Stakeholder Center: Measuring Patient Experience of Patient-Centered Clinical Decision Support

Agency for Healthcare Research and Quality
5600 Fishers Lane
Rockville, MD 20857
www.ahrq.gov
Contract No: 75Q80120D00018

Prepared by:
Megan Skillman, MPA
Priyanka J. Desai, PhD, MSPH
Caroline Peterson, MPH
Abigail Aronoff, MPH
Prashila M. Dullabh, MD, FAMIA

AHRQ Publication No. 25-0082
September 2025

AHRQ Agency for Healthcare Research and Quality

Clinical Decision Support Innovation Collaborative

PURPOSE

The Clinical Decision Support Innovation Collaborative (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. This report presents a bank of survey questions that are designed to probe patient experiences with PC CDS, which may be embedded as a whole or in part into an existing national survey. All qualitative research activities conducted by the CDSiC are reviewed by the NORC at the University of Chicago Institutional Review Board (FWA00000142).

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.

PUBLIC DOMAIN NOTICE

SUGGESTED CITATION

Skillman M, Desai P, Peterson C, Aronoff A, Dullabh P. Measuring Patient Experience of Patient-Centered Clinical Decision Support. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 25-0082. Rockville, MD: Agency for Healthcare Research and Quality; September 2025.

Table of Contents

Executive Summary

Introduction

Patient-centered clinical decision support (PC CDS) is a subset of CDS that includes digital technologies designed to give patients, caregivers, and clinicians evidence-based, patient-specific clinical guidance to inform care decisions. PC CDS encompasses a spectrum of decision making tools that significantly incorporate patient-centered factors related to knowledge, data, delivery, and use. Despite the significant link between patient experience and healthcare quality, few measures adequately capture this domain in relation to PC CDS. Currently, no nationally representative survey data of clinical and patient-focused outcomes exists—including measures of patient experience—related to the use of PC CDS. To address this, the Clinical Decision Support Innovation Collaborative (CDSiC) identified key domains that can be used to measure patient experience of PC CDS and created a bank of patient-informed survey questions to support the large-scale assessment of patients' experiences with PC CDS across care settings and geographical locations. These survey questions are intended to be placed within a nationally representative survey (e.g., Consumer Assessment of Healthcare Providers and Systems [CAHPS]) to support the standardized collection of patient-centered data and advance the field of PC CDS measurement.

Methods

We conducted a targeted literature search focused on measures of patient experience with health information technology (IT) and measures of patient experience with healthcare. We screened 549 sources and included 104 sources in the analysis, including 37 survey instruments. Information on patient experience was abstracted and synthesized using patient experience domains defined by the Agency for Healthcare Research and Quality (AHRQ) in CAHPS.

Next, we conducted eight virtual interviews across 10 key informants, including patient advocates, health system representatives, a federal representative, and CDS developers and researchers to refine and prioritize a list of patient experience domains. We produced detailed notes and used rapid qualitative content analysis to identify key themes and concepts. Additionally, we incorporated relevant feedback from the AHRQ-supported CAHPS Consortium, the entity responsible for approving all CAHPS surveys, as well as CDSiC patient advocates and PC CDS experts. Building from the literature and key informant interviews, we iteratively developed initial draft survey questions and answer options. We then conducted seven virtual cognitive testing sessions with seven patient advocates. To create the final question bank for field-testing, we revised the survey questions based on cognitive testing findings and consultation with a survey methodologist.

Findings

Below we describe findings from the literature review and key informant interviews, organized by patient experience domain in order of highest to lowest priority, as assessed across key informants.

Self-management Support. PC CDS can help patients track their condition, interpreting test results over time, and providing personalized information related to condition management. Key informants identified this domain as highly important to consider when assessing patient experience with PC CDS (6 of 10 key informants). In the literature, a few instruments probe patients' experiences managing their health using health IT (e.g., the Health Information National Trends Survey [HINTS]). Other surveys assess the self-management support capabilities of patient portals.

Access to Healthcare. PC CDS can alert patients to contact their clinicians based on personalized health information, provide patients with reminders of upcoming healthcare visits, and facilitate asynchronous communication with care teams. A majority of key informants (6 of 10) stressed access as an important domain in the context of patients' journeys navigating the healthcare system. Several instruments probe patient experience with access to care generally (e.g., CAHPS Clinician & Group Survey),[1] and some assess patient access to care in the context of using technology (e.g., CAHPS Health Information Technology Item Set).

Communication Between Patients and Clinicians. PC CDS can help patients share their health information and healthcare preferences with clinicians between appointments and also suggest questions to ask providers during appointments. Five of 10 key informants identified this domain as highly important). A small number of surveys assess communication within the context of health IT or PC CDS, focusing on messaging clinicians between appointments or sharing health information with providers (e.g., HINTS, CAHPS Health Information Technology Item Set).

Shared Decision Making (SDM). PC CDS can collect information about patients' goals, values, and preferences; equip patients with information about their options; and provide tailored recommendations based on research findings and patient-specific information. Five of 10 key informants identified this area as a priority domain. While not specific to digital health tools, several survey instruments assess whether SDM takes place during patient-clinician interactions (e.g., CAHPS Shared Decision Making Supplement and the SDM-Q-9). Some tools measure patient preferences related to how they make healthcare decisions (e.g., "I prefer that my doctor and I share responsibility for which treatment is best").

Getting Information. Getting the right information at the right time is a foundational goal of PC CDS. Patient-facing PC CDS directly provides patients information central to their decision making, such as personalized recommendations based on individual patient data. Only a few key informants felt that getting information should be prioritized for measurement (3 of 10 key informants); however, this may be due to overlap with other domains. Several survey instruments probe aspects of information-sharing from clinician to patient (e.g., assessing the timeliness of clinician response, rating clinician information-sharing from poor to excellent). There is more limited measurement, however, of how digital tools support providing information to patients.

Satisfaction with PC CDS Tool(s). Within the context of PC CDS, patient satisfaction with a PC CDS tool may speak to (1) how a patient feels about their interaction with a PC CDS tool (e.g., ease of use, technical difficulties) and (2) how a patient feels about the role of PC CDS in their experience with care (e.g., preferences). Though few key informants selected this domain as the highest priority for measurement (3 of 10 key informants), they generally viewed satisfaction as a foundational PC CDS domain. Several studies assessed patients' satisfaction with health interventions, including telemedicine and CDS tools. Similarly, standardized instruments, such as the Short Assessment of Patient Satisfaction, use Likert scale questions to gauge patients' satisfaction with their overall care. Measurement tools like the Post Study System Usability Questionnaire measure users' perceived satisfaction with a website, software, or digital tool.

Usability. Usability encompasses IT users' perceptions about a tool's ease of use, effectiveness, and efficiency, and the consistency of its interface. Usability often intersects with measures of satisfaction, because the functionality of a health IT tool can significantly impact users' satisfaction with it. Only a few key informants indicated that ease of using PC CDS was a critical domain to measure about patient experience (3 of 10 key informants). Multiple survey instruments assess the perceived usability of digital tools, including measurement instruments like the Mobile App Rating Scale, System Usability Scale, Health Information Technology Usability Evaluation Scale,[2] and mHealth App Usability Questionnaire (MAUQ).

Care Coordination. PC CDS can support information exchange among patients, caregivers, and their care teams (e.g., sharing patient preference information and test results from multiple providers via a single online portal). Few key informants prioritized this domain (2 of 10 key informants) and instead prioritized related domains, such as communication with clinicians and SDM. Several surveys assess the capabilities of health IT tools to enhance care coordination (e.g., MAUQ, HINTS, the Mobile Application Rating Scale: User Version). A few surveys ask broad questions about care coordination (e.g., whether healthcare is "organized in a way that works for [the patient]").

Courtesy, Respect, and Empathy. PC CDS can facilitate courteous, respectful, and empathetic care by helping patients share preferences with their healthcare providers, for example, their beliefs or preferred language. Key informants recognized that courtesy, respect, and empathy are vitally important aspects of healthcare but did not prioritize this domain, indicating that this domain is largely determined through person-to-person interactions and would be difficult to measure in relation to PC CDS. Although no surveys identified in the literature review assess respect and courtesy in the context of using health IT or PC CDS tools, many assess patient experiences interacting person-to-person with healthcare providers (e.g., CAHPS, Hospital CAHPS [HCAHPS], National Health Service General Practitioner Patient Survey).

Culturally Appropriate Care. PC CDS can provide decision support that reflects a patient's preferred language and cultural beliefs. While recognizing the importance of culturally appropriate care, key informants did not prioritize this domain and noted limited measures of and opportunities to examine cultural competence as it relates to PC CDS. Proving this point, there was a dearth of survey instruments covering this domain. Only one questionnaire asked questions about perceptions of clinicians' respect for a patient's religious, spiritual, or cultural beliefs.

Patient Experience Survey Questions and Considerations

We identified high-priority patient experience domains from the literature and through discussions with key informants, which shaped a bank of survey questions focused on patient experience with PC CDS. The survey questions are intended to fill a gap in the landscape of PC CDS measurement and can be placed within a nationally representative survey (e.g., CAHPS) to support the standardized collection of patient-centered data and advance the field of PC CDS measurement.

The final survey bank includes 41 questions in total, including 9 screening questions that seek to understand the respondent's use of PC CDS as well as 18 questions to probe patient experience with PC CDS, which are organized by high-priority domains: self-management support, communication with clinicians, SDM, getting information, and usability. In addition, we include 12 questions about cross-cutting outcomes of PC CDS, as well as a question on patients' willingness to continue to use PC CDS. The bank concludes with a question on willingness to try PC CDS in the future and a question that asks about patients' willingness to try AI-supported healthcare tools in the future. The questions in the bank are not intended to be fielded as a full survey instrument, but instead are designed as a set of ready-made questions to choose from to embed in an existing national assessment.

Qualitative discussions raised methodological considerations related to measuring patient experience with PC CDS using survey instruments. These include defining PC CDS clearly for survey respondents; stratifying survey question results by clinical context to meaningfully interpret survey data; assessing patient experience with PC CDS as well as patients' willingness to interact with PC CDS tools; and considering the increasing use of artificial intelligence (AI)-supported PC CDS.

Future Directions

Assessing patient experience with PC CDS at a national level will create additional opportunities for meaningful measurement. Anticipating the greater uptake of PC CDS tools in the field, it may be appropriate to introduce questions that assess change over time. Additionally, while uptake of AI-based PC CDS tools may currently be less common, it will be important to ask survey questions about patient experience with AI-supported PC CDS in the future.

Due to the scope of this effort, we did not develop a full-fledged survey instrument. Further work to validate the survey questions is needed, including validating with patients who have different levels of exposure to PC CDS, patients who may be using PC CDS within different clinical contexts, and patients who represent an array of subpopulations and characteristics. Further work is also needed to identify appropriate instrument(s) in which to embed questions.

As the field of PC CDS develops, these questions can be further adapted and refined to ensure they remain relevant and can inform actionable change in response to new and emerging PC CDS technologies.

1. Introduction

Patient-centered clinical decision support (PC CDS) is a subset of CDS that includes digital technologies designed to give patients, caregivers, and clinicians evidence-based, patient-specific clinical guidance to inform care decisions.[3] PC CDS encompasses a spectrum of decision making tools that significantly incorporate patient-centered factors related to knowledge, data, delivery, and use.[4]

- **Knowledge** refers to the use of comparative effectiveness research or patient-centered outcomes research (PCOR) findings.
- **Data** focuses on the incorporation of patient-generated health data, patient preferences, and other patient-specific information.
- **Delivery** refers to directly engaging patients and/or caregivers across different settings.
- **Use** focuses on facilitating bi-directional information exchange in support of patient-centered care, including shared decision making (SDM).

As PC CDS evolves, there are increasing opportunities to implement patient-facing PC CDS. Measurement and monitoring of PC CDS are integral to advancing patient-centeredness by (1) ensuring alignment with clinical workflows and patients' lives and (2) better tailoring tools for patients' care to their specific needs and goals.

Previously, the Clinical Decision Support Innovation Collaborative (CDSiC) explored available measures of PC CDS performance, including patient-focused outcome measures.[5,6] In conducting this work, the CDSiC determined that it is integral to understand patient experience with PC CDS and incorporate those perspectives into its development and deployment. The Agency for Healthcare Research and Quality (AHRQ) defines patient experience as "encompass[ing] the range of interactions that patients have with the healthcare system, including their care from health plans, and from doctors, nurses, and staff in hospitals, physician practices, and other healthcare facilities."[7] Despite the significant link between patient experience and healthcare quality,[8,9] few measures adequately capture this domain in relation to PC CDS, particularly in areas related to care coordination, patient activation, communication quality, and self-management.[6]

The lack of robust patient experience measures in PC CDS limits the collection of generalizable data supporting its effectiveness. One way to address this gap is to gather nationally representative data on patient experience with PC CDS. Currently, there exists no nationally representative survey data of clinical and patient-focused outcomes—including measures of patient experience—related to the use of PC CDS.[4,6] Therefore, the CDSiC created a bank of patient-informed survey questions to support the large-scale assessment of patients' perspectives on and experiences with PC CDS across care settings and geographical locations. The objectives of this work were to:

- Identify key domains that can be used to measure patient experience of PC CDS.
- Prioritize key domains of patient experience measurement of PC CDS based on patient perspectives.

- Identify the challenges and opportunities with measuring the prioritized domains of patient experience measurement in PC CDS.

These survey questions are intended to be placed within a nationally representative survey (e.g., Consumer Assessment of Healthcare Providers and Systems [CAHPS], Health Information National Trends Survey [HINTS]) to support the standardized collection of patient-centered data and advance the field of PC CDS measurement. If fielded longitudinally, the questions could reveal changes in patient experiences and perceptions over time with the emergence of new PC CDS technologies, further informing other areas of work needed to advance PC CDS.

1.1. Roadmap of the Report

This report is organized in the following sections:

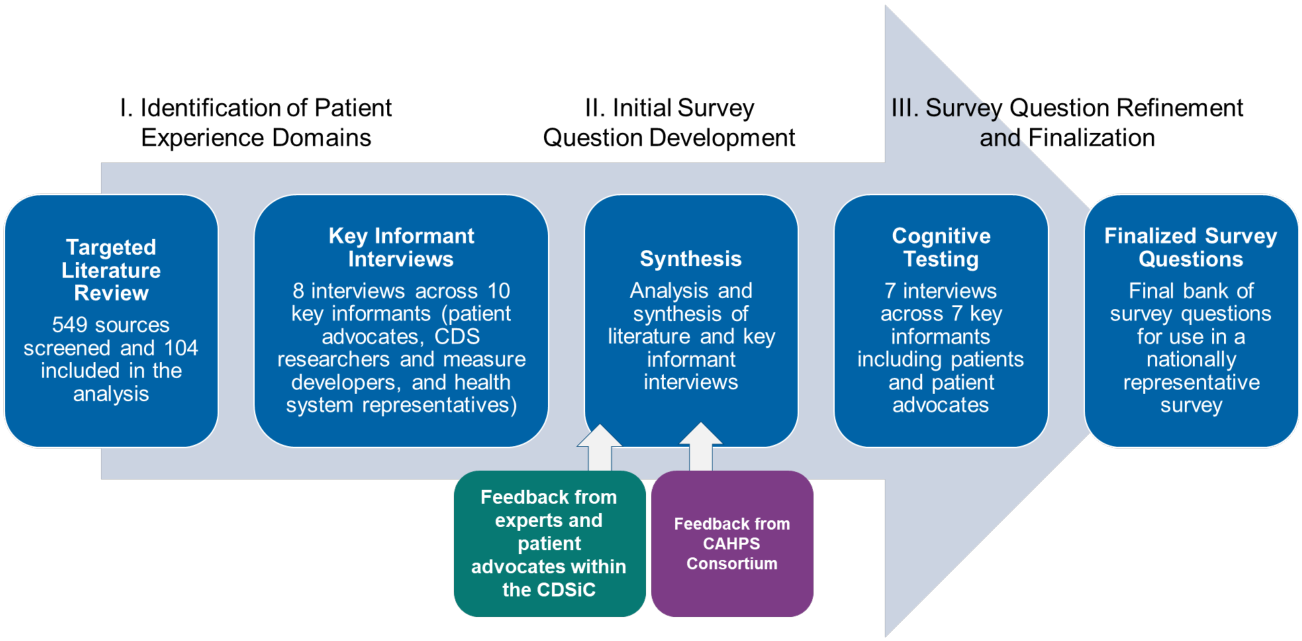
- **Section 2** describes the methods used to develop the survey questions, which included a targeted literature search, key informant interviews, and cognitive testing.
- **Section 3** presents findings of the targeted literature search and key informant interviews, including priority patient experience domains and other considerations related to survey question development.
- **Section 4** includes the final bank of survey questions, including a description of insights generated during cognitive testing.
- **Section 5** presents a discussion highlighting future opportunities to advance patient experience measurement with PC CDS.
- **Section 6** provides a brief conclusion summarizing the key findings.

The intended audiences for this report and accompanying bank of survey questions are CDS researchers and survey developers interested in patient-centered measurement across the PC CDS lifecycle.

2. Methods

We conducted a literature review and series of key informant interviews to inform the development of an initial survey question bank. Next, we consulted with a NORC at the University of Chicago (NORC) survey methodologist and conducted cognitive testing sessions with patient advocates. We revised and finalized the questions in response to this feedback. See **Exhibit 1** for an illustration of our methods for survey question development.

Exhibit 1. Methods for Survey Question Development



2.1. Identification of Patient Experience Domains

Targeted Literature Review. We conducted a targeted literature search focused on two key topics: (1) measures of patient experience with health information technology (IT) and (2) measures of patient experience with healthcare. The literature search included sources published in English from 2018 to 2024 and included peer-reviewed articles identified through PubMed, as well as grey literature from federal agency and professional association websites (**Appendix A**). Through the literature, we also identified a number of patient experience survey instruments and patient experience measures. To identify relevant sources, we conducted title and abstract screening and then a full-text review if sources met inclusion criteria. In total, we screened 549 sources and included 104 sources in the analysis (50 peer-reviewed sources, 17 grey literature sources, and 37 survey instruments).

Within the peer-reviewed literature, we identified 23 studies that used surveys to evaluate patient experience with care and patient experience with health IT, shown in **Table B1** in **Appendix B**. The remaining studies described formative components of patient experience and satisfaction, as well as patient experience survey development methodologies. The 37 survey instruments include some validated instruments assessing patient experience with care and health IT and nationally representative patient experience surveys (e.g., CAHPS, HINTS) (**Table B2** in **Appendix B**).

Abstraction and Analysis. During the full-text review, we abstracted information on patient experience domains and measures, including specific questions from instruments designed to assess patient experience. We synthesized and classified the extracted information in an Excel matrix,[10] initially using patient experience domains articulated by AHRQ in CAHPS: culturally appropriate care, care coordination, courtesy and respect, access to care, communication with clinicians, getting information, SDM, and self-management support.[7] As we continued to explore the literature, we refined these domains and added satisfaction with PC CDS tool(s) and technology usability.

Key Informant Interviews. We conducted eight 60-minute interviews across 10 key informants (4 patient advocates, 2 health system representatives, 1 federal representative, and 3 CDS developers/researchers) from January through March 2025.* The goals of these interviews were to refine our list of patient experience domains identified from the literature, identify additional domains, and learn about parallel efforts to assess patient experience with digital health technologies. We conducted and recorded all interviews via Zoom with participants' consent. An experienced CDSiC team facilitator led each interview, while another team member produced detailed notes. We used rapid qualitative content analysis to identify key themes and concepts and organized key informant feedback by patient experience domains defined by CAHPS.[7,10,11]

2.2. Initial Survey Question Development

Building from the literature and key informant interviews, we developed a bank of initial survey questions and answer options. To begin, we drafted an extensive series of survey questions comprised of (1) screening questions that assessed how the respondent used PC CDS and (2) survey questions that corresponded with the major patient experience domains identified in the literature (access to care, care coordination, communication with clinicians, courtesy and respect, culturally appropriate care, getting information, SDM, self-management support, usability of PC CDS, and satisfaction with PC CDS tools). To the extent possible, we modeled survey questions and answer options from existing survey instruments, then adapted question or answer options to be specific to patient experience with PC CDS.

We iterated upon the survey question bank based on emerging themes and prioritized patient experience domains from the key informant interviews. Additionally, we incorporated relevant feedback (e.g., terminology suggestions, balancing broad questions with specific questions) from the CAHPS Consortium, the responsible entity for approving all CAHPS surveys, as well as from CDSiC patient advocates and PC CDS experts. With support from an experienced NORC survey methodologist, we further refined the survey questions to reduce duplication and clarify structure and phrasing, resulting in a core set of 30 initial survey questions.

2.3. Survey Question Refinement and Finalization

We interviewed patient advocates to cognitive test the survey questions and the answer options, then further refined the survey question bank. From April to May 2025, we conducted seven virtual, 60-minute cognitive testing sessions over Zoom with seven patient advocates. We recorded conversations with participants' consent and took detailed notes. During each session, a CDSiC team facilitator reviewed the survey questions with the patient advocate, who provided feedback on question comprehension, clarity, and potential gaps or improvements.

We implemented an iterative approach to question refinement based on cognitive testing, revising the questions based on initial feedback from the first three testers and then using the revised questions during sessions with the remaining four testers. As an additional measure, an experienced NORC survey methodologist reviewed the revised questions. The final question bank reflects the synthesized

---

* Two of the eight interviews included more than one key informant.

feedback of patient partners, including screening questions that assess how the respondent used PC CDS and questions mapped to patient experience domains prioritized by key informants.

3. Findings: Patient Experience Domains

In the following sections, we describe (1) findings on each patient experience domain and (2) cross-cutting PC CDS measurement considerations, both drawn from the literature review and key informant interviews.

3.1. Patient Experience Domains

Below, we describe findings organized by patient experience domain in order of highest to lowest priority as assessed across key informants: self-management support, access to care, communication with clinicians, SDM, getting information, satisfaction with PC CDS tool(s), usability, care coordination, courtesy and respect/empathy and caring, and culturally appropriate care. Each section summarizes the domain definition, key informant feedback on each domain, findings from the literature, and methodological considerations specific to each domain. Although each domain of patient experience has a specific definition and meaning, domain attributes may be interrelated, resulting in overlapping findings across multiple domains.

3.1.1. Self-management Support

Self-management support is a commitment to patient-centered care that includes "providing comprehensive patient education, creating a clinical team composed of clinicians and administrative staff with clearly defined roles and responsibilities, and using office systems to support followup contact and tracking of patients."[12] Self-management support also means involving patients in goal setting and decision making, providing tailored health education, and making referrals to relevant social services.[13] PC CDS can facilitate self-management support by helping patients track their condition (e.g., collecting and analyzing patient data), interpreting test results over time (e.g., generating charts or visuals), and providing personalized information related to condition management (e.g., medication options and tradeoffs).

Key informants identified self-management support as one of the most important domains to consider when assessing patient experience with PC CDS (6 of 10 key informants). They saw self-management support as an area where PC CDS can have a clear and important role. For example, they noted a role for PC CDS to support self-management using patient portals, which allow patients to request medication refills, send patients refill reminders, visualize trends in health data, and leverage artificial intelligence (AI) to receive personalized health information.

Findings in the Literature. In the literature, most survey instruments did not tend to ask questions about self-management support for a chronic condition and instead focused on questions about managing overall health and wellness. A few survey instruments ask questions about patients' experiences managing their health using health IT, specifically telehealth, patient portals, wearable devices, and a mobile health application (mHealth app). HINTS asks patients whether they used telehealth for managing a chronic condition, mental health, or substance abuse.[14] For example, HINTS probes the use of wearable devices and health or wellness apps on a tablet or smartphone, including whether patients are willing to or have shared data from wearables and apps with their clinician. The mHealth App Usability Questionnaire (MAUQ) assesses the efficacy of an mHealth app in supporting patients' health management through the following item: "The app helped me manage my health effectively."[15] Other surveys assess the self-management support capabilities of patient portals by asking about clarity of information, including information offered about medical tests and treatments[16,17] and whether the portal led the patient to do something to improve their health.[16,17,18]

Some survey instruments ask patients questions on managing their overall health and focus on process outcomes critical to self-management, such as receiving clear information from healthcare providers, having confidence in managing health generally and in following the instructions of a healthcare provider, and participating in goal setting with a healthcare provider.** The Clinician & Group CAHPS Adult Survey (version 3.0) and Interpersonal Processes of Care (IPC) Survey include questions that address self-management support, including whether patients can implement the recommended treatment, whether the healthcare provider asked about things that made it hard for the patient to take care of their health, provider communication (e.g., easy-to-understand medication instructions), goal setting, and whether providers discussed all medications the patient was taking.[19,20] The Organisation for Economic Cooperation and Development's (OECD's) Patient-Reported Indicator Surveys Patient Questionnaire (PaRIS) focuses broadly on a patient's ability to manage their health and well-being. Some questions focus on a patient's confidence managing their overall health, as well as questions focused on healthy behaviors (e.g., diet, physical activity levels) and communicating with providers about healthy behaviors or lifestyle changes.[21]

Measurement Considerations. Key informants discussed some potential challenges in assessing patient experience with PC CDS and self-management support. They noted that patient experience with PC CDS self-management support tools may vary given patients' different perceptions of self-management, as well as clinical context. Patients may define self-management success in different ways, such as independently managing aspects of their condition versus fully managing their condition(s). This may result in variation in how patients conceptualize self-management success using PC CDS and lead to inconsistent survey question interpretation. A survey question on self-management would ideally define self-management support as well as what success looks like. Key informants also noted that patients may think about PC CDS and self-management differently based on their clinical care needs and where they are in terms of their experience with their condition (i.e., initial diagnosis versus later years).

3.1.2. Access to Healthcare

Access to healthcare encompasses patients' ability to receive "personal health services to achieve the best health outcomes."[22] PC CDS can support access to care by alerting patients to contact their clinicians based on personalized health information (e.g., recommend an appointment based on test results), providing patients with reminders of upcoming healthcare visits, and facilitating asynchronous communication with care teams.

** While the 2024 National Health Interview Survey (NHIS) Questionnaire asks about chronic conditions, most questions focus on whether the respondent has been diagnosed with a chronic condition and whether they are taking medications or undergoing related treatments.

A majority of key informants (6 of 10) stressed access as an important domain in the context of patients’ journeys in navigating the healthcare system. They noted a range of factors that impact a patient’s ability to access care, some of which have a limited role in the context of PC CDS, such as insurance coverage, costs, ability to schedule appointments, and trust in the healthcare system.

Findings in the Literature. Several available instruments probe patient experience with access to care generally. For example, the CAHPS Clinician & Group Survey probes patient experiences related to getting timely appointments, care, and information.[23] We also identified survey tools that assess patient access to care in the context of using technology. Like the CAHPS Clinician & Group Survey, the CAHPS Health Information Technology Item Set includes questions that probe timeliness of access. Specifically, the questions assess patients’ ability to receive an appointment as soon as possible using email or a website and the timeliness of responses to emailed medical questions.[24] In addition, the mHealth App Usability Questionnaire includes a question that probes views on improvement in access to services related to the use of an app (“the app improved my access to healthcare services”).[15]

Measurement Considerations. When asked what types of questions may be relevant to patients’ experience with PC CDS and access to care, key informants recommended probing whether tools used patient-provided information to share appointment reminders at the patient’s preferred time and using their preferred method (e.g., phone call, patient portal messages).

3.1.3. Communication with Clinicians

Communication between patients and clinicians (i.e., healthcare providers) is most effective when it is respectful, trusting, and supportive; clear; personalized; and discussion-based (e.g., patients feel free to ask questions, clinicians actively listen).[25,26] PC CDS can support patient-clinician communication by helping patients share their specific health information and healthcare preferences with clinicians between appointments. In addition, PC CDS can have a role in preparing patients to have discussions with their healthcare provider(s) by suggesting relevant questions to ask during appointments that reflect the patient’s unique health status or preferences.

Key informants identified communication with clinicians as important to assessing patient experience with PC CDS (5 of 10 key informants). Multiple key informants emphasized that effective patient-clinician communication is a critical component of SDM, a best practice that makes care more collaborative and results in improved patient satisfaction and adherence to treatment, among other positive outcomes.[27] (See more on SDM in Section 3.1.4.) Additionally, key informants shared specific ways in which PC CDS can facilitate patient communication with clinicians, such as the use of a patient portal to access treatment plans between visits, having PC CDS spell out the next clinical steps or options for their care, enabling patients to share their healthcare preferences with healthcare providers, and interacting with AI-supported PC CDS to exchange messages with their clinician.

Findings in the Literature. A small number of surveys assess communication within the context of health IT or PC CDS, focusing on exchanging messages with clinicians between appointments, sharing health information with clinicians, and assessing how mHealth apps can create more touchpoints between patients and clinicians. For example, HINTS and the CAHPS Health Information Technology Item Set ask whether patients have used their patient portal to message their healthcare providers via email between appointments[14,28] and assess the timeliness of provider responses to messages[28] and whether patients have used the Internet to send a message to a healthcare provider or a healthcare provider's office or to view medical test results.[14] The MAUQ assesses the impact of PC CDS on communication with clinicians by asking how mHealth apps make communication more convenient; how mHealth apps provide more opportunities to communicate with healthcare providers; and patients' level of comfort communicating with their clinicians via mHealth apps.[15] Lastly, the Patient's Use of Computers (University of Missouri at Columbia) instrument features a series of questions gauging the respondent's interest in using a website to message their healthcare provider and share health information (e.g., data tracking diet, exercise, or health condition[s]).

A number of surveys ask general questions about the patient and clinician relationship. Survey questions vary from probing patient perceptions on whether clinicians shared clear information, whether clinicians took patient preferences into account, whether a patient felt comfortable asking questions of their clinician, or whether the clinician explained things to the patient's satisfaction.[29,30] For example, the CAHPS Clinician & Group Adult Visit Survey assesses patients' perceptions of whether their clinician listened carefully, explained things in an understandable way, showed respect for what the patient said, and spent enough time with the patient.[31]

Measurement Considerations. Key informants raised some contextual considerations that may affect the framing and specificity of survey questions about PC CDS and communication with clinicians. Patients tend to see clinicians whom they feel are good communicators and stop seeing clinicians they feel are poor communicators. Therefore, patients are likely to report high satisfaction on questions about communicating with clinicians. Consequently, scores for these questions may be inflated or biased by experiences that are not directly related to PC CDS (e.g., trusting relationships with providers). Ideally, survey questions about communication with clinicians would be specific to PC CDS and represent the full range of possible patient experiences in this domain.

In addition, perceptions of good communication with clinicians may depend on patient preferences. Key informants acknowledged that some PC CDS tools are designed to *limit* interactions between patients and clinicians (e.g., using AI to draft basic messages to patients to make communication more efficient). Patients with a strong preference to communicate directly with their clinician may be less likely or willing to use PC CDS. This could bias responses to questions in this domain. For example, key informants noted that patients may indicate poor experience with a PC CDS tool that functions as intended due to a preference for direct communication.

3.1.4. Shared Decision Making

Shared decision making is a "collaborative process in which patients and clinicians work together to make healthcare decisions informed by evidence, the care team's knowledge and experience, and the patient's values, goals, preferences, and circumstances."[32] PC CDS can facilitate shared decision making by collecting information about patients' goals, values, and preferences; equipping patients with information about their options; and subsequently providing tailored recommendations based on research findings and patient-specific information.[33]

Half of key informants identified this area as a priority domain when assessing patient experience with PC CDS (5 of 10 key informants). This was due to the role of PC CDS in supporting SDM, which they saw as a key method for improving patients’ interactions with their clinicians and, ultimately, improving health outcomes. However, key informants also noted that not all patients prefer to be actively involved in making healthcare decisions or that these preferences could be context-specific. Consequently, it would be important to understand patients’ general preferences for decision making to contextualize their experience.

Findings in the Literature. While not specific to digital health tools, several survey instruments assess whether SDM takes place during patient-clinician interactions. Both the CAHPS Shared Decision Making Supplement[34] and the SDM-Q-9[35] probe whether the patient and clinician discussed treatment options together, whether the clinician asked the patient what action was best for them, and whether the patient and clinician reached an agreement on how to proceed using either a Likert-type scale or a dichotomous Yes/No answer format.

In addition to these SDM-specific surveys, other tools measure patient preferences related to how they make healthcare decisions. For example, the Control Preferences Scale assesses patients’ preferred role in decision making (e.g., “I prefer that my doctor and I share responsibility for deciding which treatment is best”),[36] while the Patient-Reported Indicator Surveys Patient Questionnaire measures patients’ preferences related to seeking health information (e.g., “I rely on healthcare professionals to tell me everything I need to know to manage my health”).

Measurement Considerations. Key informants noted that a challenge in assessing patient experience is that SDM overlaps with other domains, such as communication with clinicians and getting information.

In addition, patients may not recognize that SDM occurred or that a decision was made. CAHPS Consortium members provided the example of “watching and waiting” as something that may not register as a clear decision for patients. To address these challenges, key informants recommended probing the role of PC CDS in the individual components of SDM, such as whether PC CDS supported patients in understanding the risks and benefits of their options or helped patients in sharing their goals and preferences.

Several key informants also recommended including questions about how PC CDS contributes to key SDM outcomes, such as confidence in decision making and self-efficacy in achieving healthcare goals.

3.1.5. Getting Information

Getting the right information at the right time is a foundational goal of PC CDS.[37] Patient-facing PC CDS allows patients to directly receive information central to their decision making, such as personalized recommendations based on their own data.

While providing information is a core function of PC CDS, key informants shared mixed responses regarding the relative importance of probing this domain in terms of patient experience. Only a few key informants felt that getting information should be prioritized for measurement in a survey about patients’ experience with PC CDS (3 of 10 key informants); however, this may be partially due to the overlap between this domain and SDM and self-management support. Key informants who prioritized this domain noted how receiving useful, personalized information from PC CDS can support patients in making better, more informed decisions about their care. This echoed the perspective of key informants who discussed the importance of receiving personalized information within the context of the domains mentioned above.

Findings in the Literature. Several survey instruments probe aspects of information-sharing from clinician to patient (e.g., assessing timeliness of clinician response, rating clinician information-sharing from poor to excellent).[38,39] There is more limited measurement, however, of how digital tools support providing information directly to patients. The CAHPS Health Information Technology Item Set includes several questions about the helpfulness of clinicians' websites (i.e., patient portals) in providing patients with access to test results and visit notes (e.g., was the information timely, easy to find, easy to understand).[24]

Measurement Considerations. Key informants suggested that survey questions focus on specific types of information exchange, such as providing data from wearable devices or receiving tailored information from a patient portal, to better understand how PC CDS supports these processes.

3.1.6. Satisfaction with PC CDS Tools

Patient satisfaction is a potential outcome of a patient's experience that reflects whether the care provided met the patient's needs and expectations.[7,40] Within the context of PC CDS, patient satisfaction with PC CDS tools may speak to (1) how a patient feels about their interaction with a PC CDS tool (e.g., ease of use, lack of technical difficulties) and (2) how a patient feels about the role of PC CDS in their experience with care (e.g., whether the PC CDS helped the patient receive care aligned with their needs and preferences).

Key informants felt that satisfaction is a foundational domain for PC CDS and articulated the overarching goal of PC CDS is to enhance the clinical experience for patients. Though few selected this domain as the highest priority for measurement (3 of 10 key informants), many noted its importance. Some of this lack of explicit prioritization may be attributed to the cross-cutting nature of patient satisfaction, as key informants noted the importance of measuring usefulness of PC CDS (see more on usability in Section 3.1.7.) and satisfaction within domains, such as satisfaction with communication with clinicians or satisfaction with the information patients receive from PC CDS tools.

Findings in the Literature. Several studies assessed patients' satisfaction with varied health interventions, including telemedicine and CDS tools. These studies used brief questionnaires to assess patients' overall satisfaction with care or satisfaction with specific aspects of care, such as information provided by clinicians or how they were treated by the clinician.[41,42] Similarly, standardized instruments, such as the Short Assessment of Patient Satisfaction (SAPS),[43] use Likert scale questions to gauge patients' satisfaction with their overall care, as well as specific components, such as explanations provided by the care team, the effect of treatment or care, and the choices patients had in the decisions impacting their care. The literature review also identified some measurement tools, such as the Post Study System Usability Questionnaire (PSSUQ),[44] that measure users' perceived satisfaction with a website, software, or digital tool. This questionnaire assesses the user's overall satisfaction with the tool and several subdomains, such as the tool's simplicity, usefulness, and functionalities.

Measurement Considerations. Key informants identified three potential challenges with measuring patient satisfaction in relation to PC CDS. First, patients often seek out healthcare providers they are satisfied with (see Communication with Clinicians in Section 3.1.3.), which can create a “ceiling effect” where responses are skewed towards higher levels of satisfaction. Second, variation in patients’ expectations can also make it difficult to interpret the responses to satisfaction-related questions. For instance, a patient who has very high expectations for their healthcare may be consistently dissatisfied, but a patient with lower expectations who receives the same general quality of care could report a high level of satisfaction. Third, patient satisfaction with PC CDS can be difficult to measure given that it is inherently broad and cuts across the other domains. Key informants suggested focusing satisfaction questions on a particular component of PC CDS, such as self-management support provided by a PC CDS tool, as an alternative to broadly probing satisfaction.

3.1.7. Usability

In the context of health IT, ***usability*** is “the extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency, and satisfaction in a specified context of use.”[45] Usability can intersect with measures of patient satisfaction with PC CDS, as the functionality of a health IT tool can significantly impact users’ satisfaction with it. In key informant interviews, this theme emerged as a component of patient satisfaction.

Only a few key informants indicated that ease of using PC CDS was a critical domain to measure about patient experience (3 of 10 key informants). However, to achieve their intended purpose, PC CDS tools must fundamentally be usable by a wide range of patients.

Findings in the Literature. We identified multiple survey instruments that assess the perceived usability of digital tools. Measurement instruments like the Mobile App Rating Scale[46] and the System Usability Scale (SUS)[47] can be used to assess general usability and user experience independent of the healthcare context (e.g., if the user felt confident using the system, if the system was easy to use or unnecessarily complex, and if the user would like to use the system frequently).[48] Other instruments had a specific focus on healthcare tools, such as the Health Information Technology Usability Evaluation Scale (Health-ITUES)[2] and the mHealth App Usability Questionnaire.[15] These instruments incorporate questions assessing the tool’s specific health-related functions. For instance, the mHealth App Usability Questionnaire includes questions probing whether the user felt comfortable communicating with their clinician using the app and whether the user was confident that the information sent to their clinician through the app would be received.

Measurement Considerations. Key informants noted that patient perceptions regarding the usability of PC CDS may be mediated by both patients’ digital health literacy and their general level of comfort sharing health information via technology.

3.1.8. Care Coordination

Care coordination involves “organizing patient care and sharing information among all participants concerned with a patient’s care to achieve safer and more effective care.”[49] Care coordination activities can include sharing information between clinicians and patients, creating care plans, and supporting patients' self-management goals.[49] PC CDS can facilitate care coordination by supporting information exchange among patients, caregivers, and their care teams. For example, PC CDS can share patient preference information or after-visit summaries and test results from multiple healthcare providers via a single online portal. Care coordination is an especially salient aspect of patient experience with PC CDS as it is a broad, multi-faceted concept that can span other common domains of patient experience, such as communication with clinicians and self-management support.

Few key informants prioritized this domain as important to measure with respect to patient experience with PC CDS (2 of 10 key informants). Generally, key informants prioritized domains representing specific patient-facing care coordination activities (e.g., communication with clinicians, self-management support, SDM).

Findings in the Literature. In the literature, several surveys assessed the capabilities of health IT tools (e.g., apps, patient portals, telehealth) to enhance care coordination. No questions, however, were specific to PC CDS, and many care coordination concepts overlapped with higher-priority domains such as self-management support and communication with clinicians. In particular, the MAUQ,[15] HINTS,[14] and the Mobile Application Rating Scale: User Version (uMARS)[50] assess the usability of health IT and how digital apps can contribute to care coordination. For example, survey questions ask whether mHealth apps provided an acceptable way for patients to receive healthcare services and access educational materials[15] and whether a patient was able to send health information to another healthcare provider via their online provider portal.[14] While not specific to PC CDS, HINTS asks questions about coordinating among multiple providers (e.g., how often patients got the help they needed from their primary care provider's office to manage their care among different providers and services).[14] Additionally, HINTS asks whether the patient has "ever used an app like 'Apple Health Records' or 'CommonHealth' to combine [their] medical information from different patient portals or online medical records into one place."[14]

A few surveys ask broad questions about care coordination outside of a health IT context, including whether respondents feel their healthcare is "organized in a way that works for [them]"[21] or how often the patient and their doctors worked out a treatment plan together.[51] Both the National Health Service General Practitioner (GP) Patient Survey and CAHPS Clinician & Group Survey ask questions about how often or whether a patient felt a healthcare professional "had all the information they needed to know" about a patient's medical history.

Measurement Considerations. Key informants noted major challenges in measuring patient experiences with care coordination facilitated by PC CDS. Multiple key informants noted that patients may not be aware of clinician-to-clinician coordination activities taking place on their behalf, such as how often their providers communicate. It would not be feasible, therefore, for patients to answer survey questions about clinician-facing care coordination activities in a patient experience survey.

In addition, patient-facing PC CDS care coordination tools, such as cross-provider dashboards or portals integrating information across multiple clinicians, are part of an emerging field; the uptake of these tools is currently low. As a result, few patients may be able to report on their experience with these tools. Lastly, key informants pointed out that patient experiences with care coordination can vary depending on their health status and the level of coordination needed for their care. Consequently, it would be challenging to interpret survey data on patient experience with PC CDS and care coordination without requiring extensive questions or answer options to reflect the full range of care coordination needs.

3.1.9. Courtesy, Respect, and Empathy

Courtesy, respect, and empathy in healthcare means that patients are served ethically, respectfully, and by a professional oath.[52] Courteous, empathetic, and respectful care has been associated with better health outcomes, higher patient satisfaction, and increased likelihood of adherence.[53,54] Examples of courteous and respectful care include a clinician's attentiveness to the patient's needs, approaching interactions with cultural humility, honoring beliefs, and recognizing family and personhood.[55] PC CDS can facilitate courteous, respectful, and empathetic care by helping patients document and share preferences with their healthcare providers, such as preferred literacy and health literacy levels, beliefs, or preferred language.

Key informants recognized that courtesy, respect, and empathy are vitally important aspects of healthcare but did not prioritize this domain for assessing patient experience with PC CDS. They indicated that courtesy, respect, and empathy would be difficult to measure in relation to PC CDS tools, as this area of the field is nascent and there are few use cases at present. Several key informants perceived that respectful and empathetic care is primarily determined by patients' perceptions of their clinician's attitudes and behaviors rather than interactions with PC CDS technology. Assessing patient experience with PC CDS under this domain, therefore, may not be interpretable if patient attitudes about courtesy, respect, and empathy are largely determined through person-to-person interactions.

Findings in the Literature. Although no survey instruments identified in the literature review measure courtesy, respect, and empathy in the context of using health IT or PC CDS tools, many survey instruments touch upon this domain in terms of assessing patient experiences interacting in person with healthcare providers. For instance, CAHPS,[56] HCAHPS,[57] the Survey of Healthcare Experiences of Patients (SHEP),[58] and the UK's National Health Service GP Patient Survey[38] include questions on how often providers showed respect for what the patient had to say, listened carefully to the patient, and treated the patient with courtesy and empathy (e.g., taking into account a patient's mental wellbeing).[38]

Measurement Considerations. Clinicians are increasingly employing AI-supported PC CDS to communicate with patients. Although it may currently be difficult to identify a large sample of patients who have experience with AI-supported PC CDS, many key informants agreed that it is becoming increasingly important to assess the technology's capabilities to ensure that PC CDS tools are respectful, empathetic, and unbiased.

3.1.10. Culturally Appropriate Care

Culturally appropriate care, or culturally competent care, tailors health services to different cultures and language preferences with the goal of improving health outcomes.[7,59] PC CDS can support culturally appropriate care by providing decision support reflecting a patient's preferred language and cultural beliefs or communicating with patients in their preferred language, for example, via AI-supported conversational agents.

Key informants noted that culturally appropriate care is essential to delivering high-quality healthcare and is strongly related to patient satisfaction. They primarily discussed culturally appropriate care in the context of AI-supported PC CDS, emphasizing the importance of assessing patient experience with AI-based tools across different populations to detect and address biases in the tools. However, key informants also noted a dearth of potential measures and opportunities to examine cultural competence as it relates to PC CDS.

Findings in the Literature. In alignment with key informant insights, there were few survey instruments that contained items related to the provision of culturally competent care. One study assessed patient satisfaction and experiences with respectful and culturally competent care in OB/GYN clinics, fielding a questionnaire that asked patients' perceptions of clinicians' respect for their religious, spiritual, or cultural beliefs.[60] Another study interviewed care teams about the use of AI to identify patients with language barriers. Stakeholders recognized that AI has the potential to override clinician bias and provide access to linguistic interpretation services for patients who need it, while also voicing concerns related to the technology's accuracy, transparency, and the potential for clinician overreliance on AI.[61]

Measurement Considerations. Key informants indicated that it may be challenging to recruit large sample sizes of patients who can report on culturally competent care supported by PC CDS, particularly if survey questions are not translated into multiple languages. Fielding survey questions in multiple languages would help address this issue and enrich understanding of this domain.

3.2. Cross-cutting PC CDS Measurement Considerations

Key informants who participated in interviews and cognitive testing sessions, as well as CAHPS Consortium members, raised additional methodological considerations related to measuring patient experience with PC CDS.

Defining PC CDS for Survey Question Respondents. PC CDS is a nuanced topic and should be clearly understood by survey respondents to yield valid survey results.

- **Confusion About Healthcare "Decision" Terminology.** Echoing feedback on the SDM patient experience domain, multiple key informants noted that patients may not recognize healthcare decisions as such and therefore may be confused by survey questions about CDS or types of healthcare decisions. Further, patients may not recognize PC CDS as having a role in healthcare decision making because they are also collaborating with their doctor and care team during this process. A clear definition of PC CDS and reminders of the definition will help mitigate these challenges. Further, additional plain-language definitions, such as health IT, digital tools, and health management apps, may be helpful to respondents.[62]

- **Using Web-based Survey Features To Remind Respondents of Definitions and Examples.** Multiple key informants expressed concern that survey question respondents may forget the definition of PC CDS or require examples to accurately interpret survey questions. One way to address these concerns in a web-based instrument would be to employ hover-over definitions and example text throughout the survey questions so respondents can see clarifying terms and examples as needed.

Suggestions on Survey Question Terminology. Key informants pointed out the following nuances:

- **Describing Patient Portals.** "Doctor's office patient portal" is clearer than "patient portal," as patients may confuse their clinician's patient portal with an insurance patient portal. Further providing examples of patient portals like Epic or MyChart may also be helpful.
- **Describing Clinicians.** Some patients have multiple clinicians (e.g., specialists, nurses) or may broadly consider people involved in their healthcare to include caregivers, family members, and non-clinical positions like community health workers. Therefore, the combination of "doctor" or "clinician" with "care team" or "healthcare team" may more accurately reflect the experience of all patients.

Emphasis on Patient "Goals." Key informants across all groups stressed the importance of asking survey questions about whether PC CDS helped patients meet their individual health goals. Key informants distinguished goals (e.g., reducing pain, being more physically active) from preferences (e.g., receiving treatment intravenously or orally, receiving information in a preferred language), noting that PC CDS should ultimately support patients in meeting their goals. One key informant noted that "healthcare choices" may also appeal to some respondents if they are unclear on their healthcare goals.

Variation in Clinical Context. Many key informants noted that the way patients answer survey questions will depend on their unique healthcare needs. For example, someone receiving only routine primary care may have different exposure to and experiences with PC CDS compared to someone who has more contact with the healthcare system (e.g., with an acute or chronic condition).

- Stratifying survey question results by clinical context may be helpful for meaningfully interpreting survey data on patient experience with PC CDS.
- Relatedly, it is critical to select an appropriate reference timeframe when posing survey questions (e.g., recalling experiences within the past year or the past six months). Some patients interact with the healthcare system frequently while others do not want or need to access healthcare for longer periods of time (e.g., annual primary care visits).

Willingness To Use PC CDS. Some patients may not have interacted with a PC CDS tool, or may not remember interacting with PC CDS. However, it is still valuable to capture the perspectives of these patients in terms of their willingness to interact with PC CDS tools in the future. Including these types of questions will yield a larger sample of respondents.

Use of AI in PC CDS. The use of AI and related privacy and trust issues are becoming increasingly relevant in the PC CDS landscape. AI-supported PC CDS tools, such as automated messaging or chat features, have the potential to impact patients' trust and satisfaction.[63] Using AI-supported technology raises a range of legal (e.g., privacy and data security) and ethical concerns (e.g., transparency in disclosing when patients interact with AI).[64,65] At the same time, there is evidence that AI has robust capacity to engage in empathetic interactions with humans, suggesting new roles for AI in healthcare.[66] While the uptake of AI-based PC CDS tools may currently be limited, it will be important to ask survey questions about patient experience with AI-supported PC CDS in the near future. Current CDSiC efforts have explored how AI can enhance PC CDS, highlighted how AI could be used to scale up implementation and adoption of PC CDS, and summarized strategies for improving AI-supported PC CDS to ensure these tools support, rather than compromise, SDM and care quality.[67,68,69]

Privacy Concerns. Key informants raised concerns related to the use of PC CDS, such as protecting patient data and privacy, transparency about how patient data informs PC CDS, and the need to clearly inform patients when they are interacting with AI-supported PC CDS. While these concerns were not within scope of this project, and such questions about trust sharing medical data are available in other instruments (e.g., HINTS),[14] these may be helpful supplemental questions to aid with interpreting survey data on patient experience with PC CDS.

4. Patient Experience Survey Questions

Based on the literature review and initial key informant interviews, we developed a focused question bank that probed key aspects of the priority patient experience domains described above. As much as possible, we consulted specific scales, styles of questions, and measures to inform survey question development. The number and depth of questions were guided by key informant feedback as well as where there are opportunities to use PC CDS tools—for example, PC CDS has many potential applications within the domain of getting information. The questions in the bank are pilot questions and as such are not intended to be fielded as a full survey instrument. Instead, they are designed as a set of ready-made questions to choose from to field-test and embed in an existing national assessment.

As discussed above, key informants noted that the access to care; courtesy, respect, and empathy; and culturally appropriate care patient experience domains were extremely important to receiving high-quality healthcare, but they saw little to no direct relevance of these domains to PC CDS. As a result, the question bank does not probe on these domains.

Similarly, taking into account key informant insights, the domain of patient satisfaction is cross-cutting and ultimately represented in the questions about assessing the overall outcomes of PC CDS and patient experience. In addition to asking questions about process measures related to using PC CDS, we identified a number of cross-cutting patient experience outcomes in interviews and the literature, such as greater knowledge, empowerment, and better healthcare experience. We framed these outcomes within the context of PC CDS and developed a set of questions focused on overall outcomes and patient experience with PC CDS.

Cognitive Testing. During cognitive testing (seven interviews with seven individuals), patient advocates shared feedback on survey questions and answer option comprehension and clarity. They also noted where questions were difficult to answer (e.g., offered feedback on phrasing or the relevance of the topic); where there might be gaps in questions or answer options; and where examples would be helpful. See Section 3.2, Cross-cutting PC CDS Measurement Considerations, for more on the insights key informants shared.

Description of the Survey Question Bank. The question bank is intended to be comprehensive, and some questions may overlap or be closely related. For consistency, many of the questions in the question bank have a similar structure and answer options. Additionally, each question is accompanied by a short set of directions. Depending on the overall survey instrument that will draw from the question bank (e.g., the overall survey's preferred reading level for questions, scale or structure of entire instrument, and number of questions that can be dedicated to patient experience with PC CDS), there may be opportunities to adapt questions and streamline directions for the respondent to reduce burden.

The final question bank includes 41 questions in total (**Exhibit 2**):

- Nine screening questions seek to understand the respondent's use of PC CDS, providing context to their experiences as well as screening them for eligibility to answer questions about their experience with PC CDS. Depending on how respondents answer the screening questions in a survey instrument, they may be directed to specific survey questions relevant to their experience. The answers from these questions may also be used to stratify the patient experience data and to support making meaningful interpretations by subgroup.

- Eighteen questions probe patient experience with PC CDS, corresponding to high-priority domains: self-management support, communication with clinicians, SDM, getting information, and usability.***

- Twelve questions probe cross-cutting outcomes of PC CDS as it relates to patient experience, including a question on patients' willingness to continue to use PC CDS for their healthcare.

- One question designed for patients who have not used PC CDS asks about their willingness to try PC CDS in the future

- One question for all patients asks about their willingness to try AI-supported healthcare tools in the future.

Questions ask patients to reflect on their overall experience with PC CDS. We acknowledge that patients may have varied experiences with PC CDS or specific PC CDS features over time. For example, a patient may see some information offered by PC CDS as helpful, while other information from PC CDS may be less helpful or satisfactory. For many questions, applying a Likert scale for answer options based on level of agreement gives patients the opportunity to reflect these nuances in their answer, providing insight into their "average" experience. A Yes/No answer option will capture less nuanced answers. While the current structure of these survey questions may present analytic benefits, there may be pragmatic considerations for embedding questions into an existing instrument, such as rules about question structure, answer options, and question consistency. The final structure of specific questions and answer options may require adaptation to adhere to the standards of the survey instrument in which they are embedded.

*** Question 25 in the "usability of PC CDS" domain includes five sub-questions.

Exhibit 2. Final Survey Question Bank

Screening Questions		
Number	**Question**	**Response Options**
1.	The following questions focus on your experience with patient-centered clinical decision support. These questions ask about your own healthcare. Do not include the times you went for dental care visits. **Patient-centered clinical decision support** includes tools that (1) are digital (e.g., web-based), (2) use your health data, and (3) use scientific evidence and other information to support you and your clinicians (e.g., doctors and care teams) to make healthcare decisions. These **healthcare decisions** can be related to taking medications, undergoing treatments or procedures, making lifestyle changes, and more. Typically, these decisions <u>do not</u> include discussions about health insurance costs or coverage. Here are some **examples** of how patient-centered clinical decision support can be used: • A patient can share information about their care preferences through an online patient portal, which helps their care team make tailored treatment recommendations. • A patient can use a smartphone application to track their health and receive personalized information about their symptoms or condition, helping them to choose next steps with their care team. In the past 6 months, have you used patient-centered clinical decision support? *Select one.*	a) Yes b) No c) Unsure

Screening Questions		
Number	**Question**	**Response Options**
2.	Patient-centered clinical decision support comes in many different forms. In the past 6 months, what **health information tools** did you use? *Select all that apply.*	a) An online patient portal from my doctor's office b) A smartphone application connected to an electronic wearable device that tracks my health (e.g., Fitbit, Apple Watch, Garmin Vivofit) c) A smartphone application I use to submit my health information to my doctor(s) or care team (e.g., my symptoms, satisfaction with treatment, my ability to perform daily activities) d) None of the above
3.	*If respondent selected answer choice A in S2:* In the past 6 months, how did you use your **healthcare provider's online patient portal**? *Select all that apply.*	a) Viewed visuals or graphs to understand my health status, diagnosis, or medical test results over time b) Exchanged messages with my doctor(s), specialist(s), or care team c) Linked my healthcare provider's patient portal with a digital app or wearable device I use to monitor my health d) Received personalized health information that helped inform decisions about my care e) Interacted with a chatbot that could address questions about my health in real time f) Filled out questionnaires about my healthcare preferences g) Unsure h) None of the above
4.	*If respondent selected answer choice B in S2:* In the past 6 months, how did you use a **smartphone application connected to a wearable device** to track or manage your health? *Select all that apply.*	a) Viewed visuals or graphs to understand my health status, diagnosis, or medical test results over time b) Received reminders about my health, such as taking my medication c) Received personalized health information that helped inform decisions about my care d) Interacted with a chatbot that could address questions about my health in real time e) Unsure f) None of the above

Screening Questions		
Number	**Question**	**Response Options**
5.	*If respondent selected answer choice C in S2:* In the past 6 months, how did you use a **smartphone application to submit your health information to your doctor(s) or care team**? *Select all that apply.*	a) Provided information about my symptoms (e.g., pain level, coughing) b) Entered health data that I collected (e.g., blood pressure, blood glucose, mobility) c) Completed a brief questionnaire or form about my health or healthcare preferences d) Unsure e) None of the above
6.	Patient-centered clinical decision support can offer personalized information that helps patients make decisions with their care team. In the past 6 months, what types of **personalized health information** did you access through a patient-centered clinical decision support tool? *Select all that apply.* *Please count personalized and tailored information in your response. Do not count general information about a disease or condition.*	a) Information specific to my unique diagnosis or condition b) Information about my treatment options c) Information interpreting my medical test results d) None of the above
7.	Patients can use patient-centered clinical decision support tools to make healthcare decisions with their doctor(s) or care team. In the past 6 months, what kind of **decisions** did patient-centered clinical decision support help you make with your doctor(s) or care team? *Select all that apply.*	a) Starting, changing, or stopping my medication(s) b) Choosing which medical tests I should receive c) Making a care plan or treatment plan d) Whether to see a specialist e) Whether to have a medical procedure f) Choosing the type of procedure I will receive g) Making lifestyle changes h) Other health-related decision(s) i) I did not use patient-centered decision support tools to make a healthcare decision in the past six months j) Unsure

Screening Questions

Number	Question	Response Options
8.	Please choose the statement that best describes how you prefer **treatment decisions** to be made about your healthcare. *Select one.*	a) I prefer to make the final decision about my treatment b) I prefer to make the decision about my treatment after seriously considering my doctor's opinion c) I prefer that my doctor and I share responsibility for deciding which treatment is best d) I prefer that my doctor makes the final treatment decision but seriously considers my opinion e) I prefer to leave all treatment decisions to my doctor f) Unsure
9.	How much **information** do you prefer to receive about your health or medical condition from your doctor(s) or care team? *Select one.*	a) A lot of information b) Some information c) A little information d) No information e) Unsure

Questions for Patients with Experience with PC CDS, by Patient Experience Domain

Number	Question	Response Options
Self-management Support		
10.	Thinking about your experience with patient-centered clinical decision support in the past 6 months: I **opted in to receiving reminders** to manage my condition or illness, such as taking my medications or flagging concerning symptoms or test results. *Select one.*	a) Yes b) No c) Unsure d) Not applicable
11.	*If respondent selected answer choice A in Question 10:* I found these **reminders helpful**. *Select one.*	a) Yes b) No c) Unsure d) Not applicable

Questions for Patients with Experience with PC CDS, by Patient Experience Domain		
Number	**Question**	**Response Options**
Communication with Clinicians		
12.	The following question is about your communication with all doctors, nurses, specialists, or other health professionals in your clinical care team you saw during the past 6 months: *Select the answer that reflects your level of agreement with the following statement:* Patient-centered clinical decision support helped me **share my healthcare preferences** with my doctors or clinical care team. For example, preference about taking a pill instead of a shot, being treated in a clinical setting or my home, choices about lifestyle changes, how I prefer to communicate with my care team (e.g., in-person or via patient portal messages between visits).	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable
Shared Decision Making		
13.	Thinking about your experience with patient-centered clinical decision support in the past 6 months: Patient-centered clinical decision support gave me information **when I needed** to make decisions with my care team. S*elect the answer that reflects your level of agreement with the statement.* For example, deciding to have a medical test, procedure, or surgery done; deciding to start, stop, or change a treatment.	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable
14.	Thinking about your experience with patient-centered clinical decision support in the past 6 months: Patient-centered clinical decision support gave me information that helped me **weigh the benefits and risks of my treatment options**. *Select one.*	a) Yes b) No c) Unsure d) Not applicable

Questions for Patients with Experience with PC CDS, by Patient Experience Domain		
Number	**Question**	**Response Options**
15.	Patient-centered clinical decision support provides patients with information when they need to make decisions with their care team (e.g., deciding to have a medical test, procedure, or surgery). Thinking about your experience with patient-centered clinical decision support in the past 6 months: The information I entered into my patient-centered clinical decision support tool allowed my doctor(s) or care team to **discuss by healthcare options based on my preferences**. *Select the answer that reflects your level of agreement with the statement.*	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable
Getting Information		
16.	Thinking about your experience with patient-centered clinical decision support in the past 6 months: Patient-centered clinical decision support gave me **health information** that was specific to my situation. *Select the answer that reflects your level of agreement with the statement.* For example, steps to manage a chronic condition, how to make lifestyle changes, or the risks and benefits of different medications or treatments.	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable
17.	Thinking about your experience with patient-centered clinical decision support in the past 6 months: Patient-centered clinical decision support gave me information that was **useful**. *Select the answer that reflects your level of agreement with the statement.*	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable

Questions for Patients with Experience with PC CDS, by Patient Experience Domain

Number	Question	Response Options
18.	Thinking about your experience with patient-centered clinical decision support in the past 6 months: I **trusted** the information I received through patient-centered clinical decision support. *Select the answer that reflects your level of agreement with the statement.*	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable
19.	Thinking about your experience with patient-centered clinical decision support in the past 6 months: Information from patient-centered clinical decision support **did not help me make decisions** about my healthcare. *Select one.*	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable
20.	Thinking about your experience with patient-centered clinical decision support in the past 6 months: It was **difficult for me to understand** the health information that I received from patient-centered clinical decision support. *Select the answer that reflects your level of agreement with the statement.*	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable
21.	Thinking about your experience with patient-centered clinical decision support in the past 6 months: Patient-centered clinical decision support gave me information that **was relevant to my health and well-being**. *Select the answer that reflects your level of agreement with the statement.*	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable

Questions for Patients with Experience with PC CDS, by Patient Experience Domain		
Number	**Question**	**Response Options**
22.	Thinking about your experience with patient-centered clinical decision support in the past 6 months: Patient-centered clinical decision support gave me information that **reflected my unique healthcare preferences**. *Select the answer that reflects your level of agreement with the statement.* For example, preference about taking an oral medication instead of an injection, being treated in a clinical setting or my home, choices about lifestyle changes, how I prefer to communicate with my care team (e.g., in-person or via patient portal messages between visits).	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable
23.	Thinking about your experience with patient-centered clinical decision support in the past 6 months: The information I received from patient-centered clinical decision support **helped me make decisions with my care team when I needed to**. *Select the answer that reflects your level of agreement with the statement.* For example, making a decision to have a medical test, procedure, surgery; or to start, stop, or change a treatment.	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable
24.	The information I received from patient-centered clinical decision support **was <u>not</u> an accurate summary of my options**. *Select the answer that reflects your level of agreement with the following statement.* For example, information was outdated, not reflective of my treatment options, or not reflective of my preferences.	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable

Questions for Patients with Experience with PC CDS, by Patient Experience Domain

Number	Question	Response Options
Usability of PC CDS		
25.	The next questions ask about your comfort using patient-centered clinical decision support technology functions in a patient portal, digital application, or wearable device that tracks your health. *Select the answer that reflects your level of agreement with each of the following statements.* Thinking about your experience with patient-centered clinical decision support in the past 6 months: I felt **comfortable** using patient-centered clinical decision support technology to: A. Access health information that is specific to my situation (e.g., data tracking health or test results) B. Access information to understand the benefits, risks, and harms of treatment options C. Answer online questionnaires about my care preferences D. Share information with my doctor or care team E. Connect data from a digital application or wearable device to my doctor's office patient portal	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable *[Respondents will select an answer for each question (25A-25E)]*
26.	Thinking about your experience with patient-centered clinical decision support in the past 6 months: I thought patient-centered clinical decision support was **easy to use**. *Select the answer that reflects your level of agreement with the statement.*	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable

Questions for Patients with Experience with PC CDS, by Patient Experience Domain		
Number	**Question**	**Response Options**
27.	Thinking about your experience with patient-centered clinical decision support in the past 6 months: It was **difficult to learn how to use patient-centered clinical decision support**. *Select the answer that reflects your level of agreement with the statement.*	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable
Overall Outcomes of PC CDS and Patient Experience		
28.	Thinking about your experience with patient-centered clinical decision support in the past 6 months: Patient-centered clinical decision support helped me **effectively manage my illness or condition**. *Select the answer that reflects your level of agreement with the statement.*	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable
29.	Thinking about your experience with patient-centered clinical decision support in the past 6 months: Patient-centered clinical decision support helped me feel **empowered to manage my health** with my doctor(s) or care team. *Select the answer that reflects your level of agreement with the statement.*	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable

Questions for Patients with Experience with PC CDS, by Patient Experience Domain

Number	Question	Response Options
30.	Thinking about your experience with patient-centered clinical decision support in the past 6 months: Patient-centered clinical decision support helped me **make healthcare decisions** with my doctor or care team. *Select the answer that reflects your level of agreement with the statement.* For example, decisions to select a treatment or medication or make lifestyle changes to improve my health.	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable
31.	Thinking about your experience with patient-centered clinical decision support in the past 6 months: Patient-centered clinical decision support helped me feel **confident** in making decisions with my doctor and care team. *Select the answer that reflects your level of agreement with the statement.*	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable
32.	Thinking about your experience with patient-centered clinical decision support in the past 6 months: Patient-centered clinical decision support helped me feel **knowledgeable** about my health. *Select the answer that reflects your level of agreement with the statement*	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable

Questions for Patients with Experience with PC CDS, by Patient Experience Domain

Number	Question	Response Options
33.	Thinking about your experience with patient-centered clinical decision support in the past 6 months: Patient-centered clinical decision support helped me **identify the right questions** to ask my doctor(s) or care team. *Select the answer that reflects your level of agreement with the statement.*	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable
34.	Thinking about your experience with patient-centered clinical decision support in the past 6 months: Patient-centered clinical decision support **improved my communication** with my doctor and/or other clinicians I work with (e.g., nurse, specialist). *Select the answer that reflects your level of agreement with the statement.*	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable
35.	Thinking about your experience with patient-centered clinical decision support in the past 6 months: Patient-centered clinical decision support **improved my healthcare experience**. *Select the answer that reflects your level of agreement with the statement.*	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable
36.	Thinking about your experience with patient-centered clinical decision support in the past 6 months: Patient-centered clinical decision support improved the **quality of my healthcare**. *Select the answer that reflects your level of agreement with the statement.*	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable

Questions for Patients with Experience with PC CDS, by Patient Experience Domain

Number	Question	Response Options
37.	Thinking about your experience with patient-centered clinical decision support in the past 6 months: Patient-centered clinical decision support helped me receive healthcare that aligned with **my preferences**. *Select the answer that reflects your level of agreement with the statement.*	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable
38.	Thinking about your experience with patient-centered clinical decision support in the past 6 months: Patient-centered clinical decision support helped me work towards **my personal health goals**. *Select the answer that reflects your level of agreement with the statement.*	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable
39.	If given a choice, I would continue to **use patient-centered clinical decision support** to help me make healthcare decisions with my doctor(s) or care team. *Select the answer that reflects your level of agreement with the statement.*	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable

Question for Patients Who Have Not Used PC CDS		
Number	**Question**	**Response Options**
40.	Patients can use patient-centered clinical decision support tools such as patient portals and digital applications or wearable devices that track their health. These tools can offer patients personalized health information and collect data and information from patients to inform their care. Patient-centered clinical decision support can help patients and their care teams make decisions about medications, treatments, making lifestyle changes, and treatment plans. *Select the answer that reflects your level of agreement with the following statement:* I am **willing to try patient-centered clinical decision support** to receive information about my health that informs decisions I make with my doctor(s) or care team.	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable

Question for All Patients		
Number	**Question**	**Response Options**
41.	There are many opportunities for patient-centered clinical decision support to use artificial intelligence to deliver personalized health information to patients. For example, artificial intelligence may help make medical information more understandable. It may also help patients interpret their medical test results, identify questions to ask their doctor(s) care team, or answer questions about their unique health status. *Select the answer that reflects your level of agreement with the following statement:* I am **willing to try artificial intelligence tools** (e.g., chatbots) to receive information about my health that informs decisions I make with my doctor(s) or care team.	a) Strongly agree b) Agree c) Neither agree nor disagree d) Disagree e) Strongly disagree f) Unsure g) Not applicable

5. Discussion

Assessing patient experience with PC CDS at a national level will create additional opportunities for meaningful measurement. Anticipating the greater uptake of PC CDS tools in the field, it may be appropriate to introduce questions that assess change over time (e.g., whether self-management support improved compared to before using PC CDS or first using PC CDS). Currently, due to the limited uptake of PC CDS technology, patients may not be able to clearly answer these types of pre/post exposure questions. Similarly, with the growing use of AI to inform healthcare, there may be opportunities to expand or add questions about AI-supported PC CDS to this survey question bank. Questions can be specific to the ways in which patients interface with AI-supported PC CDs and the value of these functions relative to their healthcare experience.

As health IT systems become more advanced, there may be opportunities to ask about PC CDS within the context of delivering information to patients about healthcare costs and insurance coverage. Key informants indicated that this is an important concern to patients, but the uptake of health IT tools that present health information alongside insurance information for patients is currently low to nonexistent.

Next Steps. Due to the scope of this effort, we did not develop a full-fledged, field-tested instrument. Further work to validate the survey questions is needed, including validating with patients who have different levels of exposure to PC CDS, patients who may be using PC CDS within different clinical contexts, and patients who represent an array of subpopulations and differences. Further work is additionally needed to identify appropriate instrument(s) in which to embed questions, as well as to align the questions with the format and mode of administration of those instruments. This may require adapting questions or answer options.

Limitations. We acknowledge the limitations of question development efforts. Firstly, while we reviewed a significant amount of literature to identify measures of patient experience with health IT or healthcare broadly, some sources may have been missed. As a result, this report does not reflect a systematic review or compilation of all relevant measures in these areas, such as attitudes towards AI.

Secondly, even among patients familiar with PC CDS, we found that key informants thought about and understood PC CDS in different ways. Therefore, the questions should be tested more widely across populations with varying levels of experience with PC CDS—from those with little or no experience with PC CDS to those who are highly familiar with PC CDS.

Thirdly, we cognitively tested survey questions with patient advocates but did not obtain feedback more extensively from patients with a wide range of healthcare needs, diagnoses, backgrounds, or experiences. Testing the survey questions across a broader sample of patients, including different populations such as those with and without chronic conditions and those who prefer to communicate in a language other than English would be optimal for ensuring the accuracy and validity of the survey questions.

6. Conclusion

The measurement of PC CDS performance is a bourgeoning field that requires the input and experiences of patients to inform the development, deployment, and implementation of these technologies. This project identified core domains of patient experience and operationalized them into survey questions focusing on a PC CDS context. The survey questions described in this report serve as the groundwork for a baseline assessment of patient experiences with PC CDS tools. The adoption of these survey questions into a nationally representative field-tested survey would collect valuable data on the current state of PC CDS nationwide, leading to the technology's betterment and alignment with patient preferences and goals. As the field of PC CDS develops, these questions can be further adapted and refined to ensure they remain relevant and can inform actionable change in response to new and emerging PC CDS technologies.

Appendix A: Detailed Methods

Exhibit A1. Targeted PubMed Literature Review Search Strings

Goal #1: Identify patient experience/ satisfaction instruments & measures and CDS	Date of search: November 19, 2024	("decision support systems, clinical"[MeSH] OR "shared decision making" OR "clinical decision making"[MeSH] OR "clinical decision support"[MeSH] OR "patient-centered clinical decision support") AND ("patient experience"[Title/Abstract] OR "Patient-reported outcomes"[Title/Abstract] OR "patient perception*"[Title/Abstract])) AND ("measure*"[Title/Abstract] OR "survey*"[Title/Abstract]) AND ("tool")
Goal #2: Characterize patient experience with health IT	Date of search: November 21, 2024	("mHealth" OR "mobile health" OR "digital health") AND ("patient experience"[title/abstract] OR "patient perception"[title/abstract] OR "patient satisfaction") AND ("survey"[title/abstract] OR "questionnaire"[title/abstract])
Goal #3: Identify specific domains of patient experience	Date of search: December 9, 2024	("decision support systems, clinical"[MeSH] OR "clinical decision making"[MeSH] OR "clinical decision support" OR "patient-centered clinical decision support" OR "clinical care") AND ("patient experience"[Title/Abstract] OR "patient perception*"[Title/Abstract] OR "patient satisfaction") AND ("respect" OR "courtesy")
Goal #4: Capture patient experience survey development methods	Date of search: December 4, 2024	("patient experience"[Title/Abstract] OR "Patient-reported outcome*"[Title/Abstract] OR "patient perception*"[Title/Abstract] OR "patient satisfaction"[Title/Abstract]) AND ("measure*"[Title/Abstract] OR "survey*"[Title/Abstract] OR "questionnaire"[Title/Abstract]) AND ("survey development"[Title/Abstract] OR "measure development"[Title/Abstract])

Exhibit A2. Websites Scanned During Targeted Literature Review

HHS Agency Websites
Agency for Healthcare Research and Quality (AHRQ)
Assistant Secretary for Technology Policy/Office of the National Coordinator for Health Information Technology (ASTP/ONC)
Centers for Medicare & Medicaid Services (CMS)
National Institutes of Health (NIH)
Other Relevant Stakeholder Websites
American College of Surgeons (ACS)
American Heart Association (AHA)
American Hospital Association (AHA)
National Academy of Medicine (NAM)

Appendix B: Patient Experience Survey Tables

Exhibit B1. Sources Identified in the Targeted Literature Review

No.	Study	Country of Origin	Brief Description	Survey Subject
1	Barrett, Sibaliia & Kim (2024)[70]	Canada	Assessed the domains of the clinic that patients most valued	Healthcare
2	Bhuiyan & Loder (2024)[60]	United States	Assessed patient experience with care in an OB/GYN clinic	Healthcare
3	de Batlle, et al. (2020)[71]	Spain	Assessed the usability, acceptability, and satisfaction among patients with multiple chronic conditions trying an integrated care model	mHealth application
4	Eturkmen, et al. (2019)[72]	Spain, Sweden, United Kingdom	Assessed the experiences of using a care planning model	CDS tool
5	Gashaw, et al. (2024)[73]	Chile	Assessed patient satisfaction with a home-based isolation and care program	Telehealth
6	Grodon, et al. (2024)[74]	United Kingdom	Assessed musculoskeletal patient experiences with using an mHealth exercise application	mHealth application
7	Irfan Khan, et al. (2018)[75]	Canada	Assessed patient experiences with an ePRO tool for patients with multiple chronic conditions	mHealth application
8	Kim, et al. (2020)[76]	Korea	Assessed patient experiences with a personal health record application in emergency environments	mHealth application
9	Lee & Lee (2020)[77]	Korea	Assessed patient satisfaction with a Watson for Oncology tool	CDS tool
10	Lines, et al. (2022)[78]	United States	Assessed the impact of illness burden on care experiences	Healthcare

No.	Study	Country of Origin	Brief Description	Survey Subject
11	Liu, et al. (2022)[79]	United States	Assessed patient experiences with a COVID-19 symptom checker mHealth application	mHealth application
12	Mahmood, et al., (2022)[80]	The Netherlands	Assessed patient experience with rheumatologists after a shared decision making training program	Healthcare
13	Mason & Mason (2022)[81]	United States	Assessed patient satisfaction with telemedicine care	Telehealth
14	Mercer, et al. (2018)[82]	United States	Assessed the feasibility of a risk calculator and decision aid tool for shared decision making	CDS tool
15	Portz, et al. (2019)[83]	United States	Assessed the usability of a patient portal tool for patients with multiple chronic conditions	CDS tool
26	Ratanjee-Vanmali, et al. (2020)[41]	South Africa	Assessed patient experience with a hybrid auditory health service	Healthcare
17	Rencz, et al. (2020)[84]	Hungary	Assessed patient satisfaction with their decision making with clinicians	Healthcare
18	Resnik, et al. (2021)[85]	United States	Assessed patient experience with upper limb prostheses	Medical resource
19	Rose, et al. (2021)[86]	United States	Assessed patient experience with telehealth services	Telehealth
20	Senitan & Gillespie (2020)[87]	Saudi Arabia	Adapted the CAHPS survey to assess patient experiences with healthcare	Healthcare
21	Torain, et al. (2021)[88]	United States	Assessed the impact of interpersonal aspects on care experience	Healthcare
22	van der Storm, Hensen & Schijven (2023)[89]	The Netherlands	Assessed patients’ satisfaction with their stoma care and their willingness to use an app to promote self-efficacy	Healthcare
23	Zand, et al. (2021)[90]	United States	Assessed irritable bowel disease patient experiences with an integrated care mHealth application	mHealth application

Exhibit B2. Patient Experience Surveys Identified through the Targeted Literature Review

No.	Instrument	Country of Origin	Brief Description
1	Components of Primary Care Index (CPCI)[29]	United States	Assesses patient satisfaction with their primary care
2	Consumer Assessment of Healthcare Providers and Systems (CAHPS) Clinician & Group Survey,[56] including Health Information Technology Item Set and Shared Decision Making Items	United States	Assesses patient experiences in primary care and specialty care settings
3	Consumer Assessment of Healthcare Providers and Systems (CAHPS) Health Plan Survey[91]	United States	Assesses patient experiences with their health plans
4	Consumers and Health Information Technology: A National Survey[17]	United States	Assesses patient experiences with health information technology
5	Control Preferences Scale (CPS)[92]	Canada	Assesses patients' preferred roles in decision making
6	End User Mobile Application Ratings Scale (uMARS)[50]	Australia	Assesses the quality of mHealth apps for end users
7	Evaluating Patient Experiences with Patient-Centered and Inclusive Care in Academic Obstetrics and Gynecology Outpatient Clinics–Survey[60]	United States	Assesses patient experiences with culturally appropriate care at an OB/GYN clinic
8	Express Care Online Post-Visit Patient Survey[86]	United States	Assesses patient satisfaction with virtual care visits
9	Functional Assessment of Chronic Illness Therapy–Treatment Satisfaction–Patient Satisfaction (FACIT-TS-PS)[93]	United States	Assesses patient satisfaction with chronic illness treatment
10	GP Patient Survey[38]	United Kingdom	Assesses patient experiences in primary care and specialty care settings
11	Health Information National Trends Survey (HINTS)[14]	United States	Evaluates public knowledge of health-related and cancer-related information online
12	Health Information Technology Usability Evaluation Scale (Health-ITUES)[94]	United States	Assesses the usability of a technological system

No.	Instrument	Country of Origin	Brief Description
13	Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS)[57]	United States	Assesses patient experiences in hospital settings
14	IN-PATSAT32[95]	Europe	Assesses patient experiences in hospital settings
15	Interpersonal Processes of Care (IPC) Survey[51]	United States	Assesses patient experiences in interactions with their healthcare providers
16	IQHealth: Patient's Enrollment Experience and Expectations[96]	United States	Assesses patient experiences with their personal health records and messaging
17	Mobile App Rating Scale (MARS)[46]	Ausralia	Assesses the quality of mHealth apps
18	mHealth App Usability Questionnaire (MAUQ)[15]	United States	Assesses the usability of mHealth applications
19	National Health Interview Survey (NHIS)[97]	United States	Assesses general health data among the U.S. population
20	Oklahoma Patient Experience Survey[16]	United States	Assesses patient experiences with electronic health records
21	Patient Experience and Satisfaction With Hearing Health Care Received[41]	South Africa	Assesses patient satisfaction with hearing healthcare
22	Patient Experience Survey for EHR-Integrated COVID-19 Symptom Checker[79]	United States	Assesses patient experiences with a CDS COVID-19 symptom checker tool
23	Patient Experience Survey for PhysiApp[74]	United Kingdom	Assesses patient experiences with a mHealth exercise app
24	Patient Experience Survey for UCLA eIBD[90]	United States	Assesses patient experiences with a mHealth exercise app
25	Patient-Reported Indicator Surveys (PaRIS)[21]	Europe	Evaluates patient experiences at an international scale
26	Patient Experiences Across Care Sectors (PEACS 1.0)[98]	Germany	Assesses patient experiences with healthcare

No.	Instrument	Country of Origin	Brief Description
27	Patient's Use of Computers: University of Missouri–Columbia[99]	United States	Assesses patient experiences with patient portals
28	Portal and Non-Portal User Surveys to Assess MyPreventiveCare Portal[18]	United States	Assesses patient experiences with patient portals
29	Post Study System Usability Questionnaire (PSSUQ)[44]	United States	Evaluates satisfaction with the usability of a system
30	Satisfaction Concerning Stoma Care Questionnaire (SSCQ)[89]	The Netherlands	Assesses patient experiences with stoma care
31	Shared Decision Making Questionnaire (SDM-Q9)[35]	United States	Assesses patient decision making experiences with their clinician
32	Short Assessment of Patient Satisfaction (SAPS)[43]	Australia	Evaluates patient satisfaction with their treatment
33	Survey of Healthcare Experiences of Patients (SHEP)[58]	United States	Assesses quality of hospital care
34	System Usability Scale (SUS)[47]	United States	Evaluates the usability of technology systems
35	Technology Acceptance Model (TAM)[100]	United States	Assesses how users use and accept technology
36	Use of Web-Based Health Information – for Patient Practice Portal Users[101]	United States	Assesses patient experiences with home health portals
37	Usefulness, Satisfaction, and Ease of Use Questionnaire (USE)[102]	United States	Assesses the usability of a technology

References

[1] Agency for Healthcare Research and Quality. *CAHPS Clinician & Group Survey 3.0 Measures*. Rockville, MD: Agency for Healthcare Research and Quality; content last reviewed September 2020. Accessed June 20, 2025. https://www.ahrq.gov/cahps/surveys-guidance/cg/about/survey-measures.html.

[2] Schnall R, Cho H, Liu J. Health Information Technology Usability Evaluation Scale (Health-ITUES) for usability assessment of mobile health technology: Validation study. JMIR mHealth uHealth. 2018 Jan 5;6(1):e4. doi: 10.2196/mhealth.8851. PMID: 29305343; PMCID: PMC5775483.

[3] Agency for Healthcare Research and Quality. About the CDSiC. Accessed April 3, 2024. https://cdsic.ahrq.gov/cdsic/cdsic-about.

[4] Dullabh P, Sandberg SF, Heaney-Huls K, et al. Challenges and opportunities for advancing patient-centered clinical decision support: Findings from a horizon scan. J Am Med Inform Assoc. 2022;29(7):1233-1243. doi:10.1093/jamia/ocac059.

[5] Dullabh PM, Heaney-Huls K, Jiménez F, et al. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.

[6] Kuperman G, Nanji K, Cope E,et al. Outcomes and Objectives Workgroup: Patient-Focused Outcome Measures for Patient-Centered Clinical Decision Support. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23- 0086. Rockville, MD: Agency for Healthcare Research and Quality; September 2023.

[7] What Is Patient Experience? Content last reviewed October 2024. Agency for Healthcare Research and Quality, Rockville, MD. https://www.ahrq.gov/cahps/about-cahps/patient-experience/index.html.

[8] Ahmed F, Burt J, Roland M. Measuring patient experience: concepts and methods. Patient. 2014;7(3):235-241. doi:10.1007/s40271-014-0060-5.

[9] Eversole J, Grimm A, Patel N, et al. Why measure patient experience in physical therapy? Arch Physiother. 2021;11(1):11. doi:10.1186/s40945-021-00105-2.

[10] Brown R, Cigarroa Kennedy S, Carranco Chávez E, et al. Evaluation of a notes-based rapid qualitative analysis method to facilitate implementation. Implement Sci Commun. 2025;6(1):23. doi:10.1186/s43058-025-00709-w.

[11] Vindrola-Padros C, Johnson GA. Rapid techniques in qualitative research: A critical review of the literature. Qual Health Res. 2020;30(10):1596-1604. doi:10.1177/1049732320921832.

[12] What is Self-Management Support? Content last reviewed February 2016. Agency for Healthcare Research and Quality, Rockville, MD. https://www.ahrq.gov/ncepcr/tools/self-mgmt/what.html.

[13] Self-Management Support. Content last reviewed February 2016. Agency for Healthcare Research and Quality, Rockville, MD. https://www.ahrq.gov/ncepcr/tools/self-mgmt/home.html.

[14] National Cancer Institute. Health Information National Trends Survey 7 (HINTS 7): Annotated English Instrument. Revised February 7, 2025. Accessed June 22, 2025. https://hints.cancer.gov/docs/Instruments/HINTS7-AnnotatedEnglish.pdf.

[15] Zhou L, Bao J, Setiawan IMA, Saptono A, Parmanto B. The mHealth App Usability Questionnaire (MAUQ): Development and validation study. JMIR mHealth uHealth. 2019;7(4):e11500. Published 2019 Apr 11. doi:10.2196/11500.

[16] Agency for Healthcare Research and Quality; Tahlequah City Hospital. *Oklahoma Patient Survey*. AHRQ; Accessed June 20, 2025. https://digital.ahrq.gov/sites/default/files/docs/survey/oklahoma-patient-survey.pdf

[17] California HealthCare Foundation; Lake Research Partners. *Consumers and Health Information Technology: A National Survey*. California HealthCare Foundation; April 2010. Accessed June 20, 2025. https://www.chcf.org/wp-content/uploads/2017/12/PDFConsumersHealthInfoTechnologyNationalSurvey.pdf.

[18] Virginia Commonwealth University; Agency for Healthcare Research and Quality. *Portal and Non-Portal User Surveys to Assess MyPreventiveCare Portal*. Virginia Commonwealth University; 2011. Accessed June 20, 2025. https://digital.ahrq.gov/sites/default/files/docs/survey/portal-and-non-portal-user-surveys-to-assess-mypreventivecare-portal.pdf.

[19] CAHPS Clinician & Group Survey. Content last reviewed March 2025. Agency for Healthcare Research and Quality, Rockville, MD. https://www.ahrq.gov/cahps/surveys-guidance/cg/index.html.

[20] Torain MJ, Bennett GG, Matsouaka RA, et al. The patient's point of view: characterizing patient-level factors associated with perceptions of health care. Health Equity. 2021;5(1), 457–465. https://doi.org/10.1089/heq.2021.0062.

[21] Organisation for Economic Co-operation and Development (OECD). PaRIS Patient Questionnaire. Accessed June 22, 2025. https://www.oecd.org/content/dam/oecd/en/about/programmes/patient-reported-indicator-surveys/PaRIS%20patient%20questionnaire.pdf.

[22] Agency for Healthcare Research and Quality. Access to Care. Updated May 2023. Accessed June 22, 2025. https://www.ahrq.gov/topics/access-care.html.

[23] Agency for Healthcare Research and Quality. CAHPS Clinician and Group Survey 3.0 Measures. Updated September 2020. Accessed June 22, 2025. https://www.ahrq.gov/cahps/surveys-guidance/cg/about/survey-measures.html.

[24] Agency for Healthcare Research and Quality. CAHPS Health Information Technology Item Set: Measures. Accessed June 22, 2025. https://www.ahrq.gov/cahps/surveys-guidance/item-sets/HIT/measures.html.

[25] Agency for Healthcare Research and Quality. Tool 4: Tips for Communicating Clearly with Patients. Accessed June 22, 2025. https://www.ahrq.gov/health-literacy/improve/precautions/tool4.html.

[26] Paget L, Han P, Nedza S, et al. Patient-Clinician Communication: Basic Principles and Expectations. National Academy of Medicine. Published June 15, 2011. Accessed June 22, 2025. https://nam.edu/perspectives/patient-clinician-communication-basic-principles-and-expectations/.

[27] Office of the National Coordinator for Health Information Technology. Shared Decision Making Fact Sheet. Published December 2013. Accessed June 22, 2025. https://www.healthit.gov/sites/default/files/nlc_shared_decision_making_fact_sheet.pdf.

[28] Agency for Healthcare Research and Quality. Supplemental Items for the CAHPS Clinician & Group Adult Survey 3.0: Health Information Technology. Updated October 2022. Accessed June 22, 2025. https://www.ahrq.gov/cahps/surveys-guidance/item-sets/HIT/suppl-healthit-items-cg-survey30-adult.html.

[29] Flocke SA. Measuring attributes of primary care: development of a new instrument. J Fam Pract. 1997 Jul;45(1):64-74. PMID: 9228916.

[30] Centers for Medicare & Medicaid Services. HCAHPS Survey Instruments. Updated December 3, 2024. Accessed June 22, 2025. https://www.hcahpsonline.org/en/survey-instruments/.

[31] Agency for Healthcare Research and Quality. CAHPS Clinician & Group Survey 4.0 (Adult) – English. Updated October 2023. Accessed June 22, 2025. https://www.ahrq.gov/sites/default/files/wysiwyg/cahps/surveys-guidance/cg/adult-eng-cg40-3351a.pdf.

[32] Agency for Healthcare Research and Quality. About Shared Decision Making. Content last reviewed May 2023. https://www.ahrq.gov/sdm/about/index.html.

[33] Desai PJ, Nanji K, Dullabh PM, et al. Outcomes and Objectives Workgroup: Integration of Patient-Centered Clinical Decision Support Into Shared Decision Making. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0084. Rockville, MD: Agency for Healthcare Research and Quality; September 2023.

[34] Agency for Healthcare Research and Quality. Supplemental Items for the CAHPS Clinician & Group Adult Survey 3.0: Shared Decision Making. Updated November 2017. Accessed June 22, 2025. https://www.ahrq.gov/cahps/surveys-guidance/item-sets/cg/suppl-decisionmaking-cg30-adult.html.

[35] Scholl I, Härter M. SDM-Q-9/SDM-Q-DOC—the 9-item Shared Decision Making Questionnaire. Patient-als-Partner.de. Published online (German site, English version available). Accessed June 22, 2025. https://www.patient-als-partner.de/index.php?article_id=20&clang=2/.

[36] Rencz F, Péntek M, Gulácsi L, et al. Did you get what you wanted? Patient satisfaction and congruence between preferred and perceived roles in medical decision making in a Hungarian national survey. Value Health Reg Issues. 2020;22:103-109.

[37] Clinical Decision Support Innovation Collaborative (CDSiC). Patient-Centered Clinical Decision Support Explained [infographic]. Published May 1, 2024. Accessed June 22, 2025. https://cdsic.ahrq.gov/cdsic/patient-centered-clinical-cds-infographic.

[38] NHS England. GP Patient Survey 2024: Public Questionnaire. Accessed June 22, 2025. https://www.gp-patient.co.uk/downloads/2024/qandletter/GPPS_2024_Questionnaire_PUBLIC.pdf.

[39] European Organisation for Research and Treatment of Cancer (EORTC). IN-PATSAT32: Specimen English Questionnaire. Accessed June 22, 2025. https://www.eortc.org/app/uploads/sites/2/2018/08/Specimen-IN-PATSAT32-English.pdf.

[40] Larson E, Sharma J, Bohren MA, Tunçalp Ö. When the patient is the expert: measuring patient experience and satisfaction with care. Bull World Health Organ. 2019;97(8):563-569. doi:10.2471/BLT.18.225201.

[41] Ratanjee-Vanmali H, Swanepoel W, Laplante-Lévesque A. Patient Uptake, Experience, and Satisfaction Using Web-Based and Face-to-Face Hearing Health Services: Process Evaluation Study. J Med Internet Res. 2020 Mar 20;22(3):e15875. doi: 10.2196/15875. PMID: 32196459; PMCID: PMC7125439.

[42] Mahmood S, Hazes JMW, Veldt P, van Riel P, Landewé R, Bernelot Moens H, Pasma A. The Development and Evaluation of Personalized Training in Shared Decision-making Skills for Rheumatologists. J Rheumatol. 2020 Feb;47(2):290-297. doi: 10.3899/jrheum.180780. Epub 2019 Apr 1. PMID: 30936289.

[43] Sansoni J, Hawthorne G, Marosszeky N, Sansoni E. The Short Assessment of Patient Satisfaction (SAPS): Report. Centre for Health Service Development, University of Wollongong; 2020. Accessed June 22, 2025. https://www.continence.org.au/sites/default/files/2020-05/Academic_Report_Short_Assessment_of_Patient_Satisfaction_SPAS.pdf.

[44] UIUX Trend. Post-Study System Usability Questionnaire (PSSUQ) Template. Accessed June 22, 2025. https://www.uiuxtrend.com/wp-content/uploads/PSSUQ-Questionnaire-PDF-Template.pdf.

[45] International Standards Organization. 4.19 Usability of Consumer Products and Products for Public Use—Part 2: Summative Test Method. 2013. https://www.iso.org/obp/ui/#iso:std:iso:ts:20282:-2:ed-2:v1:en.

[46] Stoyanov SR, Hides L, Kavanagh DJ, Zelenko O, Tjondronegoro D, Mani M. Mobile app rating scale: a new tool for assessing the quality of health mobile apps. JMIR mHealth uHealth. 2015;3(1):e27. doi:10.2196/mhealth.3422.

[47] Sauro J. Measuring usability with the System Usability Scale (SUS). MeasuringU. Published February 3, 2011. Accessed June 22, 2025. https://measuringu.com/sus/.

[48] Albert W, Tullis TS. Self-Reported Metrics. In: Albert W, Tullis TS, eds. *Measuring the User Experience*. 3rd ed. Morgan Kaufmann; 2023:109-151. doi:10.1016/B978-0-12-818080-8.00005-4.

[49] Agency for Healthcare Research and Quality. Care Coordination. Content last reviewed November 2024. https://www.ahrq.gov/ncepcr/care/coordination.html.

[50] Stoyanov S, Hides L, Kavanagh D, Wilson H. Development and validation of the User Version of the Mobile Application Rating Scale (uMARS). JMIR mHealth uHealth. 2016;4(2):e72. https://mhealth.jmir.org/2016/2/e72. doi: 10.2196/mhealth.5849.

[51] Stewart AL, Nápoles-Springer AM, Gregorich SE, Santoyo-Olsson J. Interpersonal processes of care survey: patient-reported measures for diverse groups. Health Serv Res. 2007 Jun;42(3 Pt 1):1235-56. doi: 10.1111/j.1475-6773.2006.00637.x. PMID: 17489912; PMCID: PMC1955252.

[52] Jemal K, Hailu D, Mekonnen M, Tesfa B, Bekele K, Kinati T. The importance of compassion and respectful care for the health workforce: a mixed-methods study. Z Gesundh Wiss. 2023;31(2):167-178. doi:10.1007/s10389-021-01495-0.

[53] Beach MC, Sugarman J, Johnson RL, Arbelaez JJ, Duggan PS, Cooper LA. Do patients treated with dignity report higher satisfaction, adherence, and receipt of preventive care? Ann Fam Med. 2005;3(4):331-338. doi:10.1370/afm.287

[54] Beach MC, Roter DL, Wang NY, et al. Are physicians’ attitudes of respect accurately perceived by patients and associated with more positive communication behaviors? Patient Educ Couns. 2006;62(3):347-354. doi:10.1016/j.pec.2006.06.004.

[55] Mayfield E, Highfield MEF, Mendelson S. Meaning of courtesy and respect: Nurse and patient experiences. J Nurs Care Qual. 2020;35(2):177-181. doi:10.1097/NCQ.0000000000000424.

[56] Agency for Healthcare Research and Quality**.** CAHPS Clinician & Group Survey 3.1 (Adult) – English. Updated October 2020. Accessed June 22, 2025. https://www.ahrq.gov/sites/default/files/wysiwyg/cahps/surveys-guidance/cg/adult-english-cg-3-1-2351a.pdf.

[57] Centers for Medicare & Medicaid Services. HCAHPS Survey Instrument: English Mail Version, Effective January 1, 2025. Accessed June 22, 2025. https://www.hcahpsonline.org/globalassets/hcahps/survey-instruments/mail/effective-january-1-2025-and-forward-discharges/october_2024_final_survey-instruments_english_mail.pdf.

[58] U.S. Department of Veterans Affairs. VA Form 10-1465-5: SHEP Patient Centered Medical Homes (PCMH) Short Form. OMB Control No. 2900-0712. Accessed June 22, 2025. https://omb.report/icr/202102-2900-017/doc/109373100.

[59] U.S. Department of Health and Human Services, Office of Minority Health. What is CLAS? Think Cultural Health. Accessed June 23, 2025. https://thinkculturalhealth.hhs.gov/clas/what-is-clas.

[60] Bhuiyan J, Loder C. Evaluating patient experiences with patient-centered and inclusive care in academic obstetrics and gynecology outpatient clinics. J Patient Exp. 2024;11:23743735241297620. doi:10.1177/23743735241297620.

[61] Barwise AK, Curtis S, Diedrich DA, Pickering BW. Using artificial intelligence to promote equitable care for inpatients with language barriers and complex medical needs: clinical stakeholder perspectives. J Am Med Inform Assoc. 2024;31(3):611-621. doi:10.1093/jamia/ocad224.

[62] Federal Register: Request for Information; Health Technology Ecosystem. https://www.federalregister.gov/documents/2025/05/16/2025-08701/request-for-information-health-technology-ecosystem.

[63] Witkowski K, Okhai R, Neely SR. Public perceptions of artificial intelligence in healthcare: Ethical concerns and opportunities for patient-centered care. BMC Med Ethics. 2024;25(1):74. Published 2024 Jun 22. doi:10.1186/s12910-024-01066-4.

[64] Naik N, Hameed BMZ, Shetty DK, et al. Legal and Ethical Consideration in Artificial Intelligence in Healthcare: Who Takes Responsibility? Front Surg. 2022 Mar 14;9:862322. doi: 10.3389/fsurg.2022.862322. PMID: 35360424; PMCID: PMC8963864.

[65] Shen J, DiPaola D, Ali S, et al. Empathy toward artificial intelligence versus human experiences and the role of transparency in mental health and social support chatbot design: comparative study. JMIR Ment Health. 2024;11:e62679. doi:10.2196/62679.

[66] Ovsyannikova D, Oldemburgo de Mello V, Inzlicht M. Third-party evaluators perceive AI as more compassionate than expert humans. Commun Psychol. 2025;3(1):4. doi:10.1038/s44271-024-00182-6.

[67] Kawamoto K, Ryan S, Heaney-Huls K, et al. Implementation, Adoption, and Scaling Workgroup: Landscape Assessment on the Use of Artificial Intelligence To Scale PC CDS. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 24-0069-1. Rockville, MD: Agency for Healthcare Research and Quality; June 2024.

[68] Dullabh P, Ryan S, Desai P, et al. Exploring How Artificial Intelligence (AI) Can Enhance Patient-Centered Clinical Decision Support. Agency for Healthcare Research and Quality. https://cdsic.ahrq.gov/cdsic/AI-viewpoint. Published February 25, 2025. Accessed July 29, 2025.

[69] Ryan S, Heaney-Huls K, Kawamoto K, et al. Implementation, Adoption, and Scaling Workgroup: Artificial Intelligence-Supported Patient-Centered Clinical Decision Support: A Summary of Considerations. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 25-0057. Rockville, MD: Agency for Healthcare Research and Quality; June 2025.

[70] Barrett D, Sibalija J, Kim RB. Patients' experiences of a precision medicine clinic. J Patient Exp. 2024;11:23743735241229384. doi:10.1177/23743735241229384.

[71] de Batlle J, Massip M, Vargiu E, et al. Implementing mobile health-enabled integrated care for complex chronic patients: patients and professionals' acceptability study. JMIR mHealth uHealth. 2020;8(11):e22136. doi:10.2196/22136.

[72] Erturkmen GBL, Yuksel M, Sarigul B, et al. A collaborative platform for management of chronic diseases via guideline-driven individualized care plans. Comput Struct Biotechnol J. 2019;17:869-885. doi:10.1016/j.csbj.2019.06.003.

[73] Gashaw DG, Alemu ZA, Constanzo F, et al. COVID-19 patient satisfaction and associated factors in telemedicine and hybrid system. Front Public Health. 2024;12:1384078. doi:10.3389/fpubh.2024.1384078.

[74] Grodon J, Tack C, Eccott L, Cairns MC. Patient experience and barriers of using a mHealth exercise app in musculoskeletal (MSK) physiotherapy. PLOS Digit Health. 2024;3(10):e0000626. doi:10.1371/journal.pdig.0000626.

[75] Irfan Khan A, Gill A, Cott C, et al. mHealth tools for the self-management of patients with multimorbidity in primary care settings: Pilot study to explore user experience. JMIR mHealth uHealth. 2018;6(8):e171. https://mhealth.jmir.org/2018/8/e171. DOI: 10.2196/mhealth.8593.

[76] Kim SM, Kim T, Cha WC, et al. User experience of mobile personal health records for the emergency department: mixed methods study. JMIR mHealth uHealth. 2020;8(12):e24326. doi:10.2196/24326.

[77] Lee K, Lee SH. Artificial intelligence-driven oncology clinical decision support system for multidisciplinary teams. Sensors (Basel). 2020;20(17):4693. doi:10.3390/s20174693.

[78] Lines LM, Cohen J, Kirschner J, et al. Associations between illness burden and care experiences among Medicare beneficiaries before or after a cancer diagnosis. J Geriatr Oncol. 2022;13(5):731-737. doi:10.1016/j.jgo.2022.02.017.

[79] Liu AW, Odisho AY, Brown W III, et al. Patient experience and feedback after using an electronic health record-integrated COVID-19 symptom checker: Survey study. JMIR Hum Factors. 2022;9(3):e40064. doi:10.2196/40064.

[80] Mahmood S, Hazes JMW, Veldt P, et al. The development and evaluation of personalized training in shared decision-making skills for rheumatologists. J Rheumatol. 2020;47(2):290-297. doi:10.3899/jrheum.180780.

[81] Mason AN, Brown M, Mason K. Telemedicine patient satisfaction dimensions moderated by patient demographics. Healthcare (Basel). 2022;10(6):1029. doi:10.3390/healthcare10061029.

[82] Mercer MB, Rose SL, Talerico C, et al. Use of visual decision aids in physician–patient communication: a pilot investigation. J Patient Exp. 2018;5(3):167-176. doi:10.1177/2374373517746177.

[83] Portz J, Bayliss E, Bull S, Boxer R, Bekelman D, Gleason K, Czaja S. Using the Technology Acceptance Model to Explore User Experience, Intent to Use, and Use Behavior of a Patient Portal Among Older Adults With Multiple Chronic Conditions: Descriptive Qualitative Study. J Med Internet Res. 2019;21(4):e11604. doi: 10.2196/11604.

[84] Rencz F, Tamási B, Brodszky V, et al. Did you get what you wanted? Patient satisfaction and congruence between preferred and perceived roles in medical decision making in a Hungarian national survey. *Value Health Reg Issues*. 2020;22:61-67. doi:10.1016/j.vhri.2020.07.573

[85] Resnik LJ, Borgia ML, Clark MA, et al. Structural validity and reliability of the patient experience measure: a new approach to assessing psychosocial experience of upper limb prosthesis users. *PLoS One*. 2021;16(12):e0261865. doi:10.1371/journal.pone.0261865

[86] Rose S, Hurwitz HM, Mercer MB, et al. Patient experience in virtual visits hinges on technology and the patient-clinician relationship: a large survey study with open-ended questions. *J Med Internet Res*. 2021;23(6):e18488. doi:10.2196/18488

[87] Senitan M, Gillespie J. Health-care reform in Saudi Arabia: patient experience at primary health-care centers. *J Patient Exp*. 2020;7(4):587-592. doi:10.1177/2374373519872420

[88] Torain MJ, Bennett GG, Matsouaka RA, et al. The patient's point of view: characterizing patient-level factors associated with perceptions of health care. *Health Equity*. 2021;5(1):457-465. doi:10.1089/heq.2021.0062

[89] van der Storm SL, Hensen N, Schijven MP. Patient satisfaction with stoma care and their expectations on mobile apps for supportive care. *Colorectal Dis*. 2023;25(9):1852-1862. doi:10.1111/codi.16658

[90] Zand A, Nguyen A, Reynolds C, Khandadash A, Esrailian E, Hommes D. Patient experience and satisfaction with an e-health care management application for inflammatory bowel diseases. *Int J Environ Res Public Health*. 2021;18(22):11747. doi:10.3390/ijerph182211747

[91] Agency for Healthcare Research and Quality. CAHPS Health Plan Survey. Content last reviewed March 2025. https://www.ahrq.gov/cahps/surveys-guidance/hp/index.html.

[92] Degner LF, Sloan JA, Venkatesh P. The Control Preferences Scale. Can J Nurs Res. 1997;29(3):21-43.

[93] FACIT.org. Functional Assessment of Chronic Illness Therapy (FACIT) Measurement System: Questionnaire PDF. Accessed June 22, 2025. https://www.facit.org/_files/ugd/c0dc3a_fd8b3039d5f54326a84a6d993f091c67.pdf.

[94] Yen PY, Wantland D, Bakken S. Development of a customizable health IT usability evaluation scale. AMIA Annu Symp Proc. 2010;2010:917-921.

[95] Nguyen TV, Bosset JF, Monnier A, et al. Supplementary material for: Determinants of patient satisfaction in ambulatory oncology: a cross sectional study based on the OUT-PATSAT35 questionnaire. *BMC Cancer*. 2011;11:526. Published 2011 Dec 28. doi:10.1186/1471-2407-11-526

[96] Agency for Healthcare Research and Quality. *IQHealth: Patient Enrollment Experience and Expectations*. Published circa 2016. PDF. Accessed June 20, 2025

[97] Centers for Disease Control and Prevention, National Center for Health Statistics**.** National Health Interview Survey (NHIS): 2024 English Questionnaire. Accessed June 22, 2025. https://ftp.cdc.gov/pub/Health_Statistics/NCHS/Survey_Questionnaires/NHIS/2024/EnglishQuest.pdf.

[98] Noest S, Ludt S, Klingenberg A, et al. Involving patients in detecting quality gaps in a fragmented healthcare system: Development of a questionnaire for Patients' Experiences Across Health Care Sectors (PEACS). Int J Qual Health Care. 2014;26(3):240-249. doi:10.1093/intqhc/mzu044.

[99] Agency for Healthcare Research and Quality. *Patient Use of Computer Systems in Health Care Settings*. Circa 2010. PDF. Accessed June 20, 2025.

[100] Davis FD. Perceived usefulness, perceived ease of use, and user acceptance of information technology. MIS Q. 1989;13(3):319-340. doi:10.2307/249008.

[101] Agency for Healthcare Research and Quality; Virginia Commonwealth University. Use of Web-Based Health Information (Patient/Practice Portal Users and Non-Users). Richmond, VA: Virginia Commonwealth University; circa 2021. Questionnaire. Accessed June 20, 2025.

[102] Lund AM. Measuring usability with the USE questionnaire. *Usability Interface*. 2001;8(2):3-6. https://www.researchgate.net/publication/230786746_Measuring_Usability_with_the_USE_Questionnaire.