Outcomes and Objectives Workgroup: Integration of Patient-Centered Clinical Decision Support Into Shared Decision Making

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PURPOSE

The Clinical Decision Support Innovation Collaborative (CDSiC) Outcomes and Objectives Workgroup is charged with (1) identifying near- and long-term goals that will advance the translation of patient-centered outcomes research-based evidence into clinical practice through safe and effective patient-centered clinical decision support (PC CDS), (2) developing measurement and effectiveness criteria for assessing the impact of PC CDS on health-related outcomes, and (3) informing the CDSiC's objectives for advancing PC CDS and the desired impact of the collaborative based on stakeholder input. The Workgroup is composed of nine experts and stakeholders representing a diversity of perspectives within the CDS community. The PC CDS Shared Decision Making (SDM) Framework is intended to be primarily used by developers of PC CDS, healthcare organizations looking to make use of PC CDS in the context of SDM, and patient advocates. The CDSiC will also use the framework to inform product development under its Stakeholder and Community Outreach Center Workgroups and for projects developed through its Innovation Center.

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Executive Summary

Patient-centered clinical decision support (PC CDS) are digital tools to support healthcare decision making informed by patient-centered factors related to knowledge, data, delivery, and/or use. In order to provide care that is patient-centered, clinicians must be able to convey complex evidence and risk information while tailoring their recommendations to the individual needs, preferences, values, goals, and circumstances of their patients. This can be achieved through shared decision making (SDM), a process in which the clinician and patient and/or caregivers(s) work together to make a healthcare decision that is best for the patient. The Agency for Healthcare Research and Quality's (AHRQ's) SHARE Approach outlines a process for SDM that includes seeking patient participation, helping patients explore and compare treatment options, assessing patient values and preferences, reaching a decision with the patient, and evaluating the patient's decision.

Although much is known about SDM, there is a knowledge gap regarding how PC CDS can best support some or all aspects of the SDM process. This report takes an important step in addressing this gap, providing a framework for the use of PC CDS tools in SDM. The information in this report is primarily designed for clinicians and healthcare systems aiming to enhance SDM through the incorporation of PC CDS, patient advocates championing the elicitation and subsequent use of preference and other patient-specific information at the point-of-care, and developers of PC CDS and electronic health records (EHRs).

Methods

We conducted a targeted review of the peer reviewed and grey literature to identify relevant models of SDM and examples of the application of PC CDS in SDM. Preliminary findings informed the development of a PC CDS-SDM Framework, which was supplemented and validated by subject matter experts through key informant interviews.

Findings

Findings from the literature scan and key informant interviews informed the development of a PC CDS-SDM integrated framework, building on the Three Talk Model of SDM. The Three-Talk Model, which defines SDM as a collaborative decision making process in which trustworthy information about options is shared in accessible formats, outlines three phases of SDM: *team talk, option talk, and decision talk*. Each type of talk represents a type of collaboration and consultation within the SDM process. The PC CDS-SDM Framework crosswalks the three phases of SDM with three elements of PC CDS: *knowledge* (e.g., patient-centered outcomes research [PCOR]), *data* (e.g., patient-reported outcomes [PROs], social determinants of health [SDOH]) and *delivery* (e.g., access and engagement via applications, portals) to showcase how PC CDS can support SDM.

In *team talk*, patients and clinicians acknowledge that there is a decision to be made. PC CDS can initiate team talk by drawing on evidence-based findings (*knowledge*) and patient information (*data*) to generate an alert or recommendation that lets patients and/or clinicians know that a decision needs to be made (*delivery*).

In *option talk*, patients and clinicians discuss available options for the decision to be made, while considering the benefits and risks of each option. PC CDS can support this phase of SDM by providing recommendations based on PCOR (*knowledge)* as well as collecting and integrating patient-specific information (*data* and *delivery*) to inform the benefits and risks of available options.

In *decision talk***,** the patient and clinician discuss information about potential options with a focus on what is the most important to the patient (i.e., their values), the care that best aligns with their individual characteristics (i.e., their preferences) and life context (i.e., circumstances), and their preferred outcomes (i.e., their goals). PC CDS can support this phase through the collection and integration of this information (*data* and *delivery*). Decision talk contextualizes the risks and benefits (*knowledge*) presented in the option talk phase.

Areas for Future Work

While our framework demonstrates the potential for PC CDS to support SDM, we lack evidence on the design, implementation, and evaluation of the role and impact of digital, PC CDS tools in the SDM process. Several challenges and opportunities must be explored to effectively harness PC CDS for SDM. Findings from the literature and key informant interviews highlighted areas for future work:

Impact and Implementation: Barriers and concerns around implementation and impact at both the patient and clinician level continue to be raised. While clinician barriers primarily focus on time required for use and actionability of patient-generated health data (PGHD) in decision making, larger concerns arise when considering the potential for increased health disparities as populations with higher digital and health literacy disproportionately benefit from use of these tools. Attention is needed to address equal distribution of benefits and the impact of tailored and personalized PC CDS on patient understanding of healthcare and health outcomes. This includes examining mitigating factors and best practices for conducting needs assessments, collaborative design, and field testing of PC CDS tools for SDM.

Data Visualization and Risk Communication: Data visualization tools can help aggregate, interpret, and present data in a way that contributes to clinical deliberation. Research is needed to better understand how PC CDS should present data to patients and clinicians, and how to increase presentation and utilization of individualized risk data in risk communication to patients during SDM. SDM would be better supported by a standardized definition of minimal clinically important difference (MCID) for PRO data and other PGHD that reflects actionability.

Equity and Engagement: To avoid further exacerbation of disparities, solutions that address challenges related to access, activation, usability, and engagement need to be identified. This includes examining the impacts of patient factors like digital and health literacy, SDOH, culture, language, ability, and infrastructure. Additionally, research exploring the impact of PC CDS customization across different contexts, and the feasibility and cost of tool development and customization at scale is needed.

Conclusion

As patients' access to health data, information, and tools continues to increase, patients are likely to become better equipped to monitor their own health and engage their clinicians in informed discussions

about their care. Medical professionals have a responsibility to support patient decision making both within and beyond the clinical encounter. This will require the curation of trustworthy digital tools to support collaboration between patients and their clinician in SDM, improved integration of patient-contributed data into PC CDS, and the integration of PC CDS within the phases of SDM.

1. Introduction

Over the past two decades, the emergence and evolution of digital health technologies such as patient portals, mobile applications (apps), and websites targeting patients and healthcare consumers has led to a rapid expansion in the types of resources that individuals can use when making decisions about their health.[1] At the same time, health systems are increasingly recognizing that empowering patients with easier access to health data, information, and tools may lead to improved health outcomes and satisfaction with care.[2,3] While adoption rates among patients and consumers remain low,[4,5] investment in digital health companies continues to expand, underscoring the strong interest in and anticipated potential of using digital health tools to drive improved care.[6] Accordingly, patients can expect to be presented with greater opportunity to make choices about their care in the foreseeable future.

Many advances in the development of CDS have enhanced health-related decisions and actions with pertinent clinical knowledge and patient information. CDS encompasses digital tools designed to enable timely decision making and subsequent delivery of evidence-based care.[7] Early development and adoption were typically clinician-facing and used to deliver diagnostic and treatment guidance.[7] As the broader movement toward patient-centered care has steadily gained momentum, it has motivated a focus on the development of PC CDS, which can be patient-facing, clinician-facing, or both. Patient-facing PC CDS can be tools that patients or their caregivers use. PC CDS is informed by patient-centered factors related to (1) knowledge—findings from PCOR and comparative effectiveness research (CER), (2) data—including patient-generated, patient-reported, and patient-specific data, (3) delivery—incorporation of patient-facing tools (e.g., apps, websites, patient portals, and text messages), and/or (4) use (see **Exhibit 1**).[8-10]

Exhibit 1. Definition of Patient-Centered Clinical Decision Support

 Knowledge	 Data	 Delivery	 Use
Using evidence-based findings from comparative effectiveness research and patient-centered outcomes research.	Incorporating data affecting individual patient health such as patient-generated health data, including patient reported outcomes, patient preferences, patient-specific information, and social determinants of health.	Directly engaging patients or caregivers across different settings through apps or patient portals.	Facilitating patient-clinician information exchange that ensures mutually acceptable decisions by exploring and comparing benefits, harms, and risks.

Care is patient-centered when it is "respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions."[11,12,13] As part of patient-centered care, clinicians must be able to convey complex evidence and risk information while tailoring their recommendations to the individual needs, preferences, values, goals, and circumstances of their patients. This can be achieved through SDM, which is an inherently collaborative process

bringing together patient preferences and other information with clinician guidance.[14] It occurs when a clinician and a patient and/or caregivers(s) work together to make a healthcare decision that is best for the patient. SDM often involves a decision between two or more evidence-based options.[8,9,15] The optimal decision considers evidence-based information about available options, the AHRQ's SHARE Approach outlines a process for healthcare providers to facilitate shared decision making, emphasizes engaging patients in meaningful conversation about the benefits, harms, and risks of available options.[14] SDM is increasingly advocated as an ideal model of care, which aims to promote patient autonomy, limit practice variation, and ensure that care decisions reflect patient preferences.[16,17,18]

Although much is known about SDM, there is a knowledge gap regarding how PC CDS can best support some or all aspects of the SDM process. This brief report presents a PC CDS-SDM framework that highlights opportunities for PC CDS to enhance SDM and discusses an agenda for future work. The report is primarily designed for clinicians and healthcare systems aiming to enhance SDM through the incorporation of PC CDS, patient advocates championing SDM and integration of preference and other patient-specific information at the point-of-care, and developers of PC CDS and EHRs.

2. Methods

A targeted literature search of peer-reviewed and grey literature was conducted to identify relevant models of SDM, literature relevant to PC CDS and SDM, and examples of PC CDS tools that may facilitate SDM. Based on this search, a conceptual model of SDM was selected to guide development of the PC CDS-SDM Framework. Qualitative interviews with experts were conducted to validate the framework, enrich our understanding of salient issues, and identify additional relevant examples of PC CDS tools from the field. Additional targeted searches were conducted to supplement findings on PC CDS tools and concepts raised in qualitative interviews. A brief summary of our methods is presented below.

2.1 Development of PC CDS-SDM Framework

A range of SDM models are available in the literature. For the purposes of developing the PC CDS-SDM Framework, the Outcomes and Objectives Workgroup focused on selecting a model that reflected the nonlinearity and iterative nature of the SDM process. In the initial scan, the CDSiC team identified and reviewed five systematic reviews and specific models of SDM.[18-22] Ultimately, the Workgroup selected the Three-Talk Model, due to its iterative and nonlinear depiction of the SDM process, which Workgroup members found to be most representative of SDM in practice.[23]

To develop the PC CDS-SDM Framework, we crosswalked the steps of SDM within the Three-Talk Model with three patient-centered factors for PC CDS (knowledge, data, and delivery), drawing on relevant examples in the literature. For the purposes of the PC CDS-SDM crosswalk, the use component of PC CDS was assumed to be SDM throughout. The Outcomes and Objectives Workgroup, which includes patient advocates, was engaged in framework validation efforts during monthly Workgroup meetings and through asynchronous feedback between March and July 2023. Targeted discussion questions regarding quality and completeness of framework mapping, utility of the framework, relevance to PC CDS, and awareness of existing examples were presented for their reflections and contributions.

2.2 Key Informant Interviews

To further validate development of the PC CDS-SDM Framework, we conducted a series of key informant interviews (KIIs) between June and July 2023. The purpose of these interviews was to obtain feedback on the preliminary framework, surface implementation considerations and evidence gaps, and solicit recommendations for additional examples of tools. Purposive and snowball sampling was used to identify candidate interviewees, and specific recommendations were solicited from the Outcomes and Objectives Workgroup members.

A total of four (n=4) KIIs were conducted, representing the following stakeholder perspectives: SDM experts (n=1), EHR developers (n=2), and CDS content developers (n=1). A semistructured discussion guide was developed to support the interviews. Each interview was approximately 60 minutes in duration, conducted via Zoom, and video and audio recorded. Insights from the KIIs prompted targeted searches of the peer-reviewed and grey literature to identify example tools. Interviews were also analyzed using qualitative content analysis to identify key opportunities and challenges related to integrating PC CDS within SDM.[24]

2.3 Targeted Tool Scan

The purpose of the targeted tool scan was to identify existing examples of PC CDS tools used in the context of SDM. Given that the underlying evidence base for PC CDS is not always reported and that multiple modalities of PC CDS may support SDM, the search for tools focused on data as a patient-centered factor. The scan was approached three ways: keyword search in Google, peer-reviewed literature search, and search of well-known decision aid repositories (the Ottawa Hospital Research Institute A to Z Inventory of Decision Aids, Washington State Health Care Authority Certified Patient Decision Aids, and Mayo Clinic Shared Decision-Making National Resource Center). We searched decision aid repositories given the well-established use of decision aids in SDM.[25] While not all patient decision aids are PC CDS, there is conceptual overlap between the two, given that both aim to support patients in making informed healthcare decisions and that CDS can encompass a range of tools, including patient data summaries and relevant reference information.[26,27] To ensure that included tools aligned with PC CDS, we included only web-based or digital tools that incorporated patient-specific data, such as:

- SDM experience factors (e.g., communication, information-seeking, decision making preferences; health and/or digital literacy).
- Patient values, preferences, and/or goals.
- Patient-contributed data such PGHD and SDOH.

Additional information about these resources, as well as search strategies, are described in **Appendix A.** All scan-related searches were conducted between May and July 2023.

3. Key Findings

PC CDS can support discussions between patients, caregivers, and care teams throughout the SDM process. While not an exhaustive search of available tools, our scan for digital and web-based tools

indicates that clinicians and researchers are exploring innovative and functional ways to incorporate PC CDS in the SDM process. These tools reflect a range of capabilities for data capture and integration (e.g., patient preferences, health history and risk factors, and PGHD) and delivery modalities (patient-facing, clinician-facing, or both). However, key informants also noted that there are several challenges to address and opportunities to explore in order to fully harness PC CDS for SDM.

In the sections that follow, we present the PC CDS-SDM Framework, which crosswalks the Three-Talk SDM model with three factors of PC CDS. We then review challenges and opportunities surfaced by key informants for using PC CDS in SDM.

3.1 The PC CDS-SDM Framework

The Three Talk Model outlines three phases of SDM (team talk, option talk, and decision talk) (**Exhibit 2**). The PC CDS-SDM Framework crosswalks the three phases of SDM (**Exhibit 3**) with three elements of PC CDS—knowledge, data, and delivery. For the purposes of the PC CDS-SDM crosswalk, the use component of PC CDS was assumed to be SDM throughout and, therefore, is not depicted. Below, we elaborate on how PC CDS aligns with SDM within these three phases, highlighting example tools from our scan (A full list of tools identified in the scan is provided in **Appendix B**). We refer to the patient and clinician within our description of the framework; however, caregivers and multiple members of the care team may participate in SDM.

Exhibit 2. Simplified Three-Talk Model of shared decision making (adapted from Elywn et al. 2017)

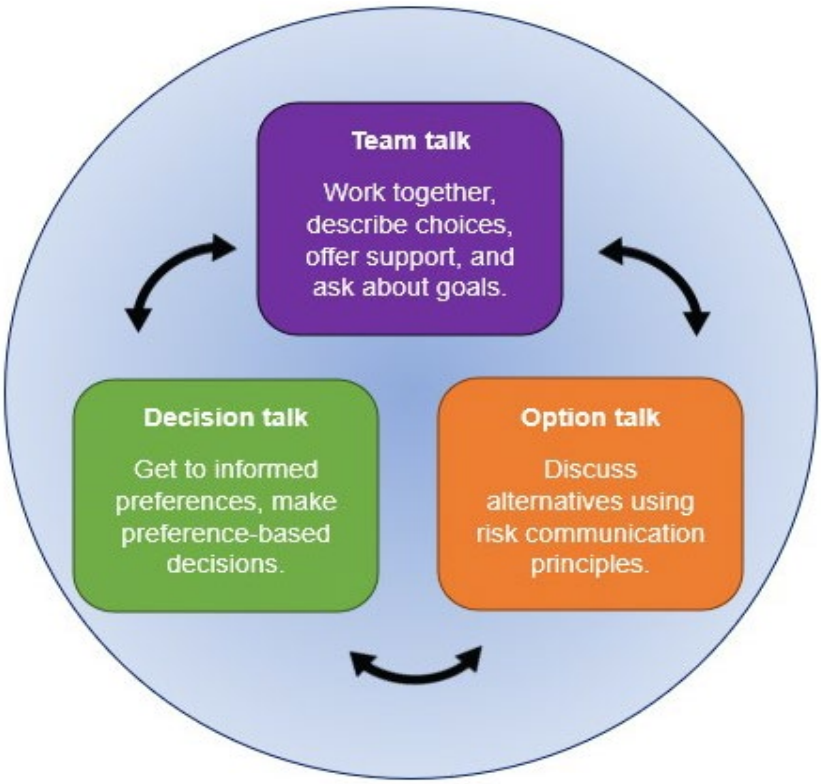

Exhibit 3. PC CDS-SDM Framework

	TEAM TALK Recognize there is a decision to be made.	**OPTION TALK** Discuss benefits and risks of options.	**DECISION TALK** Make informed decisions together based on patient's preferences.
Knowledge *PCOR or CER findings*	PC CDS alerts and recommendations can ensure that SDM is initiated based on patient-centered evidence.	PC CDS can provide information about options that is based on outcomes important to patients.	
Data *PROs and other PGHD, SDOH, and values, preferences, and goals*	PC CDS can incorporate decision making preferences and patient-specific data to ensure that SDM is initiated based on the characteristics and health history of the patient.	PC CDS can use patient-specific data (e.g., health history, PGHD, SDOH) to personalize the risk and benefits of options.	PC CDS can integrate patient values, preferences, and goals that contextualize options based on the needs of the patient and inform decision making.
Delivery *Direct patient engagement via applications and portals*	PC CDS that is both patient- and clinician-facing can establish the partnership dynamic that is needed for SDM.	Clinician-facing PC CDS can support the presentation of options to patients. PC CDS that is both patient- and clinician-facing can continue the partnership dynamic.	PC CDS that is patient-facing can support the direct collection of patient preferences to inform decision making.

3.1.1 Team Talk

In team talk, patients and/or caregivers and clinicians acknowledge that there is a decision to be made. Critically, in this phase clinicians ensure that patients feel supported to make decisions and establish that they will work in partnership with patients/caregivers (i.e., as a team) to navigate the discussion.[23,28] This phase also serves as an opportunity to begin to discuss patient goals related to their care, quality of life, and outcomes. PC CDS can initiate this phase of SDM by drawing on evidence-based findings (knowledge) and patient information (data) to generate an alert or recommendation that lets patients/caregivers and/or clinicians know that a decision needs to be made (delivery).

Knowledge. All CDS is based on evidence-based findings.[29] CDS that addresses knowledge as a patient-centered factor specifically incorporates findings from PCOR or CER. Within the context of SDM, this ensures that the PC CDS alerts and recommendations that initiate team talk are based in evidence that has considered patient characteristics for outcomes important to patients.[10]

Data. PC CDS that incorporates patient decision-making preferences (e.g., whom the patient would like to be involved in decision making and how they prefer to make decisions), may help inform how clinicians should initiate and support team talk. In addition, PC CDS that incorporates patient-specific data (e.g., genetic information, family history,

PGHD) can ensure that team talk is initiated and supported based on both the characteristics of the patient and clinical guidelines. For example, the Breast Cancer Risk Estimator-Decision Aid is an EHR-integrated software platform focused on breast cancer screening decisions. The platform incorporates family history, race, ethnicity, and breast density to generate a risk profile. Recommendations to initiate team talk and facilitate SDM accompany the risk profile.[30]

Delivery. PC CDS can be patient-facing only, clinician-facing only, or both patient- and clinician-facing. Patient-facing CDS (e.g., through a web-based tool, mobile application, or patient portal) can prime patients/caregivers for team talk during a clinical encounter. For example, the HealthWise Symptom Checker is a patient-facing tool used by Dartmouth Health to allow patients/caregivers to check their symptoms and determine if they need to seek medical care.[31] The tool generates questions and care recommendations based on patient-entered data and risk calculators, and patients can learn more about symptoms, possible conditions, and care options. Separately, clinician-facing tools could be used by care providers to surface SDM needs (e.g., risk calculation) and guide care plan option eligibility, features, and outcome probabilities discussions with the patient. The CHA_2DS_2-VASc is an example of a clinician-facing risk stratification tool, which guides conversations between clinicians and patients around atrial fibrillation treatment planning.[32]

While all three modes of delivery can initiate a discussion, PC CDS that is both patient- and clinician-facing is most primed to initiate team talk by establishing the partnership dynamic that is needed to move forward to the next phases of SDM.[33] The VA facilitates team talk using apps and web-based tools that support preventive care, treatment, care planning, and chronic disease management. The Share My Health Data, Annie, and My VA Images apps allow veterans to share images, videos, and data captured during activities of daily living, allowing clinicians to track trends in a veteran's day-to-day health and well-being and recognize symptoms or potential health problems before they become more serious.[34] Clinicians can add key data points and trends from Bluetooth and wearable devices to the veteran's EHR, to further support team talk.

3.1.2 Option Talk

During option talk, patients and clinicians discuss available options for the decision to be made, while considering the benefits and risks of each option.[23,28] PC CDS can support this phase of SDM by providing recommendations based on PCOR (knowledge) as well as collecting and integrating patient-specific information (data and delivery) to inform the benefits and risks of available options.

Knowledge. PCOR helps patients, care teams, and caregivers make better informed-decisions by addressing patient-centered questions related to healthcare options (e.g., benefits and harms of options, addressing patient-relevant or patient-important outcomes, examining these outcomes based on a personal characteristics).[35] PC CDS based on PCOR can facilitate option talk by providing information about the risks and benefits of options that is patient-centered and is based on outcomes important to patients. However,

the information provided by PC CDS can be tailored only to the extent that PCOR findings stratified by patient characteristics have been reported.

Data. During option talk, patient-specific data captured by PC CDS can be used to better understand the risks and benefits of options and recommendations. In particular, decision support tools that use personalized risk calculators can facilitate option talk. These calculators provide numerical summaries or visual depictions of risk along with recommendations. For example, the DynaMed Decision platform includes tools that provide individualized clinical practice guideline recommendations, information on risk stratification or differential diagnosis, risk estimates, and other information to help clinicians and patients/caregivers make decisions based on an individual's risks, comorbidities, values, and preferences.[36]

PC CDS also has the potential to use PGHD like PROs or data from wearable devices, as well as SDOH. When integrated into decision support tools, these data can support option talk by further tailoring the risks and benefits of healthcare options to the patient. While the use of these types of data for PC CDS are at a nascent stage, some patient-facing apps can collect PGHD and support integration with EHRs. For example, Apple Health collects and integrates patient-provided data from iPhone, Apple Watch, and other health apps.[37] It integrates with Epic and Cerner to allow patients to share their health data with clinicians and download medical records.

Delivery. PC CDS that is only clinician-facing can support the presentation of risk and benefits to patients/caregivers (through clinician-initiated sharing and discussion). However, tools that provide both patient- and clinician-facing interfaces may be more primed to facilitate option talk and continue the partnership established during team talk. The Priorities Wizard is an EHR-linked, web-based CDS that uses national guidelines to support chronic disease management and preventive care.[38] Researchers previously tested the tool with pre-diabetes patients at risk of cardiovascular disease based on patient characteristics (medical history, blood sugar, cholesterol, weight, medication). The patient- and clinician-facing versions indicated priority areas and provided recommendations and considerations.[39]

3.1.1 Decision Talk

During decision talk, the patient/caregiver and clinician discuss information about potential options with a focus on what is most important to the patient (i.e., their values), the care that best aligns with their individual characteristics (i.e., their preferences) and life context (i.e., circumstances), and their preferred outcomes (i.e., their goals).[23,28,40] PC CDS can support decision talk through the collection and integration of this information (data and delivery). While knowledge is still important to deliberations between patient/caregiver and clinician, the evidence about benefits and risks of the available options has already been presented and discussed in option talk. Decision talk contextualizes those benefits and risks in terms of what matters most to the patient.[23,28]

Data. PC CDS that is able to collect and integrate values, preferences, circumstances, and goals can support patients/caregivers and clinicians in making more-informed decisions that factor in benefits and risks based on both clinical evidence and the individual needs of the patient. For instance, it could elicit care-related preferences to inform the relative prioritization of treatment recommendations that were presented during option talk. For example, InvolveMe is a clinician and patient interface developed for smartphones, tablets, and data-encrypted hospital computer systems.[41] InvolveMe provides patients/caregivers an opportunity to self-report symptoms, information needs, and care preferences for chronic health symptom management, such as willingness to try prescription medications or preferences for nonmedicated strategies for pain relief. Clinicians send a survey link to initiate the engagement, and information from the tool can be integrated into an existing patient portal. Its counterpart, MyRec, supports secure messaging between patients/caregivers and clinicians.

Delivery. PC CDS that is clinician-facing can still support the collection and use of preferences during decision talk. One example of this is DDInteract, an SDM tool designed to help clinicians and patients/caregivers understand the risk of drug interactions between blood thinners and nonsteroidal anti-inflammatory drugs (NSAIDs).[42-44] A clinician-facing app pulls in clinical data from the EHR and prompts clinicians to collect patient preferences about pain treatment (medication vs. nonmedication) and medication type (oral NSAIDs vs. other medication). Using clinical risk factors and patient preferences, it generates risk for gastrointestinal bleeding based on NSAID use and alternative pain treatment options.

However, PC CDS that is also patient-facing allows for the direct collection of patient preferences, which can then be used for decision talk. Patient preference data may be collected through web-based applications (third party or patient portals), mobile applications, EHR portals, or standalone computerized decision support software. For example, the Joint Insights tool is an artificial intelligence (AI)-enabled decision aid for patients living with knee osteoarthritis.[45] Designed to help patients/caregivers understand the risks and benefits of knee replacement surgery, the app includes a preference assessment module focusing on preferences related to pain relief, postoperative recovery, and surgical risk.

3.2 Challenges and Opportunities for the Use of PC CDS for SDM

While reviewing the preliminary framework, key informants surfaced several factors that require consideration when using PC CDS for SDM. Key informants noted several evidence gaps as future opportunities for the field of PC CDS.

3.2.1 Patient Engagement & Activation

While engaging patients in their care decisions is critical for patient-centered care, some patient populations may not have access to the tools and/or infrastructure to access the PC CDS that is intended to facilitate SDM. For instance, one informant questioned, “If we’re moving toward a model of personalized decision making that is contingent on this personal data, and we only have the ability to

personalize it for a subset of the population, are we exacerbating known disparities?" They then further emphasized the critical need to engage and empower patients.

Beyond potential lack of access, other patient populations may not be accustomed to taking an active role in decision making and instead default to deferring to their clinician(s). An informant highlighted the need to help patients understand their goals, reflecting that some patients may not understand or identify with the concept. Patients may defer to the clinician's expertise, as described by the informant: "I've had a lot of patients tell me, when I've asked them about goals, 'My goal will be whatever my provider tells me I should be doing or trying to do,' and they don't think of it so much in terms of what they're trying to get out of the care." Another informant similarly observed that some patients—such as older adults who may not have previously been brought into medical decision making—did not see themselves as having an important role to play in the decision-making process. Multiple informants suggested that PC CDS use during team talk may provide an opportunity for patient empowerment through incorporating an explanation of the importance of patient participation, either as part of the tool itself or within the implementation guidance.

3.2.2 MCID & Data Visualization

When using PC CDS for SDM, an informant further raised the importance that the data integrated and presented by PC CDS are actionable and interpreted in light of their clinical meaningfulness, or the MCID, which is the smallest change in an outcome that represents a meaningful change for the patient.[46,47] Data visualization tools and principles can be used to aggregate, meaningfully interpret, and present complex data to patients/caregivers and clinicians to aid with decision making and identifying an MCID.[48]

3.2.3 Implementation

Informants additionally identified potential barriers and facilitators to the implementation and use of PC CDS to enhance SDM. Logistical barriers included preconceived notions among clinicians related to the amount of time it takes for both using PC CDS and engaging in SDM (e.g., contending with limited time during primary care visits). Clinicians might additionally be reticent to review patient-generated data due to a time burden and/or uncertainty around the actionability of the data in terms of making an informed decision with the patient/caregiver. Technology and software frameworks are also needed for scalability and interoperability. As one informant noted, "each shared decision-making [tool] is almost a separate software application, so to scale that, we need frameworks beyond this conceptual [PC CDS-SDM] framework," along with further considerations for how data are captured and stored.

Several enabling factors may mitigate these barriers. Key informants suggested that better preparation for the patient encounter could enhance both the experience and the impact of PC CDS-supported SDM. For example, PC CDS that provides content and questions to a patient/caregiver in advance by mining the EHR and sharing the information via the patient portal can help prepare the patient/caregiver for the discussion, as noted by one informant. However, when such pre-visit information is collected, it is important that it is used during the visit or at the very least acknowledged—failure to acknowledge these data can paradoxically be a barrier to patient engagement and SDM. Providing resources to the

patient in followup can facilitate the patient/caregiver's continued thinking after the encounter, enhancing subsequent SDM discussions.

Facilitators on the care providers' side include building talking points into a tool such that the clinician has access to information during the visit. This may assist in alleviating some of the clinician burden due to limited preparation before visits and facilitating the retrieval of expert knowledge at the point-of-care. For example, a fall prevention toolkit that incorporated clinician talking points resulted in a 15% reduction in patient falls.[49]

3.2.4 Health & Digital Literacy

In addition to these barriers and facilitators, concern exists that proliferation of digital tools may exacerbate, or at least not mitigate, disparities by disproportionately benefitting already advantaged populations who may have more personal data available electronically, higher literacy and health literacy levels, and access to technology.[50] Greater attention to disadvantaged populations is needed to ensure that the benefits of PC CDS-supported SDM are equitably distributed.[51] By explicitly addressing inequities and ensuring accessibility to disadvantaged populations, there may be untapped opportunity for PC CDS to help mitigate disparities in SDM.

4. Discussion

The use of PC CDS tools in support of SDM can empower patients/caregivers with knowledge, generating informed preferences, and enabling deliberative discussions with care teams.[52] Recent proliferation of patient-facing decision support tools, as well as preference management in consumer technology more generally, provides a useful springboard for consideration of how PC CDS could be operationalized in the context of SDM.

We surfaced multiple challenges and opportunities for the use of PC CDS in SDM, including patient engagement and activation, implementation, MCID and data visualization, and health and digital literacy of patients. While PC CDS presents the opportunity to engage patients in their care decisions, developers and administrators should be mindful to not exacerbate existing disparities in patient engagement and participation. These tools may not be fully accessible to all populations due to lack of infrastructure to support such tools or limited health or digital literacy to engage with and/or activate these tools. Additionally, those administering and developing PC CDS-support SDM should carefully consider implementation factors to facilitate clinicians' use of these tools. Data should be actionable, relevant, and delivered in ways that allow clinicians to easily digest patient-generated data.

4.1 Directions for Future Work

While our framework demonstrates the potential for PC CDS to support SDM, we lack evidence on the design, implementation, and evaluation of impact of digital, patient-centered decision support tools in the SDM process. **Exhibit 4** outlines potential areas for future work to address knowledge gaps about the use of PC CDS in SDM based on the literature scan and conversations with key informants. Focus areas for research include significance and impact, data and risk communication, equity, and implementation.

Exhibit 4. Future Work Needed to Address Knowledge Gaps Related to Use of PC CDS in SDM

Focus Area	Topics
Significance & Impact	• How does tailoring or personalization of a PC CDS tool based on communication, information-seeking, or other personal preferences impact a participant's understanding of their healthcare and outcomes? • What are best practices for conducting needs assessments, collaborative design, and field testing to ensure maximum impact of PC CDS tools for SDM upon wide release?
Data & Risk Communication	• How do we define the MCID in PRO and other PGHD over time (in samples/populations as well as individuals)? • How should PGHD be presented to clinicians and patients to ensure they contribute meaningfully to deliberations, particularly those related to risk communication? • Our understanding of how to present and use individualized data is limited (e.g., PGHD)—what impacts might this have on risk communication? What is the best way to address this with the patient?
Equity	• How might SDOH data be used to tailor option feasibility? What are the implications of building this as part of an automated process that lacks transparency to patients? • What is the best way to translate what we have learned about health literacy/numeracy and digital literacy to this context in order to effectively support SDM with PC CDS?
Implementation	• What special usability considerations are there and how might they vary by end user (patient, clinician, or both)? • What are the effects of interface design and customization in differing clinical, cultural, and decision-making contexts? How scalable will these tools be?

5. Conclusion

Patients are becoming increasingly empowered through data, information, and tools—offered both through their interactions with the healthcare delivery system and via third-party vendors. Moving forward, it can be expected that patients will be better supported in monitoring their health and engaging their clinicians in informed discussions about their care. In this climate, medical professionals have a responsibility to support patients/caregivers beyond the walls of the encounter. Supporting this transformation will entail improving the integration of patient-contributed data in clinical information system and increasing transparency related to use of patient data and quality of care to support the use of PC CDS in SDM.

Appendix A. Search Strategies for Targeted Tool Scan

We targeted four resources for our targeted tool scan: the Ottawa Hospital Research Institute A to Z Inventory of Decision Aids, Washington State Health Care Authority (HCA) Certified Patient Decision Aids (PDAs), Mayo Clinic Shared Decision Making National Resource Center, and peer-reviewed tool descriptions identified via PubMed. A total of five systematic reviews and 21 tool examples were identified and included in the scan. Of the 21 tools listed in Appendix B, 11 were found in PubMed searches, 5 were found when searching the decision aid repositories, and 5 were found from key word searches. Below, we provide context for the selection of the decision aid repositories and describe the search of PubMed.

Search of Decision Aid Repositories

Ottawa Hospital Research Institute A to Z Inventory of Patient Decision Aids. Established in 2006, this international inventory contains 284 decision aids for 134 different health conditions.[53]

The inventory provides the following information for each tool: health condition, type of decision, decision options, target audience, format, language, development/update details, evidence citations, access details, and rating against International Patient Decision Aid Standards criteria.[27] We reviewed all English-language tools to identify web-based tools that were adaptive based on incorporation of preferences and/or patient-specific information.

Washington State HCA. The Washington State HCA maintains certifications for 30 PDAs spanning end-of-life care, maternal and labor/delivery care, cancer screening, and total joint replacement and spine care.[54] We reviewed all tools, but no web-based tools that were adaptive based on incorporation of preferences and/or patient-specific information were identified.

Mayo Clinic Shared Decision Making National Resource Center. The Resource Center maintains an inventory of 14 internally developed and evaluated decision support tools spanning 10 health conditions. We reviewed all tools and included web-based tools that were adaptive based on incorporation of preferences and/or patient-specific information.

PubMed and Key Word Searches

A series of structured, snowball, and hand searches of the literature were conducted to identify systematic reviews on PC CDS and SDM and relevant PC CDS examples. Search strings are presented in **Table A1**. Articles were iteratively reviewed based on title, abstract, and full text. Articles were included if they described implementations of PC CDS for SDM or described specific examples of interactive, computerized tools for SDM that incorporated the data factor (with detailed descriptions and at least one screenshot).

Table A1. Search Strategies and Limits.

Source *Limits*	Search Strategy
PubMed *Published in the past 10 years, English-language publications*	("Decision Support Systems, Clinical"[Mesh] OR “clinical decision support”[tiab]) AND ("shared decision making"[tiab] OR “Decision Making, Shared”[Mesh])
PubMed *Systematic review, published in the past 10 years, English-language publications*	(Computer*[tw] OR electronic health records [Mesh] OR internet[Mesh] OR electronic medical record*[tw] or website[tw] or web site[tw]) AND (decision making[tw] OR decision support[tw] OR decision support techniques[MESH]) AND (shared[tw] OR patient[Mesh] OR patient*[tw] OR patient*centered OR family[tw] OR physician patient relations[Mesh] OR surrogate[tw] OR professional family relations[Mesh] OR professional family relations[Mesh])
Google *Published within past 10 years, English*	electronic health records OR electronic medical records OR shared decision making OR clinical decision support OR patient centered OR digital decision support OR personalized decision support

Appendix B. PC CDS-SDM Example Tools

Table B1. Example Tools Sourced from Targeted Inventory and Literature Searches.

Tool Name*	Health Condition	Type of Decision	Target Audience	Mode of Access [web, app, portal]	Approach to Personalization	Source
InvolveMe	Chronic Health	Chronic Care	Patients and clinicians in chronic health care settings	App	Report symptoms and preferences to clinicians and use secure messaging to interact with the clinicians.	Seljelid B, Varsi C, Solberg Nes L, Stenehjem AE, Bollerslev J, Børøsund E. Content and system development of a digital patient-provider communication tool to support shared decision making in chronic health care: InvolveMe. *BMC Med Inform Decis Mak.* 2020;20(1):46. Published 2020 Mar 4. doi:10.1186/s12911-020-1065-8
Healthwise	Multiple Clinical Conditions	Treatment	Patients determining whether to seek care at a medical facility.	Website	Advises on care based on PGHD, including patient-reported symptoms and preference.	Dartmouth Health. Make Better Health Decisions. Accessed July 17, 2023. Retrieved from: https://www.healthwise.net
Decision aid for people with Chronic Kidney Disease and signs of Coronary Heart Disease	Coronary Artery Disease	Treatment	Patients with coronary artery disease and kidney disease and their care teams	Website	Risk factors and treatment adapts based on patient-entered lab markers and medical history	My Heart Care and CKD. Decision Aid for Chronic Kidney Disease & Signs of Coronary Heart Disease. Accessed July 17, 2023. Retrieved from: https://myheartandckd.ca/
My Kidney Life Plan	Chronic Kidney Disease	Treatment	1. Known, progressive chronic kidney disease (CKD). 2. Unknown CKD, "crashing" into end-stage kidney . 3. Failing kidney transplant; dialysis will be required. 4. Now on dialysis; unhappy with current treatment option.	Website	Treatment options adapt based on patient-entered values (related to lifestyle, health, relationships)	Medical Education Institute. My Kidney Life Plan. Accessed July 17, 2023. Retrieved from: https://mykidneylifeplan.org/

Tool Name*	Health Condition	Type of Decision	Target Audience	Mode of Access [web, app, portal]	Approach to Personalization	Source
Concussion or Brain Bleed	Minor head injury	Screening	Emergency room patients with minor head injury	App	Assesses risk and makes a recommendation regarding CT imaging based on questionnaire responses and the CT Head Rule	Melnick ER, Hess EP, Guo G, et al. Patient-Centered Decision Support: Formative Usability Evaluation of Integrated Clinical Decision Support With a Patient Decision Aid for Minor Head Injury in the Emergency Department. *J Med Internet Res.* 2017;19(5):e174. Published 2017 May 19. doi:10.2196/jmir.7846
BREASTChoice	Breast cancer	Procedure Identification	Breast reconstruction after mastectomy	Website	Provides surgical risk estimate and questions for surgeon based on patient	Lee CN, Sullivan J, Foraker R, et al. Integrating a Patient Decision Aid into the Electronic Health Record: A Case Report on the Implementation of BREASTChoice at 2 Sites. *MDM Policy Pract.* 2022;7(2):23814683221131317. Published 2022 Oct 8. doi:10.1177/23814683221131317
Lung Cancer Screening: Is it right for me?	Lung cancer	Screening	Adults who currently smoke or have smoked in the past and meet eligibility criteria for lung cancer screening in the U.S.	Website	Assess eligibility for lung cancer screening and assesses lung cancer risk based on patient-provided information	Project Connect. Is lung cancer screening right for me? Accessed July 17, 2023. Retrieved from: https://lungscreen.health/
Prostate Cancer Decision Aid for Early-stage Patients	Prostate cancer	Treatment	Men diagnosed with low- or intermediate-risk early-stage prostate cancer.	Website	Provides treatment information based on patient-entered treatment preferences and then patients revisit factors that may impact their treatment of choice through prioritization.	Queen's University: Division of Cancer Care & Epidemiology, Cancer Research Institute. Decision Support Tools to Help You Understand Your Diagnosis and Select a Treatment. Accessed July 17, 2023. Retrieved from: https://decisionhelp.qcancercare.com/
Priorities Wizard	> 20 clinical domains	Treatment	Patients diagnosed with one or more of the clinical domains	EHR	Extracts relevant data from the EHR to identify patients and provide appropriate evidence-based treatment recommendations	Sperl-Hillen JM, Rossom RC, Kharbanda EO, et al. Priorities Wizard: Multisite Web-Based Primary Care Clinical Decision Support Improved Chronic Care Outcomes with High Use Rates and High Clinician Satisfaction Rates. *EGEMS (Wash DC).* 2019;7(1):9. Published 2019 Apr 3. doi:10.5334/egems.284

Tool Name*	Health Condition	Type of Decision	Target Audience	Mode of Access [web, app, portal]	Approach to Personalization	Source
MyLynch	Lynch syndrome	Risk Calculator	Patients with Lynch Syndrome	App	Provides personalized cancer risk estimates and interventions to lower risks	Knapp ST, Revette A, Underhill-Blazey M, et al. MyLynch: A Patient-Facing Clinical Decision Support Tool for Genetically-Guided Personalized Medicine in Lynch Syndrome. *Cancers (Basel).* 2023;15(2):391. Published 2023 Jan 6. doi:10.3390/cancers15020391
Joint Insights	Knee Osteoarthritis	Treatment	Total knee replacement	Web-based	Use of PRO measurement data to generate personalized total knew replacement outcomes	Jayakumar P, Moore MG, Furlough KA, et al. Comparison of an Artificial Intelligence-Enabled Patient Decision Aid vs Educational Material on Decision Quality, Shared Decision-Making, Patient Experience, and Functional Outcomes in Adults With Knee Osteoarthritis: A Randomized Clinical Trial. *JAMA Netw Open*. 2021;4(2):e2037107. Published 2021 Feb 1. doi:10.1001/jamanetworkopen.2020.37107
Movement is Life	Knee Osteoarthritis	Treatment	Women, African Americans, & Hispanics	Web-based	Assesses impacts on pain, activities of daily living, and finances	Johnson CB. A Personalized Shared Decision-Making Tool for Osteoarthritis Management of the Knee. *Orthop Nurs. 2021;40(2):64-70. doi:10.1097/NOR.0000000000000739*
Web-based Brest Cancer Decision Making Application	Breast cancer	Treatment	Women with breast cancer	App	Provides risk, benefits, recovery timelines based on therapy option using info from initial consult	Wyatt KD, Jenkins SM, Plevak MF, Venegas Pont MR, Pruthi S. A personalized, web-based breast cancer decision making application: a pre-post survey. *BMC Med Inform Decis Mak. 2019;19(1):196. Published 2019 Oct 21. doi:10.1186/s12911-019-0924-7*
Personal Patient Profile-Prostate (P3P)	Prostate cancer	Treatment	Men newly diagnosed with localized prostate cancer.	Web-based	Recommendations tailored by tailored to race, age, and personal factors reported as influencing the decision.	Berry DL, Halpenny B, Wolpin S, et al. Development and evaluation of the personal patient profile-prostate (P3P), a Web-based decision support system for men newly diagnosed with localized prostate cancer. *J Med Internet Res. 2010;12(4):e67. Published 2010 Dec 17. doi:10.2196/jmir.1576*

Tool Name*	Health Condition	Type of Decision	Target Audience	Mode of Access [web, app, portal]	Approach to Personalization	Source
Health Decision	Cardiology	Preventive Care	Patients with atrial fibrillation considering options to reduce stroke risk	Web-based	Integrated Decision Aid (IDeA) designed to increase patient knowledge and lessen decision making uncertainty around stroke prevention in atrial fibrillation	Schott SL, Berkowitz J, Dodge SE, et al. Personalized, Electronic Health Record-Integrated Decision Aid for Stroke Prevention in Atrial Fibrillation: A Small Cluster Randomized Trial and Qualitative Analysis of Efficacy and Acceptability. *Circ Cardiovasc Qual Outcomes. 2021;14(6):e007329. doi:10.1161/CIRCOUTCOMES.120.007329*
Statin Choice Decision Aid	Cardiology	Risk Calculator	Adults	Web-based	Facilitate discussions about statin use for primary cardiovascular disease prevention	Mayo Clinic. Statin Choice Decision Aid. Accessed July 17, 2023. Retrieved from: https://statindecisionaid.mayoclinic.org/
CardioSmart	Afib	Risk Calculator	Patients with Afib	Web-based	Assess stroke and bleeding risk based on co-morbidities	CardioSmart – American College of Cardiology. Stroke and Bleeding Risk Calculator. Accessed July 17, 2023. Retrieved from: https://www.cardiosmart.org/stroke-and-bleeding-risk-calculator
Share my Health Data, Annie, & My VA Images	Chronic and preventive care	Preventive and chronic care	Veterans	App and Web-based	Preventive care, treatment, care planning, and chronic disease management; video & image sharing	U.S. Department of Veterans Affairs. Patient-Generated Health Data at VA. Accessed July 17, 2023. Retrieved from: https://connectedcare.va.gov/patient-generated-health-data
DynaMed	Cancer screening	Screening	Women between 35-74 years old	Web-based	Assesses a patient's risk of invasive breast cancer	DynaMed Decisions. Breast Cancer Screening. Accessed July 17, 2023. Retrieved from: https://decisions.dynamed.com/shared-decision-making/breast-cancer-screening
DDInteract	Drug-drug interactions	Treatment	Patients taking warfarin	EHR-integrated app	Assesses risk of drug-interactions based on patient data	Reese TJ, Del Fiol G, Morgan K, et al. A Shared Decision-making Tool for Drug Interactions Between Warfarin and Nonsteroidal Anti-inflammatory Drugs: Design and Usability Study. JMIR Hum Factors. 2021 Oct 26;8(4):e28618. doi: 10.2196/28618.

Tool Name*	Health Condition	Type of Decision	Target Audience	Mode of Access [web, app, portal]	Approach to Personalization	Source
Breast Cancer Risk Estimator-Decision Aid	Breast cancer screening	Screening	Women between 40–49 years old	EHR	Personalizes risk profile based on family history, race, ethnicity, and breast density	Liu Y, Kornfield R, Yang EF, Burnside E, Keevil J, Shah DV. Patient-provider communication while using a clinical decision support tool: explaining satisfaction with shared decision making for mammography screening. BMC Med Inform Decis Mak. 2022 Dec 7;22(1):323. doi: 10.1186/s12911-022-02058-3.

**A link to the tool has been provided when available.*

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