HOW TO:
COLLABORATE WITH PATIENTS ON PATIENT-CENTERED CLINICAL DECISION SUPPORT

Featuring Products From the AHRQ Clinical Decision Support Innovation Collaborative

OVERVIEW

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Involving patients, caregivers, and care teams in the development and implementation of digital health tools—including patient-centered clinical decision support (PC CDS)—helps ensure these resources are focused on the information, preferences, priorities, and outcomes that are most important to their users.

Patient-centered clinical decision support (PC CDS) encompasses healthcare decision making tools that consider patients' individual preferences, needs, and circumstances. These digital tools aim to provide patients and their care teams with evidence-based, personalized guidance to inform their care, ultimately facilitating shared decision making and patient-centered care.

Established in 2021, the Clinical Decision Support Innovation Collaborative (CDSiC) brings together stakeholders across the healthcare ecosystem to advance the development, implementation, and adoption of high-quality PC CDS. The CDSiC aims to better understand what makes CDS patient-centered by creating resources to support developing, testing, implementing, tracking, and measuring PC CDS in the real world.

The CDSiC developed four products that help a variety of CDS stakeholders enhance their collaboration with patients to support the development of CDS resources that are responsive to patient needs.

To help ensure that PC CDS is inclusive, trustworthy, and impactful, the CDSiC has developed a series of resources that provide actionable strategies for designing, developing, and implementing PC CDS tools in collaboration with patients.

Collaborating with patients and caregivers supports the development of PC CDS tools aligned with their priorities and that deliver information a manner and format that is most helpful to end-users. End-users may include patients and caregivers interacting with the tools directly or clinicians who will use the tools to provide patient-

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centered care.[1] However, PC CDS development has historically been spearheaded by health system leaders, electronic health record (EHR) developers, and informaticians. Unless CDS developers prioritize end-user needs and preferences or invite end-user input during design, PC CDS may not align with clinician workflows or patient lifeflows—the sequence of events and activities that patients experience throughout their healthcare journey, encompassing both clinical interactions and daily life activities.[2]

Acknowledging this challenge, the CDSiC developed multiple products to advance patient collaboration in the development and implementation of PC CDS. Together, these resources examine core aspects of collaborating with patients on PC CDS efforts—spanning approaches for codesigning tools alongside patients and caregivers, strategies for meaningful engagement throughout the CDS lifecycle, and methods to ensure patient perspectives shape both implementation and scale-up efforts.

This guide offers an overview of the CDSiC's resources on patient collaboration, highlighting how these tools can be used by patients, clinicians, researchers, and PC CDS developers to ensure that decision support is truly responsive to the needs, values, and lived experiences of patients.

CDSiC PRODUCT DESCRIPTIONS

1 A Lifecycle Framework Illustrates Eight Stages Necessary for Realizing the Benefits of Patient-Centered Clinical Decision Support[3]

PC CDS Opportunity. Collaborative design, development, implementation, use, and evaluation of high-quality PC CDS are all necessary if we are to **achieve the quadruple aim of healthcare improvement**. This involves integrating patient perspectives at each stage: informing evidence generation, shaping decision support tools, and engaging patients in the clinical environment. **Maintaining continuous collaboration with patients is key** to creating relevant PC CDS tools that support informed decision making and personalized care throughout the patient journey.

How the CDSiC Addressed the Opportunity. To foster a shared understanding among researchers, patients, clinicians, and policymakers about the potential for patient participation in the PC CDS lifecycle, the CDSiC created a PC CDS lifecycle framework. This framework, published in the Journal of the American Medical Informatics Association (JAMIA), places the patient or their caregiver at the center and demonstrates their involvement throughout. The framework includes three overarching phases: **Knowledge Generation**, where patient-centered outcomes research (PCOR) guides evidence creation; **Clinical Decision Support**, where evidence is transformed into patient-specific recommendations; and **Healthcare Delivery**, where decisions are made in consultation with the patient, their caregivers, and care teams. By utilizing this comprehensive framework, stakeholders are reminded that the development, implementation, and assessment of PC CDS is a multifaceted, sociotechnical endeavor that must take all eight stages into account.

Drawing on peer-reviewed and grey literature, as well as expert input, the handbook highlights **engagement methods** such as consensus-building, codesign, and group concept mapping. It also provides **real-world examples** of patient engagement activities and suggests how researchers, developers, and patient partners can apply them in practice. By making these methods accessible and actionable, the handbook supports the broader goal of developing PC CDS that is aligned with patient needs, values, and lived experiences.

How You Can Use This Resource:

The PC CDS lifecycle framework offers a strategic approach for facilitating patient and caregiver involvement at each stage of the lifecycle. Integration of patient input at every phase is essential for achieving meaningful, patient-centered outcomes in healthcare.

Researchers and developers can use this framework to guide the development of evidence generation and ensure that patient perspectives are considered in all stages of PC CDS. It provides a common language to facilitate communication and collaboration between patients, caregivers, and researchers, enabling more effective, patient-centered research outcomes.

Patients, caregivers, and patient advocates can use the framework to advocate for meaningful engagement at all stages of PC CDS, ensuring their voices are considered in the development and use of CDS tools.

Healthcare systems and clinicians can apply this framework to incorporate patient involvement throughout the entire lifecycle of PC CDS, helping to ensure care is truly patient-centered.

2 An Introductory Handbook for Patient Engagement Throughout the Patient-Centered Clinical Decision Support Lifecycle[4]

PC CDS Opportunity. The meaningful engagement of patients throughout the development and implementation of PC CDS remains limited. Despite growing recognition of the need to include patients in these processes, many developers and implementers lack clear guidance on how to do so effectively. Without **intentional strategies for patient engagement**, PC CDS may fall short of being truly patient-centered—limiting opportunities to address patient priorities, build trust, and improve health outcomes. To advance effective PC CDS, **researchers and developers need practical, accessible tools** that support the meaningful engagement of patients and caregivers across the entire lifecycle.

How the CDSiC Addressed the Opportunity. In response, the CDSiC created the Introductory Handbook for Patient Engagement Throughout the Patient-Centered Clinical Decision Support Lifecycle, which directly addresses the lack of **consistent, practical guidance on how to engage patients** in the development and implementation of PC CDS. The handbook outlines how patient engagement can and should occur across all stages of the PC CDS lifecycle—from identifying evidence to informing tools, to codesigning and codeploying CDS interventions, and, finally, to evaluating their impact.

How You Can Use This Resource:

This practical handbook offers guidance for facilitating patient engagement across the PC CDS lifecycle. It outlines key methods and real-world examples to help make PC CDS more responsive, trustworthy, and patient-centered—supporting more effective codesign, implementation, and evaluation of PC CDS.

Researchers can apply engagement methods to design PC CDS projects that integrate patient input at every stage, starting with the selection of a clinical problem area to address.

Developers can use the handbook to identify the most appropriate and effective strategies for engaging patients in the PC CDS development process to create PC CDS tools that reflect patient needs.

Patients, caregivers and patient advocates can use the handbook to identify how and when they can contribute their experiences and insights to inform PC CDS.

3 Methods for Involving End-Users in PC CDS Codesign[5]

PC CDS Opportunity. PC CDS tools often fail to **fully reflect the realities of clinical workflows and patient lifeflows** because end-users—patients, caregivers, and clinicians—are not always involved in their design. Historically, health system leaders' and informaticians' perspectives drive PC CDS design, limiting the opportunity to incorporate the lived experiences, needs, and preferences of those most impacted by the PC CDS tools. Without meaningful end-user engagement, PC CDS tools risk being ineffective, burdensome, or misaligned with user priorities.

How the CDSiC Addressed the Opportunity. To guide stakeholders in effectively involving end-users in the codesign of PC CDS, the report **identifies a range of codesign methods** and describes how they can be used across different phases of the design process. It outlines defining features, potential benefits, and tradeoffs of each method, helping stakeholders choose the right approach for their needs and constraints. Drawing on a literature review validated by key informant interviews, the resource also offers **practical guidance on codesign**, such as fostering bidirectional communication, ensuring inclusivity, and building infrastructure to support ongoing user participation. In doing so, it helps developers move beyond traditional design processes and create tools that reflect the lived experiences and priorities of those they are meant to serve.

How You Can Use This Resource:

This report offers practical, real-world guidance for incorporating the perspectives of end-users—patients, caregivers, and clinicians—into the design and development of PC CDS. By outlining proven methods and clear implementation strategies, it serves as a valuable tool for creating more usable and trusted PC CDS tools.

Developers can use this resource to identify and implement codesign methods tailored to different phases of PC CDS development. The report provides insights into selecting the most effective methods for gathering end-user input, ensuring that the resulting tools align with both patient and clinician needs, and fostering collaborative, user-centered design.

Patients, caregivers, and patient advocates can use this resource to understand how their experiences, preferences, and perspectives can shape the design of PC CDS tools—ensuring the final products reflect what truly matters to those receiving care and support more meaningful shared decision making.

4 Exploring Challenges and Opportunities for Patient Engagement, Implementation, Adoption, and Scaling Through PC CDS Case Studies[6]

PC CDS Opportunity. Incorporating PC CDS into healthcare practices requires overcoming several key barriers. **Patient engagement, data interoperability, and system integration remain significant challenges, as well as clinician and patient acceptance**. While PC CDS tools offer the potential to improve patient-centered care by incorporating individual patient needs, preferences, and circumstances, effective methods for collecting and utilizing patient-centered data are often inconsistent or underdeveloped.

How the CDSiC Addressed the Opportunity. To provide practical insights into overcoming the challenges faced when implementing and scaling PC CDS, this report aggregates **lessons learned from nine AHRQ-funded PC CDS projects**, offering a comprehensive overview of the key obstacles encountered in areas such as patient engagement, data interoperability, and user adoption. By highlighting the innovative solutions developed by these projects, the report helps stakeholders better understand the complexities involved in integrating PC CDS into clinical practice. It provides **actionable recommendations** for overcoming challenges related to the codesign process, EHR limitations, data quality, and system integration, ultimately ensuring that PC CDS can be effectively deployed across diverse healthcare settings to improve patient care and outcomes.

How You Can Use This Resource:

This report offers valuable insights and actionable recommendations for addressing challenges in the implementation, adoption, and scaling of PC CDS. It provides practical guidance based on real-world case studies, which stakeholders can apply to improve patient outcomes and the integration of PC CDS tools.

Researchers can use the findings to inform future studies on PC CDS, focusing on improving patient engagement, enhancing data quality, and optimizing the functionality of decision support tools in varied healthcare settings.

Developers can use the report to identify solutions to common challenges such as EHR integration, data interoperability, and user adoption, leveraging the lessons learned from AHRQ-funded projects.

For more information about the CDSiC projects described in this guide, please reach out to the AHRQ team at ClinicalDecisionSupport@ahrq.hhs.gov.

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