

# STAKEHOLDER CENTER PROGRESS REPORT

DECEMBER 2023

## 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 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 the project's third year (Q4 2023).

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 an overview of updates to the Stakeholder Center and Workgroups in the Option Year and a summary of the status of all projects and activities conducted within the CDSiC Stakeholder Center from October 2023 through December 2023.

## Stakeholder Center Updates

### Stakeholder Center Leadership

The Stakeholder Center consists of two leadership components: 1) Center leadership, including a Stakeholder Center Planning Committee, which provides oversight, and 2) four topic-focused Workgroups that are dedicated forums for stakeholder engagement and product development.

**Stakeholder Center Leadership.** Priyanka Desai, PhD, MSPH, from NORC leads the Stakeholder Center. She works collaboratively with Workgroup leadership to ensure that each Workgroup provides meaningful input to CDSiC activities and creates products to help advance CDS development and implementation. Desai, along with CDSiC Principal Investigator (PI) Prashila Dullabh, MD, FAMIA, Co-Investigators Dean Sittig, PhD, and David Lobach, MD, PhD, MS, FACMI, Workgroup leadership (see below), and AHRQ project leadership form the Stakeholder Center Planning Committee.

**Workgroup Leadership.** Each Workgroup is led by two Co-Leads (see Exhibit 1). Workgroup leads set the overall direction for the development of Workgroup products, facilitate meetings, lead product development, assign roles and responsibilities to members, monitor progress, ensure products are developed consistent with proposed timelines, and communicate regularly with Stakeholder Center leadership.

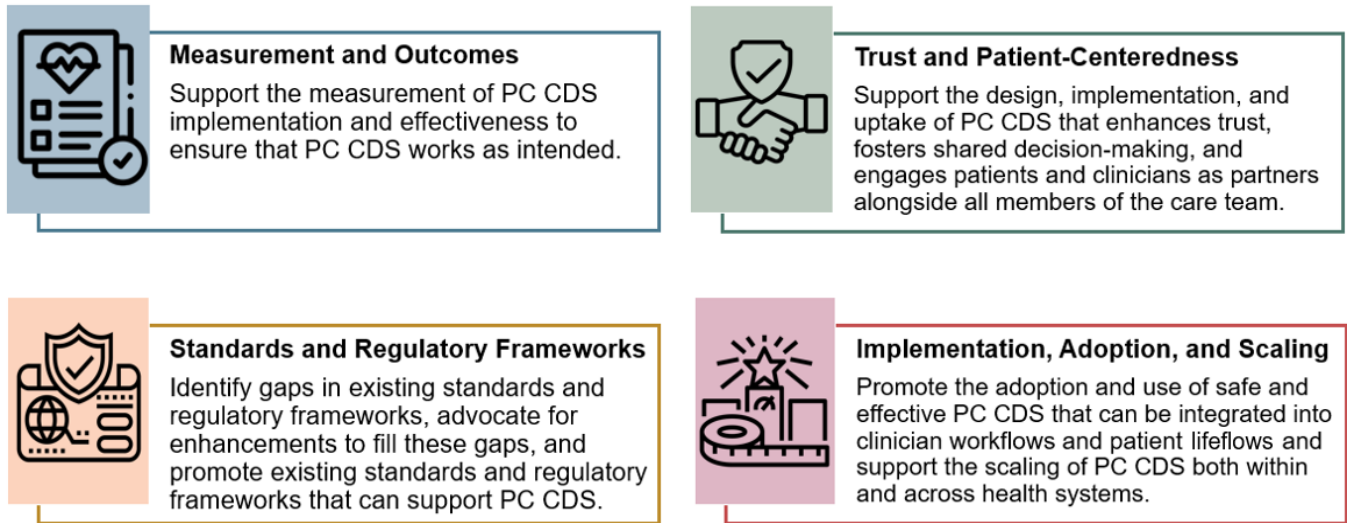
**Exhibit 1.** Workgroup Leadership

Workgroup	Workgroup Co-Leads (Affiliation)
Measurement and Outcomes	<ul style="list-style-type: none"> <li>■ Polina Kukhareva, PhD, MPH, FAMIA (University of Utah)</li> <li>■ Mustafa Ozkaynak, PhD, MS (Colorado University)</li> </ul>
Implementation, Adoption, and Scaling	<ul style="list-style-type: none"> <li>■ Ken Kawamoto, MD, PhD, MHS, FACMI, FAMIA (University of Utah)</li> <li>■ David Lobach, MD, PhD, MS (Elimu Informatics)</li> </ul>
Trust and Patient-Centeredness	<ul style="list-style-type: none"> <li>■ Jessica Ancker, PhD, MPH, FACMI (Vanderbilt University)</li> <li>■ Angela Dobes, MPH (Crohn’s &amp; Colitis Foundation)</li> </ul>
CDS Standards and Regulatory Frameworks	<ul style="list-style-type: none"> <li>■ Aziz Boxwala, MD, PhD, FACMI (Elimu Informatics)</li> <li>■ Rachel Richesson, PhD, MPH, MS (University of Michigan)</li> </ul>

**Workgroup Structure**

In the first two years of the CDSiC, there were two measurement-focused Workgroups, CDS Outcomes and Objectives and Scaling, Measurement, and Dissemination of CDS. In an effort to further clarify scopes and prevent overlap between activities, the CDSiC team established two distinct Workgroups. The CDS Outcomes and Objectives Workgroup was renamed the Measurement and Outcomes Workgroup and the Scaling, Measurement, and Dissemination of CDS Workgroup is now the Implementation, Adoption, and Scaling Workgroup. Exhibit 2 provides a brief description of the four Workgroups and their scopes.

## Exhibit 2. Current CDSiC Workgroups



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, completed in 9-11 months. Level 3 projects are shorter-term activities, taking 4-6 months to complete. Three Workgroups (Measurement and Outcomes, Implementation, Adoption, and Scaling, 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.

## Status Report

The status report provides updates on the progress of the activities of the Stakeholder Center from October 2023 to December 2023, including welcoming new CDSiC Workgroup leads and members, kicking off Workgroups for the year, and developing product ideas for each Workgroup.

## Planning Committee

This period saw the establishment of a new Planning Committee to reflect the new Workgroup leads joining the project. A new meeting schedule was determined, with the Planning Committee convening five times in 2024: January, February, March, June, and September.

## Stakeholder Center Workgroups

With the introduction of two new Workgroups and new Workgroup leadership across Workgroups, the CDSiC invited 15 individuals to participate in a Workgroup. These individuals had previously expressed interest in joining the CDSiC or participated as key informants during Workgroup product development in the first two years of the CDSiC.

Between September and December 2023, all Workgroups developed and refined product ideas. Workgroups met in October and December for bi-monthly Workgroup meetings, where they discussed product ideas, potential methods, experts to consult as key informants, and product development updates, including preliminary findings from literature reviews. NORC submitted product proposals to AHRQ for review and approval in October-November 2023. Exhibit 3 briefly summarizes the products that Workgroups will develop this year.

**Exhibit 3. Option Year Workgroup Proposed Products**

Product Title (Level)	Description
<b>Workgroup: Measurement and Outcomes</b>	
Inventory of Measurement Tools to Assess Patient Preferences (Level 3)	The Workgroup will conduct a landscape assessment to 1) identify existing instruments/tools to collect patient preferences and measures to assess patient preferences, 2) aggregate available measures/instruments in an inventory, and 3) provide an accompanying narrative that describes practical challenges with using a select number of measures, tools, and instruments identified, current gaps in the measurement of patient preferences, and limitations. This inventory will build on the <a href="#">Taxonomy of Patient Preferences</a> developed by the Outcomes and Objectives Workgroup.
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. We will use the <a href="#">patient health journey measurement areas</a> identified in previous CDSiC work for the prioritization activities and engage patient partners to participate in these activities. The final deliverable will take the form of a report and a prioritized list of measurement areas.
Rapid PC CDS Planning, Implementation, and Reporting Checklists (Level 2)	The Workgroup will work with external partners to field test the CDSiC-developed <a href="#">PC CDS Planning, Implementation, and Reporting Tool</a> on existing PC CDS interventions. The Workgroup will then adjust the tool's content based on feedback and develop rapid versions of the checklist for the four phases covered. Part of field testing may include exploring other formats for the tool (e.g., accessible Word document) that support usability.
<b>Workgroup: Standards and Regulatory Frameworks</b>	
Taxonomy of Override Reasons for PC CDS Recommendations (Level 2)	The Workgroup will develop a written taxonomy of PC CDS override reasons, encompassing reasons for both clinicians as well as patients/caregivers. The Workgroup will identify PC CDS override reasons currently in use through a limited review of the relevant literature, a review of override reasons in electronic health record (EHR) systems obtained from healthcare organizations, and a review of exclusions specified in electronic clinical quality measures (eCQMs), as well as by engaging with experts and clinicians in the field.




<p>Prioritizing Patient Preferences for Standardization to Support PC CDS (Level 2)</p>	<p>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 roundtable may include patient representatives, CDS developers, health IT developers, clinicians, researchers, and standards developers.</p>
<p><b>Workgroup: Implementation, Adoption, and Scaling</b></p>	
<p>Landscape Assessment on the Use of Artificial Intelligence (AI) to Scale PC CDS (Level 3)</p>	<p>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 AI, including large language models such as ChatGPT. The Workgroup will conduct a landscape assessment to understand key opportunities and considerations for the use of AI to scale PC CDS and CDS.</p>
<p>Case Studies of PC CDS Implementations to Identify Challenges, Opportunities, and Recommendations for the Implementation, Adopting, and Scaling of PC CDS (Level 3)</p>	<p>Case studies offer an opportunity to identify insights that only become apparent when delving into specific use cases. The Workgroup will conduct case studies of real-life PC CDS implementations, with a particular focus on those implementations supported by AHRQ, and derive more detailed insights into challenges, opportunities, and recommendations for the implementation, adoption, and scaling of PC CDS.</p>
<p>Examine Return on Investment (ROI) for PC CDS (Level 2)</p>	<p>Favorable ROI is critical to the widespread implementation, adoption, and scaling of any healthcare intervention. However, there is limited literature on ROI for PC CDS. This is a significant barrier to its widespread dissemination. The Workgroup will catalog opportunities and approaches for PC CDS to provide a favorable ROI based on a focused literature review and key informant interviews.</p>
<p><b>Workgroup: Trust and Patient-Centeredness</b></p>	
<p>Patient and Caregiver Perspectives on AI in PC CDS Tools (Level 3)</p>	<p>The Workgroup will conduct focus group sessions to understand patient and caregiver perspectives on the use of generative AI tools (e.g., chatbots) by health systems and clinicians. The final product will be a report describing patient and caregiver perspectives on AI and develop a list of considerations for the development of AI-enabled PC CDS tools that support trust and patient-centeredness.</p>
<p>Capturing Patient Preferences for PC CDS within Clinician Workflows and Patient Lifeflows (Level 3)</p>	<p>The Workgroup will identify methods for capturing patient preference data in ways that reduce the burden for both patients and clinicians. Using a targeted literature review and key informant interviews, the Workgroup will develop a guide of best practices for capturing patient preference data in clinical and non-clinical settings. The guide will include a diagram that illustrates the optimal process for collecting patient preference data, considerations to reduce burden, and implications for PC CDS.</p>










Action Plan for Incorporating Social Determinants of Health (SDOH) into PC CDS (Level 2)	The Workgroup will develop an action plan that outlines key challenges in using 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 decision support tools. The action plan may speak to various needs related to PC CDS design, development, and implementation.
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These products provide a holistic approach to foundational work for several salient topics and advance the field of PC CDS. In doing so, the products address many aspects of the PC CDS Lifecycle.<sup>1</sup> Additionally, many of the Workgroup products that will be developed in the third year complement and build off products developed in the first two years of the CDSiC. Specifically, products in the first two years of the CDSiC focused on six topic areas (Exhibit 4): 1) patient engagement, 2) trust, 3) implementation, 4) patient preferences, 5) workflows and lifeflows, 6) measurement, and 7) standards. This year, Workgroups will produce synergistic products that address five of the six topic areas and also explore three new topics: AI, SDOH, and ROI.

**Exhibit 4. Workgroup Product Topic Areas**

Topic Area	Previously Developed Workgroup Products	Workgroup Products for This Year
 <p><b>Patient Engagement</b> <i>Engaging patients across the PC CDS lifecycle</i></p>	<ul style="list-style-type: none"> <li>• T&amp;PC Methods for Involving End Users in PC CDS Co-Design</li> <li>• T&amp;PC An Introductory Handbook for Patient Engagement Through the PC CDS Lifecycle</li> </ul>	<ul style="list-style-type: none"> <li>• T&amp;PC Patient/Caregiver Perspectives on AI in PC CDS*</li> </ul>
 <p><b>Trust</b> <i>Exploring factors that contribute to patient, caregiver, and care team trust in PC CDS</i></p>	<ul style="list-style-type: none"> <li>• T&amp;PC Improving the Source Credibility of PC CDS Tools</li> </ul>	<ul style="list-style-type: none"> <li>• T&amp;PC Patient/Caregiver Perspectives on AI in PC CDS*</li> </ul>
 <p><b>Implementation</b> <i>Providing resources and guidance that inform the implementation of PC CDS</i></p>	<ul style="list-style-type: none"> <li>• SMD PC CDS Planning, Implementation, &amp; Reporting Checklist</li> <li>• O&amp;O Integration of PC CDS Into Shared Decision Making</li> </ul>	<ul style="list-style-type: none"> <li>• M&amp;O Rapid PC CDS Planning, Implementation, &amp; Reporting Checklists</li> <li>• IA&amp;S PC CDS Implementation Case Studies</li> </ul>

<sup>1</sup> Dean F Sittig, Aziz Boxwala, Adam Wright, Courtney Zott, Priyanka Desai, Rina Dhopeswarkar, James Swiger, Edwin A Lomotan, Angela Dobes, Prashila Dullabh, A lifecycle framework illustrates eight stages necessary for realizing the benefits of patient-centered clinical decision support, Journal of the American Medical Informatics Association, Volume 30, Issue 9, September 2023, Pages 1583–1589, <https://doi.org/10.1093/jamia/ocad122>

Topic Area	Previously Developed Workgroup Products	Workgroup Products for This Year
 <p><b>Patient Preferences</b> <i>Understanding how to capture and integrate patient preferences in PC CDS</i></p>	<ul style="list-style-type: none"> <li>• O&amp;O Patient Preferences Taxonomy</li> <li>• SRF Advancing Standardized Representations for Patient Preferences to Support PC CDS</li> </ul>	<ul style="list-style-type: none"> <li>• SRF Prioritizing Patient Preferences for Standardization to Support PC CDS</li> <li>• M&amp;O Inventory of Measurement Tools to Assess Patient Preferences</li> </ul>
 <p><b>Workflows and Lifeflows</b> <i>Examining clinician workflows and patient lifeflows for PC CDS</i></p>	<ul style="list-style-type: none"> <li>• SMD Approaches to Measuring PC CDS Workflow and Lifeflow Impact</li> </ul>	<ul style="list-style-type: none"> <li>• T&amp;PC Patient Preferences for PC CDS in Clinician Workflows/Patient Lifeflows</li> </ul>
 <p><b>Measurement</b> <i>Examining available measures to assess the impact of PC CDS on processes and outcomes</i></p>	<ul style="list-style-type: none"> <li>• O&amp;O Patient-focused Outcome Measures for PC CDS</li> <li>• SMD PC CDS Performance Measurement Inventory</li> </ul>	<ul style="list-style-type: none"> <li>• M&amp;O Prioritizing Patient-centered Measure Areas for PC CDS</li> </ul>
 <p><b>Standards</b> <i>Understanding available PC CDS standards and priorities for future standards development</i></p>	<ul style="list-style-type: none"> <li>• SRF Standards and Regulatory Frameworks Environmental Scan</li> <li>• SRF Improving Interoperability of Patient Apps with the Health IT System</li> </ul>	<ul style="list-style-type: none"> <li>• SRF Taxonomy of Override Reasons for PC CDS Recommendations</li> </ul>
 <p><b>Artificial Intelligence</b> <i>Exploring the use of AI to help scale PC CDS</i></p>	<p>—</p>	<ul style="list-style-type: none"> <li>• IA&amp;S Landscape Assessment on the Use of AI to Scale PC CDS</li> <li>• T&amp;PC Patient/Caregiver Perspectives on AI in PC CDS*</li> </ul>
 <p><b>SDOH</b> <i>Understanding what is needed to advance the use of SDOH in PC CDS</i></p>	<p>—</p>	<ul style="list-style-type: none"> <li>• T&amp;PC Action Plan for Incorporating SDOH into PC CDS</li> </ul>
 <p><b>Return on Investment</b> <i>Exploring factors that contribute to ROI for PC CDS</i></p>	<p>—</p>	<ul style="list-style-type: none"> <li>• IA&amp;S Return on Investment for PC CDS</li> </ul>

\*Product is relevant to multiple topics

IA&S=Implementation, Adoption, and Scaling; O&O=Outcomes and Objectives; M&O=Measurement and Outcomes; SMD=Scaling, Measurement, and Dissemination; SRF=Standards and Regulatory Frameworks; T&PC=Trust and Patient-Centeredness

## 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.