

# Patient-Centered Clinical Decision Support—Where Are We and Where to Next?

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**Abstract.** Patient-centered clinical decision support (PC CDS) includes digital health tools that support patients, caregivers, and care teams in healthcare decisions that incorporate patient-centered factors related to four components: knowledge, data, delivery, and use. This paper explores the current state of each factor and how each promotes patient-centeredness in healthcare. We conducted a literature review, reviewing 175 peer-reviewed and grey literature, and eighteen key informant interviews. Findings show a need for more research on how to incorporate patient input into the guideline selection and prioritization for PC CDS, development and implementation of PC CDS tools, technical challenges for capturing patient contributed data, and optimizing PC CDS across various settings to meet patient and caregiver needs. While progress is being made in each of the four components of PC CDS, critical gaps remain.

**Keywords.** clinical decision support, patient-centered outcomes, patient-contributed data

## 1. Introduction

Patient-centered clinical decision support (PC CDS) provides novel ways to ensure patients, caregivers, and care teams have patient-specific, evidence-based clinical guidance to inform healthcare decision-making. PC CDS that incorporates patient-generated health data (PGHD) or other patient-centered data (e.g., patient preferences and social determinants of health [SDOH]) enhances patient and clinician decision-making by providing a fuller picture of a patient's needs, preferences, health, and social risk factors. PC CDS will have the most impact when these data can be integrated into electronic health records (EHRs) and other digital health technologies to support patient engagement—to produce clinical recommendations that account for unique patient needs and preferences.

Since 2016, the Agency for Healthcare Research and Quality (AHRQ) has been advancing PC CDS through a dedicated program of activities [1]. Through PC CDS, AHRQ seeks to accelerate the movement of evidence from patient-centered outcomes research (PCOR) into clinical practice and endeavors to make PC CDS more shareable, standards-based, and publicly available.

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This paper explores the emergence of PC CDS tools that significantly incorporate patient-centered factors related to knowledge, data, delivery, and use [2]. We leverage the previously established definition of PC CDS and discuss each of the four components, their current state of maturity, and relevance to supporting the quintuple aims of improving population health, enhancing patients' care experience, reducing costs, reducing burnout among healthcare workers, and advancing health equity [3].

## 2. Methods

We used two methods: 1) a literature review of peer-reviewed and gray literature on PC CDS; and 2) key informant interviews with PC CDS stakeholders. The literature review included a search of peer-reviewed literature using the academic database PubMed and gray literature using Google search and Google scholar to identify literature in the past 10 years that capture the current state of PC CDS. In total, we included 139 articles from our published literature and 36 resources from our grey literature review (n=175). We conducted eighteen key informant interviews to gather additional perspectives on the current state of PC CDS and areas for future PC CDS research and initiatives.

## 3. Results

PC CDS includes four components with important patient-focused elements: 1) a knowledge base that is evidence-based and derived from patient-centered outcomes research (PCOR) evidence; 2) patient data including PGHD, patient-reported outcomes (PROs), patient preferences, and SDOH data; 3) delivery of information to the patient or their caregivers by mechanisms such as patient apps, patient portals, chatbots, or conversational agents; and 4) use of the CDS to support the involvement of the patient and/or their caregivers in the joint decision-making process with their clinicians [2].

### 3.1. Knowledge Base

Clinicians and patients need evidence to make informed decisions about patient care. Ideally, the evidence base driving patient centered CDS is derived from PCOR or comparative effectiveness research (CER) that includes patients throughout the research process so that the research reflects the needs, preferences, and outcomes that are meaningful to patients [4]. Evidence-based clinical practice guidelines that involve patient and patient representatives in the development process provide the opportunity for the patient voice to be incorporated into assessing guideline priorities, informing how recommendations interact with patient preferences, encouraging holistic approaches to care, and more [5,6]. We found no studies of PC CDS that discussed how evidence-based guidelines were assessed and prioritized for inclusion in CDS, such as whether patient input was sought in this process. Patient involvement as partners in knowledge generation is needed if we are to realize the vision of true patient-centered care.

### 3.2. Data

Patients and their caregivers contribute numerous types of health data, both within and outside the clinical setting, such as PROs, PGHD, SDOH, genetic data, and patient

preferences data. These data can be solicited by the healthcare team or be unsolicited (i.e., data individuals collect on their own to understand and manage their own health). These data can also come from a variety of sources, such as remote monitoring devices (e.g., wearables, implants, or mobile health apps); questionnaires or prompts (e.g., health histories, patient-reported outcome measures); and previous clinical settings [7, 8].

Within the diverse sources of patient-provided information, PROs have seen more standardization to ontologies like LOINC [9]. There are several implementation guides on the integration of PRO data into EHRs [10]. Other data sources with varying degrees of standardization, include SDOH [11] and genetic data [12]. There are early efforts to standardize PGHD, develop standardized measures, such as step counts across platforms, and mapping measures to vocabulary standards [13]. Patient preference data also provide insight into what treatment or management options may be best for patients based on their desired goals and outcomes. PC CDS informed by patient provided data including SDOH supports more equitable care at both the patient and population level.

### 3.3. *Delivery*

PC CDS can be delivered in various technical modalities and settings. We identified studies in which PC CDS is delivered through digital apps, websites, patient portals, short message systems (SMS)/text, as well as EHRs with most studies indicating PC CDS being used via mobile apps (n=27). We found that these modalities reflect a critical need to align PC CDS modalities with patients' daily lives [2].

PC CDS interventions are used outside the clinical setting in the patient's home or community and within the clinical setting. Most studies (n=46) cited the patient's home or community as the setting for PC CDS use. The setting for the PC CDS intervention can reflect the specific need for PC CDS and how PC CDS integrates into patients' daily lives. The multitude of settings for PC CDS use aligns with national shifts in health care delivery over the past decade—from care concentrated in acute settings shifting to ambulatory settings—and a further shift from ambulatory settings to care in the home and community. PC CDS tools that are well designed and implemented in a way that accounts for patient life flows can provide clinicians and care teams with relevant and timely data and potentially reduce healthcare work burden and support more efficient care.

### 3.4. *Use*

PC CDS is intended to be (1) patient-centered and (2) support decision-making. Most people want to be involved in decisions about their health care [14]. The ultimate vision of PC CDS efforts is to support dialogue between patient and clinician that fosters agreement between the patient and clinician. This process is informed by research on patient decision-making and supported by PC CDS tools that help bridge the divide between patients and clinicians, by facilitating patient-clinician information exchange that ensures mutually acceptable decisions exploring and comparing benefits, harms, and risks. Incorporating patient needs and context into planning care can improve patient healthcare outcomes [15]. Almost two-thirds of PC CDS interventions included in our study were designed with components for patient and clinician interaction (n=55), while about one-third were designed for only patient interaction (n=34).

## 4. Discussion

Through our research, we found key areas for future investigation across the four components of PC CDS.

*Knowledge Base.* More research is needed to determine the best methods for capturing patient input in PC CDS development including the critical stages of guideline development, prioritization, and selection of evidence for PC CDS development and implementation.

*Data.* The inclusion of patient preference data is still nascent and current terminology standards support the limited capture of patient preference data and patient health goals within the EHR [16,17]. Across all patient-contributed data sources there remain numerous technical challenges in the capture, exchange and integration of patient provided health data into PC CDS tools [18].

*Delivery.* Research is needed to determine optimum methods and technical modalities by which PC CDS should be delivered and how these tools integrate into patients' lives.

*Use.* There are unanswered questions regarding how to engage patients using PC CDS technology. While studies point to design features that support more user-friendly interactions with PC CDS tools, less is understood about which strategies and approaches are most effective for creating and maintaining patient engagement (e.g., longitudinal tracking capabilities, [19] frequency of notifications [20], ability to engage directly with the provider [21]).

## 5. Conclusions

PC CDS offers new and innovative ways to support evidence-based care that reflects the values and preferences of patients and their caregivers. While progress is being made in each of the four components of PC CDS, critical gaps remain. More research is needed in each of these four areas of PC CDS to further its implementation and use in support of national healthcare priorities.

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