

STAKEHOLDER CENTER PROGRESS REPORT

DECEMBER 2024

CDSiC Stakeholder Community and Outreach Center: Quarterly Report

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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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Introduction

NORC at the University of Chicago (NORC) is pleased to submit the twelfth 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 fourth 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. 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 October 2024 through December 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. A new meeting schedule was determined, with the Planning Committee convening three times in 2025: January, March, and August.

Stakeholder Center Workgroups




With the start of a new project year in October 2024, the Workgroups collectively added 12 new Workgroup members. These individuals had previously expressed interest in joining the CDSiC or were recommended by colleagues who participated in the CDSiC 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.

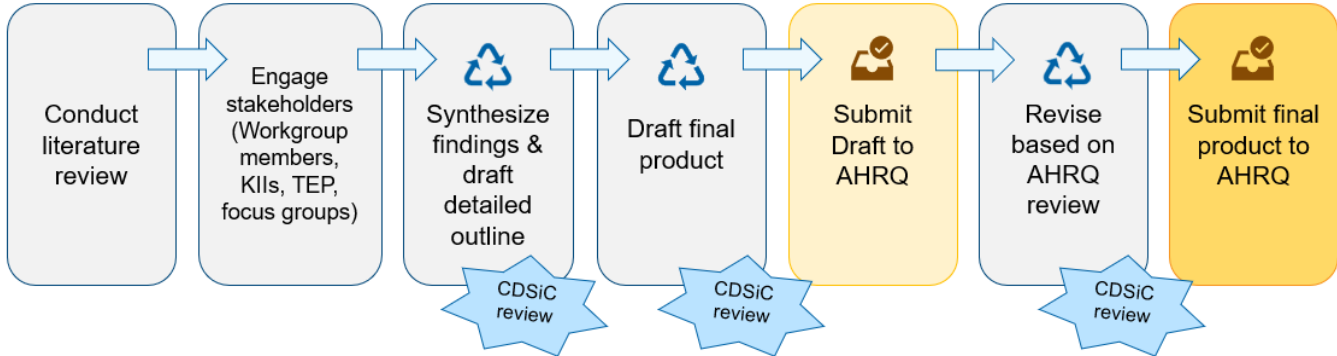
The Measurement and Outcomes; Implementation, Adoption, and Scaling; and Standards and Regulatory Frameworks Workgroups will each create three standalone products, including one Level 2 manuscript, one Level 3 CDSiC Topic Highlight product, and a Level 3 or Level 2 product that focuses on a new topic 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. Option Year 2 Workgroup Product Types

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

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



Between September and December 2024, all Workgroups developed and refined product ideas. Workgroups met in October and November, where they discussed product ideas, potential methods, experts to consult as key informants, and product development updates. NORC submitted product proposals to AHRQ for review and approval in October 2024. Exhibit 3 briefly summarizes the products that Workgroups will develop this year.

Exhibit 3. Option Year 2 Workgroup Products

| Product Title | Description |
|--|--|
| Workgroup: Measurement and Outcomes | |
| Manuscript: Physician and Patient Prioritization of Measurement Areas for Patient-Centered Clinical Decision Support | This resource will build on the <i>Patient Prioritization of Measurement Areas for Patient-Centered Clinical Decision Support</i> report, to understand similarities and differences in the priorities for patients and clinicians. The Workgroup will repeat a modified Delphi panel with primary care physicians. |
| Topic Highlight: A Unified PC CDS-Shared Decision Making Framework | Leveraging the CDSiC's <i>Integration of Patient-Centered Clinical Decisions Support into Shared Decision Making</i> report, the Workgroup will align 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. |

| Product Title | Description |
|--|---|
| Report: Considerations for Minimizing Patient Burden and Fatigue When Providing Data for PC CDS | This report will explore what PC CDS developers and implementers should consider when gathering patient-provided data to reduce response fatigue and burden for patients. It will include a list of considerations and best practices to optimize patient data collection, and any factors identified as contributors to fatigue/burden. |
| Workgroup: Standards and Regulatory Frameworks | |
| Manuscript: Taxonomy of PC CDS Override Reasons | The Workgroup will further validate and refine the Workgroup's <i>Initial Taxonomy of Override Reasons for PC CDS Recommendations</i> based on clinical use cases. |
| Topic Highlight: Current State of Interoperability of Patient Apps with the Health Information Technology (IT) Ecosystem | Building off the Workgroup's prior report, <i>Improving Interoperability of Patient Apps With the Health IT Ecosystem</i> , this product will update the PC CDS integrated health IT ecosystem diagram and identify additional examples of standards-based patient-facing apps incorporated into the PC CDS ecosystem to serve as illustrative use cases. |
| Report: Developing Implementation Strategies for the Override Taxonomy | This report will describe an adapted <i>Override Taxonomy</i> for front-end CDS recipients and recommended approaches to encourage uptake and use of the taxonomy in real-world settings. This report will create standardized override taxonomy language that can be adopted by PC CDS end users and standards developers to express override reasons. |
| Workgroup: Implementation, Adoption, and Scaling | |
| Manuscript: Advancing Patient Engagement | Leveraging the Workgroup's <i>Exploring Challenges and Opportunities for Patient Engagement, Implementation, Adoption, and Scaling Through PC CDS Case Studies</i> , the Workgroup will analyze 3-4 additional case studies demonstrating patient engagement. The manuscript will summarize lessons and strategies on meaningfully engaging patients in PC CDS research as well as how to improve adoption of PC CDS. |
| Topic Highlight: Summary of Considerations for Understanding and Leveraging Artificial Intelligence (AI) in PC CDS | This plain-language resource will describe information about AI and considerations for its use in PC CDS from two previously developed CDSiC resources for patients and other partners who are less familiar with AI-related concepts. |
| Report: Playbook for Implementing, Adopting, and Scaling Text Message Facilitated PC CDS | This playbook will describe 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. |
| Workgroup: Trust and Patient-Centeredness | |
| Manuscript: Patient- and Caregiver-Informed Considerations for Use of AI in PC CDS | Building on the Workgroup's <i>Patient and Caregiver Perspectives on Generative AI in PC CDS</i> , this manuscript will describe how patients and caregivers perceive the use of generative AI in PC CDS and present a list of robust and prioritized patient- and caregiver-informed considerations for implementation and use of generative AI in PC CDS. |

| Product Title | Description |
|--|---|
| Topic Highlight: Incorporating Patient Preferences in PC CDS | Building on prior CDSiC products focused on patient preferences, this will be a patient-facing resource that defines patient preferences and their utility within PC CDS, how incorporation of patient preferences supports shared decision making, and methods for sharing and capturing patient preferences and integrating them in PC CDS. |

Center-Wide Product

In addition to the 11 Workgroup products described above, the Stakeholder Center will develop a cross-cutting product that addresses areas relevant to several Workgroups. The product, titled *Measuring Patient Experience of Patient-Centered Clinical Decision Support*, will align with AHRQ’s expected level of effort for a Level 1 product (i.e., 12-14 months). Under this product, the CDSiC will develop 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 report’s target audience broadly includes policymakers, patients/caregivers and their care team, clinicians, health system leaders, CDS researchers, and payers. The Stakeholder Center team will comply with the expectations set forth for Workgroup products and will follow similar product development processes as described above. The CDSiC Stakeholder Center will lead this work and NORC will work collaboratively with Workgroup Leads and members as well as the CDSiC Steering Committee as appropriate.

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.