

STAKEHOLDER CENTER PROGRESS REPORT

SEPTEMBER 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 tenth 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 third 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 produced 11 products between September 2023-September 2024.

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

Status Report

Planning Committee

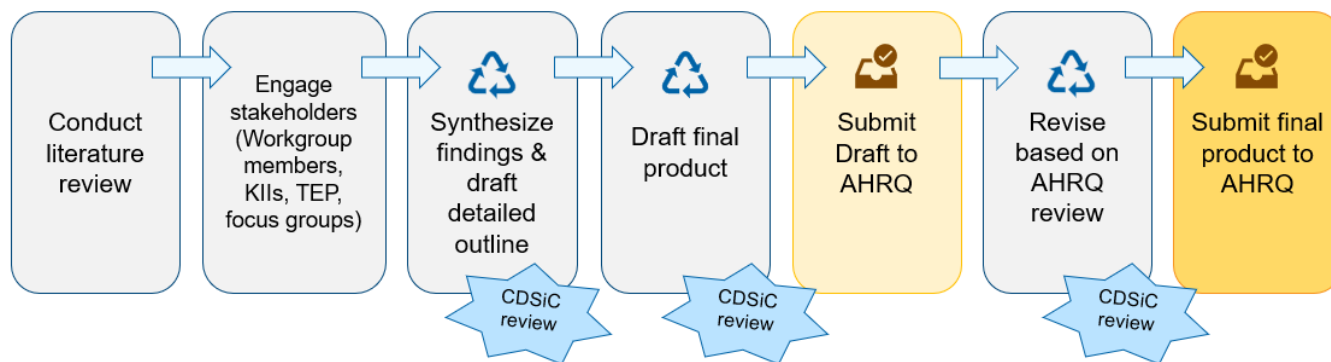
The Stakeholder Center Planning Committee is comprised of the Stakeholder Center Lead, AHRQ project officers, the CDSiC Primary Investigator and Co-Investigators, and Workgroup Co-leads. The Planning Committee met in September 2024. As the final Planning Committee Meeting of the 2023-2024 Option Year, the group discussed the vision for Workgroups and planning for Workgroup products in the second option period.

Stakeholder Center Workgroups

Across the four Workgroups, the Stakeholder Center produced 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 produced Level 2 and Level 3 products. 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) produced three products each, including one Level 2 product and two Level 3 products. The Standards and Regulatory Frameworks Workgroup produced two Level 2 products.

Twelve Workgroup support staff members 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 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 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. 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.

Exhibit 1. Workgroup Product Development Process



Below we provide a description of each Workgroup product and their individual value to the field. Products are grouped together according to aspects of PC CDS that they target to advance the broader field: design and development; implementation; measurement; and cross-cutting products. As of September 2024, all product content has been finalized. Links to all Workgroup products developed by the CDSiC are provided in the appendix. Products are organized by topic area.

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. 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. The findings in this landscape assessment will enable PC CDS stakeholders to better understand and leverage AI to scale PC CDS more widely and encourage the use of AI in PC CDS among clinicians, patients, and their care teams.

Exploring Challenges and Opportunities for Patient Engagement, Implementation, Adoption & Scaling through PC CDS Case Studies (Level 3)

Case studies offer an opportunity to identify insights that only become apparent when delving into specific use cases. This product describes 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. The Workgroup conducted key informant interviews (KIIs) with nine prior AHRQ grantees who received AHRQ funding to implement PC CDS interventions in their clinical settings. The report describes key findings from each case study, including common challenges, corresponding solutions, and opportunities for future work to foster adoption and scale PC CDS initiatives. The report uses an organizing framework that presents findings via four domains, including patient engagement, implementation, adoption, and scaling. Through the real-life examples of PC CDS implementations, these findings will support PC CDS developers in implementing, adopting, and scaling PC CDS.

Key Factors and Considerations for Assessing the Value of Patient-Centered Clinical Decision Support (Level 2)

PC CDS planning begins with identifying organizational and end-user needs and describing how PC CDS addresses those needs. Understanding the economic, financial, and clinical impact of PC CDS is a key part of the planning process and can inform healthcare organization investment decisions. To identify methods and key considerations for assessing PC CDS value, the Workgroup conducted a literature review, key informant interviews, and convened PC CDS stakeholders during the 2024 CDSiC Annual Meeting. The report identifies methods that can be used to assess the value of PC CDS; summarizes examples of the economic impacts, patient outcomes, and the financial return on investment assessed via economic evaluations of CDS interventions; discusses challenges of assessing PC CDS value; and presents alternative considerations for assessing value. Importantly, the report includes a research agenda to advance PC CDS value assessments.

Measurement and Outcomes Workgroup

Inventory of Patient Preference Measurement Tools 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 as well as current gaps in patient preferences measurement. The final inventory includes 43 instruments/tools for capturing patient preferences. The report and inventory can serve several audiences including CDS developers, providers, researchers, health system informaticians, and patient partners among others to 1) identify measurement tools to implement within health systems or incorporate into PC CDS design, 2) develop workflows to capture patient preferences and configure PC CDS to support preference-informed care, and 3) determine where there are gaps in the elicitation and measurement of patient preferences.

Patient Prioritization of Measurement Areas for PC CDS (Level 3)

The Workgroup consulted nine patient advocates to develop a prioritized list of measurement areas that 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 the patient advocates to determine which outcomes of interest are most important to patients. The final report summarizes the panel methods as well as key themes and findings from the panel, and it provides the prioritized list of measurement areas. Implications of these findings for PC CDS measurement as well as future directions are discussed. Of the 15 patient health journey measurement areas, patients ranked communication quality, trust in clinician, and access to information as the three most important areas to measure.

PC CDS Planning and 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 refined the tool and its accompanying user guide for improved clarity, usability, and accessibility to enable broader adoption of the tool. To refine the tool, the Workgroup consulted several experts in CDS through various formats, including usability testing sessions and focus group discussions with CDS experts and novices. The tool and accompanying user guide can be used by PC CDS researchers, electronic health record (EHR) and app developers, and users and evaluators of PC CDS in consistently and comprehensively describing how PC CDS was designed, developed, deployed, used, maintained, and evaluated along four key sections: 1) planning and needs assessment; 2) design and development; 3) implementation and adoption; and 4) evaluation, maintenance, and sustainability.

Standards and Regulatory Frameworks Workgroup

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

The Workgroup developed a written taxonomy of PC CDS override reasons, encompassing override reasons for both clinicians as well as patients/caregivers. The taxonomy serves 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. The taxonomy can be used to support analysis of why PC CDS guidance was not accepted by end users within a particular setting or comparatively across different healthy systems or institutions. This may ultimately improve advance standard representation of override reasons and research in CDS implementation.

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 hosted a multi-stakeholder roundtable to identify priority patient preference domains/sub-domains for standardization. Roundtable participants included individuals representing patient, informatician, EHR developer, researcher, and standards developer perspectives. The report summarizes these methods and findings and provides actionable next steps for the standards development community to move patient preferences standardization forward. Next steps are prioritized by the short-term and long-term needs for standardization. Immediate actions identified in the report include working to standardize high priority preferences including those around communication (e.g., notification preferences and preferred communication mode), personal characteristics, preferences for receiving telehealth care, participation in clinical trials, and data sharing (e.g., how data is stored and shared). The product can serve standards development organizations in determining which patient preference concepts to standardize. Additionally, the product can inform efforts to standardize patient preference data elements, such as in future versions of the United States Core Data for Interoperability (USCDI).

Trust and Patient-Centeredness Workgroup

Patient and Caregiver Perspectives on Generative Artificial Intelligence in Patient-Centered Clinical Decision Support (Level 3)

With healthcare on the cusp of an AI revolution, this product aimed to describe patient and caregiver views on the use of generative AI for CDS to better understand how the use of AI in PC CDS may impact patient trust in clinicians and clinical information. The Workgroup conducted three small group discussions 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 report, the Workgroup synthesizes and describes patient and caregiver perspectives on AI and provides a list of seven considerations for

the development of AI-enabled PC CDS tools that support trust and patient-centeredness, including providing patients with choices in using AI tools for PC CDS, educating patients and caregivers on AI-enabled tools, and using AI to supplement, rather than replace, clinicians' work, among others. Health system leaders, PC CDS developers and researchers, informaticians, and patients and clinicians can all use the report's considerations to better foster trust and patient-centeredness in generative AI-supported PC CDS tools.

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 developed this product that identifies methods for capturing patient preference data in ways that reduce burden for both patients and clinicians. The Workgroup synthesized findings from over 50 publications and from KIIs with nine clinicians and patients to discuss the collection of patient preferences within clinical workflows and patient lifeflows. The final report summarizes approaches for collecting and integrating patient preferences in PC CDS workflows and lifeflows and includes illustrative swim lane diagrams that show where patient preference data can be collected in the clinician workflow and patient lifeflow for specific use cases. The report also provides key considerations to optimize collection and use of patient preferences as well as short and long-term opportunities to advance the incorporation of patient preferences in PC CDS. The report may support PC CDS researchers, developers, and health systems in aligning the collection of patient preference data for PC CDS with patient lifeflows and clinicians' workflows, which could help bolster decision making processes and patient-provider relationships.

Action Plan to Collect and Use Social Determinants of Health Data in PC CDS (Level 2)

The Workgroup developed an action plan that outlines key challenges and current efforts in using social determinants of health (SDOH) data for PC CDS as well as potential short-term and long-term opportunities to address challenges. The action plan speaks to various needs related to PC CDS design, development, and implementation across the PC CDS Lifecycle. It identifies five key areas, or needs, that must be addressed to incorporate SDOH factors across each phase of the PC CDS Lifecycle. Within each of the five needs, the action plan describes relevant challenges to uptake of SDOH relevant to PC CDS and current efforts and corresponding opportunities to overcome those challenges. 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. In synthesizing findings from the literature, the Workgroup developed a schema that maps PC CDS needs, challenges, current efforts, and opportunities for future work for incorporating SDOH into PC CDS. This product encourages the CDS community to identify ways to address health inequities by incorporating critical SDOH data domains in PC CDS tools. By promoting the use of SDOH data in PC CDS, this product can support enhanced patient and clinician decision making by providing a fuller picture of a patient's needs, health, and social risk factors

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.