

# Standards and Regulatory Frameworks Workgroup: Prioritizing Patient Preferences for Standardization to Support PC CDS

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5600 Fishers Lane  
Rockville, MD 20857  
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## Prepared by:

Desirae Leaphart, MPH and Rachel L. Richesson, PhD, MPH, FACMI  
Kiran H. Correa, MPP  
Azam Ahmed, BA  
Aziz A. Boxwala, MD, PhD, FACMI  
Priyanka J. Desai, PhD, MSPH  
Prashila M. Dullabh, MD, FAMIA  
CDSiC Standards and Regulatory Frameworks Workgroup

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## PURPOSE

The Clinical Decision Support Innovation Collaborative (CDSiC) aims to advance the design, development, dissemination, implementation, use, measurement, and evaluation of evidence-based, shareable, interoperable, and publicly available patient-centered clinical decision support (PC CDS) to improve health outcomes of all patients by creating a proving ground of innovation. The Standards and Regulatory Frameworks Workgroup is charged with identifying, monitoring, and promoting standards for the development of PC CDS and examining the current state of the regulatory environment. The Workgroup is composed of 19 experts and stakeholders representing a diversity of perspectives within the CDS community. This report is intended to be used by the broader CDS community to advance the use of standards for PC CDS. All qualitative research activities conducted by the CDSiC are reviewed by the NORC at the University of Chicago Institutional Review Board (FWA00000142).

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# Contributors: CDSiC Standards and Regulatory Frameworks Workgroup

Members of the Standards and Regulatory Frameworks Workgroup who contributed to this report are listed below.

Name	Affiliation
Guilherme Del Fiol	University of Utah
Sonja Fulmer	FDA
Robert Greenes	University of California San Diego, Arizona State University, and Mayo Clinic
Robert Jenders	University of California Los Angeles
Brian Levy	Oracle Cerner
Chris Moesel	MITRE
Jan Oldenburg	Participatory Health
Vishwasrao (Vishwa) Salunkhe	Wolters Kluwer Health
Howard Strasberg	Wolters Kluwer Health and UpToDate
Andrew G. Ten Have	Wolters Kluwer Health and UpToDate

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# Executive Summary

Patient preferences are the relative desirability or acceptability to patients of specified alternatives or choices among structures, processes, outcomes, or experiences of interactions with the healthcare delivery system. Patient preference information, when it is collected, is often collected as unstructured data in electronic health records (EHRs) and thus may not be used by clinicians or in digital health tools to inform patient care. Patient-centered clinical decision support (PC CDS) enables the timely delivery of evidence-based guidance, informed by patient-specific data, to support patient engagement in healthcare and facilitate shared decision making. Standardized, structured encoding of patient-preference data will allow those data to be used by and shared across various systems, including EHR systems and PC CDS tools. PC CDS tools will have more impact when they can produce clinical recommendations that incorporate and account for patients' preferences. This report explores the standardization of patient preference information for inclusion in PC CDS.

## Background

Prior work by the Clinical Decision Support Innovation Collaborative (CDSiC) concluded that some types of patient preferences can be encoded with existing terms in standardized codes and terminologies for use in PC CDS tools, but others cannot. As a result, patient preferences may not be seamlessly incorporated into PC CDS tools and recommendations. To advance the use of patient-preference data in PC CDS, it is important to understand patient preference types that should be prioritized for standardization. One conclusion from the prior CDSiC report is that our current understanding of which patient preference concepts should be unstructured and prioritized for standardization is poor.

Using information collected through a multistakeholder roundtable discussion and subsequent key informant interview, this report discusses which patient preference concepts lend themselves best to standardization. It discusses the challenges associated with collecting patient preferences in a structured and standardized way and attempts to define priorities for patient preference standardization.

## Methods

To develop this report, the CDSiC team conducted and analyzed themes from a 10-person roundtable that included perspectives from patient representatives, EHR developers, informaticians, researchers, standards developers, and clinicians. Participants of the roundtable discussed the patient preference information that should be prioritized for standardization utilizing the CDSiC Outcomes and Objectives Workgroup Patient Preferences Taxonomy as an organizing framework for different types of patient preferences. The team also analyzed themes from an additional key informant interview conducted to validate findings from the roundtable. Finally, the team reviewed the draft United States Core Data for Interoperability (USCDI) version 5 to determine which of the patient preference priorities from the roundtable might be considered for inclusion in a future version of USCDI.

## Key Findings

The roundtable generated several key themes in terms of participants' experiences with the routine collection of patient preferences for their clinical care, patient information that should be prioritized for standardization in the short and long term, and challenges with standardizing patient preference information. Key themes that came through based on participant discussion include the following:

- **Participants shared that generally their preferences as patients are not collected routinely as part of their healthcare.** Participants also noted that when patients share their preferences, health systems and clinicians need to use this information, creating an important feedback loop in which patients can feel that the information they provided is being used and incorporated into their care.
- **Participants discussed challenges they anticipate with standardizing patient-preference data,** including the changing nature of patient preferences over time; the burden of collecting patient preference information; the nuances of some patient preferences, which may not be suitable for standardization; the (often limited) ability of clinicians and the health system to act upon patient preferences; and adoption and use of standards.
- **Preferences pertaining to engagement (e.g., degree to which a patient wants to be engaged in healthcare decisions, how they want others engaged, mode of engagement), access to information, communication, caregiving, and treatment were discussed as high priority for standardization** due to the importance to patients that their clinicians know this information and it is shared across healthcare teams. Participants also discussed preferences related to personal characteristics and communication as “low-hanging fruit” for standardization and addressable in the shorter term.
- **Participants shared that some preference information may be lower priority for standardization** due to lack of feasibility (e.g., disease-specific treatment patient preferences), lack of relevancy across contexts (e.g., location), or sensitivity (e.g., treatment preferences around behavioral health). Disease-specific treatment preferences (such as preferences for receiving a transplant for advanced kidney failure) were also discussed as nuanced and dynamic, making such preferences more suitable for standardization in the longer term.

The exhibit below categorizes the patient preferences as priorities for standardization in the short (2–5 years) versus long term (5–10 years) based on discussion during the roundtable.

Patient Preference Domain	Examples Discussed	Short Term or Long Term
Personal Characteristics	<ul style="list-style-type: none"> <li>• Language*</li> </ul>	Short Term
Communication	<ul style="list-style-type: none"> <li>• Timing</li> <li>• Mode</li> <li>• Frequency</li> </ul>	Short Term
Engagement	<ul style="list-style-type: none"> <li>• Degree</li> <li>• Inclusion of others in decisions</li> <li>• Mode</li> </ul>	Short Term
Data	<ul style="list-style-type: none"> <li>• Clinician access (e.g., coordination, health information exchange)</li> </ul>	Short Term
Healthcare Services	<ul style="list-style-type: none"> <li>• Type of treatment/intervention*</li> <li>• Receipt of treatment*</li> <li>• Care management</li> </ul>	Short Term
Healthcare Services	<ul style="list-style-type: none"> <li>• Disease-specific treatment/intervention</li> </ul>	Long Term
Access and Care Experience	<ul style="list-style-type: none"> <li>• Location for clinical care</li> <li>• Location for health services</li> </ul>	Long Term

\*Included in draft USCDI version 5.

## Future Directions

PC CDS tools will be more impactful when they can produce clinical recommendations that account for patients' preferences. Ultimately, standardizing patient preference information can advance incorporation of these data into PC CDS tools, enhancing their use for patient-centered care and shared decision making. Based on the themes that surfaced through the roundtable discussion regarding the standardization of patient preference information for inclusion in PC CDS, we identified four future directions:

1. Conduct future research that includes patients and clinicians to qualitatively assess how capture of patient preferences could be optimally included in the clinician workflow and patient lifeflow in a way that reduces patient and clinician burden and that ensures patient-preference data collected from patients are utilized. CDSiC has found that gaps remain in our understanding of optimal workflows. For more information, see the [CDSiC's Trust and Patient Centeredness Workgroup's recent product](#) on capturing different types of patient preference data.
2. Further standardize high-priority patient preference information through a multistakeholder effort (including patients, caregivers, patient advocates, clinicians, standards developers, informaticians, researchers, etc.) to submit data elements for preferences specific to engagement, access to information, communication, caregiving, personal characteristics, and data sharing for eventual inclusion in the USCDI.

3. For patient preference information that are longer-term priorities for standardization (due to lack of feasibility to standardize and their dynamic nature), engage patients, caregivers, patient advocates, clinicians, researchers, and informaticians to:
  - a. Conduct and participate in further research to understand how to make the standard capture of dynamic patient preference information more feasible.
  - b. Conduct and participate in further research to advance disease-specific validated preference solicitation measures and their adoption.
4. Continue multistakeholder discussions, research, and efforts to address the challenges identified in this report regarding standardizing patient-preference data. Patients should be centered and included in this work; an important component of this is patient education around the concepts of patient preference information and standardization.



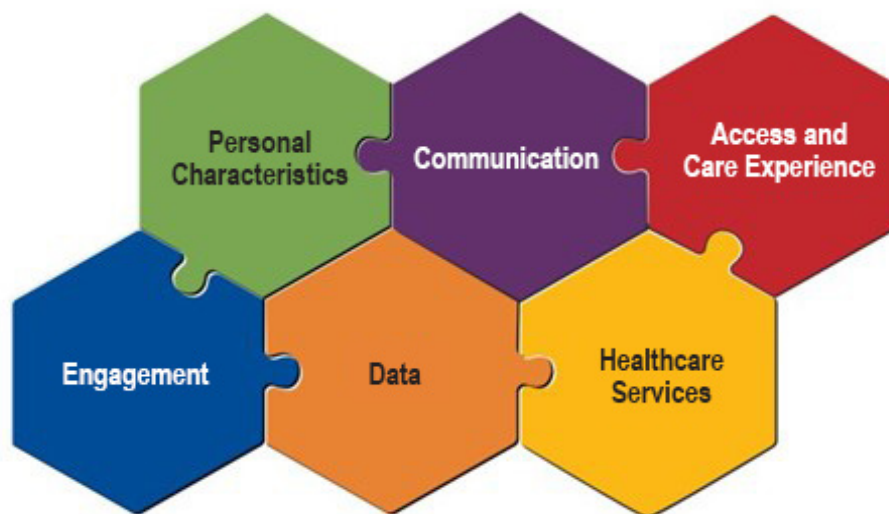
# 1. Introduction

Incorporating patient preferences into clinical decision support (CDS) allows for more tailored healthcare decision making. The Agency for Healthcare Research and Quality (AHRQ) Clinical Decision Support Innovation Collaborative (CDSiC) defines patient preferences as “the relative desirability or acceptability to patients of specified alternatives or choices among structures, processes, outcomes, or experiences of interactions with the healthcare delivery system.”<sup>1</sup> Patient preferences may include desired forms of communication, preferences around the care experience and ways to access care, and preferences regarding specific healthcare services and treatments, among others. The CDSiC Outcomes and Objectives Taxonomy of Patient Preferences defines six relevant domains of preferences, which include personal characteristics, communication, access and care experience, engagement, data, and healthcare services.<sup>1</sup> Exhibit 1 displays the six domains of patient preferences; review the [CDSiC Outcomes and Objectives: Taxonomy of Patient Preferences](#) report and Appendix A for a detailed description of each patient preference domain, including examples.

**Patient preferences provide the basis for how patients wish to:**

- Interact with their clinician or care system
- Share their personal data
- Choose a particular course of action over others
- Prioritize particular attributes or effects of healthcare<sup>1</sup>

**Exhibit 1.** CDSiC Domains of Patient Preferences



Decision making informed by patient preferences is a key component of patient-centered care and can improve adherence to prescribed therapies, experience and satisfaction with care, and health outcomes.<sup>2,3</sup> Patient-centered clinical decision support (PC CDS) encompasses a spectrum of decision making tools that significantly incorporate patient-centered factors 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. Finally, use focuses on facilitating bidirectional information exchange in support of patient-centered care, including shared decision making.<sup>4</sup>

PC CDS tools will be more impactful when they can produce clinical recommendations that incorporate and account for patients' preferences. Currently, if patient preference information is collected in electronic health records (EHRs), it is typically documented as unstructured text data in clinical notes.<sup>5</sup> This makes it hard to find and act upon patient preference information or to share patient-preference data across healthcare organizations. As a result, even when it is collected, patient preference information may not be used by clinicians or in digital health tools. Standardized, structured encoding of patient-preference data will allow those data to be used by and shared across various systems, including EHR systems and PC CDS tools.

Prior work by the CDSiC concluded that some types of patient preferences have codes in standard health terminologies (in some cases from multiple code systems), while others do not.<sup>5</sup> This limits the ability to store and exchange patient-preference data in a structured and encoded manner. The assessment found the need for codes related to patient preferences within the domains of data, access and care experience, and communication. The report also concluded that not much is understood regarding which patient preference concepts should be prioritized for standardization based on a multidisciplinary stakeholder perspective. Further, the report determined there was limited adoption of terminology codes capturing patient preferences as indicated in the current version of the United States Core Data for Interoperability (USCDI), which is "a standardized set of health data classes and constituent data elements for nationwide, interoperable health information exchange."<sup>6</sup> The report recommended inclusion of additional patient preference codes in future versions of the USCDI as it presents a growing collection of data collection elements that EHR systems must support. To advance the use of patient-preference data in PC CDS, it is important to understand which patient preference types should be prioritized for standardization given that standardizing data elements involves a process requiring buy-in and substantial effort from multiple stakeholder groups.<sup>7 8</sup>

Through a multistakeholder roundtable discussion and a subsequent key informant interview, this report discusses which patient preference concepts lend themselves best to standardization. It addresses the limited understanding of which patient preference information to prioritize for standardization from the perspectives of patients and other stakeholders, and surfaces the challenges associated with the standardization of patient-preference data. This report will distill the findings from a multistakeholder roundtable to achieve the following objectives:

- Identify types of patient preferences that are high priority to advance PC CDS and should be prioritized for standardization.
- Articulate and emphasize patients' perspectives on the advancement of standardization of patient preference information for its inclusion in PC CDS tools.

## 1.1 Roadmap of the Report

To further explore the standardization of patient preference information for inclusion in PC CDS, this report distills findings from a roundtable discussion and a key informant interview to identify which patient preference categories should be prioritized for standardization. Section 2 describes the methods used to define our questions, conduct the roundtable, synthesize the discussion topics, and draw conclusions. Section 3 presents the results, beginning with an analysis of the key takeaways and transitioning to potential challenges with standardization of patient preference information. Section 4 discusses future directions to advance patient preference standardization and address challenges, and Section 5 provides a brief conclusion.

## 2. Methods

To develop this report, the CDSiC team conducted a roundtable and an interview with a key informant, consulting with the CDSiC Standards and Regulatory Frameworks Workgroup throughout the development and analysis process. Additionally, the team reviewed the USCDI data elements proposed for inclusion in USCDI version 5 to determine which patient preference information could be considered for inclusion in future versions.

### 2.1 Roundtable Participants

Roundtable participants were selected based on their expertise and in consultation with the Standards and Regulatory Frameworks Workgroup. To ensure that the patient perspective was amplified, the majority of invited participants were patient representatives. The ten participants included four patient representatives, two EHR developers, one informatician, one patient preferences researcher, one standards developer, and one clinician. Some participants held multiple designations or roles (e.g., a clinician who was also an EHR developer), but the aforementioned categories reflect their primary professional role or perspective in the context of the roundtable. All invited participants contributed to the discussion and provided comments, insights, suggestions, and considerations to inform this report.

### 2.2 Conducting the Roundtable

A semistructured discussion guide was developed through a collaborative process that incorporated suggestions from the Workgroup members. Initially, the CDSiC team drafted the guide based on key objectives and topics for discussion. It was then circulated among Standards and Regulatory Frameworks Workgroup members for feedback and input. The CDSiC team provided a background document on PC CDS and patient preference standardization (Appendix B) to participants prior to the roundtable. Participants were also provided with the CDSiC Outcomes and Objectives Taxonomy of Patient Preferences, which served as a basis for discussing types of patient preferences.

Pre-roundtable preparatory meetings with patient representatives were conducted via Zoom, lasting 30 minutes each. These short meetings were used to prepare participants for the upcoming roundtable by familiarizing them with its goals, the overall flow of the session, and the questions that would guide the discussion. During the meetings, the CDSiC team responded to questions on the background document to ensure that patient participants were well informed and prepared to contribute meaningfully to the roundtable.

The roundtable was a 3-hour session conducted via videoconferencing using Zoom in March 2024. It began with the CDSiC team providing background on patient preference standards in the context of CDS before transitioning into the discussion portion regarding participants' perspectives on 1) patient preference information that is high priority to share with their clinical teams, 2) what patient preference information is routinely collected during clinical encounters, 3) patient preference information that would be "low-hanging fruit" for standardization versus less feasible for standardization in the longer term, and 4) challenges associated with standardizing patient preference information. The discussion involved a series of round-robin and general discussion questions presented on slides. Moderators from the CDSiC team facilitated the discussion, ensuring that all participants had the opportunity to contribute.

Following the discussion portion, the team gathered high-level takeaways from each question and presented them to the participants as a summary to elicit final reactions. Throughout the discussion, the team took notes of all comments voiced by participants and noted repeated themes, suggestions, and recommendations. If a participant raised a point that received widespread agreement from other participants, it was considered for inclusion in the key takeaways.

## 2.3 Key Informant Interview

After completion of the roundtable, the team conducted a 60-minute interview via videoconferencing in April 2024 with an experienced clinician-researcher specializing in the collection and utilization of patient preferences to inform clinical care. The key informant was invited to but unable to attend the roundtable, and hence an interview was conducted to gain additional context on actionable steps to move patient preference standardization forward and validate findings from the roundtable from an additional clinical and researcher perspective. A semistructured interview guide was developed and tailored to the interviewee's expertise.

## 2.4 Analytic Approach

With participants' approval, the roundtable session and key informant interview were recorded, and a team member drafted a word-for-word transcript. These notes were utilized via a deductive analysis approach to develop themes and conclusions from the discussions. Additionally, the team mapped the patient preference examples of the taxonomy discussed during the roundtable to the draft USCDI version 5 to determine their feasibility for standardization in the short and long term.

### 3. Findings

This section presents the major themes that culminated from the roundtable including participants' perspectives on the importance of capturing patient-preference data for standardization, high-priority preferences to share with clinicians, "low-hanging fruit" preferences for standardization, low-priority preferences for standardization, and challenges with standardizing patient preference information.

#### 3.1 Capturing Patient-Preference Data for PC CDS

**Roundtable participants shared that generally patient preferences are not collected routinely as part of their clinical care.** From the beginning and throughout the roundtable, participants noted the importance of collecting patient preference information. When asked what types of patient preference information are routinely collected during clinical encounters, there was consensus that little is currently routinely collected, and what is collected varies across health systems. There are some areas of clinical care, such as advanced directives, in which capturing patient preferences is standard, but largely participants expressed that they are not often or routinely asked about their preferences by their clinicians. Additionally, clinician and informatician participants stated that in their respective fields they do not see these data being routinely collected.

**"I think largely our preferences were not even ask[ed] about and certainly right now, and like a regular, you know, just normal doctor visit without any kind of major medical care going on, we aren't asked those questions. Especially around preferences. I've never once had anybody go, "Oh, would you rather us call or email you?" Like, they do what's convenient for them, for their systems."**

**– Roundtable Participant**

Generally, roundtable participants saw the lack of capturing patient preferences as an opportunity for improvement. They agreed that it is important for clinicians to be aware of their preferences and that this is an area for attention that can move the needle on the implementation of PC CDS. The key informant discussion validated these observations from the roundtable, with the key informant specifying that patients want their clinicians to make decisions based on their individual patient goals and preferences. During the roundtable, it was also noted that, when patients share their preferences, health systems and clinicians need to use this information; this creates an important feedback loop in which patients can feel confident that the information they provide is being used and incorporated into their care. In the next section, we describe which patient preferences roundtable participants discussed should be collected.

#### 3.2 Patient Preference Information Standardization

During the roundtable, participants were asked which types of patient preference information they felt was most important to collect from patients and share across their clinicians and care teams. The discussion also touched on which patient preferences participants thought might be easier to

standardize (i.e., “low-hanging fruit” to address in 2–5 years) and which preferences would be better suited for standardization in the longer term (5–10 years).

### 3.2.1 High-Priority Patient Preferences for Standardization

Participants discussed preference information pertaining to engagement, access to information, communication, caregiving, and treatment as high-priority domains for data collection from patients.

**Engagement Preferences.** Multiple participants felt that preferences around engagement are important to collect from patients. Specifically, they discussed the importance of collecting preferences on how patients want to engage with their clinicians regarding their healthcare. This may vary from patient to patient depending on how much time they have available; for example, during the roundtable, it was specified that some patients may prefer to be less involved and only engaged when needed to make a decision regarding their healthcare. On a related theme, there was discussion about preferences around the patient’s role in making decisions regarding their health. Some patients may prefer to co-decide with their clinician about their treatment while others may prefer to listen and defer to their clinician’s opinion. Lastly, engagement preferences around being able to designate a proxy or caregiver to be involved in decisions about a patient’s healthcare and whom the patient would like their information shared with emerged as a priority area.

“Where am I on the decider scale? Do I want to be the person that makes most of the decisions in this relationship between me and the system? Or do I want to co-decide, or do I want to kind of just listen and do what my healthcare provider says?”  
– Roundtable Participant

**Communication Preferences.** At many points in the discussion, communication preferences were raised as important to collect from patients. Specifically, participants discussed preferences regarding the frequency (e.g., how often a patient is notified about something in their record) and mode of communication (e.g., email, text, or phone call). One person stated that the way that clinicians share information about a patient’s health and healthcare matters, as patients need to be able to understand it. Another participant noted that patients can miss communication from their clinician if the patient’s preferences around communication are not recorded and applied. Generally, there was agreement that communication preferences are often not collected or acted upon.

“One of the big ones for me would be communication, and just being consistently contacted through the mode of communication that I like. I’ve missed calls from healthcare organizations because they don’t support email or they don’t try to use text messaging, or they don’t try to offer those or even respect my communication preferences.”  
– Roundtable Participant

### **Information/Data Access and Sharing**

**Preferences.** Related to engagement, participants discussed the importance of preferences regarding access to information. Specifically, there may be information that patients want to be aware of regarding their care, and some information they do not want to be informed of, because they do not know what to do with the information or it is not urgent

(e.g., nonurgent laboratory results). Additionally, preferences on how that information appears to patients were flagged as important (e.g., information in text versus representations, such as graphs). Roundtable participants also felt that patient preferences around data sharing, such as whether patients are open to their data being shared and with whom, are important. Such data sharing preferences were noted as important to collect from patients as part of healthcare, at the first visits before important treatment decisions may arise.

**Caregiving Preferences.** At multiple points during the roundtable, people raised the concept of patient preferences around caregiving/caregivers. These were discussed in two scenarios: 1) when the patient is also a caregiver (and how this impacts their health and healthcare treatment) and 2) in terms of collecting the preferences of a patient's caregiver(s). One participant shared an

example of being a caregiver for a relative and not having access to the data they needed to act as an effective caregiver. The key informant validated the consensus from the roundtable that caregiver preferences are a high priority to share with clinicians and provided the example of patients who are limited in their ability to receive certain treatments because of their responsibilities as caregivers.

### **Treatment and Care Management**

**Preferences.** Several roundtable participants discussed the importance of collecting treatment and care management preferences related to tolerance for certain treatment types (e.g., chemotherapy) and how aggressive the patient would like to be in their treatment (e.g., risk tolerance for pain). One person noted that treatment preferences should be captured as

**“But the problem is, as a patient, I may actually not want to see all of the information because I don’t know what to do with it. I don’t know what to do with a chloride level that’s 105 versus 104...So do I want to see everything, or do I just want to see the important things?”**

**– Roundtable Participant**

**“We focus so much on the patient, but they’re caregivers. Patients are also caregivers for other people, and like, being a caregiver affects your health. So do we ask routinely again to the patient you’re seeing, ‘Hey, are you a caregiver for somebody else?’”**

**– Roundtable Participant**

**“Related to preferences around aggressive treatment options, or the hypothetical of, ‘I’m asking you, patient, what would you want in this scenario for advanced care planning or end of life orders, or something like that.’ I feel like it’s probably impossible to capture that in a structured way that will stay with somebody forever. Because I think it’s impossible to say what would you imagine the future—because you could say now [you are] in some sort of relatively or normal healthy state, or whatever your current situation is—‘Here’s what I think I would want,’ and then the situation happens, and you’re thrown a curve ball, and then everything goes out the window.”**

**– Roundtable Participant**

clinicians discuss treatment goals with patients. They provided an example of a cancer patient who was not once asked by their clinicians about their preferences regarding whether they would like to undergo chemotherapy. However, there was also some agreement that, given that this information can change over time, it may be best not to standardize these data so that the nuances of a patient’s thinking/rationale remain. Additionally, the information should not be captured only once (and not revisited) or applied generally across contexts.

### 3.2.2 Patient Preferences That Are Low-Hanging Fruit for Standardization

Participants shared preferences that could be “low-hanging fruit” for standardization in the next 2–5 years, that is, preferences that can be easily captured and shared and that can have a high impact in decision making and patient care. These included preferences that, from their perspective, could be easily collected or that do not change much over time.

**Roundtable participants identified personal characteristics and communication preferences as “low-hanging fruit” for standardization.** In terms of preferences that could be collected easily,

notification preferences and preferred communication mode were discussed as being easy to collect and act upon. Regarding preferences that do not change much over time, participants thought these were important to characterize as “low-hanging fruit” because they include information patients do not want to enter repeatedly. For example, personal characteristics, including preferred language, were discussed as being easy to routinely collect and a type of preference that is not very dynamic. Additionally, it was noted that USCDI v4 includes personal characteristics, specifically patient demographics/information.<sup>9</sup> Other “low-hanging fruit” specified included preferences for receiving telehealth care, interest in clinical trials participation, and data sharing preferences (in terms of what is done with their data and how it is shared).

**“Personal characteristics should be readily able to be standardized and, I think, useful to be standardized. We just don’t want to re-enter that over and over again as we go between our systems.”**

**– Roundtable Participant**

### 3.2.3 Patient Preferences That Are Longer-Term Priority for Standardization

Participants shared types of preference information that may be a lower priority for standardization due to lack of feasibility to standardize, lack of relevance across contexts, and sensitivity of information; these preferences were discussed as more suitable for standardization in the longer term (5–10 years).

**Participants shared preferences related to location of clinical care and health services and disease-specific treatments/interventions as longer-term priorities for standardization.** During the roundtable, some preference information was considered as either not relevant for all contexts (e.g., location) or too sensitive to share across care teams (e.g., treatment preferences around behavioral health). One participant expressed that “preferred location of care,” for example, is a lower priority for them as they may not want a treatment facility’s location factored into their decisions about their healthcare. Some participants also felt that treatment preferences related to behavioral and mental



health may be a lower priority to standardize because there may be sensitivities in collecting and sharing this information across care teams. An example could include patients' willingness to accept inpatient mental health treatment. It was also noted that some treatment preferences would be better not to standardize because this information is nuanced and subject to change frequently. One participant noted, "Some of these preferences are going to change over time, based on emerging situations, and may be impossible to be captured in structured data." One suggestion was that conversations between clinicians and patients in which treatment preferences are discussed could be captured in a standardized note in the longer term.

**"Because there's so much nuanced information that's lost if we just answer a question and I think particularly around things like the treatment stuff, which I would say would be good for sort of a longer term, it might be hard to have a discrete answer to, well, what are your treatment preferences?"**

**– Roundtable Participant**

### 3.3 Challenges Related to Standardizing Patient-Preference Data

Participants highlighted several challenges they anticipate with standardizing patient-preference data. Themes surfaced around the changing nature of patient preferences over time; the burden of collecting patient preference information; the nuances of some patient preferences, which may not be suitable for standardization; the ability of clinicians and the health system to act upon patient preferences; and adoption and use of standards. These challenges are described below.

**Patient preferences may change over time, which can make it difficult to ensure that preference information is accurate and up to date.** Several roundtable participants discussed that a patient's preferences are context-specific and can be influenced by factors such as age and where they are in their health journey. For example, a patient representative shared a story of an older patient with an aggressive form of cancer whose treatment preferences evolved over the course of her disease. Initially, she opted for a series of treatments including chemotherapy and surgery, but eventually, she decided to prioritize her quality of life over additional treatments.

**"...Let's say you build a CDS tool that's going off your patient preferences. And it's giving you some recommendations based on what your preferences were, but they've changed. But the CDS doesn't know that. And if you don't know that the CDS tool is acting on previous preferences, you're just seeing the output of that—'Here's what we recommend for you [based on old preferences].' You don't know any better. You don't know that there were other options."**

**– Roundtable Participant**

The dynamic nature of preferences poses a challenge to standardization. It requires that patient preference information be captured not just once but routinely updated over time to ensure that the preferences reflected in the EHR or a CDS application are accurate and interoperable. It was also noted that some preferences may be more persistent (such as patient's preferred name) while others may need to be revisited more regularly. Balancing maintaining current preference data without overburdening patients, clinicians, and staff with data collection was raised as a related challenge.

If preference information is not maintained over time, there is a potential risk of acting on outdated preferences. Several roundtable participants raised that, if outdated preference information is embedded in CDS, the CDS may provide recommendations that do not align with the patient's current preferences. As an example, a patient with end-stage renal disease may initially indicate a preference for dialysis and that they are not interested in a kidney transplant. In turn, electronic tools including CDS that provide recommendations based on this preference information may not offer information on kidney transplant for that patient. Therefore, the patient may miss out on transplant options, even as their preferences may evolve and make them more open to a transplant.

**Collecting and maintaining patient preference information incur risk of increasing burden on patients, clinicians, and staff.** Roundtable participants expressed concerns regarding adding to the burden of patients, clinicians, or staff by collecting data on patient preferences, especially as many of these preferences may need to be revisited over time. They noted that trying to collect information on too many types of preferences may create an excess burden, especially on patients and clinicians. The key informant also expressed that tools for collecting information on patient preferences should be simple and accessible for clinicians to reduce burden and help ensure that the information is acted upon in clinical care.

**Clinicians and health systems may not be able to act on some patient preferences, even if they are collected in a standardized way.**

Several roundtable participants noted that health systems should not collect data on preferences if they are not able to address those preferences.

One suggested that asking a patient for their preferences and then not acting on them can inadvertently leave the patient feeling less empowered and that they have wasted their time,

compared to if they had not been asked at all. An example shared included that, if a care team asks for a patient's preferred format for viewing laboratory results (e.g., graphically versus in a narrative format) but cannot tailor the presentation of the results based on the patient's response, then it is probably not worth asking the patient for that information.

**"...if you ask someone to give you their preferences, and they take their time and they provide their preferences, then you should act on those preferences. If you're just collecting them just to collect more data, it's worse."**

**– Roundtable Participant**

**Some patient preference information may not lend itself to standardized data capture, but rather may be better documented in a narrative format to preserve important contextual information.** A common theme raised during the roundtable, and echoed by the key informant, was that it may not be possible to capture certain patient preferences using structured or even electronic data formats. Some preferences, such as preferred name and preferred mode of communication, are relatively straightforward and can be easily recorded electronically, such as in the EHR. Other preferences are less easy to translate into a standardized electronic format. For example, some preferences do not easily lend themselves to a "check box" or other simple data collection formats, such as patient preferences regarding disease-specific treatment options.

Additionally, several participants noted the importance of the conversation between the patient and clinician as a method for eliciting preferences, especially around complex or emotionally difficult topics. This includes preferences around complex treatment decisions. They felt that conversations can yield higher-quality data (i.e., the patient may be able to articulate their preference more accurately in a conversation than in a form or survey) and can help the patient feel heard and acknowledged in the decision-making process.

**“If it’s to inform my future treatment, I think that’s like an impossible thing to figure out in a checkbox and almost like, I don’t even want that information [as] part of my structured data [be]cause I think that’s where the real conversation...where a clinician and patient discuss things together. That conversation is the number one important thing. It’s not about the checkbox and clinical decision support tool algorithm.”**

**– Roundtable Participant**

Participants further cautioned that important contextual information around a patient’s thinking and decision making could be lost if data are pared down to the final preference. Richer data (i.e., a narrative in a clinical note) could be more useful to clinicians as they try to understand the patient’s perspective.

**Health systems may be reticent to adopt standards or to accept patient-preference data collected by external organizations without validation.** During the roundtable, two challenges were raised related to health system acceptance of standardized patient-preference data. First, one participant noted that many health systems already have their own ways in which they capture information, often based on their EHR system or other IT systems.

Second, health systems may be reticent to accept patient-preference data collected and shared electronically by an external organization without some type of internal validation. There may be concerns about the quality of the data collected (i.e., whether it is accurate). There may also be legal concerns. One roundtable participant offered as an example the Telephone Consumer Protection Act, which requires that organizations receive consent before sending certain digital communications.<sup>10</sup> Therefore, even if a patient consented to be contacted, for example, by telephone at one health system—and this was logged as their preference in their record—a separate health system may decide to ask the patient for their consent again to avoid violating any relevant legislation.

**“...one of the barriers I’ve seen working with groups in the communication space is they don’t want that data to free flow, or they don’t want to respect it, even if it does flow into their system, until they can validate with their own compliance and legal team that [they] agree that [they’ve] checked the box.”**

**– Roundtable Participant**

## 4. Discussion

Roundtable participants recognized the importance of standardizing patient preference information for its incorporation into PC CDS to enhance shared decision making. In examining the responses from a roundtable discussion of priority patient preferences domains for immediate and long-term standardization and challenges for each, several themes surfaced:

1. The routine capture of patient preference information is currently lacking and should be further explored.
2. There is patient preference information that is high priority for patients to share with their care teams and patient preference information that would be “low-hanging fruit” to collect from patients. Patient preference information that falls into these categories can be prioritized in the short term for standard capture and inclusion in PC CDS.
3. There is patient preference information that could be considered for longer-term standardization due to the feasibility of standardizing the information or how much of a priority it is for patients to share the information with their care teams.
4. There are specific challenges with standardizing patient preference information.

These themes are discussed in the following sections with corresponding suggestions for future directions.

### 4.1 Lack of Routine Capture of Patient Preference Information

According to most roundtable participants and a subsequent key informant discussion, patient preference information (with the exception of preferences pertaining to advanced directives) is not routinely collected as part of clinical encounters. Participants expressed the value of providing patient preference information to clinicians and having it considered in healthcare decisions; however, they also voiced their concerns with the burden that collecting this information can place on clinicians and other healthcare staff members, especially if it is not used to inform patient care.

Research supports that capturing patient preference information in routine clinical encounters proves difficult. Research also demonstrates that many patients feel that their preferences are not considered and assessed and that there is a disconnect between their preferences and those of their clinicians.<sup>11 12 13</sup> Additionally, while there are a number of tools to collect patient preference information, few are validated, and there are no standardized methods for collecting patient preference information.<sup>14</sup> The lack of validated methods for collecting patient preference information was also discussed by a participant in the roundtable who shared that standard data collection tools are an important consideration in terms of standardized patient preference information. Roundtable participants also expressed that they are not confident patient preference information that is collected is included in their care decisions. Research highlights this, indicating that few CDS tools include patient preference information.<sup>15</sup>

**Future Direction 1:** While it is beyond the scope of this report to discuss how the collection of patient preference information can be incorporated into the overall healthcare workflow, to advance standardization of patient preference information, there must be buy-in from clinicians, healthcare systems, and patients to support the adoption of routine capture of patient preferences. To further this, future research that includes patients and clinicians could qualitatively assess how capture of patient preferences could be optimally included in the clinician workflow in a way that reduces patient and clinician burden and that ensures patient-preference data collected from patients are used. The CDSiC has explored workflows in its work and found that gaps remain in our understanding of optimal workflows. For more information, see the [CDSiC’s Trust and Patient Centeredness Workgroup’s recent product](#) on capturing different types of patient preference data.<sup>16</sup>

## 4.2 Patient Preference Information for Standardization in the Short Term

Based on the roundtable discussion specific to patient preferences that are a high priority to collect routinely and that could be “low-hanging fruit” to standardize, certain types of patient preferences could be prioritized in the short term (e.g., next 2–5 years) for standardization.

Preferences pertaining to engagement, access to information, communication, and caregiving and treatment goals were discussed as high priority. Patient preferences identified as “low-hanging fruit” for standardization included communication in terms of notification preferences and preferred communication mode, personal characteristics, preferences for receiving telehealth care, participation in clinical trials, and data sharing preferences (in terms of what is done with their patient data and how it is shared). The 2023 CDSiC report “Advancing Standardized Representations for Patient Preferences To Support Patient-Centered Clinical Decision Support” identified terminology codes and standards for preferences were lacking in these areas except for treatment, providing opportunities for standardization. Specifically, in the domain of engagement preferences, no terminology codes or standards were identified for the degree of decision making or degree of information preferred by the patient. Regarding access to information, there were no terminology codes or standards identified related to access to IT-enabled support tools. No terminology codes or standards were identified for some aspects of communication preferences, including timing, frequency, and use of communication tools.<sup>5</sup> Preferences specific to caregiving were not explored in the report.

The draft USCDI v5 includes patient-preference data elements specific to preferred language, patient demographics, care experience (specifically the patient’s goals, preferences, and priorities for overall experiences during their care and treatment), and treatment intervention preference.<sup>17</sup> The USCDI does not include data elements for preferences specific to engagement, access to information, communication, caregiving, and data sharing.

**Future Direction 2:** Next steps for furthering standardization of high-priority patient preference information could include a multistakeholder (including patients, caregivers, patient advocates, clinicians, standards developers, informaticians, researchers, etc.) effort to submit data elements for preferences specific to engagement, access to information, communication, caregiving, and data sharing for eventual inclusion in the USCDI as it is the basis for making these data elements

interoperable. In particular, incorporating additional elements related to patient preferences into the USCDI will facilitate their adoption since Health IT Certified to USCDI–referenced certification criteria are required to be able to exchange.<sup>17</sup> As new standards are developed for patient preferences, EHR developers can incorporate these standards into their products, which will allow for smoother implementation in health systems and practices.

### 4.3 Patient Preference Information for Standardization in the Long Term

Based on the roundtable discussion, multiple patient preferences were identified for standardization in the long term (e.g., 5–10 years) due to less feasibility and lower priority for wanting to share the information with care teams. Preferred location of care, sensitive preference data that patients only want to share in specific circumstances (e.g., behavioral health treatment preferences), and treatment preferences regarding tolerance for disease-specific treatments may be a long-term goal for standardization and inclusion in PC CDS. Additionally, patient preference information that changes over time (such as acceptance of certain treatments) was also identified as not yet feasible for standardization.

**Future Direction 3:** Next steps for patient preference information that are longer-term priorities for standardization (due to lack of feasibility to standardize and the dynamic nature of most types of patient preferences) could include engaging patient advocates, clinicians, researchers, and informaticians to:

- Conduct and participate in further research to understand how to make the standard capture of dynamic patient preference information more feasible.
- Conduct and participate in further research to advance disease-specific validated preference solicitation measures and their adoption.

Exhibit 2 provides a summary of the patient preference information discussed for short- and long-term standardization.

**Exhibit 2.** Summary Exhibit With Prioritized List for Short-Term and Long-Term Standardization

Patient Preference Domain	Examples Discussed	Short Term or Long Term
Personal Characteristics	<ul style="list-style-type: none"> <li>• Language*</li> </ul>	Short Term
Communication	<ul style="list-style-type: none"> <li>• Timing</li> <li>• Mode</li> <li>• Frequency</li> </ul>	Short Term
Engagement	<ul style="list-style-type: none"> <li>• Degree</li> <li>• Inclusion of others in decisions</li> <li>• Mode</li> </ul>	Short Term
Data	<ul style="list-style-type: none"> <li>• Clinician access (e.g., coordination, health information exchange)</li> </ul>	Short Term

Patient Preference Domain	Examples Discussed	Short Term or Long Term
Healthcare Services	<ul style="list-style-type: none"> <li>Type of treatment/intervention*</li> <li>Receipt of treatment*</li> <li>Care management</li> </ul>	Short Term
Healthcare Services	<ul style="list-style-type: none"> <li>Disease-specific treatment/intervention</li> </ul>	Long Term
Access and Care Experience	<ul style="list-style-type: none"> <li>Location for clinical care</li> <li>Location for health services</li> </ul>	Long Term

\*Included in draft USCDI v5.

#### 4.4 Engagement With Patient Advocates and Other Stakeholders To Further Standardization

Additional efforts are needed to advance the standardization of patient preference information for inclusion in PC CDS and address the challenges specified in Section 3.3 of this report, including the changing nature of patient preferences over time; the burden of collecting patient preference information; the nuances of some patient preferences, which may not be suitable for standardization; the ability of clinicians and the health system to act upon patient preferences; and adoption and use of standards.

**Future Direction 4:** All the challenges identified in this report can be further explored through additional research and multistakeholder efforts. Patients should be engaged in this work from the beginning as research partners. This can also include continued multidisciplinary stakeholder discussions. An important component of engaging patients in these efforts is patient education around the concepts of patient preference information and standardization.

#### 4.5 Limitations

This is a synthesis of an initial convening of multistakeholder perspectives to discuss standardization of patient preferences. It also presents actionable future directions that emphasize a multistakeholder approach to advance standardization or patient preferences.

A key limitation is that this work includes a sample of patient advocates, clinicians, EHR developers, informaticians, and standards developers that does not reflect the experience that all stakeholders would have; thus, findings in this report are not generalizable. Additionally, the findings are based on one roundtable discussion and one key informant interview, limiting the amount of information from which to draw conclusions.

## 5. Conclusion

PC CDS tools will have a broader and more meaningful impact when they can produce clinical recommendations that account for patients' preferences. This report incorporated multiple perspectives to examine which patient preferences, if standardized in the short or long term, hold potential to improve PC CDS. These patient preference categories were prioritized through an in-depth roundtable discussion involving multiple stakeholders from a range of backgrounds and areas of expertise and a subsequent key informant interview. This report also presented four opportunities for future directions involving multiple stakeholders to advance research and efforts that would further the standardization of patient preference information. The report also included examples of patient preference information that could be prioritized in the short and long term for standardization, and the eventual inclusion in future versions of USCDI. Ultimately, standardizing patient preference information can advance incorporation of these data into PC CDS tools, enhancing their utility for patient-centered care and shared decision making.



## Appendix A. Taxonomy of Patient Preferences: Domains and Subdomains

Domain	Subdomain (if applicable)	Example Concepts	Relevance to PC CDS
<b>Personal Characteristics</b>		<ul style="list-style-type: none"> <li>Title (e.g., Mr., Mrs., Mx., Dr., etc.)</li> <li>Preferred name</li> <li>Pronouns</li> <li>Language</li> </ul>	<ul style="list-style-type: none"> <li>Allows for personalization of PC CDS-related communication with patients.</li> <li>Demonstrates respect for the individual.</li> <li>Builds trust between PC CDS clinician and patient.</li> <li>Increases likelihood that PC CDS will be considered, adopted, and adhered to.</li> </ul>
<b>Communication</b>		<ul style="list-style-type: none"> <li>Timing (e.g., time of day, time in relation to clinical visit/care, etc.)</li> <li>Mode (e.g., verbal, e-questionnaire, paper questionnaire, phone call, text, email, smartphone applications, patient portal)</li> <li>Frequency (e.g., once a month, every 6 months)</li> <li>Use of communication tools (e.g., option to discontinue use of communication tools such as messaging with healthcare organizations through the patient portal)</li> </ul>	<ul style="list-style-type: none"> <li>Allows for naturally integrating PC CDS into patient lifeflow.</li> <li>Facilitates engaging patients in a convenient and comfortable manner.</li> </ul>
<b>Access and Care Experience</b>	<b>Accessibility</b>	<ul style="list-style-type: none"> <li>Timeliness of care</li> <li>Location for clinical care</li> <li>Location for health services (e.g., pharmacy, lab, imaging site)</li> </ul>	<ul style="list-style-type: none"> <li>Shapes the delivery and receipt of PC CDS to improve patients' overall experience.</li> <li>Ensures that PC CDS reach patients by methods they prefer.</li> </ul>
	<b>IT enabled support tools</b>	<ul style="list-style-type: none"> <li>Telehealth access</li> <li>Self-scheduling (e.g., web/mobile appointment manager)</li> <li>Support access (e.g., secure messaging, Online chatting)</li> <li>Notifications and reminders (e.g., appointment reminders)</li> </ul>	
	<b>Interpersonal / Relational</b>	<ul style="list-style-type: none"> <li>Clinician relationship (e.g., prior relationship, established trust, etc.)</li> </ul>	
	<b>Clinician / System</b>	<ul style="list-style-type: none"> <li>Clinician qualifications/skills</li> <li>Clinician identity factors (e.g., gender/racial/ethnic identity, etc.)</li> <li>Access to spiritual/religious care (presence/use of prayer, clergy, talk of death)</li> </ul>	

Domain	Subdomain (if applicable)	Example Concepts	Relevance to PC CDS
<b>Engagement</b>	<b>Information seeking</b>	<ul style="list-style-type: none"> <li>• Mode (how the patient prefers to receive information related to their care or condition, e.g., verbal, written, email, video, portal, etc.)</li> <li>• Degree (level/amount of information a patient prefers to receive about their health condition, health state, treatment options, etc., including whether patients would like to receive “bad news”)</li> <li>• Tailored health data feedback and education</li> </ul>	<ul style="list-style-type: none"> <li>• Increases the likelihood of generating personally-relevant recommendations that yield patient engagement in their care.</li> <li>• Increases patient understanding of guidance offered by PC CDS tools.</li> <li>• Improves patient ability to interact with, understand, and adopt PC CDS.</li> </ul>
	<b>Decision making</b>	<ul style="list-style-type: none"> <li>• Degree (level of patient responsibility in making decisions around treatment, care, etc.)</li> <li>• Inclusion of others in decisions (e.g., caregiver/family involvement)</li> <li>• Use of decision aids/tools</li> </ul>	
	<b>Self-management</b>	<ul style="list-style-type: none"> <li>• Use of self-management tools (e.g., personal health record [PHR], applications that allow patients to access information regarding potential treatment side effects, support services, lifestyle changes, alternative therapies, managing finances, etc.)</li> <li>• Access to community of peer support (e.g., access to “patients like me” for support in managing one’s health condition)</li> </ul>	

Domain	Subdomain (if applicable)	Example Concepts	Relevance to PC CDS
<b>Data</b>	<b>Access</b>	<ul style="list-style-type: none"> <li>• Patient access to their own data</li> <li>• Clinician access (e.g., coordination, health information exchange)</li> <li>• Designee access (e.g., family member)</li> <li>• Research access (e.g., consent processes to share data for research)</li> <li>• Level of access (e.g., whole record vs. granular control of sharing one's EHR data)</li> <li>• Duration of access (e.g., expiration of access agreement)</li> </ul>	<ul style="list-style-type: none"> <li>• Enhances the relevance and accuracy of PC CDS recommendations and interventions.</li> <li>• Mitigates potential safety implications of omitting patient health data from PC CDS.</li> </ul>
	<b>Use of data</b>	<ul style="list-style-type: none"> <li>• Personal use (e.g., use within PHR or other tool as a self-maintained, self-controlled complete record of health information)</li> <li>• Research/clinical trial use (e.g., data used to research new ways to prevent cancer)</li> <li>• Healthcare quality improvement (e.g., data used to evaluate how well your doctor provides care)</li> </ul>	
<b>Healthcare Services</b>	<b>Prevention</b>	<ul style="list-style-type: none"> <li>• Receipt of preventive services, treatments, or programs (e.g., vaccines)</li> </ul>	<ul style="list-style-type: none"> <li>• Prioritizes care based on patient preferences (e.g., goals, situation, values) over a clinician's preferences.</li> </ul>
	<b>Receipt of results</b>	<ul style="list-style-type: none"> <li>• Type of tests (e.g., screening tests, genetic tests, follow up)</li> <li>• Return of results (e.g., receipt of genetic testing results)</li> </ul>	
	<b>Treatment</b>	<ul style="list-style-type: none"> <li>• Type of treatment/intervention (preferences related to the actions or ways of treating a patient or a condition medically, nonmedically, or surgically; management and care to cure, ameliorate, or slow progression of a medical condition, e.g., medication vs. surgery)</li> <li>• Receipt of treatment (preferences around whether or not a patient would like to receive or undergo a specific treatment option)</li> </ul>	
	<b>Advance Care Directives</b>	<ul style="list-style-type: none"> <li>• Cardiopulmonary resuscitation</li> <li>• Intubation and ventilation</li> </ul>	
	<b>End-of-life care</b>	<ul style="list-style-type: none"> <li>• End-stage treatment</li> <li>• Alignment with family preferences</li> <li>• Location (location of death)</li> </ul>	

## Appendix B. Background Document on PC CDS and Patient Preferences Standardization

### What is Clinical Decision Support?

Clinical decision support (CDS) are tools <sup>1</sup> that provide timely information, usually at the point of care, to help inform decisions about a patient's care. CDS can effectively improve patient outcomes and lead to higher-quality healthcare. The Clinical Decision Support Innovation Collaborative (CDSiC) <sup>2</sup> is focused on making CDS more patient-centered. One way of doing so is by incorporating data about patient preferences into CDS.

### How do we define patient-preference data?

The CDSiC defines patient preferences as the relative desirability or acceptability to patients of specified alternatives or choices among structures, processes, outcomes, or experiences of interactions with the healthcare delivery system. In other words, patient preferences provide the basis for how patients wish to:

- Interact with their clinician, care system, or personal data
- Choose a particular course of action over others
- Prioritize particular attributes or effects of healthcare

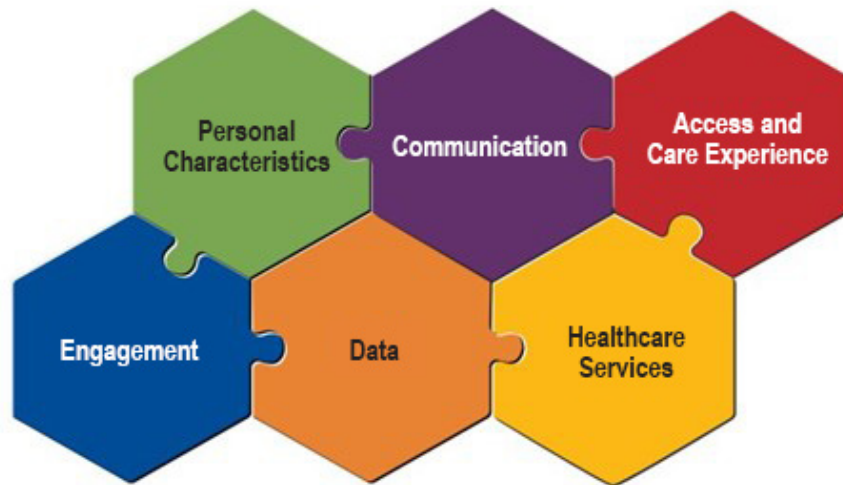
In a CDSiC report<sup>3</sup>, we define six relevant categories of preferences which include personal characteristics, communication, access and care experience, engagement, data, and healthcare services. See Appendix A for detailed definitions and examples of each category.

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<sup>1</sup> <https://www.ahrq.gov/cpi/about/otherwebsites/clinical-decision-support/index.html>

<sup>2</sup> <https://cdsic.ahrq.gov/cdsic/home-page>

<sup>3</sup> Kuperman G, Nanji K, Cope EL, Dullabh PM, Desai PJ, Catlett M, Weinberg S, Hoyt S, and the CDSiC Outcomes and Objectives Workgroup. Outcomes and Objectives Workgroup: Taxonomy of Patient Preferences. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0038-EF. Rockville, MD: Agency for Healthcare Research and Quality; May 2023.



### Why are patient-preference data important to collect and standardize?

Patient preferences are an essential component of the patient voice, and collecting and using this information can advance patient-centered care. Currently, most patient preference information is collected as unstructured data in electronic health records (EHRs). This makes it hard to act upon patient preference information or to share patient-preference data across healthcare organizations. As a result, even when it is collected, patient preference information may not be used by clinicians or in digital health tools.

Standards allow data to be shared, integrated, and implemented in various systems, including EHR systems and clinical decision support tools. Therefore, by collecting and documenting patient preferences data in a standardized way, it will make it easier to develop CDS tools that leverage these data.

### What would we like to accomplish?

The CDSiC Standards & Regulatory Frameworks Workgroup <sup>4</sup> produced a report that characterized the standards landscape <sup>5</sup> for patient preferences. We found that some of the six categories of patient preferences are more routinely collected and standardized compared to others. We also found that not much is understood regarding which patient preference concepts should be prioritized for standardization based on the views and experiences of patients.

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<sup>4</sup> The Clinical Decision Support Innovation Collaborative (CDSiC) Standards and Regulatory Frameworks Workgroup is charged with identifying, monitoring, and promoting standards for the development of patient-centered clinical decision support (PC CDS) and examining the current state of the regulatory environment. The Workgroup is comprised of 14 experts and stakeholders representing a diversity of perspectives within the CDS community.

<sup>5</sup> Richesson RL, Dullabh PM, Leaphart D, Correa KH, Desai PJ, Gordon JR, Boxwala AA, and the CDSiC Standards and Regulatory Frameworks Workgroup. Advancing Standardized Representations for Patient Preferences to Support Patient-Centered Clinical Decision Support. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0074. Agency for Healthcare Research and Quality; August 2023.

Through the Roundtable Discussion on Patient Preference Standards for Patient-Centered Clinical Decision Support, we would like to get consensus on which patient preferences are high priority to be standardized. Prioritizing is important because there is a process for standardizing data elements that involves buy-in from multiple stakeholders. The Roundtable will include ten participants bringing different sets of expertise, including patient representatives, clinicians, informaticians, researchers, and developers.

The final product from this discussion will be a report published to AHRQ CDSiC's website that outlines patient preferences that should be prioritized for standardization as well as actionable steps for the standards development community to move patient preference standardization forward. The report will articulate and emphasize the patient's perspective on the incorporation of patient preferences into CDS tools.

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