

Trust and Patient-Centeredness Workgroup: Patient and Caregiver Perspectives on Generative Artificial Intelligence in Patient-Centered Clinical Decision Support

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PURPOSE

The Trust and Patient-Centeredness Workgroup is charged with (1) supporting the design, implementation, and uptake of patient-centered clinical decision support (PC CDS) to enhance trust, foster shared decision making, and engage patients and clinicians as partners alongside all members of the care team; (2) promoting and enabling the use of PC CDS and developing related outputs that can support clinicians and patients as partners in a care team, equally committed to creating effective treatment and care coordination plans; and (3) ensuring that PC CDS products are understandable by the care team, designed with end-users (including both clinicians and patients) in mind, and involving them from the very beginning of PC CDS development. The Workgroup is composed of 13 experts and stakeholders who represent diverse perspectives within the CDS community. This report is intended to share patient and caregiver perspectives on the use of generative artificial intelligence technologies for PC CDS. All qualitative research activities by the CDSiC are reviewed by the NORC at the University of Chicago Institutional Review Board (FWA00000142).

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Executive Summary

This product describes patient and caregiver perspectives on generative artificial intelligence (AI)-enabled patient-centered clinical decision support (PC CDS) tools and provides considerations for the development and implementation of future tools to support trust and patient-centeredness.

Background

As the use of AI in healthcare settings continues to increase, federal agencies, healthcare systems, researchers, professional societies, industry, and several public-private partnerships are working to establish guidelines to support the development and implementation of safe, effective AI-enabled health technology. Furthermore, there is a fundamental need to understand patient and caregiver viewpoints on AI's role in healthcare, particularly in the implementation of PC CDS. PC CDS can harness AI to collect and analyze data, streamline communication between patients or caregivers and their care team, and inform clinical decision making. Given the centrality of trust and patient-centeredness to effective PC CDS, it is imperative to incorporate patient and caregiver views to shape the development and implementation of AI-powered PC CDS tools.

This need is even more apparent with the recent expansion of generative AI into the public sphere and its emergence in healthcare settings. More research is needed to understand patient and caregiver perspectives on this growing technology in healthcare. To support these efforts, this report aims to describe patient and caregiver perspectives on the use of generative AI in PC CDS and its impact on trust and the patient–clinician relationship, while providing specific considerations for the development and implementation of generative AI-supported PC CDS tools.

Methods

Small group discussions were conducted with seven patient (n=5) and caregiver (n=2) advocates. Participants were identified using purposive and convenience sampling. The project team, which included members of the CDS Innovation Collaborative (CDSiC) Trust and Patient-Centeredness Workgroup, developed a small group discussion guide that incorporated use case scenarios built around two generative AI prototypes to probe on trust in generative AI tools and their impact on the patient–provider relationship. To refine our discussion and ensure understanding of the terms and concepts described in the guide, we conducted three virtual cognitive debriefings with patient representatives and researchers.

Three small group discussions were held in January and February 2024. Participants were provided with a brief overview document summarizing AI, PC CDS, and examples of the use of AI for PC CDS prior to the session. Sessions were approximately 75 minutes and conducted via Zoom with audio- and video-recording. The sessions were led by a designated facilitator, while another team member produced detailed notes. Rapid qualitative content analysis was used to identify themes and concepts shared during the small group discussions.

Key Findings

In general, participants' views on the use of AI in healthcare were dependent on previous experiences with healthcare, familiarity with technology, and personal preferences. Participants expressed a spectrum of attitudes toward AI in healthcare, from very positive to somewhat skeptical.

Participant Views on the Use of AI in Healthcare. Participants agreed that AI can enhance healthcare delivery by streamlining communication and administrative tasks and improving clinicians' clinical decision making. However, participants cautioned that AI may contribute to challenges, chiefly that AI-enabled tools could create additional work for patients and/or clinicians and barriers to patient–clinician communication. Participants also expressed concerns that AI may have a limited ability to address serious health issues and doubted its capacity to accurately and comprehensively use the necessary data needed to inform patient-centered recommendations.

Factors that Influence Trust in AI Technology. In general, participants reported that their trust in an AI tool would be influenced by factors related to the relationship with their clinician or health system. This included a patient's previous healthcare journey or comfort with technology. Participants also noted that existing issues with the implementation and use of health technology may contribute to doubts about the utility of new AI-powered tools in healthcare. Most participants agreed that they would be more likely to trust an AI tool for PC CDS if it was introduced by a trusted clinician or health system. They emphasized that the manner in which the tool was introduced would impact their trust in it, underscoring the need for clinicians and health systems to describe the mutual benefit of an AI tool to support its acceptance.

Participants also described several factors related to transparency that would influence their trust in AI technology. They agreed that users should explicitly be informed when they are interacting with AI rather than a human care team member. Participants also stressed the importance of understanding who has access to data collected by the tool and providing users with information on the tool's ownership, data sharing, and storage practices. Finally, they noted that they would trust an AI-enabled device if they knew the underlying evidence base was providing accurate, up-to-date information.

Impact of AI Use on the Patient–Clinician Relationship. Participants expressed that the use of an AI-enabled PC CDS tool would not impact their view of their clinician. Rather, their views would be influenced by how their clinician used AI tools in clinical care. Participants agreed that, when used in a collaborative manner, AI tools could streamline administrative tasks and allow their clinician to focus on direct patient care.

However, participants also agreed that AI may disrupt certain aspects of the patient–clinician relationship. They emphasized that AI technology should not replace patient–clinician interactions, including the need to follow up with patients to confirm the accuracy of AI-produced summaries. Participants stressed that clinicians' overreliance or unquestioning acceptance of AI findings would negatively impact their view of their clinician.

Considerations for Implementation and Use of AI in PC CDS. Participants described seven considerations for the design and implementation of patient-facing, generative AI-supported PC CDS tools:

1. Consult patients and provide choice when introducing AI tools for PC CDS.
2. Provide education and training to support patients' and caregivers' use and understanding of AI-enabled tools.
3. Develop standards and design principles to promote the transparent, safe, and secure implementation of AI in healthcare.
4. Use AI as a supplementary tool to support and strengthen clinicians' work.
5. Conduct continuous monitoring, critical appraisals, and due diligence when implementing AI technologies for PC CDS.
6. Consider how to holistically use all data to personalize and tailor outputs in AI-enabled PC CDS.
7. Consider potential challenges related to mistrust, particularly for historically marginalized or vulnerable populations.

Future studies should continue to explore the impact of generative AI-based PC CDS tools on trust and patient-provider relationships, especially post-pilot testing. While this effort attempted to include individuals from diverse backgrounds, there is a need to explore views across different populations based on factors like age, race, level of health literacy, and disease states. As noted by participants, inclusion of these perspectives in the development and implementation of AI in PC CDS is vital to combatting mistrust and inequities in healthcare.

Conclusion

This report documents the perspectives of patients and caregivers on the use of AI in healthcare, with a specific focus on the use of generative AI for PC CDS.

Findings revealed varied perspectives on several AI-related topics, including trust in the validity and implementation of AI tools and potential impacts on the patient and clinician relationship. Additional research is needed to further gather diverse perspectives to inform work in this ever-changing area.

1. Introduction

Artificial intelligence (AI) applies computer science methods to understand information from large datasets to create technology that can complete tasks typically requiring human intelligence.² AI tools are equipped to help collect and analyze large amounts of patient health data “generated from various sources, such as electronic health records (EHRs), laboratory data, and diagnostic imaging.”³

Within the context of patient-centered clinical decision support (PC CDS), care teams can potentially leverage AI to complete a number of tasks central to PC CDS, such as provide timely information for patient care, help inform decisions about patient care, support clinical teams by facilitating routine tasks, filter information, and warn of potential problems that have been shown to impact patient outcomes and quality of healthcare.^{3,4}

Opportunities for the use of AI in PC CDS include:

- Helping a doctor diagnose or predict disease or complication risks in patients using clinician notes and patient data found in their EHR
- Personalizing treatment recommendations based on a patient’s condition, genetics, preferences, and goals
- Summarizing complex clinical information and/or answering medical questions
- Automating administrative tasks such as scheduling, appointment reminders, or referrals

As the use of AI in healthcare settings continues to rise, there is increasing awareness of the need to ensure the trustworthiness and safety of these technologies. To address this, federal agencies have prioritized the development of guidelines and tools to advance safe, secure, and trustworthy AI. The White House issued an Executive Order in October 2023 emphasizing the urgent need to govern the safe and responsible development and use of AI in healthcare.^{5,6} In December 2023, the U.S. Department of Health and Human Services (HHS) through the Office of the National Coordinator for Health Information Technology (ONC) finalized its *Health Data, Technology, and Interoperability: Certification Program Updates, Algorithm Transparency, and Information Sharing (HTI-1) rule*. The rule establishes “first of its kind transparency requirements” for AI in CDS tools, which will allow users to access critical information to help assess algorithms for core characteristics such as fairness, validity, and safety.”^{7,8}

In tandem with these efforts, there is a fundamental need for clinicians, developers, and researchers to understand patient and caregiver perspectives on the role of AI in healthcare.⁹ Understanding patient

CDS is patient-centered when it significantly incorporates patient-centered factors¹ related to knowledge, data, delivery, and use:

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

and caregiver perspectives is especially critical given increasing applications of generative AI in healthcare settings. Generative AI, a subset of AI, is skilled at pattern creation and can function as a standalone application or work in conjunction with other AI modalities. It utilizes technology that has the ability to process information; communicate using natural language; create written, audio, or visual products; and use online information to learn from and generate new, unique knowledge or content.^{10,11} For example, generative AI-enabled chatbots outside of the EHR are being explored as one of the many modalities to deliver PC CDS.¹²

To date, little research has explored patient and caregiver perspectives on the use of generative AI specifically in PC CDS. Given the growing interest in using AI for PC CDS, this report details patient and caregiver perspectives on generative AI to support PC CDS.

1.1 Report Roadmap

This report contains the following sections:

- Section 2, *Methods*, describes our primary research aim and approaches used for qualitative data collection and analysis, which include participant recruitment, instrument development, and the facilitation of small group discussions.
- Section 3, *Findings*, shares key findings in four critical areas: 1) participant views on the use of AI in healthcare; 2) factors that influence trust in AI technology; 3) the impact of AI use on the patient–clinician relationship; and 4) considerations for the implementation and use of AI in PC CDS.
- Section 4, *Discussion*, describes the significance of the report’s findings, identifies the limitations of our approach, and shares recommendations on how this report can be used to further inform PC CDS development.
- Section 5, *Conclusion*, summarizes the report’s key takeaways and the future implications of our findings.

2. Methods

The CDSiC project team conducted small group discussions with patient and caregiver advocates to understand their perspectives on the use of generative AI to support PC CDS and to specifically understand the potential impact of these tools on patient trust in the information provided and in their clinicians.

2.1. Discussion Guide Development

We developed a semi-structured discussion guide to solicit general perspectives on the use of AI in healthcare and its impact on patient and caregiver trust in their clinician and the healthcare system. To anchor the discussion, we presented two use case scenarios featuring examples of generative AI-enabled tools for PC CDS (see **Exhibit 1**). The use case scenario descriptions were adapted from two CDSiC’s Innovation Center pilot prototype projects underway at the time of these discussions. The

scenarios provided participants with real-world PC CDS examples to anchor the discussion. We used probing questions to invite participants to discuss the potential benefits and concerns related to the use of these prototype tools, their level of trust in these tools along with influencing factors, and the impact on the patient–clinician relationship.

To refine the discussion guide, we conducted three 60-minute virtual cognitive debriefings with patient representatives and researchers to improve understanding and ensure comprehension of discussion questions. During the cognitive debriefing sessions, we prompted participants to respond to each discussion guide question to ensure it could elicit meaningful responses. We requested their feedback and suggestions on the phrasing of the questions and use case scenario explanations. Cognitive debriefing participants also provided feedback on a background document on PC CDS and AI that would be shared with focus group participants.

Exhibit 1: Two Generative AI Prototype Examples Used for Small Group Discussions

Example 1: Patient Follow-up Question Application
A tool that uses AI to ask patients clarifying questions. For example, a patient asks a question about their runny nose in their online patient portal. The AI-powered tool uses evidence-based information to generate follow-up questions in real time and collect additional information about the patient’s concern. Once the tool has gathered enough information from the patient, it summarizes the information and shares the summary with the doctor. The doctor then moves forward with any next steps needed to address the runny nose, such as ordering a lab test, sending a prescription to the pharmacy, or asking them to come into the office for further evaluation.
Example 2: AI-Based Intervention to Support Medication Adherence
To help patients remember to take their newly prescribed medications consistently, an AI-based application automatically sends check-in messages to patients who were recently prescribed a new medication. The application communicates with the patient via text messages using the patient’s selected language, such as English or Spanish. The application sends medication reminders and generates questions about any new symptoms. By using the patient’s responses and asking relevant follow-up questions, the application can then provide updates to the patient’s doctors, nurses, or other care team members so that they can monitor the patient and make any recommendations or changes.

2.2 Small Group Discussions

We used purposive and convenience sampling to identify participants for the small group discussions. Patient and caregiver advocates were identified by the CDSiC team and through recommendations provided by Trust and Patient-Centeredness Workgroup members. We conducted three small group discussions (n=2, n=2, n=3) with a total of five patient advocates and two caregiver advocates between January and February 2024. Prior to the discussions, participants received the brief background document that provided a summary of PC CDS and AI in lay terms and examples illustrating the application of AI in PC CDS.

An experienced facilitator led each session using the discussion guide, and a CDSiC member took detailed transcript-style notes. The sessions were conducted via Zoom, audio- and videorecorded, and lasted approximately 75 minutes.

2.3 Analysis and Synthesis

We performed a rapid qualitative content analysis of the detailed transcript notes across the three small group discussions to inductively identify key concepts and themes.¹³ The structure of the discussion guide informed the inductive coding. We identified themes related to general views on the use of AI for healthcare purposes, the factors influencing trust, the impact on the patient–clinician relationship, and considerations for generative AI's implementation for PC CDS.

3. Findings

Patient and caregiver participants had a range of experiences with AI. While most participants reported limited experience seeking out AI technology for health-related purposes, a minority of participants shared that they had explored publicly available generative AI tools (e.g., ChatGPT) to summarize healthcare visit notes that they had access to through OpenNotes to generate action items for themselves. Most participants believed that they had encountered AI tools in a healthcare context; however, participants were unable to recall specific instances where they were *certain* they had interacted with healthcare AI. Most often, participants suspected that online tools used to facilitate administrative tasks, such as appointment scheduling, were powered by AI. None of the participants reported being directly informed by their healthcare provider that an AI tool was in use.

Below, we detail findings related to participant views on AI in healthcare, factors that influence trust in AI, the potential impact of AI on the patient–clinician relationship, and participant-generated considerations for the use of AI in healthcare.

3.1 Participant Views on the Use of AI in Healthcare

Participants' overarching perspectives on the use of AI in healthcare were highly individualized and ranged from cautious to optimistic. Participants recognized that views on AI were not universal and were dependent upon each patient's level of involvement in their own care, comfort using technology, and personal preferences. For instance, participants noted that some patients may prioritize face-to-face interactions with their provider, limiting their willingness to use an AI-powered communication tool, while others may be more comfortable substituting asynchronous communication for some direct interactions.

Though participants' general views of AI differed, a majority still believed that AI had the potential to strengthen healthcare delivery by improving access and efficiency. Participants agreed on AI's potential to streamline patient–clinician communication, save time, and reduce unnecessary healthcare visits. Participants noted that AI tools hold the potential to support communication and help the patient provide key information on their condition outside of an office visit, allowing patients to maximize time during appointments or avoid a visit altogether. For example, one

participant discussed the utility of an AI-enabled tool to facilitate a conversation with their provider about tapering medications. An AI tool could allow a patient to quickly exchange information with their provider and expedite any necessary treatment changes, rather than wait 3–6 months to address this during an appointment. Relatedly, participants agreed on AI’s capacity to assist with simpler administrative tasks, such as scheduling medical appointments, and improve the coordination and management of healthcare services.

Participants also agreed on AI’s potential to support clinicians’ decision making by serving as an additional tool that can be used to strengthen their practice. Subsequently, participants largely did not express concerns with AI being used by clinicians to support decision making, especially where there was the potential for close human collaboration and oversight.

“I not only don’t have a problem with [AI], but I can really see it improving ... access and efficiency. I do think there need to be precautions, and there needs to be oversight. But I don’t see it as a big, scary, evil thing, unless it’s just allowed to kind of run rampant.”

Despite the noted benefits of AI, most participants also raised concerns about how AI might create challenges in healthcare delivery. For example, clinicians may not review or use information collected by an AI tool, causing the patient to re-share information they already provided. Participants pointed out that this would eliminate key benefits of AI: its time-saving capabilities and its ability to support sharing of information before the patient–clinician encounter, which would allow for more meaningful discussions about clinical concerns and treatment options during the appointment. Additionally, AI tools have the potential to make it more difficult to reach a clinician by not allowing patients to easily opt out and connect with a human provider. Participants believed that this could hinder access to healthcare and create additional burdens for patients, especially for individuals with less experience using technology or limited digital health literacy.

Participants also described the potentially limited ability of AI tools to address complex or sensitive health concerns. While a majority of participants felt comfortable using AI tools to address basic health concerns (e.g., a cold), they were concerned with AI’s ability to effectively and sensitively respond to more serious issues (e.g., a potentially cancerous mole). Participants also noted that AI tools may have a limited capacity for the personalization and tailoring necessary to support patient-centered clinical decision making. Participants expressed doubts that AI tools would be able to integrate the information needed to make personalized recommendations for each patient. As one participant explained, *“I have 57 years of medical history under my belt, right?... How do I expect AI is going to know me well enough as a complex patient?”* Participants agreed that every patient has a unique and extensive health history, so it is inherently challenging for AI tools to give accurate recommendations to everyone.

3.2 Factors That Influence Trust in AI Technology

When presented with potential uses of AI in PC CDS, participants noted that their level of trust in and acceptance of these tools would be influenced by the relationship between the patient and the clinician or health system using the tool.

Participants’ openness to AI tools in healthcare was influenced by their individual healthcare journeys and comfort with technology. For instance, a few participants expressed reservations

about the use of AI, particularly those who had previously faced a misdiagnosis or encountered challenges with the healthcare system or their clinician. They believed that AI might not be able to address these fundamental issues in healthcare. Additionally, participants recognized that a patient's willingness to use AI tools for healthcare would depend on their comfort levels and past experiences with technology, personal preferences, and engagement in their care. For example, one participant shared an experience of receiving inaccurate answers to a simple medical question when using another AI tool. As a result, they would prefer that a trained healthcare professional reads diagnostic test results (e.g., CT scans), rather than relying on AI-powered technology.

Participants emphasized that current issues with patient-facing technology in healthcare should not be overlooked when integrating AI. Several participants noted frustration when interacting with existing healthcare technology, citing experiences where online platforms crashed or where they became stuck in a communication loop with automated appointment scheduling tools. Participants noted that many healthcare providers and systems do not implement and maintain *existing* technology well and expressed doubts about their ability to effectively deploy new AI-powered tools that will enhance patients' experiences.

Participants said they would be more likely to accept and trust an AI tool if it was introduced by a trusted clinician or health system. Some participants mentioned that they would be more inclined to use the tool if it were recommended by their doctor or a healthcare organization with whom they had a longstanding relationship.

Participants also discussed the importance of *how* clinicians introduced the tool to patients. Several participants emphasized the importance of effectively introducing the tool to prospective users, such as describing why it was mutually beneficial. All participants agreed that their confidence and readiness to use the tool would be influenced by their clinician's enthusiasm and efforts to explain its usefulness and functionality. A

"If it were just some random AI interface, I would be, hopefully, skeptical and distrustful. But if it's within the context of an organization, or a medical practice, or a group that I trust, [I'm] not saying that it's going to be problem-free, but I'll have an inherent trust in the fact that everyone has the best intentions."

A thoughtful explanation from the clinician about why they propose the use of this tool would enhance patient acceptance. However, if it seemed like a clinician was imposing the tool on patients solely for their own benefit, their perception about the tool would be altered. Participants suggested that clinicians and health systems should be willing to collaborate with patients and caregivers to establish their trust in these devices and ensure that they benefit all users.

Participants also emphasized the need for transparency regarding the use of AI technology in healthcare. They identified several factors related to transparency that would influence their level of trust in AI-powered tools used for PC CDS.

Being able to identify that the tool was supported by AI. Participants agreed that they would want to know when AI is communicating with them, rather than a human clinician or staff member. Participants wanted the tool's design to clearly communicate its use of AI technology and recommended that AI tools be accessible, easy to understand, and friendly. However, participants cautioned against excessive personalization, emphasizing the importance of avoiding "overdesign" or

"overengineering" to mimic human interaction. As one participant explained, *"I don't want the bot to chat like a human because I want to know when I'm talking to a bot."* Consequently, the tool's design and user interface were important factors that would influence participants' level of trust in and willingness to engage with an AI-enabled PC CDS tool for their care.

Understanding who has access to patient data collected by the tool. Multiple participants raised concerns about how data is stored and shared in generative AI tools. While a few participants expressed no privacy concerns in light of the current era of digital sharing, multiple participants emphasized that tools should provide transparent information on ownership (i.e., if a third party outside of the health system owned the tool) to make it clear who ultimately owns and can access the tool's data. Participants also emphasized that providing disclaimers to clarify the purpose of the tool, along with information on how and where the patient's shared data is stored, would support their trust in the device.

Receiving information about the underlying data source. Participants agreed that they would trust an AI-enabled PC CDS tool if they knew it was providing accurate information. Some participants raised issues around the credibility and outdatedness of the underlying evidence that may inform the AI tool, given the time-consuming nature of conducting and publishing research. For example, one participant described an experience with discovering that the evidence used to inform a treatment decision was outdated. They noted that similar outcomes may result if AI technology uses outdated or limited evidence to base its findings or develop recommendations. Relatedly, a few participants also noted the potential issue of modeling bias in the development of these tools, where the perceived accuracy of the data might not represent the true patient population and may exclude historically marginalized or vulnerable groups. One participant highlighted the importance of using accurate, representative data, stating that *"[t]he tools are only as good as the information that they have and the information that they're being trained on. As long as there's lack of information, there's major concerns for how that's going to impact certain groups."*

In general, participants noted that they would trust that AI-enabled tools were providing accurate information once they saw the tool in practice. This would allow them to understand whether the tool is generating the right prompt or question and yielding results or outcomes relevant to their concern.

3.3 Impact of AI Use on the Patient–Clinician Relationship

Participants suggested that the use of AI technology for PC CDS would not *inherently* influence their perspectives on or trust in their clinician. For instance, participants did not feel that providers who use AI were automatically more or less trustworthy. Instead, the provider's approach to using the tool would influence their perspective on their provider. **However, participants identified two primary factors as having the potential to impact the patient–clinician relationship.**

Use of AI tools in a collaborative manner. Some participants suggested that the use of an AI tool in a collaborative manner could improve their clinician's practice and enhance the patient–clinician

relationship. This could include using AI tools that specifically benefit patients, such as timesaving tools that give the patient the opportunity to focus on their priorities. One participant noted, *“I’m not going to think less of the provider [for using AI], like I’m going to appreciate that the provider and I are both putting value in the things that I do think should take up providers’ time.”* Participants agreed that the utilization of tools to enhance the patient experience and mutually benefit both the patient and their provider could build and strengthen the patient-clinician relationship.

“Healthcare is a team sport. So, I [think] any additions to the team that can help provide a correct diagnosis or better cure for cancer, I think we can all support that idea.”

Disruption of patient–clinician interactions. The use of AI technology that disrupts patient–clinician interactions could cause distrust toward healthcare providers. Participants emphasized that AI tools should not fully replace patient-clinician interactions. Instead, these tools should be viewed as supplementary or facilitative. Participants noted that AI tools that occupy a space between the patient and their clinician, such as tools that summarize a patient’s concerns and share that information with a provider, require AI to accurately represent a patient’s information. Since this is a more complex task, participants discussed the potential need for providers to follow up with patients to inform next steps, and not solely rely on the AI.




“The doctor is going to get some summary that says, this is what the AI thinks [the symptom] is, and it could very well be wrong. So, what does that mean? Is the doctor just going to take the summary the AI gives them as gospel? Or is he or she going to call me and ask a few more questions that relate to my history? There’s a lot of room for error.”





Several participants noted that a clinician’s overreliance on an AI tool’s findings or recommendations could negatively impact their perception of their provider. Participants underscored that clinicians should not place absolute trust in AI tools, and instead should maintain the continued use of other sources and ongoing verification of findings to inform their clinical care. As one participant explained, *“It’s a massive risk if we assume that because these systems are so smart, they know everything legitimate. The door needs to be open for somebody to comment and I don’t think that could be absorbed algorithmically.”*

3.4 Considerations for Implementation and Use of AI in PC CDS

Participants identified seven areas (see **Exhibit 2**) that healthcare organizations should consider when implementing patient-facing, generative AI-supported PC CDS tools.

Exhibit 2: Considerations for the Implementation and Use of AI in PC CDS

	Consult patients and provide choices when introducing AI tools for PC CDS
	Provide education and training to support patients’ and caregivers’ use and understanding of AI-enabled tools
	Develop standards and design principles to promote transparent, safe, and secure implementation of AI in healthcare

	Use AI as a supplementary tool to support and strengthen clinicians' work
	Conduct continuous monitoring, critical appraisal, and due diligence when implementing AI technologies for PC CDS
	Consider how to holistically use all data to personalize and tailor AI outputs in the development of AI-enabled PC CDS
	Consider challenges related to mistrust and navigating the existing healthcare system, particularly for historically marginalized or vulnerable populations

1. Consult patients and provide choice when introducing AI tools for PC CDS. To support patient-centeredness, participants suggested that healthcare delivery systems should engage their patient and caregiver community through advisory groups to gather feedback and input before implementing AI-enabled PC CDS tools. Participants also expressed the desire to have a choice in what instances they would use the AI tool. They seemed open to using AI tools for simpler healthcare situations, such as medication reminders or asking about a runny nose. However, one participant explicitly stated that alternative workflows should be in place for complex medical issues, especially those relevant to the multimorbid older patient.

“These types of tools are going to be person- or patient-specific. Some folks are going to be comfortable using them, some are not. And you’re never going to change those who are not. Some people may be comfortable using the technology itself, others are not.”

Accordingly, participants also noted that patients should have the opportunity to opt out of using an AI tool. Some participants suggested the use of a “help desk” or a convenient option to bypass the AI tool and communicate directly with a member of the care team to address their concerns. One participant specifically suggested that the generative AI tool for PC CDS should offer a superior experience compared to navigating a "phone tree." Participants observed that younger demographics may be more open to utilizing these tools. However, other groups may be averse to using AI technology and would prefer the status quo. Individuals in this category should have the option to opt out of using AI-supported PC CDS tools.

2. Provide education and training to support patients' and caregivers' use and understanding of AI-enabled tools. Participants highlighted the importance of providing patients and caregivers with thorough training and education on the effective use of AI-enabled tools. Given the prevalence of misinformation online, participants noted that generative AI can pose risks for individuals unfamiliar with its proper usage. Moreover, while reflecting on the specific use cases presented, a few participants pointed out that not all patients will know how to ask the right questions when interacting with generative AI-based PC CDS tools. Education and training on AI-powered tools will support the proper and effective use of this technology by patients and caregivers.

3. Develop standards and design principles to promote the transparent, safe, and secure implementation of AI in healthcare. Participants noted that healthcare organizations encouraging patients to use these tools need to provide very clear information, using lay terms, regarding the tools' data ownership and privacy to help patients feel secure and address their potential concerns. This includes transparency about the underlying data used to inform and train AI-enabled tools. As one participant explained, *“For me personally, I would want to know, where is the data coming from?”*

Because if you're learning on a subset [that] doesn't match me at all, then, that's not helpful."

Participants underscored the importance of reviewing this prior to using the tool (e.g., at the point of accepting the tool's Terms and Conditions) and having ongoing, easy access to this information should they wish to reconsider.

4. Use AI as a supplementary tool to support and strengthen clinicians' work. Participants emphasized that their willingness to embrace AI-enabled tools was dependent on if the tool replaced clinician oversight. If clinicians use these tools to improve their practice by allocating more time to actively listen to patients or their caregivers, engaging in meaningful dialogues, and collaboratively utilizing these tools to enhance clinical decision making, participants would be more inclined to support their integration into clinical care. Participants rejected the notion of AI tools eliminating essential clinician involvement and oversight and cautioned against overreliance on such tools.

5. Conduct continuous monitoring, critical appraisal, and due diligence when implementing AI technologies for PC CDS. To sustain and improve trust in such tools over time, participants discussed the need for healthcare delivery systems to conduct critical, continuous evaluation of the tool's functionality and ability to provide accurate, valuable, and reliable recommendations or findings. Several participants suggested that it is crucial to incorporate appropriate oversight procedures and safeguards to mitigate potential risks arising from the current known limitations of generative AI technology. As the use of AI continues to grow in healthcare, ongoing monitoring and evaluation will help to support the quality and utility of AI-based tools for PC CDS.

6. Consider how to holistically use all data to personalize and tailor outputs in the development of AI-enabled PC CDS. While many participants expressed concerns about data privacy and security, others expressed concerns about the ability of an AI tool to access data across EHR systems and customize outputs based on patients' unique needs. Participants noted that every person is unique, some with decades-long health histories that can be challenging to convey in a conventional clinical setting. They also expressed reservations about the difficulty of communicating detailed medical information to an AI-based tool. Considerations should be made in the development of AI-based PC CDS tools to support the exchange of patient information between EHR systems in order to ensure personalization of outputs for each unique patient.

7. Consider potential challenges related to mistrust and navigating the existing healthcare system, particularly for historically marginalized or vulnerable populations. All participants emphasized the need to take patients' socioeconomic backgrounds into account when implementing AI-enabled PC CDS tools. Participants highlighted factors such as limited health literacy, access to technology, and overall comfort with AI as potential barriers to enabling its use by certain patient populations. Participants underscored that disparities, general mistrust, and cultural concerns within the healthcare system could significantly impact the

"I mean, people come from very different backgrounds and perspectives. And so, one of the things I do think about is..., does AI take into account illiteracy? Does it take into account someone's inability to access technology? So, there's going to be different levels of care based on what we each bring to the table. And some of that's already happening. But I think we can level the playing field a little bit more when we're one human to another. But I would love to know that there's some attention to that and to the disparities in [the] inability to interact with AI that are bound to come up."

ethical and equitable use of AI tools in PC CDS. Without considerations for historically marginalized or vulnerable populations, the implementation and use of AI-enabled PC CDS tools may contribute to health inequities and mistrust in the healthcare system.

4. Discussion

In this report, we share preliminary patient and caregiver perspectives on the use of generative AI technologies in PC CDS. Notably, this report goes beyond general insights and offers specific considerations to support PC CDS.

Overall, our participants were mostly optimistic about the use of AI in PC CDS and generally believed that it has the potential to be a promising tool for simple clinical scenarios, reduce lag time, and improve the efficiency of patient–provider communication. However, they also expressed potential concerns. Our findings are consistent with other research studies and literature on the use of AI in healthcare. Research has shown that Americans’ attitudes vary on the proliferation of AI in daily life, with many reporting both excitement and concern.¹⁴ Studies highlight similarly positive opinions on the use of generative AI-powered tools for healthcare but also reported similar reservations that were noted in our findings.^{9, 12, 15, 16, 17}

Moreover, participants expressed that the use of generative AI tools to support decision making will not necessarily impact their relationship with providers or change their views about them, as long as they are incorporated within the workflow in an informed manner without compromising on aspects that require human involvement. A recent qualitative study that explored patient perspectives on an AI-based CDS tool for skin cancer screening suggested that they would be receptive to the technology as long as it preserved the patient–clinician relationship; however, they did not explicitly ask about how the implementation of these tools would impact their view of their provider.¹⁸

Participants alluded to several opportunities related to transparency that could improve their trust in patient-facing generative AI tools specifically to facilitate PC CDS. These include access to information about the ownership, development, and methodology employed by the tool, data security and privacy, and procedures for continuous monitoring and evaluation. These factors align with previous CDSiC work¹⁹ that identified attributes salient for PC CDS to improve source credibility. Notably, the need for transparency around the underlying algorithms that power AI tools has also been included in the ONC’s HT-1 rule finalized in December 2023.⁸ Future studies exploring this topic might want to emphasize the importance of source attribution within generative AI systems and assess its potential impact on patient perspectives regarding AI in PC CDS, as well as investigate the feasibility of mechanisms to achieve the level of transparency desired by patients.

Future studies should also explore views and beliefs from a diverse sample to identify and compare perspectives across different populations based on factors such as age, race, and disease states. While we aimed to include individuals from diverse backgrounds and with various lived experiences, our small group discussions may not be representative of certain populations, such as individuals with limited digital literacy or historically marginalized groups. As these tools are deployed, our participants raised concerns about the potential risk to exacerbate mistrust and healthcare inequities in vulnerable populations. A recent literature review on barriers and facilitators to trustworthy and ethical AI-enabled

medical care identified a similar ethical concern that needs to be considered.²⁰ An additional limitation of this work is that the specific use case scenarios used to initiate the discussions may have influenced the areas of focus and perspectives expressed by the participants. Different scenarios or prompts might have led to additional or alternative themes regarding the use of AI for PC CDS.

Patients have expressed mixed views on the use of AI in healthcare delivery, with some seeing AI as having the potential to reduce racial and ethnic bias, but also expressing discomfort with healthcare providers' overreliance on AI tools to diagnose disease and provide treatment recommendations.²¹ Critically, views on healthcare AI often differ based on demographic characteristics, such as age, race, and education level.²² However, these views are ever-evolving as generative AI-enabled technology is relatively new (e.g., ChatGPT was launched in November 2022) and there is growing public awareness and use of AI.

5. Conclusion

This report contributes to growing literature that explores patient and caregiver perspectives on the use of generative AI in healthcare, with a specific focus on its use in PC CDS. The use of these tools has several implications for clinical decision making and the patient–clinician relationship.

Empowering patients to make informed choices about when AI is used in their care, as well as working to promote the transparent and safe implementation of healthcare AI, are paramount.

Stakeholders can take into account several considerations identified in this report for fostering trust and patient-centeredness in PC CDS tools powered by generative AI. Patient-facing generative AI tools that incorporate these considerations in the design and implementation of PC CDS have the potential to improve access to health information, enhance patient autonomy, and foster engagement.

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