STAKEHOLDER CENTER PROGRESS REPORT

MARCH 2025

CDSiC Stakeholder Community and Outreach Center: Quarterly Report

Agency for Healthcare Research and Quality
5600 Fishers Lane
Rockville, MD 20857
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Contract No: 75Q80120D00018

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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.

FUNDING STATEMENT

This project was funded under contract number 75Q80120D00018 from the Agency for Healthcare Research and Quality (AHRQ), U.S. Department of Health and Human Services (HHS). The opinions expressed in this document are those of the authors and do not reflect the official position of AHRQ or HHS.

PUBLIC DOMAIN NOTICE

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Introduction

NORC at the University of Chicago (NORC) is pleased to submit the thirteenth 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 conducted within the CDSiC Stakeholder Center in the first quarter of 2025.

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 a range of 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. During the period between September 2024-September 2025, these Workgroups will produce 11 products. The Stakeholder Center will produce one additional cross-cutting product.

The following sections provide a summary of the status of all projects and activities conducted within the CDSiC Stakeholder Center from January through March 2025.

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. The Planning Committee met in January and March to discuss Workgroup product development and findings as well as provide input on the Stakeholder Center Level 1 product. During these meetings, Workgroup leads also gave input on the CDSiC 2025 Annual Meeting agenda.

Stakeholder Center Workgroups

Across the four Workgroups, the Stakeholder Center will produce 11 products that advance the CDS field by September 2025. The products vary in terms of the scope and expected length of time to complete, falling into one of three levels defined by AHRQ. This year, two objectives guide Workgroup product development:

1) further disseminate the Workgroup's efforts by developing journal article manuscripts that build upon CDSiC products, and

2) develop resources that are shorter, more visual, and more accessible across different target audiences to engage broad swaths of the CDSiC community.

The Measurement and Outcomes; Implementation, Adoption, and Scaling; and Standards and Regulatory Frameworks Workgroups will each create three standalone products, including one Level 2 manuscript, one Level 3 CDSiC Topic Highlight product, and a Level 3 or Level 2 product that focuses on a new topic area. The Trust and Patient-Centeredness Workgroup will produce one manuscript and one CDSiC Topic Highlight. Exhibit 1 further describes these three product types.

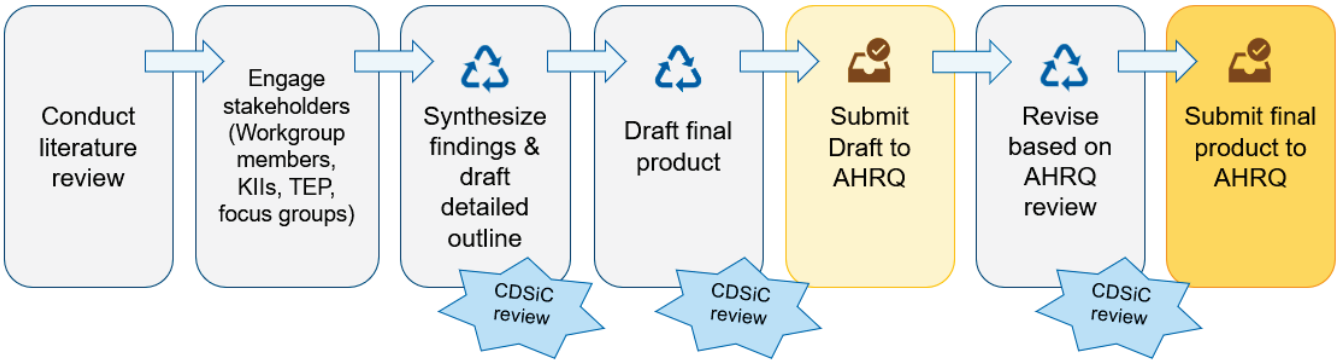
Exhibit 1. Workgroup Product Types

		
Journal Manuscript (Level 2)	**CDSiC Topic Highlight (Level 3)**	**CDSiC Report (Level 2 or 3)**
Purpose: Build upon previous CDSiC work with additional research activities to refine, validate, and/or expand product findings for manuscripts. *Target audiences:* researchers, CDS developers, health system leaders, policymakers	*Purpose:* Refine, update, and/or aggregate findings from CDSiC products to create a foundational plain-language resource. *Target audiences:* patients, clinicians, researchers, CDS developers	*Purpose:* Explore emerging topics or areas in the field of PC CDS that are distinct from prior CDSiC Workgroup products. *Target audiences:* clinicians, researchers, developers

Twelve Workgroup support staff support product development, 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 2). In

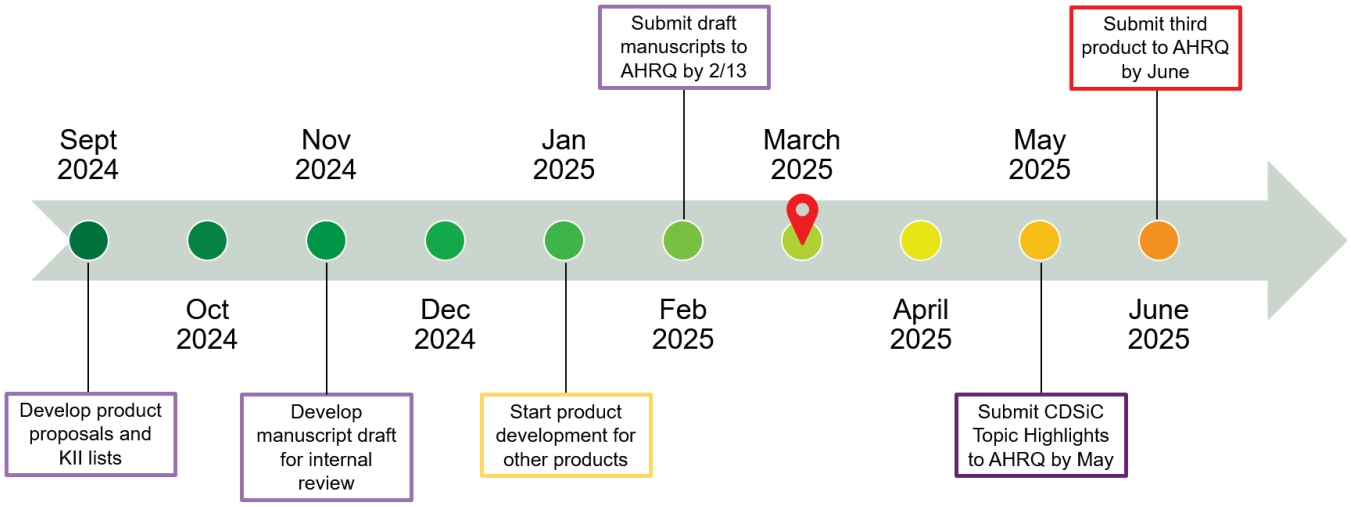
addition, product development activities involve bi-weekly meetings between Workgroup Leads and support teams. Each Workgroup product goes through a rigorous internal review process by the Stakeholder Center and CDSiC leadership team at the outline and draft stages to ensure that the products are high-quality written deliverables that provide substantive contributions to the CDS field.

Exhibit 2. Workgroup Product Development Process



Workgroups continued to advance development of products during the reporting period. Workgroups met in January and March, where they discussed product ideas, experts to consult as key informants, and product development updates including preliminary findings. All four Workgroups submitted their manuscript products by February. Exhibit 3 summarizes the Workgroup product development timeline.

Exhibit 3. Option Year 2 Workgroup Product Development Timeline



Below, we provide a description of each Workgroup product and progress updates from the reporting period.

Implementation, Adoption, and Scaling Workgroup

Manuscript: Advancing Patient Engagement in PC CDS Design, Development, and Implementation

Leveraging the Workgroup's *Exploring Challenges and Opportunities for Patient Engagement, Implementation, Adoption, and Scaling Through PC CDS Case Studies*, the manuscript includes three additional PC CDS case studies demonstrating patient engagement and summarizes lessons and strategies on meaningfully engaging patients in PC CDS research as well as how to improve adoption of PC CDS. The draft manuscript was submitted to AHRQ in February 2025.

Topic Highlight: Summary of Considerations for Understanding and Leveraging Artificial Intelligence (AI) in PC CDS

This plain-language resource describes information about AI and considerations for its use in PC CDS from four previously developed CDSiC Workgroup and Innovation Center reports and for patients and other partners who are less familiar with AI-related concepts. During the reporting period, the Workgroup analyzed findings from the literature to identify new examples of uses of generative AI-supported PC CDS and prioritized these uses with Workgroup members for inclusion in the final product. The team then drafted the final resource incorporating Workgroup member input. The Workgroup will also conduct KIIs with patients or patient advocates to gather input on the draft resource. During this time, the Workgroup identified and contacted potential informants, developed an interview protocol, and scheduled interviews.

Report: Playbook for Implementing, Adopting, and Scaling Text Message Facilitated PC CDS

This playbook describes key considerations and best practices for implementing SMS-facilitated PC CDS to better understand the barriers and facilitators healthcare organizations and patients encounter to effectively using direct-to-patient text messaging as an engagement strategy for PC CDS and offer implementation best practices. During the first quarter of 2025, the Workgroup conducted a literature review of peer-reviewed articles on text messaging health-related interventions, abstracted and synthesized findings, and drafted a report outline. The Workgroup will also conduct KIIs with PC CDS researchers, and began developing interview materials in preparation.

Measurement and Outcomes Workgroup

Manuscript: Physician and Patient Prioritization of Measurement Areas for Patient-Centered Clinical Decision Support

This manuscript builds on the *Patient Prioritization of Measurement Areas for Patient-Centered Clinical Decision Support* report, to describe similarities and differences in the measurement priorities for patients and clinicians. The Workgroup repeated a modified Delphi panel with nine primary care physicians to gain their perspectives. The draft manuscript was submitted to AHRQ in February 2025.

Topic Highlight: A Unified PC CDS-Shared Decision Making Framework

Leveraging the CDSiC's *Integration of Patient-Centered Clinical Decision Support into Shared Decision Making* report, the Topic Highlight aligns the PC CDS-Shared Decision Making Framework with AHRQ's SHARE Approach to help clinicians and patients understand how PC CDS can support the shared decision making process, and help PC CDS developers understand functionalities needed for shared decision making. During the reporting period, the Workgroup conducted KIIs with shared decision making experts to validate the PC CDS-SHARE crosswalk and, using their input, drafted the resource. The Workgroup will conduct additional KIIs with 1-2 patients or patient advocates to identify suggestions to improve the overall readability and understandability of the final product.

Report: Considerations for Minimizing Patient Burden and Fatigue When Providing Data for PC CDS

This report explores what PC CDS developers and implementers should consider when gathering patient-provided data to reduce response burden for patients. It includes a list of considerations and best practices to optimize patient data collection, and any factors identified as contributors to fatigue/burden. In the first quarter of 2025, the Workgroup conducted a targeted review of the peer-reviewed literature to identify factors of response burden and mitigating strategies that are relevant for PC CDS. They then developed a framework for patient response burden, aligning with the predictors from the Unified Theory of Acceptance and Use of Technology framework (UTAUT). During this time, the Workgroup also scheduled and prepared for KIIs with CDS researchers, clinicians, and patient advocates to validate the framework.

Standards and Regulatory Frameworks Workgroup

Manuscript: Taxonomy of PC CDS Override Reasons

The Workgroup further refines and validates the Workgroup's *Initial Taxonomy of Override Reasons for PC CDS Recommendations* based on clinical use cases. To refine the taxonomy, NORC conducted a card sorting exercise to assign override reasons to taxonomy domains with eight CDSiC partners and interviewed four PC CDS stakeholders to solicit input on the mapping. NORC validated the taxonomy through eight think-aloud interviews with clinicians/informaticians, patient advocates, and health services researchers. The draft manuscript was submitted to AHRQ in January 2025.

Topic Highlight: Current State of Interoperability of Patient Apps with the Health Information Technology (IT) Ecosystem

Building off the Workgroup's prior report, *Improving Interoperability of Patient Apps With the Health IT Ecosystem*, this product updates the PC CDS integrated health IT ecosystem diagram and identifies additional examples of standards-based patient-facing apps incorporated into the PC CDS ecosystem to serve as illustrative use cases. During the reporting period, the Workgroup conducted a literature review of the current standards landscape to update the original patient app interoperability ecosystem diagram. They then conducted KIIs with patient representatives, PC CDS researchers, and app developers to validate the diagram, identify potential use cases, and discuss the current interoperability standards landscape. Synthesizing qualitative interview findings, the team drafted the final resource.

Report: Developing Implementation Strategies for the Override Taxonomy

This report describes an adapted *Override Taxonomy* for front-end CDS recipients and recommended approaches to encourage uptake and use of the taxonomy in real-world settings. This report provides standardized override taxonomy language that can be adopted by PC CDS end users and standards developers to express override reasons. In the first quarter of 2025, the Workgroup mapped the override taxonomy to the HL7 negation value set and developed a user-facing template for terms for the existing Override Reasons Taxonomy based on a literature review and crowdsourcing of override reasons. They also prepared for and conducted two sets of KIIs with HL7 CDS Workgroup members, patient representatives, health informaticians, and clinicians to discuss 1) the user interface terms that were developed based on the Override Taxonomy and potential front-end implementation strategies, and 2) the benefits and drawbacks of using CDS Hooks and feedback on the use case.

Trust and Patient-centeredness Workgroup

Manuscript: Patient- and Caregiver-Informed Considerations for Use of AI in PC CDS

Building on the Workgroup's *Patient and Caregiver Perspectives on Generative AI in PC CDS*, this manuscript describes how patients and caregivers perceive the use of generative AI in PC CDS and presents a list of robust and prioritized patient- and caregiver-informed considerations for implementation and use of generative AI in PC CDS. To develop the manuscript, NORC conducted three additional small group discussions with a total of nine patient and caregiver advocates to supplement findings from the original resource. In these discussions, participants further refined the original list of AI implementation and use considerations, identified new considerations, and prioritized a total of seven considerations by importance. The draft manuscript was submitted to AHRQ in February 2025.

Topic Highlight: Incorporating Patient Preferences in PC CDS

Building on prior CDSiC products focused on patient preferences, this patient-facing resource defines patient preferences and their utility within PC CDS, describes how incorporation of patient preferences supports shared decision making, and provides methods for sharing and capturing patient preferences and integrating them in PC CDS. The Workgroup translated their previous patient preference-focused swimlane diagrams into patient journey maps and drafted the resource. They also prepared for KIIs with CDS researchers and patient representatives to review the draft resource, including scheduling interviews and developing the interview guide.

Center-Wide Product

In addition to the 11 Workgroup products described above, the Stakeholder Center is developing a cross-cutting product that addresses areas relevant to several Workgroups. The product, titled *Measuring Patient Experience of Patient-Centered Clinical Decision Support*, aligns with AHRQ's expected level of effort for a Level 1 product (i.e., 12-14 months). Under this product, the CDSiC is developing a set of "research ready" survey questions that measure patients' perceptions of and experiences with PC CDS tools. The final questionnaire will be accompanied by a 15-20-page report

that describes the question development process, a brief summary of literature relevant to question development, potential domains for measuring and assessing patient experience in PC CDS, areas of patient experience with PC CDS that are important to patients, and strengths and limitations of potential measures. These survey questions could be added to an existing, federally-fielded survey instrument. The CDSiC Stakeholder Center leads this work and NORC is working collaboratively with Workgroup Leads and members as well as the CDSiC Steering Committee, as appropriate.

During the reporting period, NORC conducted a literature review to identify existing survey questions and domains for assessing patient experience that would be relevant to PC CDS tools. After synthesizing literature findings, we identified nine patient experience domains and conducted interviews with patients, CDS developers, and/or health system representatives to identify priority engagement domains to focus on when developing survey questions. The NORC team presented updates on the product's development, including key findings from the literature and qualitative interviews, once to the CDSiC Steering Committee in January and twice to the Stakeholder Center Planning Committee in January and March. During these meetings, Committee members discussed the key findings and provided additional input. NORC also presented to the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Consortium in February to share the product's purpose and key findings, and to solicit input on the approach from the CAHPS Consortium as well as other considerations when developing the questionnaire.

Next Steps

We anticipate that all draft products will be submitted to AHRQ by June 2025. Product development and refinement will continue until September 2025. To support development, Workgroups will continue to meet 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 2022-2024)

Topic Area: Standards

Understanding available PC CDS standards and priorities for future standards development

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.

Standards and Regulatory Frameworks: Prioritizing Patient Preferences for Standardization to Support PC CDS
This report prioritizes short-term and long-term standardization opportunities for patient preference information.

Topic Area: Patient Trust, Engagement, and Preferences

Exploring factors contributing to trust in PC CDS, patient engagement throughout its lifecycle, and integration of patient preferences

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.

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

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.

Trust and Patient-Centeredness Workgroup: Capturing Patient Preferences for PC CDS within Clinician Workflows and Patient Lifeflows
This report describes approaches for collecting and integrating patient preferences in PC CDS workflows and lifeflows.

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.

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.

Topic Area: Measurement

Examining available measures to assess the impact of PC CDS on process and outcomes

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.

Measurement and Outcomes Workgroup: Patient Prioritization of Measurement Areas for PC CDS
This report aims to identify what measurement areas within the patient health journey are important to patients when determining if patient-centered clinical decision support (PC CDS) is achieving its intended purpose.

Measurement and Outcomes Workgroup: Inventory of Patient Preference Measurement Tools for PC CDS Report
This report describes an inventory of tools to collect patient preference information.

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

Topic Area: PC CDS Implementation

Providing resources and guidance that inform the implementation of PC CDS

Implementation, Adoption, and Scaling Workgroup: Exploring Challenges and Opportunities for Patient Engagement, Implementation, Adoption, and Scaling through PC CDS Case Studies
This report describes case studies of real-life PC CDS implementations

Standards and Regulatory Frameworks Workgroup: An Initial Taxonomy of Override Reasons for PC CDS Recommendations
This taxonomy provides a shared set of override domains that can be used by developers and researchers when analyzing why users do not accept patient-centered clinical decision support guidance.

Implementation, Adoption, and Scaling Workgroup: Key Factors and Considerations for Assessing the Value of Patient-Centered Clinical Decision Support
This report catalogs factors and considerations for assessing PC CDS value, including economic and clinical factors.

Trust and Patient-Centeredness Workgroup: Action Plan to Collect and Use Social Determinants of Health Data in PC CDS
This report speaks to various requirements for incorporating SDOH data in PC CDS design, development, and implementation across the PC CDS Lifecycle

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.

Measurement and Outcomes Workgroup: PC CDS Planning and Reporting Tool and User Guide
This product streamlines the original tool to provide a more user-friendly tool to capture PC CDS implementation features.

Use of Artificial Intelligence in PC CDS

Exploring the use of AI in transparent ways to scale PC CDS

Trust and Patient-Centeredness Workgroup: Patient and Caregiver Perspectives on Generative AI in PC CDS
This report provides descriptions of patient and caregiver perspectives on the use of generative AI in patient-centered clinical decision support.

Implementation, Adoption, and Scaling Workgroup: Landscape Assessment on the Use of AI to Scale PC CDS
This report assesses use of AI to scale patient-centered clinical decision support.