

# FINAL WORKGROUP CHARTER: TRUST AND PATIENT-CENTEREDNESS

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## Agency for Healthcare Research and Quality: Clinical Decision Support Innovation Collaborative (CDSiC)

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## CDSiC Vision and Mission

**Vision Statement:** A world where patients, caregivers, and care teams have the right information at the right time to make evidence-informed decisions that improve health and well-being for all individuals.

**Mission Statement:** 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. To achieve this, CDSiC will:

- Create a learning community to share and advance the knowledge, tools, standards, frameworks, and techniques for designing, developing, implementing, using, measuring, and evaluating high-quality, PC CDS.
- Promote the practice and adoption of PC CDS that facilitates whole-person care and considers the patient, caregivers, and clinician workflows, preferences, and values around shared-decision making.
- Advance standards-based PC CDS that can be shared with patients, caregivers, clinicians, healthcare organizations, and health IT developers across the U.S. and result in measurable improvements in healthcare, patient health, patient care experience, and provider experience.

## Purpose

The purpose of this charter is to formally establish the Trust and Patient-Centeredness Workgroup under the CDSiC the Stakeholder and Community Outreach Center (Stakeholder Center). The Affordable Care Act (Section 6301) established a mandate for the Agency for Healthcare Research and Quality (AHRQ) to engage diverse stakeholders in efforts to develop and advance the use of patient-centered outcomes research (PCOR).<sup>1</sup> Fulfilling this mandate, the CDS Trust and Patient-Centeredness Workgroup will leverage the knowledge and experience of CDS experts and amplify the voice of patients to ensure PC CDS products and tools empower patients to make healthcare decisions that align with their values and preferences.

The CDSiC, is composed of three centers: the Operations Center, the Stakeholder Center, and the Innovation Center. These Centers will undertake a series of activities to identify, prioritize,

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<sup>1</sup> Patient Protection and Affordable Care Act of 2010, Pub. L. No. 111 148, 124 Stat. 119 (2010), Codified as Amended 42 U.S.C. 18001.

and develop products that are broadly disseminated to relevant stakeholders and likely to contribute significantly to the field.

The Stakeholder Center and its Workgroups will provide crucial thought leadership for CDSiC activities and promote CDS within the U.S. healthcare system by (1) developing content-driven written products for the field, (2) advising the Steering Committee in its work guiding the overall work of the CDSiC, and (3) providing input on projects undertaken by the Innovation Center.

## Reasons for Establishing

As CDSiC advances patient-centered CDS development and implementation, it must promote approaches that put patients at the center of care processes and CDS tools that enhance the patient-clinician relationship. Critical to achieving this is the cultivation of patient and clinician trust in CDS recommendations; this will be done by fostering transparency in the processes of CDS design, development, testing, implementation, and use. The Trust and Patient-Centeredness Workgroup will fulfill this need by creating a forum through which stakeholders can advise the CDSiC Steering Committee and the Innovation Center in creating patient-centered CDS products and conducting CDS demonstration projects.

## Composition and Relevant Stakeholders

The activities of the Workgroup will be informed by the Steering Committee and the Stakeholder Planning Center Committee. The Steering Committee will provide strategic input and the Planning Center Committee will ensure that the Workgroup activities are synergistic, informed by the Steering Committee vision, and in support of Innovation Center projects.

The Workgroup will be comprised of patients and experts who reflect diversity across various dimensions, and who will draw on their respective experiences and deep connections to support Workgroup objectives and outcomes. The Workgroup will include up to 15 members who identify as patients, patient advocates, researchers with expertise in health disparities and/or data privacy, clinicians, health systems representatives, health IT developers, professionals who create or distribute content regarding or tools using CDS evidence, state and federal agency representatives, and Patient-Centered Outcomes Research Institute (PCORI) representatives.

Workgroup activities and products will be designed to reach a broad set of stakeholders. The intended audience for products, such as CDS tools, resources, and evidence, developed by the Workgroup include federal agencies/policymakers, clinicians, medical/academic institutions, patients/patient advocates, caregivers, authors of CDS guidelines, CDS developers, informaticists, standards developers, PCOR researchers, electronic health record (EHR) developers, and health systems.

**Workgroup Leads.** The Workgroup will be led by the Workgroup Chair, Tonya Hongsermeier, and Associate Lead, Angela Dobes, with support from Rachel Dungan. Hongsermeier and Dobes will co-lead Workgroup activities. Workgroup Leadership will set the overall direction for the development of Workgroup products, facilitate meetings, lead product development, assign roles and responsibilities to members, work with the CDSiC leadership team to ensure that Workgroups have the right subject matter expertise to develop products, monitor progress, ensure products are developed consistent with proposed timelines and communicate regularly with Stakeholder Center leadership.

## Objectives

The objectives of the Trust and Patient-Centeredness Workgroup are outlined below:

- Facilitate the development and dissemination of written products that support design, implementation, and uptake of PC CDS to enhance trust, foster shared decision-making, and engage patients and clinicians as partners alongside all members of the care team.
- Promote and enable the use of PC CDS by developing related products that can support clinicians and patients as partners in a care team equally committed to creating effective treatment and care coordination plans.
- Ensure that PC CDS products are understandable by the care team, designed with their end-users in mind, including both clinicians and patients, and that end-users should be involved from the very beginning in their development.

## Outputs and Projected Outcomes

In pursuit of its objectives, the Workgroup will engage in a variety of activities to generate a set of specific outputs, or high-quality, written products. Outputs will be determined by Workgroup members through discussion and deliberation. Examples of potential outputs include:

- Developing guidance (e.g., recommendations, best practices) to support CDS product designers in creating products with greater usefulness and usability to patients and their care team.
- Reviewing and synthesizing literature providing evidence of the impact of PC CDS on improving outcomes such as care team rapport, patient satisfaction with care, or improved health outcomes.
- Developing guidance (e.g., recommendations, best practices) to support clinicians and CDS product end-users in presenting and applying the tools in ways that are respectful and resonant for patients and caregivers.
- Creating tools and resources (e.g., fact sheet, framework, scales) to help inform and educate patient and caregiver end-users of CDS products and enhancing their ability to interact fully with the CDS tools.

- Drafting briefs, papers, webinars, or other dissemination products to help increase awareness throughout the field of effective strategies for (1) designing CDS products in ways that facilitate trust and transparency, and (2) engaging patients more fully in the process of decision-making using CDS tools.

If successful in operationalizing its objectives, the Workgroup, through its deliberations and outputs, will serve as a forum that:

- Responds to the CDS needs of patients, caregivers, and clinicians, strengthening the patient-provider and care team relationship(s).
- Advances and amplifies awareness and use of PC CDS among patients, caregivers, and care team members.
- Advances PC CDS-based methods to assess and assure trust and transparency during clinical and other encounters.
- Synthesizes important information regarding the best practices for leveraging CDS tools to support shared-decision making.
- Increases awareness of the extent to which CDS has been studied and validated as an effective approach to prompting new improvement and innovation in clinical workflows and health systems processes.

## Constraints and Potential Challenges

In conducting its activities, the Workgroup will adhere to the following constraints:

- All activities must be stakeholder-driven and fit within the scope and objectives of the Workgroup.
- All products developed by the Workgroup must fit within the AHRQ-provided guidelines.
- Activities must align with funding stipulations and be completed within allotted project timelines.
- Constraints of the COVID-19 pandemic in engaging stakeholders in terms of time capacity and convening settings.

Throughout its tenure, the Workgroup may encounter one or more of the following potential challenges:

- Lack of shared language with respect to the evolving definitions of "patient-centered care and patient-centered clinical decision-support" in use across healthcare and health research settings.
- Sustaining engagement with diverse Workgroup members, in alignment with their communication and participation styles.
- Reconciling differing perspectives among Workgroup members to come to a consensus on decisions for Workgroup activities.

- Allowing for a diversity of perspectives within the Workgroup and creating an inclusive space where all members feel comfortable voicing their opinions.
- To aid in mitigating these challenges, the group will establish bidirectional channels for communication and will cultivate an environment conducive to remaining strategic, adaptable, and responsive to the priorities of group members throughout the project duration.

## Decision-Making Frameworks

Workgroup decision-making will prioritize consensus methods, particularly for operational decisions or determining recommendations for elevation to the CDSiC Steering Committee and/or Innovation Center. This approach involves Workgroup deliberation to achieve a final result based on agreement of a simple majority. To the extent possible, the Workgroup will explore the use of different decision-making frameworks when majority agreement cannot be achieved in cases involving complex decisions. Such frameworks may include but are not limited to:

- Decision matrix: evaluates and prioritizes a list of options against an established list of weighted criteria and then evaluates each option against those criteria.
- Risk-benefit analysis: comparison between the risks of a situation and its benefits to determine whether a course of action is worth taking or if risks are too high.
- Feasibility-impact analysis: comparison of the factors of a project/activity that determine the probability of its successful completion relative to the significance in change that would occur as a result of the project/activity.

Workgroup leadership will be responsible for selecting the appropriate decision-making framework. The rationale for selection will be documented in the Workgroup meeting notes. However, where appropriate and prudent, anonymous voting (facilitated by a virtual platform) can be used to resolve discrepancies and finalize decisions. Workgroup Leadership will be responsible for implementing the decisions in consultation with CDSiC leadership. The goals of the Workgroup will be to achieve majority agreement. However, in the event of irreconcilable differences within the group, AHRQ will be asked for their opinion or advice, to help break the stalemate.