STAKEHOLDER CENTER PROGRESS REPORT

DECEMBER 2022

CDSiC Stakeholder Community and Outreach Center:
Quarterly Report

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Introduction

NORC at the University of Chicago (NORC) is pleased to submit the third 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 from October 2022 through December 2022.

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 status report provides updates on the progress of the activities of the Stakeholder Center from October through December 2022. Over this period, Workgroups have focused on conducting literature reviews and key informant interviews (KIIs).

Planning Committee

The Stakeholder Center established a Planning Committee comprised of Stakeholder Center Leads, AHRQ project officers, the CDSiC PI and Co-Investigators, and Workgroup Co-leads. The Committee meets once every other month 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 October and December 2022. These meetings were dedicated to presentations and discussions about Workgroup products. In October, the Committee discussed products from the Trust and Patient-Centeredness and Standards and Regulatory Frameworks

Workgroups. In December, the Committee discussed products from the Outcomes & Objectives and Scaling, Measurement, and Dissemination Workgroups. Product discussions focused on gathering substantive feedback on interim findings, discussing how CDS stakeholders would potentially use the products, and identifying potential synergies across Workgroups. The Committee will reconvene in February 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.

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. Currently, one product is under review, eight products are in development, and three products are planned (Exhibit 1). Below, we provide a detailed update on the progress of each Workgroup.

Exhibit 1. 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)	In Progress
Framework for Understanding the Role that PC CDS Could Play in Supporting Shared Decision-Making (Level 3)	Planned
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)	Under AHRQ Review
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)	Planned
Scaling, Measurement, and Dissemination Workgroup	
Catalog of Approaches Used to Measure Workflow Impact of CDS Interventions (Level 3)	In Progress
PC CDS Implementation Description Framework (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)	Planned
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 in progress as well as planned products that are expected to begin in early 2023.

Products In Progress

To date, Workgroup product development has focused on the Level 3 product *Taxonomy for Patient Preferences that are Relevant to PC CDS.* Work has also begun on the Level 1 product *Analysis of the Most Appropriate Outcomes Measures for PC CDS.*

Taxonomy for Patient Preferences that are Relevant to PC CDS (Level 3). This product will be a taxonomy that describes and categorizes patient preferences relevant to PC CDS. The product will also document challenges related to the capture or use of preference data as potential items for a research agenda. To support the development of this product, the Workgroup completed a scoping literature review of gray literature and PubMed to assess the current usage of patient preferences in CDS and other clinical information systems (e.g., electronic health records [EHRs], patient apps). To date, the Workgroup support team has screened over 200 peer-reviewed publications for this product. The team has also conducted 7 KIIs and one focus group with three patient advocates/representatives. The Workgroup support team has developed a draft taxonomy and the Workgroup leads presented the draft taxonomy to the Stakeholder Center Planning Committee in December 2022. The Workgroup support team is in the process of validating the taxonomy through input from Workgroup members and additional key informants.

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 early 2023.

Planned Products

The Workgroup will begin work on the *Framework for Understanding the Role of PC CDS in Supporting Shared Decision-Making* (Level 3) in January 2023**.** 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. To develop this product, the Workgroup will conduct a literature review, develop the framework, validate the framework, and develop a final report.

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 products under AHRQ review, products in progress, and planned products that are expected to begin in early 2023.

Products Under Review

Workgroup product development activities to date have largely focused on the *Standards and Regulatory Frameworks Environmental Scan* (Level 1). 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 draft report. The Workgroup support team also conducted interviews with nine key informants. With Workgroup member input, the team drafted a report that outlines 40 opportunities to advance the PC CDS standards landscape. The draft report is currently under AHRQ review.

Products In Progress

The Workgroup is currently developing the *Improving Interoperability of Patient Apps with the Health IT Ecosystem* (Level 2). This product will describe 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, the team is mapping out the actors within the integrated health IT ecosystem and describing the stages for requesting and obtaining data from patient apps within the ecosystem. Workgroup leads presented an initial data flow diagram of the integrated health IT ecosystem to the Stakeholder Center Planning Committee in October 2022. The team is currently conducting a targeted literature search and has identified 114 articles on mobile applications and CDS to screen for inclusion/exclusion. The Workgroup support team will begin KIIs in February 2023 for this product.

Planned Products

The Workgroup will begin work on the Level 3 product *Advancing Standardized Representations for Patient Preferences and Values to Support Scalable and PC CDS* in January 2023. 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 will leverage the patient preference taxonomy that is being developed by the Outcomes & Objectives Workgroup.

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 approximately 1,000 peer-reviewed articles across all three products (we anticipate that 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 quantitative 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 use case scenarios to demonstrate how the documented measures can be used to measure PC CDS process effects. Workgroup members have provided feedback on both the organization of measures within the product as well as the planned structure of the final product. In addition, the Stakeholder Center Planning Committee provided feedback on the product in December 2022. To date, the Workgroup support team has identified over 150 candidate measures through a scoping review of the CDS measurement literature. The Workgroup support team will convene a technical expert panel (TEP) in 2023 to develop and validate case scenarios for the product. The TEP will meet three times over the first six months of 2023.

PC CDS Implementation Description Framework (Level 2). The Framework will provide a standard approach for describing how PC CDS interventions are designed, developed, deployed, used, maintained, and evaluated. The product will aggregate guidance from existing reporting frameworks and checklists (e.g., the GUIDES framework) to provide a practical tool that can be used by CDS researchers, evaluators, patient advocates, and health system leaders can consult to describe and assess the process impacts of a given PC CDS intervention. Users populating the Framework will be encouraged and guided to describe details of how each PC CDS implementation dimension was addressed. The framework will describe four domains: planning & needs assessment, design & development, implementation & adoption, and evaluation & impact. To date, the Workgroup support team has conducted a literature review and abstracted 51 articles to develop the Framework. This literature has informed the development of a strawman for the Framework, which will be reviewed by Workgroup members in January 2023.

Catalog of Approaches Used to Measure Workflow Impact of PC CDS Interventions (Level 3). The Catalog will identify 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 Catalog will also include a sampling of workflow and user satisfaction results to support subsequent efforts to benchmark workflow and satisfaction improvements resulting from CDS interventions. To date, the Workgroup support team has abstracted 58 articles to

inform this product and identify workflow and satisfaction improvements. Additionally, the team is currently developing a workflow/life flow diagram. This diagram illustrates patient life flows outside the clinical encounter as well as workflows during the clinical encounter. This diagram was shared with Workgroup members in November 2022 and with Stakeholder Center Planning Committee members in December 2022.

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 as well as planned products that are expected to begin in early 2023.

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. To date, the Workgroup support team has screened 70 peer-reviewed articles for this product and has begun to synthesize preliminary findings. KIIs for this product will commence in early 2023.

Root Cause Analysis and Recommendations for Mitigation of Mistrust in CDS Artifacts due to Source Credibility (Level 2). The product will outline 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 artifacts among providers and patients. To inform the development of this product, the Workgroup support team has screened over 60 literature sources for this product. They have identified 13 attributes of source credibility and found that the directionality and causality of relationships between attributes are not fixed, as attributes can detract from or increase source credibility. To illustrate this, the Workgroup support team and leads have developed an information flow model to understand at what point in the flow of information attributes contribute to source credibility. This model was shared with the Stakeholder Center Planning Committee meeting in October 2022. Currently, the Workgroup support team is conducting KIIs to gather additional feedback on the information flow model and validate the factors that contribute to source credibility with a broader stakeholder audience.

Planned Products

The Workgroup will start work on the *Handbook for the Incorporation of Patient-Centered Inputs into CDS Artifact Development* (Level 3) in early 2023. This product will be a handbook that can guide CDS artifact developers in using patient-centered approaches. 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 comprehensive and representative patient-centric input into CDS as the mechanisms for delivering CDS recommendations evolve. To develop this product, the Workgroup will conduct a landscape analysis and key informant interviews, finalize the handbook scope, and then review and refine the prototypical handbook before the final submission to AHRQ.

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.