# Standards and Regulatory Frameworks Workgroup: Advancing Standardized Representations for Patient Preferences to Support Patient-Centered Clinical Decision Support

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## PURPOSE

The CDS 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 variety 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. The CDSiC will also use the report to inform product development under its Stakeholder and Community Outreach Center Workgroups and for projects developed through its Innovation Center.

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# Executive Summary

Patient-centered clinical decision support (PC CDS) enables the timely delivery of evidence-based guidance, informed by patient-specific data, to support patient engagement in healthcare and facilitate shared decision making. Despite the prominent role of patient preferences in healthcare decision making, the current state of standards for representing patient preferences is not well characterized.

This report examines the scope of data standards currently available for collecting and using patient-preference data to guide PC CDS and includes recommendations to further integrate patient-preference data into PC CDS tools. The intended audiences for this report are clinical decision support (CDS) implementers and researchers, CDS content developers, electronic health record (EHR) developers, health information technology (IT) standards developers, policymakers, payers, clinicians, patient advocacy groups, and medical specialty societies.

### Background

Patient preferences may encompass preferences for engaging with the healthcare system, preferences for receiving information, goals for managing a specific disease or condition, or goals for healthcare outcomes. The objective of this report was to qualitatively explore the current standards landscape for patient preference domains relevant to PC CDS. Standards for capturing patient preferences for their care are emerging. To better understand the current state of the evolving landscape, this report includes: 1) exemplar PC CDS applications (apps) that collect or use data on patient preferences; 2) a high-level characterization of relevant standards for representing patient preferences and potential gaps in coverage; and 3) an understanding of the data needs and standards requirements for the representation of patient preferences for effective PC CDS, including recommendations to stakeholder groups.

### Methods

To develop this report, the Clinical Decision Support Innovation Collaborative (CDSiC) team used the Agency for Healthcare Research and Quality (AHRQ) CDSiC Outcomes and Objectives Workgroup Patient Preferences Taxonomy as a framework to conduct a targeted literature review, Metathesaurus search for terminology representing patient preferences, and key informant interviews (KIIs). The Patient Preferences Taxonomy is broadly based on six domains of patient preferences: personal characteristics, communication, access and care experience, engagement, data, and healthcare services.

### Key Findings

This section includes an overview of our findings on coverage of codes in Logical Observation Identifiers Names and Codes (LOINC®) and SNOMED Clinical Terms (SNOMED CT) terminologies and in Health Level Seven International® (HL7) Fast Healthcare Interoperability Resources® (FHIR) related to patient preferences. This assessment found that standards and codes are available to capture preferences for **personal characteristics** and across the subdomains of **engagement**. We identified standards in the **data** domain for patients' preferences for how they access their data, but none regarding their preference for how their data are used. For the **access and care experience** domain, we did not identify standards for preferences for healthcare access in terms of timeliness of care and IT-enabled support tools. Patient **communication** has a code representing preferred mode of communication, but we did not identify standards or codes related to preferences for communication timing, frequency of communication, and use of communication tools. We found many codes for capturing preferences related to **healthcare services**, especially treatment, advanced care directives, and end-of-life care.

### Discussion and Conclusion

The findings of this report indicate that patient preferences related to treatment and end-of-life care are more routinely collected in clinical encounters and have standardized codes for representing these data, making them prime concepts for PC CDS implementation. We found few codes for representing patient preferences regarding communication and data use, implying that there are opportunities for additional standards development in these areas. In conclusion, we identified three key points:

- **Data in some patient preference domains were more regularly collected and ready for standardization and automated PC CDS compared to other domains in the Patient Preferences Taxonomy.** This particularly included the healthcare services domain, specifically in the areas of advanced care directives and end-of-life care. Key informants identified oncology treatment as another area mature for capturing patient-preference data.
- **There were patient preference domains lacking standards and codes.** These included patient preferences related to communication, data use, and engagement.
- **Capturing patient preferences longitudinally is a challenge.** Patient preferences evolve over time, and standards for capturing this information should reflect this.

This report also presents nine recommendations for stakeholder groups, including patient advocacy groups and medical specialty societies, standards development organizations, informaticians, and researchers, to advance standardized patient-preference data for PC CDS.

**Recommendations**

1. Leverage existing relevant data standards for representing patient preferences, and when needed, request new terms from LOINC from Regenstrief and SNOMED International. These organizations have established processes for requesting new LOINC or SNOMED CT terms that capture preferences in standardized ways to advance PC CDS.
2. Raise awareness for inclusion of additional patient preference codes (from additional patient preference domains) in future versions of the United States Core Data for Interoperability (USCDI). USCDI draft V4 indicates limited adoption of LOINC codes capturing patient preferences related to treatment intervention and care experience.
3. Develop implementation guidance for developers and implementers, as patient preferences can be represented using one or more standards.

**Recommendations**

4. Conduct pilot/demonstration projects in areas that are already “primed” to collect patient-preference data (i.e., where patient-preference data is already collected, and terminology codes exist) allowing for standardization. These areas include palliative and end-of-life care, as well as patient treatment preferences for oncological conditions.
5. Identify requirements for information systems to dynamically manage patient preferences given that patient preferences for care and experience change over time.
6. Engage in multi-stakeholder collaborations (e.g., standards development organizations, policymakers, and EHR developers) that include patients and patient advocacy groups to recognize and build consensus on the value of patient preference information to advance PC CDS.
7. Conduct assessments/evaluations to demonstrate the importance of the standardized capture of patient preferences and how standardization of these data impact health outcomes, care experiences, and other outcomes that matter to patients and clinicians.
8. Conduct research on how to effectively capture patient preferences, including how they should be delivered (worded) for patients and where they should be incorporated into the clinical workflow, data capture, and decision making.
9. Conduct research to determine which patient preference concepts lend themselves best to standardization.

To our knowledge, this is the first report exploring the existence of codes for capturing patient preferences across domains. It is also the first report to present an action plan for advancing PC CDS that incorporates patient preference information.

# 1. Introduction

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.[1] Despite the prominent role of patient preferences in healthcare decision making, the current state of standards for representing patient preferences is not well characterized.[2,3]

This report examines the scope of data standards currently available for collecting and using patient-preference data to guide PC CDS, accompanied by recommendations to further the integration of patient-preference data into PC CDS tools. The intended audiences for this report are clinical decision support (CDS) implementers and researchers, CDS content developers, electronic health record (EHR) developers, health information technology (IT) standards developers, policymakers, payers, clinicians, patient advocacy groups, and medical specialty societies.

## 1.1 Background

PC CDS focuses on delivering CDS through various modalities – including via EHRs, applications (apps), patient portals, and text messages – to the right recipients, where and when they want to receive it, in a manner that is easy for them to understand and act upon.[1] PC CDS apps include not only CDS apps historically developed for and directed to clinicians, but also CDS apps targeted to patients and their caregivers.

Patient preferences refer to 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.”[2] Patient preferences may encompass preferences for engaging with the healthcare system, preferences for receiving information, goals for managing a specific disease or condition, or goals for healthcare outcomes.[2,4] Patient preferences are important data to include in PC CDS, because aligning care with patient preferences can improve patient engagement,[5] patient satisfaction,[6] and patient outcomes.[7] PC CDS tools will thus be more impactful when they can produce clinical recommendations that account for unique patient needs and preferences.

## 1.2 Patient Preference Domains

The Agency for Healthcare Research and Quality (AHRQ) Clinical Decision Support Innovation Collaborative’s (CDSiC) Outcomes and Objectives Workgroup developed a Patient Preferences Taxonomy in 2023 using a literature review and key informant discussions. The Patient Preferences Taxonomy served as a framework for this report to identify standards related to patient preferences. The taxonomy organizes types of patient preferences using six domains relevant to PC CDS design and implementation. Each domain is briefly described below in Exhibit 1.[2]

**Exhibit 1.** Six Domains of the AHRQ CDSiC's Outcomes and Objectives Workgroup's Patient Preferences Taxonomy

| Domain | Definition | Subdomain | Examples |
|---|---|---|---|
| **Personal Characteristics** | Patient preferences for the identity components typically captured in a patient profile. Allowing patients to specify their personal characteristics – and respecting those preferences – builds trust between patients and their care teams. | No applicable subdomain | • Title (Mr., Mrs., Dr., etc.)<br>• Preferred name<br>• Language |
| **Communication** | Patient preferences related to mechanisms for information exchange, including preferences around the frequency, timing, and methods for transferring information between patient/caregiver and clinician/health system. | No applicable subdomain | • Timing (e.g., time of day, time in relation to clinical visit/care, etc.)<br>• Mode (e.g., verbal, e-questionnaire, paper questionnaire, phone call, text, email, smartphone applications, patient portal)<br>• Frequency (e.g., once a month, every 6 months)<br>• Use of communication tools (e.g., option to discontinue use of communication tools such as messaging with provider organizations through the patient portal) |
| **Access and Care Experience** | Patient preferences around the range of interactions a patient has across the healthcare system with all doctors, nurses, and staff. | Accessibility | • Timeliness of care<br>• Location for clinical care<br>• Location for health services |
| | | IT-enabled support tools | • Telehealth access<br>• Self-scheduling<br>• Support access<br>• Notifications and reminders |
| | | Interpersonal/ relational | • Provider relationship |
| | | Provider/system | • Provider qualifications/skills<br>• Provider demographic factors<br>• Access to spiritual/religious care |

| Domain | Definition | Subdomain | Examples |
|---|---|---|---|
| **Engagement** | The degree to which a patient would like to be involved in their own care. | Information seeking | - Receipt of information related to one's condition or care including mode, degree, tailored health data feedback, and education |
| | | Decision making | - How decisions should be made and who should be involved, including degree (level of patient responsibility), inclusion of others, and use of decision aids/tools |
| | | Self-management | - Use of self-management tools<br>- Access to community of peer support |
| **Data** | Patient preferences around access and use of personal health data. | Access | - Patient access to their own data<br>- Clinician access<br>- Designee access<br>- Research access<br>- Level of access<br>- Duration of access |
| | | Use of data | - Personal use<br>- Research/clinical trial use<br>- Healthcare quality improvement |
| **Healthcare Services** | Patient preferences related to care planning and the health consequences brought about by the treatment, or lack of treatment, of a health condition or as a result of an interaction with the healthcare system. | Prevention | - Receipt of preventive services, treatments, or programs (e.g., vaccines) |
| | | Receipt of results | - Type of tests<br>- Return of results |
| | | Treatment | - Type of treatment/intervention<br>- Receipt of treatment |
| | | Advanced care directives | - Cardiopulmonary resuscitation (CPR)<br>- Intubation and ventilation |
| | | End-of-life care | - End-stage treatment<br>- Alignment with family preferences<br>- Location |

## 1.3 Roadmap of Report

Standards for capturing patient preferences for their care are emerging.[2] To better understand the current state of the evolving landscape, this report includes: 1) exemplar PC CDS apps that collect or use data on patient preferences; 2) a high-level characterization of relevant standards for representing patient preferences and potential gaps in coverage; and 3) an understanding of the data needs and standards requirements for the representation of patient preferences for effective PC CDS. Chapter 2, *Methods,* describes the process used to create this report. Chapter 3, *Findings: Use of Patient Preferences in PC CDS*, briefly summarizes PC CDS applications that collect and use patient-preference data. Chapter 4, *Findings: Standards for Representing Patient Preferences*, provides examples of current standards for representing patient-preference data. Chapter 5, *Discussion,* discusses recommendations for public and private sector groups to advance the collection and use of standards for representing patient preferences in PC CDS.

# 2. Methods

The objective of this report was to qualitatively explore the current standards landscape for patient preference domains relevant to PC CDS. Although this report is not intended to be a comprehensive evaluation of coverage, it provides a high-level summary of the scope of preference standards available, with examples, and identifies potential gaps and avenues for future work to advance patient preference standards. To develop this report, the CDSiC team conducted a targeted literature review, Metathesaurus search, discussions with the CDSiC Standards and Regulatory Frameworks Workgroup, and interviews with key informants. Additional information about these methods is provided in the Appendix.

## 2.1 Identification of Standards for Patient Preferences Relevant to PC CDS

The team leveraged the CDSiC's Outcomes and Objectives Workgroup's Patient Preferences Taxonomy,[2] which provides an organizing framework to identify standards for the six patient preference domains relevant to PC CDS design and implementation—personal characteristics, communication, access and care experience, patient engagement, data, and healthcare services. The team conducted a targeted search of the grey literature to identify current standards and approaches for collecting patient preferences, as well as a targeted review of grey and peer-reviewed literature to determine apps that capture patient preferences information to inform clinical decision making. This search included the Unified Medical Language System (UMLS) Metathesaurus to identify terminology codes applicable to patient preferences.[8] The Metathesaurus search focused on identifying codes in the standard terminologies Logical Observation Identifiers Names and Codes (LOINC®)[9] and SNOMED Clinical Terms (SNOMED CT);[10] both these terminologies include codes for representing patient-generated health data and their response values.[3]

Two team members developed search terms based on the taxonomy's patient preference domains/subdomains and searched the UMLS Metathesaurus for relevant LOINC and SNOMED CT codes. The two team members then reviewed the resulting UMLS codes to determine their relevance to patient preferences, documenting all potentially relevant codes. Codes that were applicable to a topic area (e.g., telemedicine) but were not specific to patient preferences (e.g., preference regarding use of telemedicine) were excluded. Next, two additional team members validated the search terms used for the UMLS Metathesaurus as well as the patient preference codes previously documented. All discrepancies and codes with uncertain relevance to patient preferences were discussed as a team to reach consensus on their applicability and inclusion. Following the UMLS search, the team reviewed the Health Level Seven International® (HL7) Fast Healthcare Interoperability Resources® (FHIR) website to identify relevant resources, attributes, and value sets.[11] The team also searched the United States Core Data for Interoperability (USCDI)[12] and HL7 Patient Empowerment Workgroup Confluence webpage[13] to identify additional standards and implementation guides relevant to patient preferences.

The resulting list of identified preferences and a summary of coverage were reviewed by members of the Standards & Regulatory Frameworks Workgroup as well as by terminology standards experts.

## 2.2 Peer-Reviewed and Grey Literature Search for Exemplar Apps

An additional literature scan was conducted to identify exemplar PC CDS apps that collect and use patient preferences. The team first conducted a PubMed search focused on articles published in the last 5 years relevant to mobile applications, clinical decision support, and patient goals or preferences. This search did not yield any relevant exemplar apps. The team then conducted a targeted grey literature search of AHRQ's Digital Healthcare Research Program's 2021 Digital Health Research Year in Review,[14] the Substitutable Medical Applications and Reusable Technologies (SMART) App gallery,[15] and the Oracle Cerner App Gallery.[16] Additional exemplar apps were also recommended by members of the CDSiC Standards & Regulatory Frameworks Workgroup. All apps were reviewed to determine whether they collected and/or used patient-preference data for the purpose of providing PC CDS to patients and/or clinicians. Five exemplar apps were ultimately selected and are described in Chapter 3 (Exemplar PC CDS applications).

## 2.3 Key Informant Interviews and Synthesis

Between April and May 2023, the team conducted four interviews with six key informants who are experts in disciplines related to patient preferences and/or PC CDS, including three standards developers and three researchers. Semi-structured interview guides were created to facilitate the interviews. Informants were provided with the Patient Preferences Taxonomy and summary of identified standards in advance of the interviews. Each interview was conducted via Zoom, lasted approximately 60 minutes, and was recorded with the informant's consent. Transcript-style notes were created for each interview to support analysis. The team analyzed the key informant interview (KII) transcripts to identify salient themes within and across interviews.

The team then synthesized findings across the literature and KIIs to characterize the current landscape of patient preference standards, as well as an action plan for further development. The team validated the current standards and landscape and opportunities for the field with the CDSiC Standards & Regulatory Frameworks Workgroup. The findings are described below in Chapters 3 (Exemplar PC CDS applications) and 4 (Standards for Representing Patient Preferences), with opportunities described in Chapter 5.

# 3. Findings: Use of Patient Preferences in PC CDS

A selection of exemplar PC CDS applications that collect or use data on patient preferences in one or more of the patient preference domains are summarized below.

**DDInteract.**[17,18,19] DDInteract is a shared decision making tool designed to help prescribers and patients understand the risk of drug interactions between warfarin, a blood thinner, and nonsteroidal anti-inflammatory drugs (NSAIDs). DDInteract uses patient preferences related to healthcare services to deliver PC CDS. A clinician-facing app pulls in clinical information from the EHR and prompts clinicians to ask patients how they prefer to treat their pain (medication vs. non-medication), and what type of pain medication they prefer (oral NSAIDs vs. other medication). Based on clinical risk factors and patient preferences, it generates risk predictions for gastrointestinal bleeding based on the use of certain NSAIDs, as well as alternative treatment options for pain.

**Partnering Patients and Providers for Personalized Acute Care Selection (4PACS).**[20] 4PACs is an AHRQ-funded PC CDS tool that incorporates patient and caregiver preferences and evidence-based risk modeling to support shared decision making around receipt of Hospital at Home (HaH) care for patients hospitalized with pneumonia. The 4PACs app collects patient preferences related to healthcare services and engagement to help patients identify whether HaH or inpatient hospitalization better aligns with their personal care preferences.

**Apple Health.**[21] Apple Health collects and integrates patient-provided data from iPhone, Apple Watch, and other health apps to provide health tracking, analytics, alerts, and reminders. Apple Health collects and uses preferences related to data and engagement. It integrates with EHR platforms such as Epic and Cerner to allow patients to share their health data with their care team and download medical records to their phones. The app allows users to specify which people and institutions they want to share their health data with, as well as what specific data to share. Users can also choose to receive notifications when it is time to take a medication or if there are new trends in patient-provided data (e.g., vital signs).

**Joint Insights.**[22] Joint Insights is an artificial intelligence (AI)-enabled decision aid for patients living with knee osteoarthritis. Designed to help patients understand the risks and benefits of knee replacement surgery, Joint Insights incorporates patient-reported outcome measures (PROMs), preference assessment, patient education, and personalized estimates of clinical outcomes. The apps' preference assessment module focuses on preferences related to healthcare services, asking patients to rate their desired levels of pain relief, commitment to postoperative recovery, and willingness to accept surgical risk on a continuum of nonoperative to operative care.

**Multiple Chronic Conditions (MCC) e-Care Plan.**[23,24] The AHRQ-funded electronic care (e-Care) plan for people with multiple chronic conditions (MCC) project is focused on developing and piloting an interoperable e-Care plan that facilitates the collection and sharing of person-centered clinical and social determinants of health data across home, clinical, community, and research settings. This project involves the development of a patient/caregiver-facing app that supports goal-oriented shared care planning. Patients input their personal health goals and preferences related to healthcare services and engagement into the app. These data are then integrated with the EHR to allow for classification, display, and sharing of critical patient data.

# 4. Findings: Standards for Representing Patient Preferences

This section describes the current landscape of standards for electronically representing patient-preference data relevant to PC CDS, organized by each of the six preference domains defined in the

CDSiC's Objectives and Outcomes Patient Preferences Taxonomy.[2] Several existing data representation and exchange standards could be used and potentially expanded to represent, record, and exchange patient preferences in the context of PC CDS. These include the terminology standards LOINC[25] and SNOMED CT[26], as well as FHIR standards for data exchange.[27]

## 4.1 Findings Regarding Use of LOINC and SNOMED

LOINC terms are often used to capture data (e.g., observations, reports) that are structured as questions and responses for many patient-reported outcomes instruments. SNOMED CT is frequently used to record findings, including but not limited to responses to patient-directed questions, as well as to trigger clinical decision support, alerts, and other logic in the clinical workflow.[3,28,29] The findings of this report include significant areas of overlap between SNOMED CT and LOINC codes. This overlap between LOINC and SNOMED CT is not surprising as they both have significant coverage in several domains. SNOMED CT is widely used internationally, while LOINC is not as widely adopted outside the U.S.; thus, SNOMED CT provides representation of concepts present in LOINC.[30] In 2022, LOINC from Regenstrief and SNOMED International signed a collaboration agreement that extends upon a relationship, inaugurated in 2013, and ongoing efforts to link clinical semantics of SNOMED CT to LOINC concepts to support interoperability and improve efficiency and coherence across the terminologies.[30] Key informants noted that LOINC and SNOMED CT are increasingly working towards a question-response structure in which questions are modeled in LOINC and response options in SNOMED CT.

Unlike LOINC and SNOMED CT, which are terminology standards, FHIR is a standard for electronic information exchange more broadly (using specified data classes or resources that may use standardized codes systems or terminology). FHIR resources allow for standardized encoding and sharing of a range of clinical, administrative, and other data.[27] In some cases, data within FHIR resources may be encoded within LOINC, SNOMED CT, or other terminology standards; HL7/FHIR also maintains its own internal terminologies in some cases.

The standards landscape is complex and dynamic, with regular updates to standards availability and considerable nuance in how standards are used and combined in the clinical context. This assessment of standards availability for different types of patient preferences was exploratory and qualitative in nature and is not intended to be a comprehensive evaluation of coverage. There likely are additional terms and codes related to patient preferences available within LOINC, SNOMED CT, FHIR that are not captured in this report. This assessment was designed to provide a high-level characterization of the range and scope of currently available standards – with examples – that can be used to capture and represent patient preferences, and to identify areas where there appear to be no appropriate standard or standardized terms and codes. Our searches did identify examples and patterns of standards coverage (inclusion) that reveal overlaps and gaps in coverage by existing standards. Readers of this report may conduct additional customized standard/code searches when looking to identify standards for a specific use case or detailed patient preference items.

## 4.2 Overview of Findings Regarding Standards and Codes Available to Capture Preferences

This assessment found that standards and codes are available to capture preferences for **personal characteristics** and across the subdomains of **engagement;** however, for engagement, we were unable to identify codes for patient preferences related to use of self-management tools, degree of decision making, use of decision aids/tools, degree of information preferred, and tailored health data feedback and education. We identified standards in the **data** domain for patients' preferences for how they access their data, but none regarding their preference for how their data are used. For the **access and care experience** domain, we did not identify standards for preferences regarding healthcare access in terms of timeliness of care and IT-enabled support tools. Patient **communication** has a code representing preferred mode of communication, but we did not identify standards or codes related to preferences for communication timing, frequency of communication, and use of communication tools. We found many codes for capturing preferences related to **healthcare services**, especially treatment, advanced care directives, and end-of-life care. Exhibit 2 provides a summary of findings by domain and subdomain. We expand upon these findings in the remainder of this chapter.

**Exhibit 2.** Overview of Standards Coverage Across Patient Preference Domains

| Preference Domain | Subdomain | Codes Identified from any Standard | LOINC Code(s) Identified | SNOMED CT Code(s) Identified | FHIR Resource Identified |
|---|---|---|---|---|---|
| **Personal Characteristics** | No applicable subdomain | Present | Present | Present | Present |
| **Communication** | No applicable subdomain | Present | Not found | Present | Present |
| **Access and Care Experience** | Care Experience | Present | Present | Not found | Not found |
| | Accessibility | Not found | Not found | Not found | Not found |
| | IT-Enabled Support Tools | Not found | Not found | Not found | Not found |
| | Interpersonal/Relational | Present | Not found | Present | Present |
| | Provider/System | Present | Not found | Present | Not found |
| **Engagement** | Self-Management | Present | Not found | Present | Not found |
| | Decision Making | Present | Present | Present | Not found |
| | Information Seeking | Present | Not found | Present | Not found |
| **Data** | Access | Present | Present | Present | Present |
| | Use of Data | Not found | Not found | Not found | Not found |
| **Healthcare Services** | Prevention | Present | Present | Not found | Not found |
| | Receipt of Results | Not found | Not found | Not found | Not found |
| | Treatment | Present | Present | Present | Present |
| | Advanced Care Directives | Present | Present | Present | Present |
| | End-of-life Care | Present | Present | Present | Present |

## 4.3 Personal Characteristics

Preferences under the personal characteristics domain include items related to a patient's identity that may be captured in a patient's profile.[2]

**Existing codes in this domain provide good coverage.** Standards coverage is relatively high in this domain, with LOINC SNOMED CT codes available to document a patient's demographic factors,preferred title, name, and language preferences. Additionally, within FHIR, the Patient resource can capture elements, including a patient's preferred name and language for communication.[31]

**In some cases, we found multiple codes within the same terminology that relate to similar concepts.** For example, SNOMED CT provides codes for "Preferred name (attribute)"[32] and "Patient preferred name (observable entity)."[33] The different axes (observable versus attribute) for the terms reflect different approaches to using the code in real information systems. There are also variations related to the level of granularity of detail of the codes offered by different terminologies for related concepts, such as language preferences. For example, in SNOMED CT, "Language preference"[34] records a general preferred language, while "Language preference for written health-related materials"[35] is specific to written communication.

**There are no major gaps in coverage.** We identified examples of standards for preferences relate to most major personal characteristics.

## 4.4 Communication

The Communication domain includes preferences related to when, how, and how often patients prefer to receive communications regarding their healthcare.[2] We identified few standards relevant to this domain.

**There is some coverage for patients' preferred communication mode.** The SNOMED CT code, "Preferred mode of communication,"[36] broadly captures the method by which patients prefer to be engaged; a draft extension within the FHIR Patient resource can also capture preferred communication mode (written or verbal) for a given language.[37]

**Gaps exist for other areas related to communication preferences.** However, standards and codes were not identified in SNOMED CT, LOINC, or FHIR for other types of preferences related to communication, such as when a patient prefers to receive communications (e.g., time of day), how often they would like to receive communications (e.g., as they come in or batched), and whether they want to use tools such as the patient portal to communicate with their care team.

## 4.5 Access and Care Experience

The Access and Care Experience domain captures concepts ranging from the preferences around the accessibility of care to provider and system characteristics across several preference subdomains: accessibility, IT-enabled support tools, interpersonal/relational, and provider/system.[2] While terminology codes exist to capture general care experience goals and preferences as well as some specific preferences regarding interpersonal/relational aspects and providers and systems, there are gaps in coverage regarding the accessibility of care and preferences for use of IT-enabled support tools.

**There is some coverage for preferences related to care experiences, patient-provider trust, and the healthcare provider/system.** At a high-level, LOINC provides codes for documenting preferences regarding the care experience broadly: “Goals, preferences, and priorities for care experience,” which can be used to document preferences to improve the care experience,[38] as well as “Care experience preference,” which is related to preferences for care and treatment not specific to emergency or end-of-life care.[39]

Within the interpersonal/relational domain, which captures concepts such as a patient’s relationship with and trust in their provider, the SNOMED CT code, “Lack of trust in healthcare provider,” is available.[40] While not specifically a patient preference, SNOMED CT also offers a procedure code to record whether providers have engaged in the establishment of trust with the patient.[41] Within FHIR, the Patient resource also allows for the patient record of one or more nominated care providers, which could include a preferred provider, or even a care manager or organization.[31]

We also identified several codes within the provider/system subdomain. The SNOMED CT codes, “Preference for female healthcare professional”[42] and “Preference for male healthcare professional,”[43] enable capture of patient preferences related to the sex of the health professional they would like to see. We did not identify codes to specify preferences around other provider professional or personal identity factors, however. While the FHIR Practitioner resource can record information related to healthcare practitioners’ educational and clinical qualifications,[44] there is no obvious way for the patient to record their preference for a provider with specific characteristics, skills, or experiences within FHIR. Both LOINC and SNOMED CT also offer a code related to preferences for spiritual and religious care.[45,46]

**No codes were identified related to the accessibility sub-domain,** which covers preferences around timeliness of care, location of clinical care, and location of health services (e.g., pharmacy, laboratory). There is a SNOMED CT procedure code, “Discussion about preferred place of care,”[47] available to capture whether healthcare practitioners and patients have engaged in conversation about where the patient would like to receive care; it does not capture a preference, however. The IT-enabled support tools subdomain captures preferences for the use of telehealth and self-scheduling tools, as well as for notifications, reminders, and access to support (e.g., secure messaging, online chat); no relevant standards or codes were identified within this subdomain.

## 4.6 Engagement

The engagement domain captures preferences related to how patients prefer to engage in their care, including self-management of care (e.g., use of self-management tools, access to community peer support), decision making (e.g., degree of decision making, inclusion of others in decisions, use of decision aids/tools), and information seeking (e.g., mode, degree, tailored health data feedback and education).[2]

There are SNOMED CT codes for the self-management and information seeking subdomains and LOINC codes for the decision making domain. We identified LOINC codes for inclusions of others in decisions and SNOMED CT codes for access to community of peer support and preferred mode of communication. However, we did not identify examples of codes that may capture patient preferences in use of self-management tools, degree of decision making, use of decision aids/tools, degree of information received, and tailored health data feedback and education.

**There are SNOMED CT codes for the self-management concepts, but they do not necessarily capture preferences.** In terms of use of self-management tools, we found specific SNOMED CT codes for "Mental health personal health plan,"[48] "Personal health management behavior,"[49] "Health promotion behavior,"[50] "Symptom control behavior,"[51] and "Complementary therapy,"[52] but none of these relate specifically to patients' preferences for use of self-management tools to support health behaviors. In terms of access to community peer support, there are SNOMED CT codes capturing such concepts, including "Detail of care and support circumstances and networks"[53] and "Self-help group support."[54] There is no indication of how these codes are capturing specific patient preferences for these topics, but they do indicate patient access.

**There are codes for capturing patient preferences for inclusion of others in decision making, yet gaps exist in other areas.** Regarding decision making, there is a SNOMED CT code to capture "Healthcare decision making"[55] and a LOINC code for "Level of patient participation," but there is no indication of how the patients' preferences for their level of responsibility in making decisions around treatment are captured. There is a LOINC code for "Shared decision making panel"[56] that captures the patients' involvement in clinical decisions and understanding of their options. There is a SNOMED CT procedure code for "Involving client in decision making,"[57] which captures decision making involving the patient. In terms of inclusion of others in decisions, there are LOINC codes that capture these preferences, including "Family or significant other involvement in care discussions," "Goals, preferences, and priorities regarding appointment of healthcare agents," [58] and "Resident prefers family or significant other involvement in care discussions."[59] There is a SNOMED CT code for "Decision support tool,"[60] but there is no indication that this is specific to patient preferences.

**For information seeking, there are codes for capturing preferred mode of communication, but we found gaps in capturing patient preferences in other areas.** Regarding information seeking, there is a SNOMED CT code that captures "Preferred mode of communication"[61] that clearly indicates capturing patient preference. There is a SNOMED CT code for capturing "Cognitive style"[62] of the patient; however, this code seems to specify observation of the provider rather than a patient's preference. There were no codes or standards identified for the degree (e.g., level/amount) of information a patient preferred to receive, but there were SNOMED CT codes indicating if the patient was not given information[63] or if they refused to be given it.[64] We found LOINC and SNOMED CT codes to indicate patient education for specific conditions, including renal and kidney care,[64,65] although we found no indication that these codes capture patient preferences for this education.

## 4.7 Data

The data domain captures patient preferences related to access of patient data (e.g., patient access to own data, clinician access, designee access, research access, level of access, duration of access) and use of patient data (e.g., personal use, research/clinical trial use, healthcare quality improvement).[2] We identified SNOMED CT codes and FHIR resources for the data access subdomain and LOINC and

SNOMED CT codes related to patient preferences for the use of data subdomain. There appear to be gaps in coverage of key patient preferences for how patient data can be used, including personal use, research/clinical trial use, and healthcare quality improvement.

**LOINC and SNOMED CT codes exist for capturing patient preferences regarding access to their data.** In terms of data access, there is a LOINC code for capturing “Access to review healthcare data.”[66] Regarding clinician, designee, and research access to data there are SNOMED CT codes for capturing “Consent status for record sharing” [67] and “Record sharing status.”[68] The FHIR Consent Resource allows designation of the type of consent. The consent value set can capture information on level of access and the consent resource can specify duration of access.[69]

**HL7 Patient Empowerment Workgroup**

The HL7 Patient Empowerment Workgroup developed a White Paper that provides seven recommendations to the public and private sector for advancing standards for patient-contributed data, which includes patient preferences.

HL7 teams are working on Implementation Guides to specifically address the areas of Patient Corrections and Patient Treatment Goals.[72]

**We found gaps regarding codes for specifically capturing how patients prefer their data are used.** In terms of patients’ preferences for how their health data are used (e.g., personal use, research/clinical trial use, healthcare quality improvement) there is a LOINC code capturing satisfaction with healthcare data use.[70] There is a SNOMED CT procedure code capturing “research data collection;”[71] however, it does not clearly indicate if patient preference was factored into the research data collection.

## 4.8 Healthcare Services

The healthcare services domain captures patient preferences related to prevention (i.e., receipt of prevention services, treatments, or programs), receipt of results (e.g., type of tests, return of results), treatment (e.g., preference for one type of treatment over another), advanced care directives (e.g., cardiopulmonary resuscitation, intubation, and ventilation), and end-of-life care (e.g., end-stage treatment, alignment with family preferences, location of death).[2] The HL7 Patient Empowerment Workgroup is active in promoting and developing implementation guides to support standards for patient-preference data related to patient preferences for treatment.

**There are many codes for capturing preferences related to healthcare services, especially treatment, advanced care directives, and end-of-life care**. There is a LOINC code for capturing patients’ preferences for patient-reported “Goals, preferences, and priorities for care experience”[38] that could broadly encompass healthcare services preferences.

There is variation in standards for capturing treatment-specific preferences, with some conditions and scenarios having more coverage than others (e.g., end-of-life care, mental health, maternal health). Several key informants noted palliative care and end-of-life treatment as areas where patient preferences are more routinely captured in clinical care, especially in comparison to other clinical contexts and conditions. There are LOINC and SNOMED CT codes for capturing patient preferences and priorities for treatment, including:

- A LOINC code for “Mental health treatment preferences”[73]
- A LOINC code for “Goals, preferences, and priorities for medical treatment”[74]
- A LOINC code for patient-reported “Goals, preferences, and priorities for care experience”[38]
- A LOINC code for patient-reported “Goals, preferences, and priorities under certain health conditions”[75]
- A LOINC code for “Resident’s preference regarding being asked about returning to the community”[76]
- A SNOMED CT code for “Active mental health treatment preference declaration”[77]
- A SNOMED CT code for “Maternal labor preferences”[78]

Additionally, the FHIR Goal Resource[79] can be used to capture treatment preference information.

In terms of end-stage treatment, there are LOINC codes regarding advanced care directives, including “CPR orders,”[80] “Advanced directives set”[81] (which includes additional subsets), and “Thoughts on intubation.”[82] Informally, advance directives could also be represented as a Goal resource, such as “I want to die at home.” There is a SNOMED CT code on preferences for “Do not resuscitate orders.”[83] Additionally, the Post-Acute Care Interoperability (PACIO) project has developed “The Advance Directive Interoperability FHIR Implementation Guide,” which explains how to represent, exchange, and verify a person’s goals, preferences, and priorities for care using existing HL7 FHIR standards in the event that a patient is unable to communicate this themselves.[85]

There are SNOMED CT and LOINC codes regarding end-stage treatment, including palliative care plan, end-of-life care plans, and preference on consulting a supportive and palliative care team for treatment, including for example:

- A SNOMED CT code for “Has end of life care plan”[86]
- A SNOMED CT code for “End of life care plan”[87]
- A SNOMED CT code for “Palliative care plan”[88]
- A LOINC code for “Preferred kidney failure treatment if kidney disease progresses to kidney failure”[89]
- A LOINC code for “Preference on consulting a supportive and palliative care team to help treat physical, emotional, and spiritual discomfort and support family”[90]

**PACIO Project Advanced Directive FHIR Implementation Guide**

The PACIO Project is leveraging existing HL7 FHIR standards to create, update, share, verify, and exchange information about an individual’s advance medical goals, preferences, and priorities for care.

The PACIO Project has also created the Consent ValueSet, which contains the codes “dnr” – do not resuscitate, “acd” – advanced care directive, and “hcd” – healthcare directive.[84]

There are SNOMED CT codes for alignment of end-of-life care with family preferences such as “Advance directive discussed with relative,”[91] “Preference for informing others of terminal diagnosis,”[92] and “Active advance directive with verification by family.”[93] There are SNOMED CT and LOINC codes for preference for location of death, including:

- A SNOMED CT code for  “Preferred place of death”[94]
- A SNOMED CT code for “Discussion about preferred place of death”[95]

- A SNOMED CT code for “Preference for location of deceased baby”[96]
- A LOINC code for patient-reported “Goals, preferences, and priorities upon death”[97]
- A LOINC code for patient-reported “Preferred location to spend final days if possible to choose”[98]

**There were no standards identified for patient preferences in type of tests (e.g., preferred test for colon cancer screening) and receipt of results (e.g., receipt of genetic testing results).** There is a LOINC code that falls under the prevention subdomain regarding receipt of preventive vaccine services called “Preferred vaccine type.” [99]

## 5. Discussion

The collection of patient preferences is critical to PC CDS, and the standardized representations for these data on patient preferences can advance the development and implementation of PC CDS applications and the exchange of data needed for more robust and useful tools. At present, data on patient preferences are not routinely collected or universally available, and there are no required standards for representing or reporting patient preferences.

This report identifies opportunities for further advancing standards patient-preference data that can be used for PC CDS. There is variation in the presence, completeness, and use of standards for capturing treatment-specific preferences across clinical specialties and use cases, with some conditions/scenarios (e.g., end-of-life care, mental health, maternal health) having more coverage than others. In addition, there is variation in the modeling approaches used for patient preferences (e.g., preferences captured as FHIR attributes versus terminology concepts). To date, there is no consistent strategy for modeling patient preferences.

In determining concepts to prioritize for PC CDS development and implementation, we considered if the data are routinely being captured in clinical care (as validated by conversations with key informants and the Workgroup), if there are codes available to standardize the collection of this information, and if there are FHIR resources or implementation guides to support their exchange. We found that there are some patient preference domains that have more regularly collected patient-preference data that can be standardized for PC CDS, and other domains that do not.

**There were patient preference domains in which data were more regularly collected and ready for standardization and automated PC CDS.** Our findings from the literature and discussions with key informants and the Standards and Regulatory Frameworks Workgroup indicate that patient-preference data related to end-of-life care are more often used in clinical care and collected in clinical information systems; therefore, it is not surprising to see that there are codes in LOINC and SNOMED CT that can support the standardized capture of these preferences. These findings were confirmed via our KIIs and indicate that the development and use of standards for capturing end-of-life preferences is an area to prioritize to demonstrate and advance the use of patient-preference data in PC CDS development and implementation.

Some codes are highly relevant for capturing preferences around treatment, which is an area where clinicians are encouraged to have discussions with patients about their preferences.[100] For example, key informants noted oncology as an area where preferences for treatment are discussed between clinicians and patients. There is a LOINC code for capturing patients' preferences for patient-reported "Goals, preferences, and priorities for care experience,"[38] and the FHIR Goal Resource[79] can be used to support the capture of treatment preference information, making treatment of oncologic conditions an area where the field can make progress with PC CDS.

**There were patient preference domains lacking standards and codes.** There were other areas where codes could be developed to make more progress to advance the use of PC CDS to capture preferences in these areas.

Patient communication lacks codes in terms of preference for communication timing, frequency of communication, and use of communication tools. KII findings indicate that health systems tend to capture some of this information in terms of patient-preferred ways to communicate. For example, patients are asked whether they would like to receive reminders via the patient portal, text messages, or via regular mail. We did not find codes in the data domain for patient preference for data use. For the access and care experience domain, we lacked codes for preferences regarding timeliness of care and IT-enabled support tools. We did not identify codes for some concepts in the engagement domain regarding use of self-management tools, degree of decision making, use of decision aids/tools, degree of information preferred, and tailored health data feedback and education.

**Key informants noted that capturing patient preferences longitudinally is a challenge.** Patient preferences evolve over time[101] and standards for capturing this information should reflect this. Determining which areas of patient preference tend to be stable versus fluctuating over time is an ongoing area of research.[102,103] Key informants indicated preference for end-stage treatment, such as preference for a kidney transplant, as an example of an area where preferences change. Information systems should have the ability to capture patient preferences over time rather than at a single point.

## 5.1 Strengths and Limitations

To our knowledge, this is the first report exploring the existence of codes for capturing patient preferences across domains. It is also the first to present an action plan for advancing PC CDS that incorporates patient preference information.

A key limitation is that it was not always clear if a code was intended to capture patient preferences for a topic. To address this, multiple people reviewed the codes and the team had consensus meetings regarding codes in question. The team also incorporated a review of the codes by subject matter experts. There were some codes where it remained unclear if they were intended to capture patient preferences and whether new specific codes should be created; these were noted throughout the narrative.

Additionally, standardized coding systems and terminologies each have individual structures to organize their terms and therefore contain embedded semantics about what those terms mean in relation to other terms and in the context of data models or messages in which the terms and codes are used. Further, the term names and wording of questions related to patient preferences can vary and use many different terms and language, which makes the search and identification of items related to the broad label of "preferences" challenging. As such, this report is not intended to be a comprehensive catalogue of codes for capturing patient preferences, but provides examples for areas in which we were able to identify codes.

Lastly, this report organizes the search and discussion of patient preferences by the domains of the Patient Preferences Taxonomy developed by the CDSiC Outcomes and Objectives Workgroup. The Patient Preferences Taxonomy domains are useful (and the only known framework) to assess the landscape of standards for representing this broad but critical class of concepts related to patient preferences. While the taxonomy provides a framework for discussing and advancing patient preferences as a broad class/type of data, the domains are specific to those for PC CDS and do not universally reflect the organization of patient preference terms and codes used by standards policymakers (e.g., the Office of the National Coordinator for Health Information Technology USCDI), stewards (e.g., the National Library of Medicine and the Centers for Medicare & Medicaid Services), or standards developers. This makes the search and assessment for this report challenging and presents barriers in the promotion and coordination of new standard terms for patient preferences.

## 5.2 Action Plan

This report's analysis of the current state of standards for representing patient-preference data identifies several opportunities for further development. The following are ten recommendations to promote standardized patient-preference data for public and private sector groups, including patient advocacy groups, medical specialty societies, standards developers, informaticians, and researchers.

**Recommendation 1:** Leverage existing relevant data standards for representing patient preferences, and when needed, request new terms from LOINC from Regenstrief and SNOMED International; these organizations have established processes for requesting new LOINC or SNOMED CT terms that capture preferences in standardized ways to advance PC CDS.[104, 105] There are needs for standardized terms/codes for all six patient preference domains, but some types of patient-preference data (domains) could be prioritized for standards development. These include preferences directly around the support of decision making in general (across clinical areas or conditions), such as communication timing, frequency, and use of communication tools.

**Recommendation 2:** Raise awareness for inclusion of additional patient preference codes (from additional patient preference domains) in future versions of the USCDI.[106] Data standards to represent patient preferences should be promoted for use in PC CDS tools that capture and use patient preferences. USCDI draft V4 indicates limited adoption of LOINC codes capturing patient preferences related to treatment intervention and care experience.

**Recommendation 3:** Develop implementation guidance for developers and implementers. Because many patient preferences can be represented using one or more standards, developers and implementers need guidance to identify and implement the relevant standards.

- Standards organizations can further develop implementation guides to indicate which standards can be used to capture preferences, and in cases where multiple standards exist, which should be used, where, and how.
- LOINC from Regenstrief and SNOMED International have an existing collaboration agreement (as of 2022) designed to broaden adoption of standardized terminology for health data exchange worldwide.[107] Standards developers can promote more coordinated use of SNOMED CT and LOINC terminologies to reduce duplication. This can include specifications, education, incentives,

and tools to promote consistent data modeling and profiling approaches for developers using the HL7 FHIR standard.

**Recommendation 4:** Conduct pilot/demonstration projects in areas that are already “primed” to collect patient-preference data. This includes domains where patient-preference data is already collected and where terminology codes exist allowing for standardization. These areas include palliative and end-of-life care, as well as patient treatment preferences for oncological conditions.

**Recommendation 5:** Identify requirements for information systems to dynamically manage patient preferences. Patient preferences for care and experience change over time, as noted by KIIs; therefore, information systems should have the ability to capture patient preferences over time rather than at a single point. The data and/or the visualization of patient preferences collected at different time points should be explicit in this regard.

**Recommendation 6:** Engage in multi-stakeholder collaborations (e.g., standards development organizations, policymakers, and EHR developers) that include patients and patient advocacy groups to recognize and build consensus on the value of patient preference information to advance PC CDS. Organizations need incentives to advance the development of additional standards. One key informant noted that more research is needed to show the value of including patient-preference data into PC CDS applications as a way to incentivize further standards development.

**Recommendation 7:** Conduct assessments/evaluations to demonstrate the importance of the standardized capture of patient preferences and how standardization of these data impact health outcomes, care experiences, and other outcomes that matter to patients and clinicians.

**Recommendation 8:** Conduct research on how to effectively capture patient preferences, including how they should be delivered (worded) for patients and where they should be incorporated into the clinical workflow, data capture, and decision making. Until we have examples of questions that are useful for patients and clinicians, the standardization piece will be premature. This will require research that includes patients, and it will require standards efforts that include clinicians and professional medical societies.

**Recommendation 9:** Conduct research to determine which patient preference concepts lend themselves best to standardization. Some patient preferences lend themselves more easily to standardization, whereas more development may be needed to capture more complex concepts, such as preferences that shift overtime (e.g., treatment preferences regarding aggressive therapies).[108] Some concepts may be best captured in an unstructured manner (i.e., narrative is appropriate for data capture and use, and there is no value or feasibility to codify it).

## 5.3 Conclusion

Patient preferences play a prominent role in patient-centered care and should be reflected in healthcare decision making. This report examined the scope of data standards currently available for collecting and using patient-preference data to guide PC CDS and presented recommendations for stakeholder groups to further integrate patient-preference data into PC CDS tools. The findings of this report indicate that patient preferences related to treatment and end-of-life care are more routinely collected in clinical encounters and have standardized codes for representing these data, making them prime concepts for PC CDS implementation. We found few codes for representing patient preferences regarding communication and data use, meaning there are opportunities for additional standards development in these areas. We also presented eleven opportunities for stakeholder groups to advance standardized patient-preference data for PC CDS and to include patients and patient advocacy groups in this work where noted. Ultimately, PC CDS tools will be most impactful and meaningful to patients when they account for unique patient needs and preferences.

# Appendix A: Expanded Methods

## A1. Research Questions

| Question |
|---|
| **1.** What standards are available in LOINC and SNOMED CT for representing data for patient preferences in the following domains: personal characteristics, communication, access and care experience, engagement, data, and healthcare services? |
| 2. What are the challenges in implementing standards for representing patient-preference data across clinical contexts in the following domains: personal characteristics, communication, access and care experience, engagement, data, and healthcare services? |
| 3. What exemplar PC CDS applications collect or use data on patient preferences in one or more of the following domains: personal characteristics, communication, care experience, engagement, data, and healthcare/outcomes? |
| 4. What actions can public and private sector groups take to address the gaps and barriers identified? |

## A2. Strategy for PubMed Peer-Reviewed Search

| Search Topic | PubMed Search Strategy |
|---|---|
| **Patient-preference applications** | (("mobile applications"[MeSH Major Topic] AND "decision support systems, clinical"[MeSH Major Topic]) OR ("mobile applications"[MeSH Major Topic] AND ("decision support systems, clinical"[MeSH Major Topic]) OR ("clinical decision support"[Title/Abstract]) OR ("mobile health applications") AND ("patient preference"[MeSH Major Topic] OR "patient needs" OR "patient goals" OR "preferences")) |
| **Patient-preference standards and app interoperability** | (("mobile applications"[MeSH Major Topic] AND "decision support systems, clinical"[MeSH Major Topic]) OR ("mobile applications"[MeSH Major Topic] AND ("decision support systems, clinical"[MeSH Major Topic]) OR ("clinical decision support"[Title/Abstract]) OR ("mobile health applications") AND ("patient preference"[MeSH Major Topic] OR "patient needs" OR "patient goals" OR "preferences") AND ("FHIR" OR "LOINC" OR "SNOMED" OR "terminology standards" OR "interoperability standards" OR "data representation standards" OR "exchange standards")) |

| Search Topic | PubMed Search Strategy |
|---|---|
| **Patient-preferences in the EHR** | ("mobile applications"[MeSH Major Topic] OR "electronic health records"[MeSH Major Topic] OR "patient portals"[MeSH Major Topic]) AND ("patient preference"[MeSH Major Topic]) |

*All searches were filtered by “2018-present” and “human species research”

## A3. Inclusion Criteria for PubMed Peer-Reviewed Search

| Inclusion Criteria | Exclusion Criteria |
|---|---|
| • Literature reviews and pilot/implementation studies published in 2019 or later<br>• Discusses technical standards and/or implementation guidance relevant to developing, implementing, and supporting patient preferences for CDS | • Does not address use of patient preferences for clinical decision support intervention<br>• Does not include human patients (e.g., veterinary studies; algorithms or provider-focused tools that do not involve some element of patient interaction)<br>• Blog, book, news article, discussion forum, webinar |

# A4. Full Table of Search Terms for LOINC Codes, SNOMED CT Codes, and FHIR Resources Identified Using the Patient Preferences Taxonomy

| Domain | Subdomain | Examples | Search term in Metathesaurus |
|---|---|---|---|
| **Personal Characteristics** | No applicable subdomain | Title (Mr., Mrs., Dr., etc.) | "title" |
| | | Preferred name | "preferred name" |
| | | Language | "language"<br>"language preference" |
| **Communication** | No applicable subdomain | Timing (e.g., time of day, time in relation to clinical visit/care, etc.) | "communication timing"<br>"message timing"<br>"communication preference" |
| | | Mode (e.g., verbal, e-questionnaire, paper questionnaire, phone call, text, email, smartphone applications, patient portal) | "communication method"<br>"communication mode" |
| | | Frequency (e.g., once a month, every 6 months) | "communication frequency"<br>"message frequency"<br>"communication regularity"<br>"communication prevalence" |
| | | Use of communication tools (e.g., option to discontinue use of communication tools such as messaging with provider organizations through the patient portal) | "discontinue communication"<br>"cease communication"<br>"communication permission"<br>"revoke permission" |
| **Access and Care Experience** | Care experience (general) | | "care experience" |
| | Accessibility | Timeliness of care | "timeliness of care"<br>"care timing" |
| | | Location for clinical care | "location of care"<br>"preferred facility" |
| | | Location for health services (e.g., pharmacy, lab, imaging site) | "preferred pharmacy" "preferred lab" |
| | IT-enabled support tools | Telehealth access | "telehealth" |
| | | Self-scheduling (e.g., web/mobile appointment manager) | "self-scheduling" |

| Domain | Subdomain | Examples | Search term in Metathesaurus |
|---|---|---|---|
| | | Support access (e.g., Secure messaging, Online chatting) | "support access"<br>"chat"<br>"online chat"<br>"messaging" |
| | | Notifications & reminders (e.g., appointment reminders) | "notification preferences"<br>"reminder preferences"<br>"reminders" "notifications"<br>"notification, partner" |
| | Interpersonal / Relational | Provider relationship (e.g., prior relationship, established trust, etc.) | "trust" "provider trust" "provider relationship" "prior provider"<br>"clinician relationship"<br>"prior clinician"<br>"clinician trust" |
| | Provider / System | Provider qualifications / skills (Skills and qualifications of the provider) | "provider qualification"<br>"provider degree"<br>"provider education"<br>"provider skill"<br>"preference professional”<br>"clinician preference"<br>"clinician degree" |
| | | Provider identity factors (e.g., sex and other demographic characteristics etc.) | "provider sex" "provider identity" "provider demographic"<br>"preference professional"<br>"provider preference"<br>"clinician characteristics"<br>"preference for clinician" |
| | | Access to spiritual/religious care (presence/use of prayer, clergy, talk of death) | "clergy" "prayer" "religious care"<br>"spiritual" |

| Domain | Subdomain | Examples | Search term in Metathesaurus |
|---|---|---|---|
| **Engagement** | Self-management | Use of self-management tools (e.g., PHR, applications that allow patients to access information regarding potential treatment side effects, support services, lifestyle changes, alternative therapies, managing finances, etc.) | "self-management" - yields ability to self-manage or healthcare activity rather than preferences<br>"support services"<br>"engagement"<br>"personal health plan"<br>"alternative therapy" |
| | | Access to community of peer support (i.e., access to "patients like me" for support in managing one's health condition) | "peer support<br>"group support" |
| | Decision making | Degree (level of patient responsibility in making decisions around treatment, care, etc.) | "decision making preferences" |
| | | Inclusion of others in decisions (e.g., caregiver/family involvement) | "family decision making"<br>"caregiver decision making"<br>"notification, partner"<br>"decision making, shared"<br>"family involvement"<br>"preference clinician" |
| | | Use of decision aids/tools | "decision aid"<br>"decision tool" |
| | Information seeking (communications related to a patient's health condition or care. May include receiving test results, fielding and receiving answers for health/ treatment questions, etc.) | Mode (how the patient prefers to receive information related to their care or condition, e.g., verbal, written, email, video, portal, etc.) | "information preferences"<br>"informational support"<br>"learning preference"<br>"learning style"<br>"receipt of information"<br>"communication preference" |

| Domain | Subdomain | Examples | Search term in Metathesaurus |
|---|---|---|---|
| | | 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”) | "information seeking"<br>"information preferences"<br>"information desired" |
| | | Tailored health data feedback and education (ex/ HRA with data viz) | "health data feedback"<br>"tailored health feedback”<br>"tailored health data"<br>"personalized health data"<br>"health risk assessment feedback"<br>"personalized"<br>"person centered" |
| **Data** | Access | Patient access to their own data | "patient data access" |
| | | Clinician access (e.g., coordination, health information exchange) | "data access"<br>"provider access"<br>"clinician access" |
| | | Designee access(e.g., family member) | "proxy access"<br>"designee access"<br>"data sharing" |
| | | Research access (e.g., consent processes to share data for research) | "research data access"<br>"research access"<br>"clinical trials data access"<br>"data sharing" |
| | | Level of access (e.g., whole record vs. granular control of sharing one’s personal health record) | "data access level"<br>"access granted" |
| | | Duration of access (i.e., expiration of access agreement) | "access duration"<br>"sharing duration" |
| | Use of data (how personal health data is used) | Personal use (e.g., use within PHR or other tool as a self-maintained, self-controlled complete record of health information) | "data use"<br>"personal data use"<br>"patient data use" |

| Domain | Subdomain | Examples | Search term in Metathesaurus |
|---|---|---|---|
| | | Research/clinical trial use (e.g., data used to research new ways to prevent cancer) | "clinical trial data use"<br>"research data use"<br>"research data"<br>"research data access"<br>"patient data sharing clinical trials"<br>"patient data permission" |
| | | Healthcare quality improvement (e.g., data used to evaluate how well your doctor provides care) | "quality improvement"<br>"quality monitoring"<br>"quality data" |
| **Healthcare Services** | Prevention | Receipt of preventive services, treatments, or programs (e.g., vaccines) | "preventive care preferences"<br>"vaccine preferences"<br>"screening preferences" |
| | Receipt of results | Type of tests (e.g., screening tests, genetic tests, follow-up) | "diagnostics"<br>"test preferences"<br>"testing location"<br>"preferred location" |
| | | Return of results (e.g., receipt of genetic testing results) | "receipt of test result"<br>"test result preferences"<br>"test result communication"<br>"receipt of information preference" |
| | Treatment | Type of treatment/intervention (Preferences related to the actions or ways of treating a patient or a condition medically, non-medically, or surgically; management and care to prevent, cure, ameliorate, or slow progression of a medical condition, e.g., medication vs. surgery) | "treatment preferences"<br>"preference clinician"<br>"intervention preference" |
| | | Receipt of treatment (Preferences around whether or not a patient would like to receive or undergo a specific treatment option) | "treatment preference"<br>"preference care" |
| | Advanced Care Directives | Cardiopulmonary resuscitation (CPR) | "cardiopulmonary resuscitation"<br>"advance directive" |

| Domain | Subdomain | Examples | Search term in Metathesaurus |
|---|---|---|---|
| | | Intubation and ventilation | "intubation"<br>"ventilation"<br>"advance directive" |
| | End-of-life care | End-stage treatment | "end stage treatment"<br>"end of life care"<br>"advanced directive"<br>"palliative care"<br>"clinician preference" |
| | | Alignment with family preferences | "advance directive"<br>"priorities"<br>"clinician preference" |
| | | Location (location of death) | "location of death"<br>"death preferences"<br>"discussion about preferences death"<br>"preferred place of death"<br>"clinician preference"<br>"preferred location"<br>"deceased location" |

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