STAKEHOLDER CENTER PROGRESS REPORT

JUNE 2025

CDSiC Stakeholder Community and Outreach Center: Quarterly Report

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Agency for Healthcare Research and Quality

Clinical Decision Support Innovation Collaborative

PURPOSE

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

FUNDING STATEMENT

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PUBLIC DOMAIN NOTICE

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Introduction

NORC at the University of Chicago (NORC) is pleased to submit the fourteenth 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 second 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 April through June 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 did not meet in the second quarter of 2025, in lieu of the 2025 CDSiC Annual Meeting held in May. The Committee will reconvene in August 2025.

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.

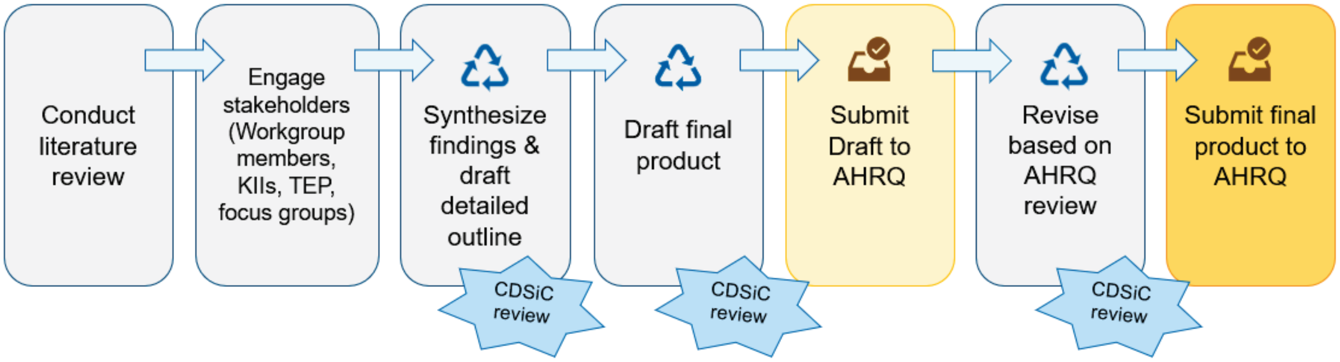
The Measurement and Outcomes; Implementation, Adoption, and Scaling; and Standards and Regulatory Frameworks Workgroups will each create three standalone products, including one Level 2 manuscript, one Level 3 CDSiC Topic Highlight product, and a Level 3 or Level 2 product that focuses on a new topic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

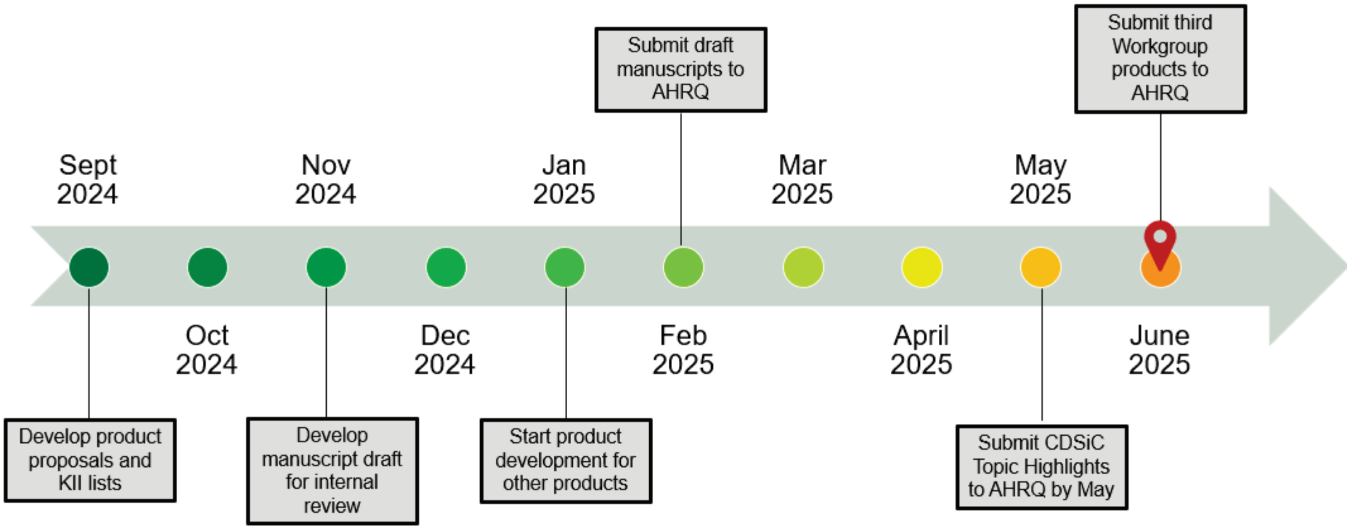
Twelve Workgroup support staff support product development, with direction from the Stakeholder Center lead and the CDSiC leadership team. The product development process varies across each product, but generally involves targeted literature searches, stakeholder input and feedback (e.g., through Workgroup 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 develop products during the reporting period. Workgroups met in April and June, where they discussed product development updates, key findings, and opportunities to share products within Workgroup members' networks. During this period, the Workgroups reviewed draft products and provided feedback both during meetings and asynchronously in writing. Each Workgroup and the Stakeholder Center Level 1 product team also presented key findings from at least one product at the 2025 CDSiC Annual Meeting for input and reflections from meeting attendees. 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: Identifying Patient Engagement Strategies and Challenges in Patient-Centered Clinical Decision Support (PC CDS): Case Studies of Federally Funded CDS Projects

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.

In the second quarter, the manuscript underwent several rounds of AHRQ review. The Workgroup iteratively revised manuscripts based on the feedback received. Upon AHRQ approval, the Workgroup will submit the manuscript to the Journal of Medical Internet Research.

Topic Highlight: Artificial Intelligence (AI)-Supported Patient-Centered Clinical Decision Support: A Summary of Considerations

This plain-language resource summarizes considerations for use of AI in PC CDS from four previously developed CDSiC Workgroup and Innovation Center reports, including challenges to using AI-enabled PC CDS and strategies and insights to develop safe, effective, and trustworthy PC CDS that uses AI. It describes key concepts in AI for patients and other partners who are less familiar with AI-related concepts and details considerations for stakeholders interested in understanding, developing, and/or implementing AI-supported PC CDS.

To develop this product, the Workgroup conducted a literature review 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 Workgroup also conducted KIIs with patient advocates to gather input on the usability and readability of the draft resource. The draft product was submitted to AHRQ in April 2025.

Report: Text Message-Facilitated PC CDS Implementation: Key Considerations and Promising Practices

This resource describes key considerations and promising practices for implementing SMS-facilitated PC CDS to better navigate the barriers and facilitators healthcare organizations and patients encounter to effectively using direct-to-patient text messaging for PC CDS. Using the PC CDS implementation phases, the report organizes considerations and promising practices into four sections: 1) planning and needs assessment, 2) design and development, 3) implementation and adoption, and 4) evaluation, maintenance, and scalability. Throughout, it also highlights areas for future research needed to advance the adoption and use of SMS-facilitated PC CDS.

This product synthesizes findings from the literature on promising practices for engaging patients in text messaging health-related interventions as well as insights from CDS researchers, behavioral scientists, and a patient advocate. The draft product was submitted to AHRQ in June 2025.

Measurement and Outcomes Workgroup

Manuscript: Measuring What Matters: Patient and Clinician Priorities for Clinical Decision Support Interactions

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 and the manuscript summarizes similarities and differences between patient and clinician perspectives. The draft manuscript was submitted to AHRQ in February 2025.

In the second quarter, the manuscript underwent several rounds of AHRQ review. The Workgroup iteratively revised manuscripts based on the feedback received. Upon AHRQ approval, the Workgroup will submit the manuscript to BioMed Central (BMC) Medical Informatics and Decision Making.

Topic Highlight: How Patient-Centered Clinical Decision Support Can Strengthen Shared Decision Making

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. It can also help PC CDS developers understand functionalities needed for shared decision making. The resource presents a direct mapping of three factors of PC CDS (knowledge, data, and delivery) to each of the five steps within AHRQ's SHARE Approach[1] to illustrate how PC CDS' functions can support patients and clinicians in shared decision making as well as an illustrative example from an AHRQ-funded PC CDS intervention for shared decision making.

To develop this product, the Workgroup conducted KIIs with shared decision making experts to validate the crosswalk of PC CDS factors to the SHARE Approach and with patient advocates to identify suggestions to improve the overall readability and understandability of the final product. The draft product was submitted to AHRQ in April 2025.

Report: Considerations for Minimizing Respondent Burden in Collecting Data for Patient-Centered Clinical Decision Support

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 causes of respondent burden and mitigating strategies to optimize patient data collection, noting causes and strategies that are relevant specifically to PC CDS and separately those applicable to other forms and assessments completed by patients through various data collection processes.

The Workgroup conducted a targeted review of the peer-reviewed literature to identify factors of response burden and mitigating strategies relevant to PC CDS. These factors and mitigating strategies are organized into a framework for patient response burden, aligning with the predictors from the Unified Theory of Acceptance and Use of Technology framework (UTAUT).[2] The Workgroup also conducted KIIs with CDS researchers and patient advocates to validate the framework. The draft product was submitted to AHRQ in June 2025.

Standards and Regulatory Frameworks Workgroup

Manuscript: A General Taxonomy of Reasons for Overriding Recommendations from Patient-Centered Clinical Decision Support

The Workgroup further refines and validates the Workgroup's *Initial Taxonomy of Override Reasons for PC CDS Recommendations* based on clinical use cases. The refined taxonomy is a result of findings from card sorting exercises to assign override reasons to taxonomy domains conducted with eight CDSiC partners and interviews with four PC CDS stakeholders as well as eight think-aloud interviews to validate the final taxonomy with clinicians/informaticians, patient advocates, and health services researchers. The draft manuscript was submitted to AHRQ in January 2025.

In the second quarter, the manuscript underwent several rounds of AHRQ review. The Workgroup iteratively revised manuscripts based on the feedback received. Upon AHRQ approval, the Workgroup will submit the manuscript to BMJ Health & Care Informatics.

Topic Highlight: Making Patient Apps Interoperable with the Health IT Ecosystem

Building off the Workgroup's prior report, *Improving Interoperability of Patient Apps With the Health IT Ecosystem*, this product describes an ideal ecosystem for interoperable clinical health IT systems, including electronic health records (EHRs), and patient-facing PC CDS apps. The resource identifies examples of standards-based patient-facing apps that are integrated into the PC CDS ecosystem as illustrative use cases. The product is intended to be a resource for PC CDS app developers and presents considerations for developing interoperable patient-facing apps.

The product is informed by findings from a literature review of the current standards landscape the Workgroup conducted in order to update the original patient app interoperability ecosystem diagram. The Workgroup also 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. The draft product was submitted to AHRQ in April 2025.

Report: Approaches to Standardizing Override Reasons for Patient-Centered Clinical Decision Support

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. The original Override Taxonomy provides standardized language for six domains and corresponding subdomains of reasons for overriding PC CDS recommendations that can be adopted by PC CDS end users and standards developers and support analysis of override reasons for research and improvement purposes. This report presents options for translating the taxonomy subdomains into user-friendly interface terms that are succinct, easy to understand for the user, specific to the CDS, and unambiguous. It also identifies potential strategies for implementing the front-end version of the Taxonomy into standards-based CDS systems.

To develop the Taxonomy, the Workgroup mapped the Override Taxonomy to the QICore Negation Reason Codes ValueSet[3] 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 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. The draft product was submitted to AHRQ in June 2025.

Trust and Patient-centeredness Workgroup

Manuscript: Patient and Caregiver Informed Considerations for Design and Implementation of Generative AI-Supported Patient-Centered Clinical Decision Support: A Qualitative Study

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 considerations for AI implementation and use, identified new considerations, and prioritized a total of seven considerations by importance. The draft manuscript was submitted to AHRQ in February 2025.

In the second quarter, the manuscript underwent several rounds of AHRQ review. The Workgroup iteratively revised manuscripts based on the feedback received. Upon AHRQ approval, the Workgroup will submit the manuscript to the Journal of Medical Internet Research.

Topic Highlight: Incorporating Patient Preferences in Patient-Centered Clinical Decision Support

Building on prior CDSiC products about patient preferences, this patient-facing resource defines patient preferences and their utility within PC CDS. It aims to help patients understand when their preferences can be collected, shared, and integrated into PC CDS to support their care and shared decision making. To do so, this Topic Highlight presents three patient journey diagrams that illustrate how patients' preferences around administrative information (e.g., preferred name, communication channels), routine or preventative care, and treatment may be collected and used in PC CDS.

To develop this product, the Workgroup adapted swimlane diagrams from the Capturing Patient Preferences for Patient-Centered Clinical Decision Support Within Patient Lifeflows and Clinical Workflows report and summarized key findings from other CDSiC preference-related products. To ensure accuracy and accessibility of the resource, the Workgroup conducted KIIs with CDS researchers and patient representatives. The draft product was submitted to AHRQ in May 2025.

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 questionnaire that the CDSiC develops will address a key gap in the field preventing large-scale assessment of patients' perspectives on and experiences with PC CDS across care settings. The final questionnaire will be accompanied by a 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 to obtain their input, as appropriate.

Earlier this year, NORC identified nine patient experience domains based on existing survey questions and domains for assessing patient experience relevant to PC CDS. These domains were prioritized by 10 patients, CDS researchers and measure developers, and health system representatives. Incorporating additional feedback from interview participants and findings from the literature, the NORC team drafted questionnaire items for seven priority domains covering varying aspects of patient experience and engagement in the second quarter of 2025. NORC has further refined and finalized the set of survey questions and has begun drafting the accompanying report during the reporting period.

Next Steps

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 products are finalized in collaboration with AHRQ for a public audience, 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.

References

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