

HOW TO: EMPOWER AND ENGAGE PATIENTS WITH PATIENT-CENTERED CLINICAL DECISION SUPPORT

Featuring Products From the AHRQ Clinical Decision Support Innovation Collaborative

OVERVIEW

Contents

1. [Taxonomy of Patient Preferences](#)
2. [Advancing Standardized Representations for Patient Preferences to Support Patient-Centered Clinical Decision Support](#)
3. [Prioritizing Patient Preferences for Standardization to Support PC CDS](#)
4. [Patient Preference Measurement Tools for PC CDS Inventory Report and Spreadsheet](#)
5. [Capturing Patient Preferences for Patient-Centered Clinical Decision Support Within Patient Lifeflows and Clinical Workflows](#)
6. [Integration of Patient-Centered Clinical Decision Support Into Shared Decision Making](#)

Empowered patients have the tools and resources to manage their care and make informed healthcare decisions. To ensure these tools have the intended impact, patients need to be engaged in their development and utilization.

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, caregivers, 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) engages key stakeholders to share and advance knowledge, resources, and methods for PC CDS. It also promotes the practice and adoption of high-quality PC CDS and advances standards-based CDS that can be shared and scaled across the U.S. healthcare ecosystem.



The CDSiC developed six products that empower patients and caregivers by advancing the use of patient preferences data and facilitating shared decision making.

The CDSiC has developed several resources that can make it easier to collect and use information about patients' preferences in their healthcare. This information can then be used to empower patients to become more involved in informed care decision making with their clinicians.

Incorporating patient preferences into PC CDS is a key method of ensuring the patient's voice is heard. Patient preferences are the values an individual patient holds regarding their healthcare decisions and are informed by the patient's experiences and beliefs. They can include patients' preferred forms of communication, preferences around the care experience, and preferences regarding healthcare services and treatments, among others.¹ The use of patient preferences in healthcare decision making empowers patients by giving them a clear opportunity to share their unique needs and priorities. This, in turn, can enhance patients' satisfaction with their care, improve health outcomes, promote patient autonomy in managing their health, and help patients follow their clinical care plans.^{2,3}

CDSiC PRODUCT DESCRIPTIONS

1 Taxonomy of Patient Preferences⁴

PC CDS Opportunity. Incorporating patient preferences into the development and implementation of PC CDS is pivotal to empower and engage patients. Responding to patient preferences ensures that a patient’s voice is heard throughout their care journey and PC CDS delivery. There is a myriad of potential patient preference information to collect, but **no framework for identifying the preferences most relevant for PC CDS and important to patients.** This underscores the need for an **organizing construct** to identify patient preferences to collect and incorporate into the development and implementation of PC CDS.

How the CDSiC Addressed the Opportunity. To build this understanding, the CDSiC team developed a framework for the incorporation of patient preferences into the delivery of PC CDS. In this report, the CDSiC presents a taxonomy for patient preference information most relevant to PC CDS across six domains: personal characteristics, communications, access and care experience, engagement, data, and healthcare services. This report and taxonomy were developed based on a scoping review of peer-reviewed and grey literature, key informant interviews, and patient perspectives focus group. This report is the **first comprehensive examination of the role of patient preferences in PC CDS.** This report offers a clear definition for patient preferences and presents a novel, validated taxonomy that clarifies patient preferences relevant to PC CDS that are most important to patients. This report first highlights each domain, provides example concepts, describes its relevance to PC CDS, and explains how it enhances patient-centered care. The report then presents challenges for operationalizing patient preferences in care and offers key considerations for addressing these challenges. Throughout the report, the team provides guidance for incorporating patient preferences into the design and implementation of PC CDS.

Infographic: Patient Preferences Are Essential to Bringing the Patient Into Focus

- Summarizes key takeaways of the report
- Provides a visual depiction of the taxonomy

How You Can Use This Resource:

The Taxonomy of Patient Preferences presented in this report provides an organizing framework for the types of patient preference information most relevant to PC CDS. Collecting and incorporating patient preferences within PC CDS recognizes the value of the patient voice in the advancement of PC CDS and facilitates patient trust in clinical care.



Developers can use this taxonomy to configure PC CDS tools to support care informed by these preferences.



Healthcare systems and clinicians can use this taxonomy to develop workflows to adequately capture patient preference information, making the patient experience more effective and engaging.



Patients, caregivers, and patient advocates can reference this report and taxonomy as they champion the collection and use of patient preferences within clinical care.

2 Advancing Standardized Representations for Patient Preferences to Support Patient-Centered Clinical Decision Support⁵

PC CDS Opportunity. Patient preferences are important data to include in PC CDS because aligning care with patient preferences can improve patient engagement in shared decision making, which ultimately influences patient satisfaction and patient outcomes. Despite the prominent role of patient preferences in healthcare decision making, the **current state of standards for representing patient preferences is not well characterized.**

How the CDSiC Addressed the Opportunity. To gain an improved understanding of this critical PC CDS topic, the CDSiC qualitatively explored the current standards landscape for patient preference domains relevant to PC CDS. Based on a literature review and key informant interviews, this report provides information on **exemplar PC CDS applications that collect or use data on patient preferences**, along with a **high-level characterization of relevant standards** for representing patient preferences and potential gaps in coverage. The report also provides **nine recommendations** to advance standardized patient preference data for PC CDS, which include creating implementation guidance for developers and implementers, since patient preferences can be represented using one or more standards; identifying requirements for information systems to allow patients to continuously update their preferences, given that patient preferences change over time; and conducting pilot/demonstration projects in areas that are already “primed” to collect patient preference data, such as palliative care.

How You Can Use This Resource:

This report serves as a valuable resource on the data standards available for collecting and using patient preference data to guide PC CDS.



Researchers can use this report’s findings to guide future research on optimizing the collection of patient preferences, such as where they should be incorporated into clinical workflows, data capture, and decision making.



Developers can use this report to review existing relevant data standards for representing patient preferences and leverage them in the development of new PC CDS tools.



3 Prioritizing Patient Preferences for Standardization to Support PC CDS⁶

PC CDS Opportunity. PC CDS tools are more impactful when they produce clinical recommendations that incorporate and account for patients' preferences. However, if patient preference information is collected in electronic health records (EHRs), it is typically documented as **unstructured text data** in clinical notes. This makes it difficult for both clinicians and digital health tools act upon patient preference information, or to share this information across healthcare settings.

How the CDSiC Addressed the Opportunity. Standardized, structured encoding of patient preference information will allow these data to be used by and shared across various systems, including EHR systems and PC CDS tools used by both clinicians and patients. In response, the CDSiC conducted a multistakeholder roundtable discussion, including patients, to **identify which patient preference concepts should be prioritized for standardization**. The CDSiC leveraged the six domains of patient preferences outlined in the CDSiC's Taxonomy of Patient Preferences (described above) as the organizing framework for the discussion. Participants identified a range of **patient preference types that should be prioritized in the short term**, such as the patient's preferred language and mode of communication with their care team, and in the **long term**, such as the patient's preferences related to a disease-specific treatment or intervention. The roundtable also yielded information on future directions for this work, including conducting further research to advance disease-specific validated preference solicitation measures and their adoption, and to understand how to make the standard capture of dynamic patient preference information more feasible for patients, clinicians, and health systems alike.

How You Can Use This Resource:

This report provides critical insights into which patient preference information should be prioritized for standardization. By leveraging this information, stakeholders can advance the incorporation of these data into PC CDS tools, enhancing their use for patient-centered care and shared decision making.



Healthcare systems and clinicians can use this report's findings to understand what types of patient preference information are most important to capture from the patient perspective, which can inform their efforts to capture this valuable data.



Developers can use this product to guide future efforts to standardize patient preference data.

4 Patient Preference Measurement Tools for PC CDS Inventory Report and Spreadsheet^{7,8}

PC CDS Opportunity. Considering patient preferences in clinical care increases the focus on delivering patient-centered care and empowers patients to participate in their healthcare decisions. However, methods for collecting patient preferences vary, and there are no established best practices or tools for collecting patient preferences relevant for PC CDS. **Validated instruments to systematically collect patient preferences** are vital to enhance the capabilities of PC CDS. Consistent, standardized patient preferences data collection increases the generalizability across patient populations and settings and ensures patient-preference data is usable across clinicians and healthcare systems.

How the CDSiC Addressed the Opportunity. Building on the Taxonomy of Patient Preferences (described above), the CDSiC conducted an environmental scan and supplemental review of peer-reviewed and grey literature to develop a patient preferences measurement tool inventory spreadsheet and report. The inventory identifies **43 unique measurement tools and instruments** used to elicit patient preferences and provides key characteristics of each tool, including questionnaire delivery methods (e.g., online, phone, paper, face-to-face), extent of adoption in healthcare (i.e., under development, pilot-tested, used in a clinic/health system, commonly used), use population, condition/disease context (i.e., if tailored to a specific condition), clinical setting, reliability, and validity. This **filterable and sortable spreadsheet** allows users to identify which patient preference measurement tools exist to fit their needs. The accompanying summary report provides key measurement considerations for using the inventory to select PC CDS measurement tools. To conclude the report, the CDSiC describes gaps and future directions for measuring patient preferences for PC CDS. These materials enable users to choose the most effective tools to capture and incorporate patient preferences in PC CDS.

How You Can Use This Resource:

The Inventory of Patient Preferences presented in this spreadsheet and report describes patient preference measurement tools that can be used for a variety of purposes related to PC CDS. Appropriate measurement of patient preferences can improve integration of this information into clinical workflows and increase patient participation in their care and decision making.



Healthcare systems and clinicians can use this inventory and report in developing workflows to capture patient preference information and configure PC CDS to support individualized care informed by these preferences.



Researchers can use this inventory to identify appropriate data collection tools for research projects and understand where there may be gap areas and a need to develop and validate new tools for collecting valid information related to patient preferences.

5 Capturing Patient Preferences for Patient-Centered Clinical Decision Support Within Patient Lifeflows and Clinical Workflows⁹

PC CDS Opportunity. Integrating patient preferences into PC CDS is a key method of ensuring healthcare decisions align with patients’ goals and priorities. However, our limited understanding of how patient preferences data are collected and used in **patient lifeflows** (activities both within and outside of healthcare encounters that impact an individual’s health) and **clinical workflows** (the series of steps required to perform a specific clinical activity) limits health systems’ ability to harness these data for PC CDS.

How the CDSiC Addressed the Opportunity. The CDSiC conducted a literature review and nine key informant interviews with patient advocates, clinicians, and researchers to develop this report, which documents how PC CDS interventions impact care team workflows and patient lifeflows during, between, and outside of healthcare encounters. To illustrate these findings, the report includes **four swimlane diagrams**—tools for representing healthcare-related workflows—each focused on a unique clinical scenario. The diagrams visualize when and how preferences are collected within each scenario, highlighting the central role patients and their caregivers play in this process. It also offers **critical guidance on optimizing the collection and use of this data to reduce burdens on both patients and clinicians**, which includes gathering preferences that are most important to patients’ care, using a multipronged approach to collect preferences from patients, and ensuring patient preference data are accessible to clinicians—for instance, creating a standardized space for recording preference information. Finally, the report shares **short- and long-term opportunities for incorporating patient preferences into PC CDS**. Short-term opportunities include promoting the importance of including patient preferences in PC CDS tools and educating clinical staff to better recognize and accommodate varied patient preferences, while long-term opportunities include exploring processes that capture changes in patient preferences over time, as well as prioritizing the implementation of robust tools for gathering patient preferences for use in clinical care.



As a followup to the initial report, the CDSiC developed a **Topic Highlight** on incorporating patient preferences into PC CDS. This digestible resource, designed for patient and caregiver audiences, shares key information on methods for collecting patient preferences and the value of this data. The Topic Highlight also features **three new, streamlined patient journey maps**, which were adapted from the full report’s swimlane diagrams and validated by four patient representatives. These diagrams center around the patient’s interactions with PC CDS technology, each highlighting the different actions the patient may take during the collection of patient preferences in a unique clinical scenario. The Topic Highlight serves as a valuable introduction to the collection and use of this key patient-provided information.

How You Can Use This Resource:

The report and Topic Highlight provide valuable insights into how patient preferences can efficiently and effectively be incorporated into clinical decision making through PC CDS.



Healthcare systems and clinicians can use this taxonomy to develop workflows to adequately capture patient preference information.



Patients, caregivers, and patient advocates can use this product to better understand when and how patient preference information is collected during their healthcare journey.



Developers can use this product to identify opportunities to strengthen the collection of patient preferences using PC CDS.

6 Integration of Patient-Centered Clinical Decision Support Into Shared Decision Making¹⁰

PC CDS Opportunity. Shared decision making (SDM) is a key method of providing patient-centered care, since it is an inherently collaborative process that brings together patient preferences and clinician guidance. SDM helps empower patients to monitor their own health, thus promoting patient autonomy, limiting practice variation, and ensuring that care decisions reflect patient preferences. Despite the known value of SDM, there are **gaps in knowledge around using PC CDS to support the SDM process**. By integrating patient-contributed data and PC CDS into SDM, patients can feel more informed and empowered to collaborate and participate in shared decision making with their care teams.

How the CDSiC Addressed the Opportunity. The CDSiC sought to fill this knowledge gap by developing a PC CDS-SDM framework that features opportunities for PC CDS to enhance SDM. This framework was developed by conducting a targeted literature search of peer-reviewed and grey literature to identify relevant models of SDM, literature relevant to PC CDS and SDM, and examples of PC CDS tools that may facilitate SDM. The CDSiC then selected a conceptual model of SDM to guide the development of the PC CDS-SDM framework, which was validated and improved through qualitative interviews with experts. This framework integrates three phases of SDM—**team talk, option talk, and decision talk**—with three elements of PC CDS—**knowledge, data, and delivery**. The report concludes by highlighting areas for future work to effectively incorporate PC CDS into SDM. This report addressed a knowledge gap by describing how PC CDS can support patients' involvement in SDM.

How You Can Use This Resource:

The framework presented in this report demonstrates the potential for PC CDS to facilitate SDM. Patient preferences and other patient-specific information can be captured and used at the point of care to enhance SDM and collaboration.



Patients and patient advocates can use this report to understand how trustworthy PC CDS can support communication and collaboration with their clinical care teams.



Healthcare systems and clinicians can reference these findings to enhance SDM at their organizations and better leverage PC CDS to empower patients to be more involved in decision making with their care teams.



Developers can use this report to understand how to design and develop PC CDS to support SDM.

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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