact patient trust in providers and clinical information.

The Workgroup conducted three focus group sessions with five patient representatives and two caregivers to understand their perspectives on the use of generative AI tools (e.g., chatbots) in PC CDS by health systems and clinicians, using example case scenarios developed by the CDSiC Innovation Center. In the product report, the Workgroup synthesizes and describes patient and caregiver perspectives on AI and provides a list of considerations for the development of AI-enabled PC CDS tools that support trust and patient-centeredness. The draft report was submitted to AHRQ for review in March 2024.

Capturing Patient Preferences for PC CDS within Clinician Workflows and Patient Lifeflows (Level 3)

To further advance the capture and use of patient preference information for PC CDS, the Workgroup will develop this product that identifies methods for capturing patient preference data in ways that reduce burden for both patients and clinicians. Using a targeted literature review and KIIs, the Workgroup will develop a report that includes illustrative swim lane diagrams that show where patient preference data can be collected in the clinician workflow and patient lifeflow.

During the reporting period, the Workgroup developed and refined swim lane diagrams that visually depict clinical workflows and patient lifeflows for capturing patient preferences based on their review of the literature. This product ties closely to the Measurement and Outcomes Workgroup’s Inventory of Patient Preference Measurement Tools for PC CDS, using the tools identified in this product as a starting point. The Workgroup conducted KIIs with five clinicians and patients to discuss the collection of patient preferences within clinical workflows and patient lifeflows and analyzed and synthesized findings to revise the swim lane diagrams further.

Action Plan for Incorporating Social Determinants of Health into PC CDS (Level 2)

The Workgroup will develop an action plan that outlines key challenges in using social determinants of health (SDOH) data for PC CDS and potential short-term and long-term opportunities to address these challenges. The action plan will incorporate illustrative CDS use cases derived from either clinical practice guidelines that reference SDOH factors or real-world examples of incorporating SDOH data into CDS tools. The action plan may speak to various needs related to PC CDS design, development, and implementation. In doing so, this product will facilitate a shared understanding of critical gaps in our ability to address SDOH factors as part of PC CDS that must be addressed.

During the reporting period, the Workgroup completed their review of the peer-reviewed literature and identified 16 potential key informants including researchers, informaticians, patient representatives, and standards developers. In synthesizing findings from the literature, the Workgroup is working to develop a schema that maps PC CDS needs, challenges, current efforts, and opportunities for future work for incorporating SDOH into PC CDS.

Next Steps

We anticipate that all draft products will be submitted to AHRQ by June 2024. Product development and refinement will continue until September 2024. To support development, Workgroups will continue to meet bi-monthly throughout the project period to refine product content and shape the overall look and feel of each product. Additionally, the Planning Committee will meet as an opportunity for Workgroup Leads to share findings from their products and collaboratively identify how products can work together to advance the overall field of PC CDS. As product development continues, Workgroup support teams will work to ensure that products align with diverse needs and benefit end users.

Appendix. CDSiC Workgroup Products (Developed 2022-2023)

Outcomes and Objectives Workgroup

Outcomes and Objectives Workgroup: Integration of Patient-Centered Clinical Decision Support Into Shared Decision Making
This report provides a framework for the use of PC CDS support to facilitate shared decision making.

Outcomes and Objectives Workgroup: Patient-Focused Outcome Measures for Patient-Centered Clinical Decision Support
This report offers measures to evaluate PC CDS impact on patient-focused outcomes.

Outcomes and Objectives Workgroup: Taxonomy of Patient Preferences
This Taxonomy identifies and characterizes patient preferences relevant to PC CDS.

Scaling, Measurement, and Dissemination of CDS Workgroup

Scaling, Measurement, and Dissemination of CDS Workgroup: Approaches to Measuring Patient-Centered CDS Workflow and Lifeflow Impact
This report examines how PC CDS interventions impact care team workflows and patient lifeflows.

Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide
This user guide identifies available measures to assess PC CDS.

Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Planning, Implementation, and Reporting User Guide
This user guide provides details on capturing PC CDS implementation features.

Standards and Regulatory Frameworks Workgroup

Standards and Regulatory Frameworks Workgroup: Advancing Standardized Representations for Patient Preferences to Support Patient-Centered Clinical Decision Support
This report describes standards for patient preferences data.

Standards and Regulatory Frameworks Workgroup: Environmental Scan
This environmental scan reveals opportunities to evolve standards and regulatory frameworks to advance PC CDS.

Standards and Regulatory Frameworks Workgroup: Improving Interoperability of Patient Apps with the Health IT Ecosystem
This report identifies opportunities for improving patient app interoperability to advance PC CDS.

Trust and Patient-Centeredness Workgroup

Trust and Patient-Centeredness Workgroup: An Introductory Handbook for Patient Engagement Throughout the Patient-Centered Clinical Decision Support Lifecycle
This handbook provides guidance and resources for patient engagement in PC CDS.

Trust and Patient-Centeredness Workgroup: Improving the Source Credibility of Patient-Centered Clinical Decision Support Tools
This report provides a framework for understanding the role of source credibility in PC CDS support tools.

Trust and Patient-Centeredness Workgroup: Methods for Involving End-Users in PC CDS Co-Design
This resource paves the way for end users' involvement in co-design of PC CDS.