Trust and Patient-Centeredness Workgroup: Charter – Option Year 2

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5600 Fishers Lane
Rockville, MD 20857
www.ahrq.gov

Contract No: 75Q80120D00018

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November 2024

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.

TASK & DELIVERABLE:

Deliverable 2.3.1: Revise and Submit Charters for Each of the Four Workgroups

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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: 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. To achieve this, the 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's 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).[1] 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, 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.

[1] 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.

Reasons for Establishing

As the CDSiC advances PC CDS development and implementation, it must promote approaches that help patients and their care teams make better patient-centered and evidence-based decisions. Critical to achieving this is cultivating patient and clinician trust in CDS recommendations; fostering transparency about CDS development and implementation; and establishing methods to support effective shared decision making (i.e., discussing and comparing benefits, harms, and risks while considering what matters most to the patient)[2] in situations when shared decision making is appropriate. To advance PC CDS, the Trust and Patient-Centeredness Workgroup will create a forum through which stakeholders will develop high-impact products to support the design and implementation of PC CDS that is created based on the needs of end users—particularly patients and caregivers—and developed transparently to ensure credibility. Ultimately, this will advance the uptake and adoption of trustworthy PC CDS that meets the needs of patients, caregivers, and the care team in navigating healthcare decision making as partners.

Composition and Relevant Stakeholders

The activities of the Workgroup will be informed by the Steering Committee and the Stakeholder Center Planning Committee. The Steering Committee will provide strategic input and the Planning Committee will ensure that the Workgroup activities are synergistic, informed by the Steering Committee's 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, and state and federal agency 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 co-leads Jessica Ancker and Angela Dobes, with support from Avantika Shah. Ancker 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

[2] The SHARE Approach: A Model for Shared Decisionmaking - Fact Sheet. Content last reviewed September 2020. Agency for Healthcare Research and Quality, Rockville, MD. https://www.ahrq.gov/health-literacy/professional-training/shared-decision/tools/factsheet.html

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 the 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 and include equitable and inclusive approaches to decision making.
- Ensure that PC CDS products are understandable by the care team, designed with their end users – including both clinicians and patients – in mind, and that end users be involved from the very beginning of 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 past outputs include:

- A resource that identifies and describes methods for PC CDS codesign, detailing their defining features, trade-offs (benefits vs. limitations), and utility during different phases of the process (pre-design, design) to elicit information, while also highlighting key considerations for involving end users.
- A report that examines best practices for eliciting patient preferences in clinical and non-clinical settings to support healthcare decision making, and illustrates workflows and lifeflows that show opportunities to capture patient preferences in specific clinical scenarios.
- A report that provides descriptions of patient and caregiver perspectives on the use of generative artificial intelligence in PC CDS and its impact on trust and the patient clinician relationship.
- An action plan that describes the needs, current efforts, and opportunities for incorporating social determinants of health data into PC CDS.

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 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.
- Advances evidence-based decision making anchored in patient-centered and patient-specific information that aligns with patient needs, preferences, values, and the environment in which they live.

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.

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 PC CDS 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 of 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 the 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 resolve the stalemate.

Acknowledging Workgroup Product and Publication Contributions

The Workgroup may produce reports, frameworks, and other documents that are publicly posted on the CDSiC website ("products"). In addition, the CDSiC may develop manuscripts based on Workgroup products for submission to peer-reviewed journals. Below, we describe guidelines for acknowledging contributions in Workgroup products and manuscript publications.

Acknowledging Workgroup Member Contributions in Products. For products posted on the AHRQ CDSiC website, the Workgroup as a whole will be included as a co-author. Workgroup members who provide input during Workgroup product development will be acknowledged for their contributions by being listed in a table of contributing Workgroup members. In order to be acknowledged in a final Workgroup product, Workgroup members must do at least one of the following:

1. Attend at least one Workgroup meeting to review and provide real-time feedback on product findings or product structure.

2. Provide asynchronous feedback on Workgroup product drafts between Workgroup meetings (e.g., via email or on SharePoint).

Authorship Guidelines for Manuscripts. The CDSiC leadership (i.e., the CDSiC PI and Stakeholder Center lead), the Agency for Healthcare Research and Quality (AHRQ), Workgroup support teams, and Workgroup leads will discuss expected contributions before manuscript development, including authorship and the anticipated order of authors. The anticipated authorship order will be determined and agreed upon before product drafting begins.

Following International Committee of Medical Journal Editors (ICJME) guidelines, authors must be able to meet the following four criteria:

1. Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND

2. Drafting the work or reviewing it critically for important intellectual content; AND
3. Final approval of the version to be published; AND
4. Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.[3]

All authors are responsible for fairly evaluating their role to ensure that authorship is attributed according to these standards. Authorship order will be discussed collectively as a group with the authors.

- The lead author is generally the individual responsible for writing the first draft of the manuscript.
- The co-authors will be listed in order of contribution to the conception, drafting, and review of the manuscript.
- The CDSiC Principal Investigator will be listed as the final author, reflecting their involvement throughout the manuscript development process, oversight, and overall strategic direction of manuscripts. Workgroup leads may be listed as co-senior authors to reflect their contribution to the conceptualization of a product, when appropriate.
- The CDSiC PI or Stakeholder Center lead will serve as the corresponding author. The corresponding author will be responsible for manuscript submission and coordination with the journal during the peer-review and publication process.
- Each manuscript will have AHRQ co-authors.

Please note that authorship order of manuscripts may not reflect the authorship order of the corresponding Workgroup product.

Acknowledging Workgroup Member Contributions. Each CDSiC Workgroup will generally be included as a co-author in the manuscript (e.g., manuscripts developed under the Measurement and Outcomes Workgroup will include "Measurement and Outcomes Workgroup" in the list of authors). Ahead of selecting a journal, NORC will reach out to target journals to confirm the Workgroup can be submitted as a co-author. In accordance with ICJME and journal guidelines, Workgroup members will be acknowledged for their valuable contributions to the work. Individual members will be named in the article's acknowledgments or contributors section. To be included in the list of Workgroup members noted in the manuscript, Workgroup members must have either:

- Contributed to the development of the original product(s) that undergird(s) the manuscript (i.e., the Workgroup member is listed as a contributor in the report), OR
- Contributed directly to manuscript development by participating in Workgroup meetings where manuscript-related activities (such as additional research activities to inform the manuscript) were discussed or providing asynchronous feedback on manuscript-focused activities.

[3] https://www.icmje.org/recommendations/browse/roles-and-responsibilities/defining-the-role-of-authors-and-contributors.html