

STAKEHOLDER CENTER PROGRESS REPORT

JUNE 2023

CDSiC Stakeholder Community and Outreach Center: Quarterly Report

Agency for Healthcare Research and Quality
5600 Fishers Lane
Rockville, MD 20857
www.ahrq.gov

Contract No: 75Q80120D00018

Prepared by:

NORC at the University of Chicago
4350 East - West Highway Suite 800
Bethesda, MD 20814



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

This project was funded under contract number 75Q80120D00018 from the Agency for Healthcare Research and Quality (AHRQ), U.S. Department of Health and Human Services (HHS). The opinions expressed in this document are those of the authors and do not reflect the official position of AHRQ or HHS.

PUBLIC DOMAIN NOTICE

This document is in the public domain and may be used and reprinted without permission in the United States unless materials are clearly noted as copyrighted in the document. No one may reproduce copyrighted materials without the permission of the copyright holders. Users outside the United States must get permission from AHRQ to reprint or translate this product. Anyone wanting to reproduce this product for sale must contact AHRQ for permission. Citation of the source is appreciated.

Table of Contents

Introduction	1
Status Report.....	1
Planning Committee.....	1
Stakeholder Center Workgroups.....	2
CDS Outcomes and Objectives Workgroup.....	3
CDS Standards and Regulatory Frameworks Workgroup	4
Scaling, Measurement, and Dissemination of CDS Workgroup.....	6
Trust and Patient-Centeredness Workgroup.....	7
Next Steps	8

Introduction

NORC at the University of Chicago (NORC) is pleased to submit the fifth 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 April 2023 through June 2023. Over this period, Workgroups have focused on advancing 11 distinct written products.

Planning Committee

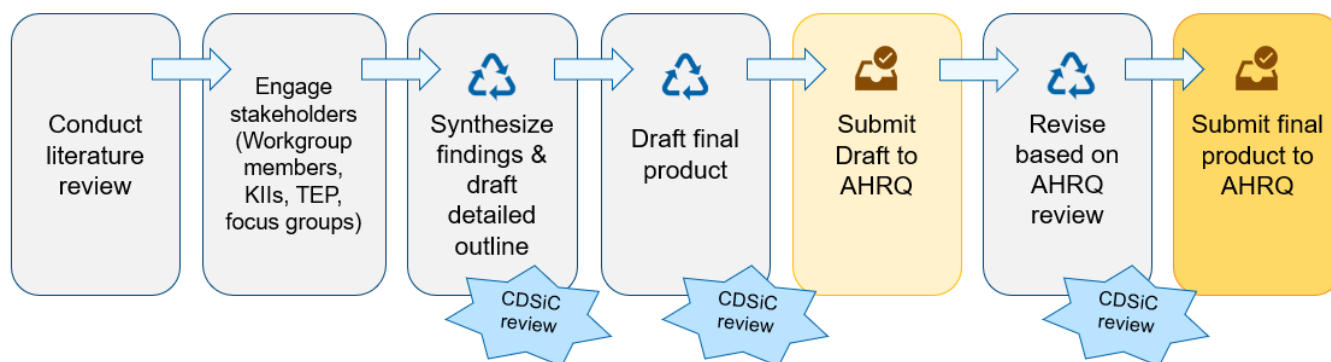
The Stakeholder Center Planning Committee is comprised of Stakeholder Center leads, AHRQ project officers, the CDSiC Primary Investigator and Co-Investigators, and Workgroup co-leads. In 2023, the Committee meets once every quarter to provide input on the overall strategic direction and coordination of the Stakeholder Center, as well as to discuss product development activities across Workgroups. However, the Planning Committee did not meet in the second quarter of 2023 given the timing of the CDSiC Annual Meeting, in which Workgroup activities and products were discussed in depth. The Planning Committee will reconvene in August 2023.

Stakeholder Center Workgroups

In the first two years of the CDSiC, the four Stakeholder Center Workgroups are tasked with developing three written products each—for a total of 12 products—that advance the CDS field. The products vary in terms of the expected length of completion time, 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 11 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 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 1. Workgroup Product Development Process



Workgroups continued to meet monthly throughout the second quarter of 2023, using meetings to update Workgroup members on product progress and solicit their input on product scope and content. One [product](#) was posted on the [CDSiC website](#) in May 2023. Another product is being finalized for posting. All other products are under AHRQ review or in development for AHRQ review (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)	Complete (anticipated posting July 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 (posted May 2023)
Improving Interoperability of Patient Apps with the Health IT Ecosystem (Level 2)	Revising based on AHRQ feedback
Advancing Standardized Representations for Patient Preferences Support PC CDS (Level 3)	In Progress
Scaling, Measurement, and Dissemination Workgroup	
Approaches to Measuring Patient-Centered CDS Workflow and Lifeflow Impact Interventions (Level 3)	Finalizing for Posting
PC CDS Planning, Implementation, and Reporting Tool (Level 2)	Revising based on AHRQ feedback
PC CDS Performance Measurement Guide (Level 1)	In Progress
Trust and Patient-Centeredness Workgroup	
Methods for Involving End-users in PC CDS Co-design (Level 1)	Under AHRQ Review
Handbook to Ensure Patient-Centered Input is Incorporated into CDS Artifact Development (Level 3)	In Progress
Improving the Source Credibility of Patient-centered Clinical Decision Support Tools (Level 2)	Finalizing for Posting

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 completed products and products in progress.

Completed Products

The Workgroup has one completed product.

The Taxonomy for Patient Preferences that are Relevant to PC CDS (Level 3). This report is being finalized for posting. 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 being finalized for posting and CDSiC team anticipates posting the product to the CDSiC website by July 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. The product captures measures within domains of patient journey outcomes (including sub-domains of decision making, engagement, and experience) and patient health outcomes (including sub-domains of symptoms, function, quality of life, and well-being). The analysis will include the identification of publicly available instruments, where known, that could be used to measure specific outcomes within these domains for PC CDS. To date, the Workgroup team has completed a review of the literature, identifying over 30 relevant patient journey measures, and is in the process of conducting key informant interviews and developing a detailed outline of the final report. The report will utilize use cases to provide examples of how patient health outcome measures could be applied to an evaluation of a PC CDS tool and corresponding considerations. An inventory of available patient journey and health outcome measures will accompany the written report.

Framework for Understanding the Role of PC CDS in Supporting Shared Decision Making (Level 3). This product will advance shared decision making using PC CDS, by providing a framework for examining the impact of PC CDS interventions on shared decision making. The product will describe the current complexities and future considerations around advancing shared decision making with the use of PC CDS. In collaboration with Workgroup leads and members, the Workgroup team determined that the [Three-Talk Model for Shared Decision Making](#)¹ will provide the underlying framework for the product. To date, the team has developed a preliminary framework integrating the [AHRQ definition of PC CDS](#) and the Three-Talk Model and is in the process of conducting key informant interviews to validate the product 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, products under revision, and products in progress.

¹ Elwyn G, Durand MA, Song J, et al. A three-talk model for shared decision making: multistage consultation process. *BMJ*. 2017;359:j4891. Published 2017 Nov 6. doi:10.1136/bmj.j4891

Completed Products

The Workgroup has one completed product.

The *Standards and Regulatory Frameworks Environmental Scan* (Level 1) is complete and was posted on the CDSiC website in May 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. Findings from the Environmental Scan related to challenges and opportunities for standards for patient-provided data were shared during a poster presentation at the AcademyHealth Annual Research Meeting in June.

Products Under Revision

The Workgroup has one product that is undergoing revisions.

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 information technology (IT) systems used by clinicians. The product also includes a discussion of priority gaps and recommendations based on the current state of app interoperability and available standards. Drawing on Workgroup lead expertise, input from Workgroup members and five key informants, and the available literature, the product maps actors and the stages for requesting and obtaining data from patient apps within the integrated health IT ecosystem. During the reporting period, the Workgroup support team developed the draft product with input from Workgroup leads, members, and CDSiC project leadership. The draft report was submitted to AHRQ in May 2023, and the Workgroup support team is currently revising the product based on AHRQ feedback.

Products In Progress

The Workgroup has one additional product under development.

Advancing Standardized Representations for Patient Preferences Support PC CDS (Level 3). This product is 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. The Outcomes & Objectives Workgroup's patient preferences taxonomy serves as an organizing framework for this product. For each domain and sub-domain outlined in the patient preferences taxonomy, this product incorporates terminology standards (specifically LOINC and SNOMED) derived from the National Library of Medicine's UMLS Metathesaurus. To inform development of this product, the Workgroup support team conducted key informant interviews with five experts in the field, including an informatician, standards developer, patient representative, and health IT developers. During the reporting period, the team produced a detailed outline of the report and draft report that was reviewed by Workgroup leads, members, and CDSiC leadership.

Scaling, Measurement, and Dissemination of CDS Workgroup

The Scaling, Measurement, and Dissemination of CDS Workgroup products will provide a standard approach for describing how PC CDS interventions are designed, developed, deployed, used, maintained, and evaluated; identify how organizations are measuring PC CDS effects on clinician workflows and patient/caregiver lifeflows; and provide recommendations on existing strategies and measures for evaluating the performance of PC CDS interventions. Below, we discuss products being finalized, products under revision, products in progress.

Products Being Finalized

The Workgroup has one product that is being finalized.

Approaches to Measuring Patient-Centered CDS Workflow and Lifeflow 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., “lifeflows”) 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 also provides a detailed standalone infographic that maps out key points in workflows and lifeflows that a PC CDS tool can be used, and it discusses the state of current evidence regarding workflow and lifeflow impacts of PC CDS and outstanding gaps. This draft product was submitted to AHRQ in April 2023 and, after receiving a revised version in May 2023, AHRQ provided approval of product content in June 2023. The product will be reviewed by AHRQ’s Office of Communications prior to being finalized for posting.

Products Under Revision

The Workgroup has one additional product under revision.

PC CDS Planning, Implementation, and 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 when planning for and reporting on the process impacts of a given PC CDS intervention. The framework describes intervention activities and patient-centered factors that should be documented and reported across four domains: planning & needs assessment, design & development, implementation & adoption, and evaluation & impact. The reporting tool and accompanying narrative were tested and reviewed by six key informants for ease of use, points of clarification, and any potential gaps. Draft materials were also reviewed by Workgroup leads, members, and CDSiC leadership. In May, the Workgroup support team submitted the draft reporting tool and accompanying narrative to AHRQ. The Workgroup support team is currently revising the product based on AHRQ feedback.

Products In Progress

The Workgroup has one additional product under development.

PC CDS Performance and Value Measurement Guide (Level 1). This product provides a user guide and inventory of quantitative and qualitative measures for evaluating three phases of the PC CDS implementation process: designing CDS, using CDS, and the results of using CDS. To date, the inventory contains over 150 measures capturing clinician and patient perspectives, derived through a scoping review of the CDS measurement literature. To support end users' navigation of the inventory, the user guide will feature four common use case scenarios that demonstrate how the documented measures can be used to measure PC CDS process effects under each scenario. In addition to obtaining Workgroup members' feedback on the organization of measures as well as the planned structure of the final product, the Workgroup support team engaged a TEP of 12 experts in the field, which met twice during the reporting period (in April and June 2023). TEP members provided input to improve the relevance and utility of the user scenarios and measurement inventory as well as dissemination suggestions. The Workgroup support team has developed a detailed outline for the user guide, which will include an overview of the PC CDS Performance Measurement Framework, methods and limitations of the review, a high-level description of the measures included in the inventory, measurement considerations when evaluating a PC CDS tool's performance, the user scenarios, and a discussion on measurement gaps and areas for future study. During second quarter of 2023, the Workgroup support team also performed a multi-step quality control process to remove duplicate measures, ensure proper coding of measures to implementation categories, and consistently format entries in the measure inventory.

Trust and Patient-Centeredness Workgroup

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

Products Being Finalized

The Workgroup has one product that is being finalized.

Improving the Source Credibility of Patient-centered Clinical Decision Support Tools (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 also discusses recommended approaches for increasing the source credibility of PC CDS tools. The report identifies 13 attributes of source credibility and an information flow model to understand at what point in the flow of information attributes contribute to source credibility. To inform the development of this product, the Workgroup support team screened 63 literature sources and conducted nine key informant interviews with informaticians, standards experts, patient representatives, and PC CDS developers. This draft product was submitted to AHRQ in April 2023 is currently under review by the AHRQ Office of Communications for approval for posting.

Products Under Review

Methods for Involving End-users in PC CDS Co-design (Level 1). This product is a guide that outlines promising practices for the co-design of PC CDS artifacts. The resource documents how best to engage patients across the PC CDS continuum from planning and designing, to building and testing. The product also highlights specific practices that have proven effective in the past, and it details information relevant to adapting the practices for co-design in new contexts and in a standardized manner. To develop the product, the Workgroup support team screened 70 peer-reviewed articles, conducted key informant interviews, and synthesized findings into a draft report, which incorporates input from CDSiC project leadership, Workgroup leads, and Workgroup members. The draft report was submitted to AHRQ in June 2023.

Products In Progress

The Workgroup has one additional product under development.

Handbook for the Incorporation of Patient-Centered Inputs into CDS Artifact Development (Level 3). This product is a handbook that can guide CDS artifact developers in 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 by describing methods to gather and incorporate patient input and showcasing available tools and resources. To develop this product, the Workgroup is conducting a targeted literature review to identify methods and resources and conducting key informant interviews to validate findings with experts.

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.