

STAKEHOLDER CENTER PROGRESS REPORT

SEPTEMBER 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 sixth 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 report is the final quarterly report describing Stakeholder Center activities during the project's base period. 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 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) 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 July 2023 through September 2023. Over this period, Workgroups focused on advancing 11 distinct written products.

Planning Committee

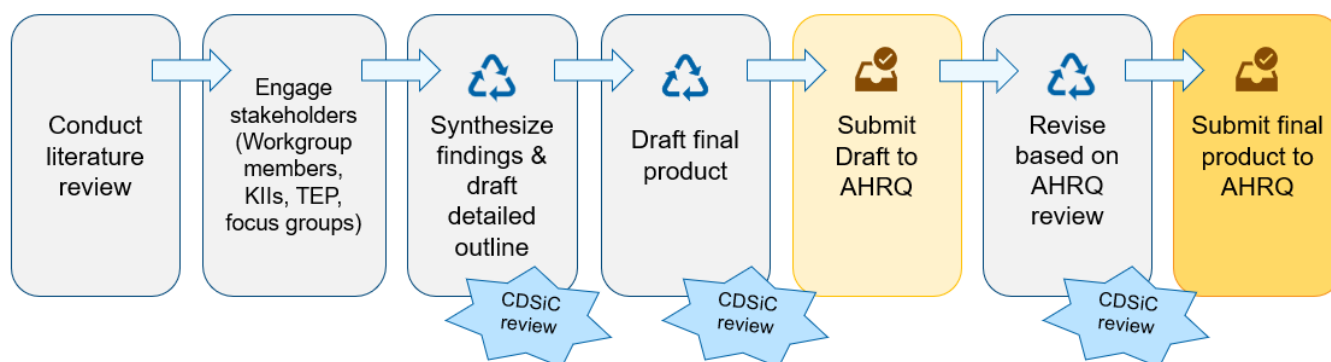
The Stakeholder Center Planning Committee is comprised of Stakeholder Center leads, AHRQ project officers, the CDSiC Primary Investigator and Co-Investigators, and Workgroup co-leads. In 2023, the Committee meets once every quarter to provide input on the overall strategic direction and coordination of the Stakeholder Center, as well as to discuss product development activities across Workgroups. The Planning Committee met in August 2023 to reflect on Center accomplishments in the base period, discuss lessons learned and areas for improvement, and preview potential ideas for Workgroup activities during the project's option year (September 2023-September 2024).

Stakeholder Center Workgroup Products

In the first two years of the CDSiC, the four Stakeholder Center Workgroups (CDS Outcomes and Objectives; CDS Standards and Regulatory Frameworks; Scaling, Measurement, and Dissemination of CDS; and Trust and Patient-Centeredness) were tasked with developing three written products each—for a total of 12 products—that advance the PC 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 involved 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. Workgroups continued to meet monthly throughout the third quarter of 2023, using meetings to update Workgroup members on product progress and solicit their input on product scope and content.

Exhibit 1. Workgroup Product Development Process



Below we provide a description of each Workgroup product and their individual value to the field. Products are grouped together according to aspects of PC CDS that they target to advance the broader field: design and development; implementation; measurement; and cross-cutting products. As of September 2023, all product content has been finalized.

Exhibit 2. Workgroup Product Categorization

PC CDS Phase	Workgroup Products (Workgroup Name)
Design and Development	<ul style="list-style-type: none"> • Taxonomy of Patient Preferences (Outcomes and Objectives Workgroup) • Improving Interoperability of Patient Apps with the Health IT Ecosystem (Standards and Regulatory Frameworks Workgroup) • Advancing Standardized Representations for Patient Preferences Support PC CDS (Standards and Regulatory Frameworks Workgroup) • Improving the Source Credibility of Patient-centered Clinical Decision Support Tools (Trust and Patient-centeredness Workgroup)
Implementation	<ul style="list-style-type: none"> • Integration of PC CDS into Shared Decision Making (Outcomes and Objectives Workgroup) • Methods for Involving End-users in PC CDS Co-design (Trust and Patient-centeredness Workgroup)
Measurement	<ul style="list-style-type: none"> • Patient-Focused Outcome Measures for Patient-Centered CDS (Outcomes and Objectives Workgroup) • Approaches to Measuring Patient-Centered CDS Workflow and Lifeflow Impact (Scaling, Measurement, and Dissemination Workgroup) • PC CDS Performance Measurement Inventory and User Guide (Scaling, Measurement, and Dissemination Workgroup)
Cross-cutting	<ul style="list-style-type: none"> • Standards and Regulatory Frameworks Environmental Scan (Standards and Regulatory Frameworks Workgroup) • PC CDS Planning, Implementation, and Reporting Tool (Scaling, Measurement, and Dissemination Workgroup) • An Introductory Handbook for Patient Engagement Throughout the PC CDS Lifecycle (Trust and Patient-centeredness Workgroup)

Design & Development

The design and development stage of PC CDS involves translating evidence-based findings into computable clinical knowledge, developing the tool and interface by which the decision support is delivered, and testing and refining the tool based on user feedback.

Outcomes and Objectives Workgroup: Taxonomy of Patient Preferences (Level 3). Patient preferences are crucial factors that must be taken into account in the care process for patient-centered care to be achieved; yet patient preferences for use in CDS are ill-defined and no standardized definition currently exists. This product presents a taxonomy that describes and categorizes patient preferences relevant to PC CDS to improve understanding of what preferences should be considered in PC CDS. The product also documents challenges related to the capture or use of preference data and outlines an agenda for future research. The organizing framework of the taxonomy can help developers, evaluators, patient advocates, and organizations advance patient care by better incorporating patient preferences into PC CDS delivery. For example, CDS developers can use the taxonomy to understand which preferences are most relevant to capture for PC CDS when developing new tools. The taxonomy can also help health information technology (IT) systems developers (other than PC CDS developers) understand what preferences may be of value to PC CDS developers so that the capture of these preferences can be built into interactions with patients. Organizations may use the

taxonomy to create new workflows or improve existing workflows to capture patient preference information and using such data in decision making. Accounting for patient preferences in the delivery of PC CDS is crucial to acceptance of PC CDS and attaining desired outcomes. The report was published May 2023; access it [here](#).

Standards and Regulatory Frameworks Workgroup: Improving Interoperability of Patient Apps with the Health IT Ecosystem (Level 2). Clinicians are increasingly prescribing patient-facing mobile applications (apps) to help track their symptoms, manage their care, and support health-related decision making. Yet, providers still face many challenges to using this data, as apps are often not integrated in electronic health records (EHRs), potentially impacting the quality of care and increasing burden placed on care teams and patients. This product describes the needs and potential approaches to addressing the lack of interoperability between patient apps and health IT systems (e.g., Health Information Exchanges [HIEs], analytic platforms, personal health data platforms, population health management tools, care management tools) used by clinicians. It also includes a discussion of priority gaps and recommendations based on the current state of app interoperability and available standards. The product maps actors and the stages for requesting and obtaining data from patient apps within the integrated health IT ecosystem. This report advances the field of PC CDS by identifying and promoting necessary standards to improve patient app-health IT system interoperability, thus reducing barriers that patients face with sharing data with their care teams, improving relevance and adoption of PC CDS to care, and improving workflows for clinicians by streamlining data sources. The report was published August 2023; access it [here](#).

Standards and Regulatory Frameworks Workgroup: Advancing Standardized Representations for Patient Preferences Support PC CDS (Level 3). At present, there is no consensus on the different types of patient preference data that can influence shared decision making. This product aims to address this gap by identifying standards for integrating patient preference data into PC CDS. As such, it reports 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 Taxonomy of Patient Preferences serves as an organizing framework for this product. For each domain and sub-domain outlined in the taxonomy, this product incorporates terminology standards (specifically LOINC and SNOMED) derived from the National Library of Medicine's UMLS Metathesaurus. This product moves the field of PC CDS forward by enabling the development and use of PC CDS that can leverage patient preference data through the use of standards identified in the report and by enabling routine collection and use of preference data through the targeted research agenda and action plan provided in the report. It also demonstrates the importance of including patients in national strategy and design of the standards infrastructure for PC CDS. The report was published August 2023; access it [here](#).

Trust and Patient-centeredness Workgroup: Improving the Source Credibility of Patient-centered Clinical Decision Support Tools (Level 2). Greater source credibility may improve trustworthiness of PC CDS and subsequently, uptake of PC CDS tools; however, little is known about what influences the trustworthiness and credibility of PC CDS. The product outlines a framework for CDS developers that defines the factors that enhance or detract from source credibility within the context of PC CDS. To support CDS developers in modifying PC CDS attributes to improve tool credibility, the report provides an information flow model that highlights the point in the flow of

information that 13 attributes contribute to source credibility. The product also outlines strategies for increasing the credibility of PC CDS tools and priority research topics to address evidence gaps and advance PC CDS source credibility. As such, it is the first step in addressing the dearth of evidence on source credibility in PC CDS and successful strategies to improve credibility. The report was published July 2023; access it [here](#).

Implementation

Implementation of PC CDS involves launching the PC CDS tool in clinical health IT systems (e.g., EHRs) and making patient-facing tools (e.g., mobile apps, patient portals) available for use.

Outcomes and Objectives Workgroup: Integration of PC CDS into Shared Decision Making (Level 3).

While a robust body of evidence on shared decision making processes exists, little is known as to how PC CDS can facilitate the integration of shared decision making into clinical practice. This product provides a framework for examining the impact of PC CDS interventions on shared decision making. In the report, we describe the current complexities and future considerations around advancing shared decision making with the use of PC CDS. The [Three-Talk Model for Shared Decision Making](#)¹ provides the underlying framework for the product, which has been cross walked with the [AHRQ definition of PC CDS](#) to serve as a framework for integrating PC CDS in shared decision making processes. This product advances the field of PC CDS by improving the understanding (among CDS developers, healthcare organizations and other stakeholders) of how PC CDS can support shared decision making.

Trust and Patient-centeredness Workgroup: 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. This report is intended to help CDS developers in involving co-design methods in their tool development and design. By providing guidance on methods to improve the patient-centeredness of PC CDS through co-design, this product supports creation of PC CDS that is more understandable, personalized, and enjoyable for end-users and it supports improved patient and care team satisfaction with PC CDS. The report was published August 2023; access it [here](#).

Measurement

Measurement focuses on evaluating a tool's impact on desired outcomes, such as improved clinician and patient decision making, care processes, and health outcomes. Measurement findings often lead to improvements to the PC CDS tool or the development of new PC CDS, creating a continuous feedback loop.

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

Outcomes and Objectives Workgroup: Patient-Focused Outcome Measures for Patient-Centered CDS (Level 1). This product identifies available outcome measures that are relevant to PC CDS, an important step in shifting the focus from clinician-centered outcomes to include outcomes important to patients and their caregivers. 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 report describes publicly available instruments, where known, that could be used to measure specific outcomes within these domains for PC CDS. The report utilizes use cases to demonstrate 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 accompanies the written report. In identifying commonly used outcome measures that are appropriate for evaluating PC CDS, this product enables expanded assessment of the impact of PC CDS on patients and caregivers as well as on clinicians and the healthcare delivery system. For example, developers of PC CDS can use the product to understand the potential impacts of their tools and ensure that data collection supports outcomes measurement. Evaluators who are seeking to assess the impact of PC CDS can use the inventory to select measures for their assessment. Finally, quality improvement program designers may wish to incorporate patient-centric measures, in addition to clinician-centric measures, into their assessments and can consult the inventory to do so.

Scaling, Measurement, and Dissemination Workgroup: Approaches to Measuring Patient-Centered CDS Workflow and Lifeflow Impact (Level 3). Little is known about the impact of PC CDS on clinician workflows on the whole, and there has been even less study of the impact on patient and caregiver activities, or “lifeflows”. This product discusses how organizations describe and measure PC CDS effects on care team workflows and patient and caregiver “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 infographic that maps out key points in workflows and lifeflows where a PC CDS tool can be used to positively impact patient lifeflows, and it discusses the state of current evidence regarding workflow and lifeflow impacts of PC CDS and outstanding gaps. This product is a practical tool that can help PC CDS developers, researchers, implementers, evaluators, and others consider how PC CDS affects care team workflows and patient or caregiver lifeflows, which can inform the design, development, and assessment of PC CDS. The list of gaps and recommendations may serve as an action plan for the research community to use in planning for the improved study of workflow and lifeflow impacts. In identifying useful measures of PC CDS impacts on workflows and lifeflows, this product acts as a critical first step in developing benchmarks for improved PC CDS value and patient and clinician satisfaction. The report was published July 2023; access it [here](#).

Scaling, Measurement, and Dissemination Workgroup: PC CDS Performance Measurement Inventory and User Guide (Level 1). This product provides a [user guide](#) and [inventory](#) of quantitative and qualitative measures and tools (i.e., standardized scales) for evaluating three phases of the PC CDS implementation process: designing CDS, using CDS, and the results of using CDS. The inventory contains over 150 measures to assess PC CDS performance that capture 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 features four common use case scenarios that

demonstrate how the documented measures can be used to measure PC CDS process effects under each scenario. It serves to support users planning to select performance measures for evaluation, based on their intervention-related aims (e.g., evaluate the performance of an evidence-based PC CDS) and who they are (e.g., community hospital, clinician informatician, informatics researcher). This product helps to address the need for increased standardization of measuring PC CDS performance and is a starting point for the identification and standardization of patient-centric measures. This guidance may enable healthcare providers, EHR and CDS developers, and others, including patients and their advocates, to measure PC CDS implementation and performance reliably and reproducibly, which can in turn improve the quality of the evidence on PC CDS effectiveness. The product was published August 2023; click to access the [user guide](#) and [inventory](#).

Cross-cutting Products

Standards and Regulatory Frameworks Workgroup: Standards and Regulatory Frameworks Environmental Scan (Level 1). This product 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 report outlines 40 opportunities to advance the PC CDS standards landscape. This report provides readers with an overview of the standards, implementation guides, and initiatives that currently support or can support PC CDS that is shareable and interoperable as well as a research agenda and action items for improving the adoption and use of standards for PC CDS. The target audience of this report includes patients/caregivers, clinicians, CDS researchers, CDS content developers, CDS vendors, health IT standards developers, policymakers, and payers. The report was published January 2023; access it [here](#).

Scaling, Measurement, and Dissemination Workgroup: 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. Additionally, CDS developers and implementors can consult the contents of the tool to guide the design of their tool, noting key elements of a CDS intervention, during the planning phase, which can improve the safety, effectiveness, and person-centeredness of tools that are developed. This product addresses the need for an overarching framework that encourages consistent and complete reporting on the implementation of PC CDS interventions. By using this tool, researchers, developers, implementers, and evaluators can enhance the quality of information available on PC CDS intervention processes, which will in turn enhance understanding of PC CDS implementations, the field's ability to produce insights on and improvements in implementation best practices, and scalability of PC CDS tools. This report was published September 2023; click to access the [user guide](#) and [fillable checklist](#).

Trust and Patient-centeredness Workgroup: An Introductory Handbook for Patient Engagement Throughout the PC CDS Lifecycle (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 product acts 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. In doing so, this product accelerates efforts to advance patient-centered care that is meaningful to patients and inclusive of patients' needs and encourages the adoption of consistent methods for the inclusion of patient input in every stage of the PC CDS lifecycle.

How These Products Can Be Used Support PC CDS Efforts

The products produced under the Workgroups provide a foundation for advancing PC CDS. Many of the products can be used in concert for PC CDS design & development, implementation, and/or measurement. Below, we provide four examples of how the products can be used together to enable end-users to develop, use, and evaluate their PC CDS tools.

Example 1: Understanding PC CDS Development Foundations

Two Workgroup products provide foundational information for new-to-the-field PC CDS developers, researchers, and other stakeholders who are looking build their knowledge base about PC CDS development. The Standards & Regulatory Frameworks **Environmental Scan** examines the current state of standards, regulatory frameworks, and technical barriers, allowing users to develop an understanding of the policy and technical system for PC CDS. The Trust & Patient-Centeredness Workgroup product **Improving the Source Credibility of Patient-centered Clinical Decision Support Tools** provides important context about the factors that enhance or detract from source credibility and defines each factor within the context of PC CDS. The product's recommended approaches for increasing the source credibility of PC CDS tools can help guide developers in creating trustworthy PC CDS.

Example 2: Engaging Patients Throughout the PC CDS Lifecycle

Engaging patients in PC CDS development, implementation, and measurement can ensure that decision support tools are focused on patients' critical information needs and that the delivery of information is in a manner and format that is most helpful to them. The Workgroups have developed three products that can be used together to help PC CDS developers and researchers engage patients as well as help patients understand their critical role in PC CDS development and implementation. The Trust & Patient-Centeredness Workgroup product **An Introductory Handbook for Patient Engagement Throughout the PC CDS Lifecycle** provides information about methods and resources that can be used engage patients in each step of the PC CDS lifecycle. A second Trust & Patient-

Centeredness Workgroup **Methods for Involving End-users in PC CDS Co-design** provides a deeper understanding of co-design methods that can specifically be used to gather patient input in the design and development of PC CDS tools. Finally, the Scaling, Measurement, & Dissemination Workgroup has developed the **PC CDS Planning, Implementation, and Reporting Tool**, which provides a mechanism for PC CDS developers and researchers to document how they have directly engaged patients and incorporated other patient-centered factors in PC CDS tools. An accompanying user guide for the tool also gives guidance about how to populate the tool and considerations for incorporating patient-centered factors.

Example 3: Developing Patient-facing PC CDS to Facilitate Shared Decision Making

Shared decision making is a collaborative process that brings together patient preferences and other information with clinical guidance to inform joint deliberation and decision making between patients (and their caregivers) and the care team.² To facilitate this process, the field of PC CDS is increasingly interested in apps that can collect data from and transmit information to patients and their caregivers. Five products developed by the Workgroups can inform the development of a patient-facing PC CDS app intended to support shared decision making. To first help understand how PC CDS fits into shared decision making, the Outcomes & Objectives Workgroup product **Integration of PC CDS into Shared Decision Making** illustrates how PC CDS intersects with the shared decision making process. This product can also inform implementation of the PC CDS within a shared decision making process.

Two products can support the elicitation and capture of patient preferences via PC CDS, a key step in the shared decision making process. The Outcomes & Objectives Workgroup product **Taxonomy of Patient Preferences** describes and categorizes patient preferences relevant to PC CDS, which can guide PC CDS developers in what information should be captured by a patient-facing app. To help PC CDS developers understand the technical complexities of capturing patient preferences, the Standards & Regulatory Frameworks Workgroup product **Advancing Standardized Representations for Patient Preferences Support PC CDS** provides information about the current use of data standards for collecting and using patient preference data.

To further support the development of a patient-facing PC CDS, the Standards & Regulatory Frameworks Workgroup product **Improving Interoperability of Patient Apps with the Health IT Ecosystem** provides information on available standards to support data flows between patient apps and the EHR.

Finally, the Scaling, Measurement, and Dissemination Workgroup **Approaches to Measuring Patient-Centered CDS Workflow and Lifeflow Impact** provides a detailed standalone infographic that maps out key points in the patient lifeflows that a patient-facing PC CDS tool can be used. This product can help PC CDS implementers understand how a patient-facing app will be incorporated into the patient's daily activities and how to assess the impact of the PC CDS on the patient's lifeflow.

² The SHARE Approach—Essential Steps of Shared Decision making: Quick Reference Guide. Content last reviewed September 2020. Agency for Healthcare Research and Quality, Rockville, MD. <https://www.ahrq.gov/health-literacy/professional-training/shared-decision/tools/resource-1.html>

Example 4: Identifying Measures to Assess PC CDS Impact

Measurement is a critical step in the PC CDS lifecycle as it allows us to understand if PC CDS is working as intended, its impact on clinician workflow and patient lifeflow, and its effect on patient outcomes. The Workgroups have developed two products that can be used together to identify relevant measures to evaluate PC CDS. The Scaling, Measurement, and Dissemination Workgroup developed a **PC CDS Performance and Value Measurement Inventory and User Guide**, which aggregates over 150 process measures related to PC CDS implementation and provides illustrative case scenarios. This product can be used in combination with the Outcomes & Objectives Workgroup product **Patient-Focused Outcome Measures for Patient-Centered CDS**, which captures measures within domains of patient journey outcomes and patient-reported health outcomes and provides illustrative use cases. Together, these products are a repository of dozens of measures that PC CDS developers, researchers, and evaluators can consult when designing, implementing, and evaluating their tools.