

STAKEHOLDER CENTER PROGRESS REPORT

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CDSiC Stakeholder Community and Outreach Center: Quarterly Report

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PURPOSE

The CDS 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 fourth 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). 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. 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 will engage 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) CDS Outcomes and Objectives, 2) CDS Standards and Regulatory Frameworks, 3) Scaling, Measurement, and Dissemination of CDS, and 4) Trust and Patient-Centeredness.

Status Report

This quarterly report provides a summary of the status of all projects and activities being conducted within the CDSiC Stakeholder Center from January 2023 through March 2023. Over this period, Workgroups have focused on advancing 12 distinct written products.

Planning Committee

The Stakeholder Center Planning Committee is comprised of Stakeholder Center Leads, AHRQ project officers, the CDSiC Primary Investigator and Co-Investigators, and Workgroup Co-leads. In 2023, the Committee is meeting once every quarter to provide input on the overall strategic direction and coordination of the Stakeholder Center, as well as discuss product development activities across Workgroups. The Planning Committee met in February 2023. This meeting was focused on discussing progress to date on Workgroup products, anticipated activities for the first two quarters of 2023, and challenges and highlights in product development. Workgroup leads noted that significant progress had been made on several products, with detailed outlines or full drafts developed for several products. Leads also noted that a key challenge in product development has been avoiding expansions in scope

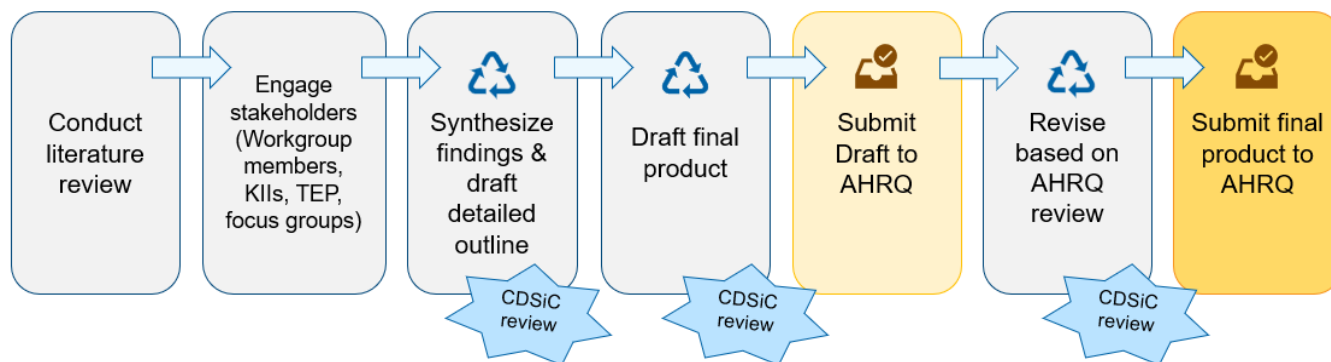
as the leads and Workgroup support teams manage input from stakeholders with different needs and perspectives. The Committee will reconvene in June 2023.

Stakeholder Center Workgroups

The four Stakeholder Center Workgroups are tasked with developing three written products each—for a total of 12 products—that advance the CDS field in the first two years of the CDSiC. The products vary in terms of the expected length of time to complete based on scope, falling into one of three levels. Level 1 projects are the largest in scope, involving significant effort. Level 2 projects involve a medium amount of effort. Level 3 projects are shorter-term activities.

Product development is supported by 10 Workgroup support staff with direction from two Stakeholder Center co-leads 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, key informants, focus groups, and/or 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 NORC 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 1. Workgroup Product Development Process



Workgroups continued to meet monthly through the reporting period, using meetings to update Workgroup members on product progress and solicit their input on product scope and activities. One product is complete and will be posted on the [CDSiC website](#) in April 2023. Another product is being finalized for posting. All other products are in progress (Exhibit 2). Below, we provide a summary of progress for each product.

Exhibit 2. Status of Workgroup Products

Product (Level)	Status
Outcomes and Objectives Workgroup	
Framework for Understanding the Role that Patient Preferences Would Play in PC CDS (Level 3)	Finalizing for Posting (anticipated posting May 2023)
Framework for Understanding the Role that PC CDS Could Play in Supporting Shared Decision-Making (Level 3)	In Progress
Analysis of Most Appropriate Outcomes for PC CDS (Level 1)	In Progress
Standards and Regulatory Frameworks Workgroup	
Standards and Regulatory Frameworks Environmental Scan (Level 1)	Complete (anticipated posting April 2023)
Improving Interoperability of Patient Apps with the Health IT Ecosystem (Level 2)	In Progress
Advancing Standardized Representations for Patient Preferences and Values to Support Scalable and PC CDS (Level 3)	In Progress
Scaling, Measurement, and Dissemination Workgroup	
Approaches to Measuring Patient-Centered CDS Workflow and Life Flow Impact Interventions (Level 3)	In Progress
PC CDS Implementation Reporting Tool (Level 2)	In Progress
CDS Performance and Value Measurement Guide (Level 1)	In Progress
Trust and Patient-Centeredness Workgroup	
Best Practices and Methodology for Patient-Centered Co-design and Co-deployment of CDS Artifact (Level 1)	In Progress
Handbook to Ensure Patient-Centered Input is Incorporated into CDS Artifact Development (Level 3)	In Progress
Root Cause Analysis and Recommendations for Optimization of Trust and Mitigation of Mistrust in CDS Artifacts due to Source Credibility (Level 2)	In Progress

CDS Outcomes and Objectives Workgroup

The Outcomes and Objectives Workgroup is developing products that will identify patient preferences relevant to PC CDS, explore the role of PC CDS in shared decision-making, and examine measurement and effectiveness criteria for assessing the impact of PC CDS on health-related outcomes. Below, we discuss products under AHRQ review and products in progress.

Products Under Review

The Taxonomy for Patient Preferences that are Relevant to PC CDS (Level 3) was submitted to AHRQ for review in February 2023. This product presents a taxonomy that describes and categorizes patient preferences relevant to PC CDS. The product also documents challenges related to the capture or use of preference data and outlines an agenda for future research. The product is currently being finalized for final review and posting and is anticipated to be completed by May 2023.

Products In Progress

The Workgroup has two additional products under development.

Analysis of the Most Appropriate Outcomes Measures for PC CDS (Level 1). This product will discuss outcome measures for PC CDS, focusing on domains such as clinical outcomes, patient-reported outcomes, patient satisfaction and engagement with care (e.g., adherence, self-management), and shared decision-making. The analyses will include the identification of publicly available instruments, where known, that could be used to measure specific outcomes for PC CDS. Initial product development activities began in the Fall of 2022, with the Workgroup support team identifying 150 potentially relevant peer-reviewed publications. To date, work for this product has centered around refining the scope and aims of the product to identify relevant outcome domains. The Workgroup support team will continue with the scoping review and conduct KIIs in Spring 2023.

Framework for Understanding the Role of PC CDS in Supporting Shared Decision-Making (Level 3). This product will be a framework for advancing shared decision-making using PC CDS. The product will describe the complexities and considerations around advancing shared decision-making with the use of PC CDS and identify how PC CDS can help enable shared decision-making within clinical workflows. The Workgroup team has identified a previous systematic review of shared decision-making models that identifies common components across 40 shared decision-making models.¹ The Workgroup will examine the role that PC CDS plays in shared decision-making using the common components as an underlying framework.

CDS Standards and Regulatory Frameworks Workgroup

The CDS Standards and Regulatory Frameworks Workgroup is developing products that will examine the current state of PC CDS standards and regulatory frameworks and identify gaps; describe the needs and potential approaches to addressing the lack of interoperability between patient apps and health IT systems used by clinicians; and report on the current state of content adoption and use of data standards for collecting and using patient preference data to guide PC CDS. Below, we discuss completed products and products in progress.

Completed Products

The *Standards and Regulatory Frameworks Environmental Scan* (Level 1) is complete and will be posted on the CDSiC website in April 2023. The environmental scan examines the current state of standards, regulatory frameworks, and technical barriers, and identifies salient gaps, opportunities, and challenges to support the development of interoperable PC CDS. The Workgroup support team completed a scoping review, including 58 peer-reviewed publications and 132 gray literature sources in its report. The Workgroup support team also conducted interviews with nine key informants. The report outlines 40 opportunities to advance the PC CDS standards landscape.

¹ Bomhof-Roordink H, Gärtner FR, Stiggelbout AM, Pieterse AH. Key components of shared decision making models: a systematic review. *BMJ Open*. 2019 Dec 17;9(12):e031763.

Products In Progress

The Workgroup has two additional products under development.

Improving Interoperability of Patient Apps with the Health IT Ecosystem (Level 2). This product describes the needs and potential approaches to addressing the lack of interoperability between patient apps and health IT systems used by clinicians. In collaboration with Workgroup leads and with input from Workgroup members and five key informants, the team has mapped out the actors within the integrated health IT ecosystem and described the stages for requesting and obtaining data from patient apps within the ecosystem. The Workgroup support team has drafted a detailed outline and is currently in the process of gathering Workgroup member feedback on the outline. The final product will include a discussion of gaps and recommendations based on the current state of app interoperability and available standards.

Advancing Standardized Representations for Patient Preferences and Values to Support Scalable and PC CDS (Level 3). This product will be a report on the current state of content adoption and use of data standards for collecting and using patient preference data to guide PC CDS, accompanied by a set of recommendations to address any gaps or implementation barriers for these standards. To produce this product, the Workgroup is leveraging the patient preference taxonomy that is being developed by the Outcomes & Objectives Workgroup. The Workgroup support team has searched for terminology standards (specifically LOINC and SNOMED) for each domain and sub-domain of the patient preference taxonomy through the National Library of Medicine's UMLS Metathesaurus.

Scaling, Measurement, and Dissemination of CDS Workgroup

The Scaling, Measurement, and Dissemination of CDS Workgroup products will provide recommendations on strategies and measures for evaluating the performance and value of PC CDS interventions; provide a standard approach for describing how PC CDS interventions are designed, developed, deployed, used, maintained, and evaluated; and identify how organizations are measuring PC CDS effects on workflows/life flows. Below, we discuss products in progress.

Products In Progress

All three of the Workgroup products are currently under development. To date, this Workgroup support team has screened over 1,000 peer-reviewed articles across all three products (literature findings will be relevant to multiple products).

PC CDS Performance and Value Measurement Guide (Level 1). This product will provide a catalog of quantitative and qualitative measures for evaluating each step of the PC CDS development and implementation process. The product will focus on outlining measures for three areas: designing/building CDS, using CDS, and the results of using CDS. The product will also feature use case scenarios to demonstrate how the documented measures can be used to measure PC CDS process effects for various scenarios. Workgroup members have provided feedback on both the organization of measures within the product as well as the planned structure of the final product. The

Workgroup support team convened a TEP in January 2023 to discuss user scenarios for the product and how measurement concepts map to specific scenarios. The TEP will meet twice more between April and June 2023. To date, the Workgroup support team has identified over 150 candidate measures through a scoping review of the CDS measurement literature.

PC CDS Implementation Reporting Tool (Level 2). The product provides a standard approach for describing how PC CDS interventions are designed, developed, deployed, used, maintained, and evaluated. The product aggregates guidance from existing reporting frameworks and checklists (e.g., the GUIDES framework) to provide a practical tool that CDS researchers, evaluators, patient advocates, and health system leaders can consult to describe and assess the process impacts of a given PC CDS intervention. The framework will describe four domains: planning & needs assessment, design & development, implementation & adoption, and evaluation & impact. The Workgroup support team has drafted a reporting tool and accompanying narrative that will form this product. The tool and narrative are currently being tested by key informants to determine ease of use, points of clarification, and any potential gaps.

Approaches to Measuring Patient-Centered CDS Workflow and Life Flow Impact (Level 3). This product discusses how organizations describe and measure PC CDS effects on care team workflows and patient and caregiver activities (i.e., “life flows”) across three types of PC CDS interventions: clinician-facing CDS, clinician- and patient-facing CDS that supports shared decision-making, and patient-facing CDS. The product will also discuss the state of current evidence regarding workflow and life flow impacts of PC CDS and outstanding gaps. To date, the Workgroup support team has developed a workflow/life flow diagram, a detailed outline, and a draft product. This diagram illustrates patient life flows outside the clinical encounter as well as workflows during the clinical encounter. This product will be submitted to AHRQ in April 2023.

Trust and Patient-Centeredness Workgroup

The Trust and Patient-Centeredness Workgroup is developing products that will outline recommended best practices to promote patient partnerships in the co-design and co-deployment of PC CDS artifacts; define factors that enhance or detract from source credibility, and guide CDS artifact developers in using patient-centered approaches. Below, we discuss products in progress.

Products In Progress

Best Practices and Methodology for Patient-Centered Co-design and Co-deployment of PC CDS Artifact and Interventions (Level 1). This product will be a guide outlining promising practices for the co-design and co-deployment of PC CDS artifacts. The resource guide will document how best to engage patients across the PC CDS continuum from planning and designing, to building and testing, and through the deployment and adoption phases of work. The final product will highlight specific practices that have proven effective in the past, and it will detail any information relevant to adapting the practices for use in new contexts. The Workgroup support team has screened 70 peer-reviewed articles for this product and has begun to synthesize preliminary findings into a detailed outline.

Root Cause Analysis and Recommendations for Mitigation of Mistrust in CDS Artifacts due to Source Credibility (Level 2). The product outlines a framework for defining the factors that enhance or detract from source credibility and define each factor within the context of PC CDS. The product will also discuss recommended approaches for increasing the source credibility of PC CDS tools. To inform the development of this product, the Workgroup support team has screened 63 literature sources for this product. They have identified 13 attributes of source credibility and developed an information flow model to understand at what point in the flow of information attributes contribute to source credibility. The Workgroup support team has developed a detailed outline for the product. This product will be submitted to AHRQ in April 2023.

Handbook for the Incorporation of Patient-Centered Inputs into CDS Artifact Development (Level 3). This product will be a handbook that can guide CDS artifact developers in using obtaining patient input at each stage of PC CDS development. The handbook will help to ensure patients' top priorities are consistently and appropriately incorporated into CDS artifact and intervention development. The final product will act as a guide for CDS developers to facilitate the inclusion of patient-centric input into CDS. To develop this product, the Workgroup will conduct a landscape analysis and key informant interviews.

Next Steps

We anticipate that all draft products will be submitted to AHRQ by July 2023. Product development and refinement will continue until September 2023. To support development, Workgroups will continue to meet monthly throughout the project period to refine product content and shape the overall look and feel of each product. As product development continues, Workgroup support teams will work to ensure that products align with diverse needs and benefit end-users.