Measurement and Outcomes Workgroup:

Inventory of Patient Preference Measurement Tools for PC CDS Report

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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 Measurement and Outcomes Workgroup supports the measurement of PC CDS implementation and effectiveness to ensure that PC CDS works as intended. The Workgroup is comprised of 8 experts representing a variety of perspectives related to CDS. This report is intended to be used by those interested in collecting and measuring patient preferences that are relevant to 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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1. Introduction

In 2001, the National Academy of Medicine (formerly the Institute of Medicine) report, *Crossing the Quality Chasm,* described patient-centered care as care that acts on patient needs, values, and preferences, and "ensures patient values guide all clinical decisions."[1] Collecting and acting on patient preferences in healthcare decision making are key elements of delivering patient-centered care.

Drawing from definitions of patient preferences developed by Brennan and Strombom (1998)[2] and the U.S. Food and Drug Administration (FDA),[3] the 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."[4] More simply, patient preferences describe patients' wishes with how they "1) interact with their clinician, care system, or personal data; 2) choose a particular course of action over others; or 3) prioritize particular attributes or effects of healthcare."[4]

Patient preferences can encompass a wide range of aspects related to a person's health and healthcare. Notably, patients' preferences can refer to structural components for care (e.g., clinician or health system characteristics), processes of healthcare (e.g., preferred treatment type or decision making engagement), and outcomes of care (e.g., perceptions toward health status or length of stay). Additionally, preferences refer to both patients' generalized preferences related to their medical care (e.g., communication with a clinician) or preferences specific to a given scenario (e.g., selecting one treatment over others for a particular condition).[2]

Patient-centered clinical decision support (PC CDS) should account for patient preferences. Patient preferences can be considered in several ways in PC CDS. First, health systems and researchers can use a patient's stated preference to tailor PC CDS. For example, a patient can express communication preferences for PC CDS designed to support medication adherence, which can then inform how often they are reminded to take their medication. PC CDS can also support the integration of patient preferences into healthcare decision making by alerting care teams of a patient's preference as they discuss treatment or procedure options.[5] When clinicians and patients use PC CDS in these ways, PC CDS can support healthcare organizations as they move toward the goal of delivering patient-centered care.

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 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.[6]

Despite an increased focus on delivering patient-centered care that empowers patients to participate in decisions about their care,[7,8] to date, few CDS tools consider patient preferences when implementing clinical recommendations and guidance or facilitating shared decision making.[9] To enable the integration of patient preference information into PC CDS, broader collection and measurement of patient preferences are a needed first step. Within the healthcare context, collection of patient preferences varies widely and no established best practices or tools exist around collecting patient preferences relevant for PC CDS.[4] To truly realize the full capabilities of PC CDS, the field needs validated instruments to systematically elicit patient preferences.

This Inventory builds on previous work from the CDSiC by outlining available instruments and tools to collect preference information from patients that can inform healthcare decision making. The CDSiC previously defined and categorized patient preferences relevant to PC CDS. In doing so, it developed the *Taxonomy of Patient Preferences*, which outlines six domains of patient preference types: Personal Characteristics, Communication, Access and Experience, Engagement, Data, and Healthcare Services (**Appendix A**. Taxonomy of Patient Preferences: Domains and Subdomains).[4]

The objectives of the *Inventory of Patient Preference Measurement Instruments for PC CDS* and this accompanying narrative are to:

- Identify specific patient preference measurement tools used in clinical settings and provide information on key characteristics.
- Describe considerations and challenges to adopting and using patient preference measurement tools in practice.

Together, these materials aim to enable PC CDS developers, implementers, and evaluators to incorporate patient preferences in their PC CDS.

1.1 Report Roadmap

This report describes the Inventory and outlines measurement gaps and considerations. The report includes the following sections:

- *Methods*. This section summarizes our approach to conducting an environmental scan to identify existing patient preference elicitation and measurement tools.
- *About the Inventory of Patient Preference Measurement Tools for PC CDS*. This section introduces the purpose, potential audiences, and intended uses of the Inventory. It describes the content of the Inventory, including definitions for the categories included for each measurement tool. It also includes findings from the literature on factors that influence the collection and measurement of patient preferences relevant to PC CDS.
- *Gaps in Patient Preference Measurement and Future Directions.* This section describes gaps in the current practice of eliciting and measuring patient preferences relevant to PC CDS and outlines future areas for research to address these gaps.

2. Methods

We conducted an environmental scan of the peer-reviewed and grey literature, beginning with a review of citations identified as part of the scoping review conducted to develop the *Taxonomy of Patient Preferences*. We reviewed 126 articles cited in this previous report and performed two levels of screening—a title/abstract and full-text review. At each level, we assessed whether the article provided information about patient-preference measures and tools (see **Appendix B** for eligibility criteria). We reviewed title/abstracts for the 126 articles included in the *Taxonomy of Patient Preferences* and included 42 in full-text review. After full-text review, 20 articles were included in the final Inventory.

We then conducted a supplemental review of the peer-reviewed and grey literature. We performed searches of the peer-reviewed literature in PubMed and the Association for Computing Machinery (ACM) Digital Library. These searches together yielded 160 articles. After title/abstract and full-text review, we included 24 articles. For grey literature sources, we searched Google and reviewed the National Institutes of Health's Patient-Reported Outcomes Measurement Information System (PROMIS) Toolbox and the Phenotypes and eXposures (PhenX) Toolkit. The PhenX Toolkit is an online catalog of phenotype and exposure data measurement protocols appropriate for genomic, clinical, and translational research.[10] We screened 169 records from Google, of which seven were included after full-text review. Additionally, we reviewed the protocols available in the PhenX Toolkit, but none met the eligibility criteria.

We abstracted literature data and measurement tools into the Inventory using the organizing framework of the *Taxonomy of Patient Preferences*. We then thematically analyzed and synthesized the literature on patient preference measurement considerations, challenges, and gaps. See **Appendix B.** for more information on our literature search strategy.

3. About the Inventory of Patient Preference Measurement Tools for PC CDS

The Inventory provides a list of measurement tools and instruments reported in the research literature to capture and assess patient preferences relevant to healthcare decision making. The focus of this Inventory is to capture preference measurement tools that have potential for larger-scale deployment (i.e., captured in a form, validated scale/instrument, standardized data) and have been demonstrated as feasible for implementation in clinical workflows or patient lifeflows (e.g., daily activities in daily-life contexts[11]).

The primary purpose of the Inventory is to help PC CDS developers, implementers, evaluators, and patients/caregivers identify patient preference measurement tools relevant to their needs or a given scenario. While the Inventory is not exhaustive, by collating existing elicitation and measurement tools in one place, it aims to improve awareness of and access to existing patient preference measurement tools.

This Inventory is intended for a wide variety of potential users with different perspectives, goals, and roles related to PC CDS. Potential users range from CDS developers and community hospitals to academic medical centers, researchers, health system informaticians, care team members, and patient partners, among others. Potential uses of this Inventory include:

- Assisting PC CDS designers, developers, implementers, and evaluators identify measurement tools to implement in their systems, or incorporate in the design and development of new PC CDS.
- Supporting healthcare organizations to develop workflows that capture patient preference information and configure PC CDS to support care informed by these preferences.
- Helping patients, caregivers, and patient advocates determine where there are gaps in the elicitation and measurement of patient preferences.

3.1 Types of Information Included in the Inventory

In the Inventory, we include the following information about each instrument/tool:

Delivery Method. This column describes how the instrument is delivered to and completed by the end user. The majority of patient preference elicitation and measurement tools are delivered to patients in a questionnaire format. These tools include both standardized instruments developed to collect patient preference information and surveys developed for a specific study or intervention. In these instances, patients often complete the tool online, either through a web-based survey system, through a patient-facing application, or via a standalone website. Other formats for delivering questionnaires included paper, telephone, and face-to-face. Patient preferences were also collected from patients through medical forms, such as discharge planning forms, physician orders for life sustaining treatment (POLST) forms, and advanced directives. Patient-preference measures can also be derived from information input by clinicians and captured in clinical notes in the electronic health record (EHR).

While these categories may overlap, we coded instruments to one category according to the primary method described in the source literature.

Adoption in Healthcare. This column captures how common or widespread use of the tool is in the medical field. Values include:

- *Under development.* At the time of publication, the tool was under development.
- *Pilot-tested.* The tool has been successfully pilot tested with a population.
- *Used in a clinic/health system.* The tool is used in a clinic or health system to capture patient preference information for use in clinical care.
- *Commonly used/established.* The tool is widely used in research and/or clinical practice to study preferences or capture preferences.

Use Population. This column describes the patient population the tool is designed for.

Condition/Disease Context. This column describes whether a tool is tailored to a specific condition or disease, or if it is agnostic (referred to as "nonspecific" in the Inventory).

Clinical Setting. This column describes the type of setting where the tool can be used. In some instances, tools are developed for a specific setting, while other tools are general and designed to be used across settings.

Reliability. We report whether and how reliability of the tool was assessed in the published literature and the findings of the assessment.

Validity. We report whether and how validity of the tool was assessed in the published literature and the findings of the assessment.

Since this is not an exhaustive list of measurement tools, the Inventory may not capture all preference elicitation tools currently in use or reported in the literature. In particular, instruments included under the Healthcare Services/Treatment (domain/subdomain) category are examples of condition-specific treatment preference tools that may be used in clinical care.

3.2 Inventory Summary

The Inventory captures 43 unique tools and instruments used to elicit patient preferences related to their medical care that have been used in a clinical setting or integrated into clinical workflows. It is a filterable and sortable spreadsheet to help users identify measurement tools of interest. Users can sort the Inventory by the Taxonomy domain and subdomain, or by any of the additional fields described above.

Of the identified domains, tools included in the Inventory most commonly address the Healthcare Services (n=25) and Engagement (n=20) domains. We did not identify any tools that asked about preferences related to personal characteristics (e.g., preferred name, language). Some tools are domain-specific, collecting preferences only within one of the Taxonomy domains, while other tools ask about preferences across domains. Most of the tools included in the Inventory elicit preferences specific to one domain (n=25). Over a third of all tools (n=18) address two of the six domains, and three tools address three out of six domains. Within each domain, most tools only addressed one subdomain; however, 11 tools addressed two subdomains within a single domain. See Exhibit 1 for a full description of the number of tools that address the Taxonomy domains and subdomains.

Exhibit 1. Number of Measurement Tools per Domain and Subdomain

Domain	Domain Count	Subdomain	Subdomain Count
Personal Characteristics	0	-	-
Communication	8	-	-
Access and Care Experience	6	Accessibility	2
		IT-enabled support tools	2
		Interpersonal/Relational	1
		Clinician/System	1
Engagement	20	Information seeking	7
		Decision making	17
		Self-management	3
Data	5	Access	5
		Use of data	3
Healthcare Services	25	Prevention	1
		Receipt of results	4
		Treatment	12
		Advance care directives	2
		End-of-life care	2

Note: Personal Characteristics and Communication domains have no defined subdomains in the *Taxonomy of Patient Preferences*. Instruments may apply to more than one domain/subdomain.

The majority of tools included in the Inventory captured preferences as reported by the patient, rather than a clinician's assessment of what the patient prefers based on a conversation. Only one of the tools captured in the Inventory relies on clinician notes and medical records to provide a measure of patient preferences—the Joint Commission National Quality Measure PAL-04 Treatment Preferences and Goals of Care.

Delivery Method. The way that preferences were collected varied amongst the included studies. Self-completed questionnaires were the most common delivery method. Exhibit 2 describes how tools were delivered to the respondent.

Exhibit 2. Patient Preference Measurement Tool Delivery Method

Delivery Method	Count
Self-completed questionnaire	28
Web-based	12
Paper-based	2
Web- or paper-based	4
Unspecified format	10
Website–decision aid	4
Patient-facing application	2
Paper-based medical form	2
Telephone call	2
Face-to-face interview	1
Card sorting activity	1

Adoption in Healthcare. Tools ranged in their level of adoption in research or in clinical settings. Over half (n=27) of the tools have been pilot tested. A much smaller number are commonly used or established tools (n=6), used in clinics or health systems (n=6), or under development (n=4).

Condition/Disease Context. Nearly half (n=20) of the tools in the Inventory were developed for a specific condition/disease, with the remaining tools (n=23) designed for use with a general population. Condition- /disease-specific tools span a variety of disease or condition contexts, with cancer and end-of-life most common.

Clinical Setting Context. Related to findings of disease context, only 30 percent (n=13) of the tools were for use in a generalized setting (i.e., they were not developed specifically for use in one clinical setting). The remainder of tools were developed for settings spanning the continuum of care, including outpatient, inpatient, clinical trials, intensive care unit, emergency department, nursing facility, and palliative care.

Reliability and Validity. Only a small portion of the tools in the Inventory were assessed in the literature for reliability (n=13) and validity (n=10). This is reflective of the common practice to use nonstandard questionnaires to assess patient preferences.[12] The majority of tools tested for reliability or validity were commonly used scales that measure a specific concept or construct. Results of reliability and validity tests, as conducted by tool developers and other researchers and published in the literature, are detailed in the Inventory.

Reported validity testing primarily focused on establishing content and structural validity, with a limited number of tools tested for face validity, concurrent validity, and construct validity. Tests used to establish validity vary depending on the type. Validity types and corresponding assessments used in the included studies are described in Exhibit 3. Note that this is not an exhaustive list of the validity tests that can be performed; only those reported in included studies are listed.

Exhibit 3. Types of Validity

Type of Validity	Description	Test Name
Concurrent validity	Assesses how well the results of a measurement instrument correspond to results of a previously established tool for the same construct; demonstrates the degree of agreement between the measurement tool and another tool that is proven valid.	Pearson correlation coefficient
Construct validity	Assesses how well a measurement instrument measures a given concept.	Factor analysis: • Model fit measures (e.g., Tucker–Lewis index, confirmatory factor index [CFI], chi-square) • Root mean square error of approximation (RMSEA), standardized root mean square residual
Content validity	Assesses how well a measurement instrument assess all facets of the specified construct.	Determined to have face validity or rooted in the evidence-based or a consensus-based process.
Face validity	A subjective assessment of whether a measurement instrument appears to be suitable to its stated objectives.	Cognitive interviewing
Structural validity	Assesses whether scores of a scale adequately reflect the dimensionality of the measured construct.	• Factor analysis: RMSEA • Principle component analysis (e.g., Kaiser-Meyer-Olkin)

Of the 10 tools tested for validity, only eight were considered valid by researchers. Exhibit 4 includes details on the validity results of tested scales, as well as available languages, using published validity tests performed either by tool developers or the results of a 2020 systematic review conducted by Jerofke-Owen and colleagues that assessed methodological quality using the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) checklists.[13] We document where the literature reported acceptable validity of the patient preference measurement tools;[14] we did not assess validity ourselves. The tools tested for validity cover a range of domains, including Engagement, Communication, Healthcare

Services, and Access and Care Experience. Eight of the instruments elicit preferences related to a patient's engagement in their care. All eight tools capture preferences around the engagement subdomain decision making, three capture information seeking preferences, and one captures self-management preferences. One other validated tool asks about end-of-life care (Healthcare Services domain) preferences and a second elicits communication preferences for more information about the validity testing (see the Inventory).

If planning to use one of these validated scales, users should not combine or split up validated scales. Combining or splitting scales impacts the integrity of the scale, which may make the scales no longer valid.

Exhibit 4. Validated Scales Included in the Inventory

Tool Name	Languages	Validity
4Ps[15]	English, Swedish	• Content validity: Acceptable[13] • Structural validity: Acceptable[13]
Autonomy Preference Index[16]	English, German	• Structural validity: Acceptable[13]
Communication Preferences for Patients with Chronic Illness[17]	English, German	• Content validity: Acceptable[13] • Structural validity: Not acceptable[13]
Control Preferences Scale[18,19,20,21]	English, Italian, Spanish	• Content validity: Not acceptable[13]
Desire to Participate in Medical Decision-Making Scale	English	• Content validity: Acceptable[13] • Structural validity: Not acceptable[13]
Outcome Prioritization Tool[22]	English, Dutch	• Face validity: Not acceptable • Construct validity: Not acceptable
Patient Experience of Engagement Survey[23]	English	• Construct validity: Acceptable
Patient Preferences for Engagement Tool 12-Item Short Form[24]	English	• Construct validity: Acceptable
Pelvic floor disorders Autonomy Preference Index[24]	English	• Concurrent validity: Acceptable[13]
Problem-Solving Decision-Making Scale	English, Portuguese	• Face validity: Acceptable[25,26] • Structural validity: Acceptable[25,26]

Note: Acceptable and not acceptable validity was determined by study authors using established validity tests described in Exhibit 3.

3.3 Measurement Considerations When Using the Inventory

Below, we detail five measurement considerations that users should keep in mind when using the Inventory and selecting measurement tools for PC CDS.

The Inventory is not exhaustive. The measurement of patient preferences to inform healthcare decision making is an emerging area. Given the nascent stage of the field, the literature may not reflect current practices in place to capture patient-preference information through patient- and clinician-facing technology in healthcare settings. Additionally, as we relied on information currently available in the published literature, we did not explore measurement tools used to capture patient preferences in health system EHRs that are described in non-publicly available domains. Therefore, the measurement tools included in this Inventory are not an exhaustive list of all existing resources.

The identified tools may not fit the needs of all patient populations or healthcare settings. Most of the tools we identified are accessible only in English, which limits the use of these tools in non-English speaking populations. We also did not identify measurement tools that addressed the Personal Characteristics domain, which includes preferred title, name, and language. These aspects of patient preferences are often collected as standard of care,[27] but structured instruments in these areas are not published in the literature and are often not implemented in a standard manner across health systems.[28,29]

In addition, many of the tools were pilot tested or implemented in academic medical centers. Since academic medical centers often have a different level of resources in terms of staff and infrastructure than community health systems,[30,31] additional research is needed to understand whether these patient preference elicitation tools are appropriate for use in under-resourced settings, such as community health centers or nursing homes, or if adapted versions are needed. If patient-preference instruments prove too burdensome for implementation in under-resourced settings, they may not be used or may prove not useful in those settings.

Most of the instruments in the Inventory are completed by patients and, therefore, provide self-reported preferences. Capturing preference information directly from the patient is important for delivering meaningful person-centered care. PC CDS developers should not rely exclusively on clinicians' assessments of a patient's preferences, as captured in clinical notes in the EHR, since the clinician-reported preference information may not reflect patients' true preferences. Research has shown that clinicians' perceptions of the preferences most important to patients do not always align with patients' own ranking of their preferences.[21,32] Collection of preferences directly from patients will likely require conversation to ensure there is a shared understanding of needs and preferences between patients and clinicians. Additionally, patient education may be required prior to eliciting preferences on treatments to ensure that the patients fully understand the benefits and risks of their options. Eliciting preferences directly from patients requires that tools account for differing levels of patient health literacy and digital literacy to ensure accuracy (see Section 4.4 for a discussion of literacy implications for patient preference measurement tools).

The literature lacks information on how frequently the tools should be used. Research has shown that patient preferences should be assessed periodically, as preferences change with patient education about treatment options, disease progression, age, and stage of the patient journey.[21,33] In some instances, we were able to determine the frequency at which patient preferences were measured for a given tool. However, since much of the research on patient preference assessment occurs in the context of research, the literature was not descriptive or instructive on how often a patient should complete the patient preference elicitation instruments in a real-world setting (i.e., once, annually, every visit).

Most of the tools identified in the literature search were developed using experimental methods that are not replicable in a clinical setting. Common experimental methods include discrete choice experiments,[i] conjoint analysis, ranking and rating techniques, and qualitative interviewing.[34,35,36] Consequently, it is also unclear how the identified tools can be seamlessly incorporated into workflows for use in CDS.

4. Gaps in Patient Preference Measurement and Future Directions

Through the development of the Inventory and discussions with key informants, we identified five gaps related to the measurement of patient preferences for PC CDS:

1. A need for a common definition for patient preferences.

2. A lack of validated patient-preference instruments to support standard and efficient data capture.

3. Guidance on which patient preferences should be measured for select patient populations and which can be measured more generally for all patients.

4. A need to address considerations in the measurement of patient preferences for vulnerable populations, including people with low health or reading literacy.

5. A lack of knowledge about how patient-preference measurement tools are incorporated into the clinical workflow.

Below, we further describe each gap and potential future directions for the field.

4.1 Need for a Common Definition of Patient Preferences

Within the measurement literature, there is no agreed upon use of the term "patient preferences." Researchers' use of "patient preferences" is inconsistent with the domains the CDSiC previously identified as relevant to PC CDS. For example, patients' preferences within

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[i] Discrete choice experiments elicit patient preferences by asking patients to choose between hypothetical scenarios that describe certain attributes (e.g., distance to travel to an appointment) that influence preferences. After patients select between several scenarios, researchers are able to determine each attribute's relative impact on decision making.

the Personal Characteristics domain, like preferred name, are not a feature of the patient-preference literature, although a rich set of literature exists on the development and use of these measures in other areas. Alternatively, some researchers use "patient preferences" to refer to concepts related to patient-reported outcomes. For example, the Department of Veterans' Affairs and the PROMIS Toolbox use quality-of-life metrics to assess a person's preferred indicators for quality of life or preferred health state to understand the value of one treatment over another to a patient, or the effect of a given treatment on one's quality of life and preferred health state.[37,38]

Future Directions

► The term "patient preferences" and its use in the measurement field needs clarification and consensus.

► Consistent definition and use of the term "patient preferences" is needed as a first step in order to facilitate the expansion of standardized patient preference elicitation and measurement for PC CDS.

4.2 Lack of Validated Patient Preference Instruments

Validated instruments ensure that the instrument accurately measures the construct of interest. However, as noted above, the majority of tools published in the literature that capture patient preferences are not validated, and there is no standard approach for collecting or reporting patient preferences.[33]

The lack of validated measures has implications for the ability to set gold standard instruments that can be used in assessing criterion validity. For example, currently no gold standard instruments exist for patient preferences for engagement in care,[15] despite the outsized focus on capturing preferences surrounding engagement,[39] or for assessing patient autonomy.[40]

Validated data collection instruments are crucial for consistently capturing patient preferences in a standard manner and are an important input in data standards. Without standard data collection, health systems capture data differently, making it difficult to exchange patient-preference data between clinicians that could be used to deliver more patient-centered care.[41] As an example from the Inventory, POLST forms, a medical form completed by patients to indicate preferences around end-of-life care and treatments, are increasingly captured in a patient's EHR as structured data. Data elements from the National POLST form have informed the development of the emerging implementation specification the Health Level Seven (HL7®) ePOLST Clinical Document Architecture Implementation Guide, which seeks to create an interoperable form to support decision making and documentation of advance care directives.[42]

Some clinical areas routinely collect patient-preference data and are more primed for standard capture of patient preferences. These areas include end-of-life care preferences, treatment preferences, and goals in oncology terminology, and interoperability standards are actively used to capture preference data.[43] While some preferences, like preferred language, communication

preferences, and end-of-life goals, are captured directly in the EHR through structured fields, other preference data on preferred treatment goals, engagement, and decision-making roles, are often documented in unstructured clinical notes in the EHR. Such unstructured data are often not included in CDS tools that could support care integration. For an in-depth analysis of available standards for capturing patient-preference data and salient gaps, see the report *Advancing Standardized Representations for Patient Preferences to Support Patient-Centered Clinical Decision Support*.

Future Directions

► To better determine the validity of tools eliciting patient engagement and autonomy preferences, studies are needed to define the constructs and build consensus around a gold standard for the concepts of patient engagement and patient autonomy.

4.3 Guidance on Measuring Generalized and Population-Specific Preferences

Currently, we lack the understanding of whether there are generic patient preferences that should be commonly measured across patient populations. Given the breadth of areas in which patients can provide preferences, and the potential for an overwhelming amount of data to incorporate, PC CDS developers, implementers, and evaluators would benefit from knowing which preferences serve as the most foundational and should be asked of every patient.

Additionally, PC CDS developers, implementers, and evaluators should be aware that some preferences are more relevant than others to collect for certain populations (e.g., age group, community setting, or condition/disease context). To reduce patient and clinician burden, developers may need to prioritize collection of some preferences over others, and understand which preferences are most important to collect for their target population. For example, quality-of-life and health state preferences are particularly important in the context of treatment for chronic and terminal conditions.[5] When tracked longitudinally, these preferences can give a clinician key information about the impact of a treatment on their patients' quality-of-life outcomes.[2]

While the field needs to understand which preferences should be elicited generally and for specific populations, it is important to note that the relative importance of preferences varies between individuals,[4] and preferences should never be assumed to be stable within a given population. For more information about how patient preferences can vary by patients, see the *Taxonomy of Patient Preferences.*

Future Directions

► Future work should assess whether a generalized set of patient preferences should be established and collected from all patients. If so, the field can work to develop guidance for clinical care that outlines a standard set of patient preferences that are relevant to and should be elicited from the general population.

► As patient preference collection is incorporated into clinical workflows, future studies should evaluate which preferences are most important and relevant to ask given patient populations.

4.4 Address Needs of Medically Vulnerable Populations

Incorporation of patient preferences in clinical workflow are not only paramount for patient-centered care but are also potentially necessary for addressing differences in health outcomes for patient populations.[44] However, if measurement tools are not accessible to certain populations due to language or literacy limitations, or because the tools are too burdensome to implement in under-resourced settings, including rural and low-income areas, they may exacerbate differences in the provision of patient-centered care and patient satisfaction with their care between settings or populations where patient preferences are collected and honored and where they are not.

To ensure universal access to patient preference elicitation tools, these tools must be developed with these gaps in mind. First, tools must be accessible to people of all health literacy and reading levels and languages. While some of the instruments included in the Inventory mention conducting cognitive testing, most of the instruments do not mention assessments of reading level or health literacy. Health literacy is important to account for, as it influences a patient's understanding of their condition and treatment or care options. Without measurement tools that adequately account for low levels of health literacy, the preferences expressed by patients may not be valid.[45] While we did not capture any patient preference elicitation tools in the domain of Personal Characteristics, AHRQ's Health Literacy Universal Precautions Toolkit, 3rd Edition provides example language for fields in patient intake forms that capture language preferences align with draft United States Core Data for Interoperability (USCDI) Version 5.[46]

Future Directions

► Researchers should assess the usability and the validity of new and existing patient preference scales and tools with underrepresented patient populations, especially those with low health literacy and patients served in under-resourced settings, keeping in mind the unique needs of each patient population.

► The CDS field should look to other fields to best determine how to standardize capture of patient preferences concerning patient characteristics for use in PC CDS.

4.5 Lack of Information About How Patient Preferences are Incorporated into the Workflow

Few studies captured in the Inventory described how patient preference capture, documentation, and use are integrated into clinical workflows. This is an important consideration for PC CDS and EHR developers to think through as they design processes for collecting and integrating patient-preference data into clinical workflows. For example, rather than integrating patient preferences into existing sections of the EHR, it may be necessary to create new EHR sections for specific preference domains. Accessibility within the EHR and effective prompting are key to incorporating patient-preference data into clinical care. Pew Charitable Trusts has called for policies to establish dedicated sections within the EHR for documenting and capturing patients' end-of-life preferences,[47] which clinicians have described as hard to access in the EHR, despite the broad adoption of end-of-life preferences assessment.[41]

Future Directions

- ► In future research, CDS developers and implementers need to clearly report how patient-preference data are integrated into the workflow. To better understand the utility and use of patient-preference data in clinical care, thorough and consistent reporting is needed.

- ► To aid and streamline the use of patient-preference data, while reducing patient and clinician burden, future work could study which preferences can be captured through automated processes from existing documentation within the medical record without the need for self-assessment.

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5. Conclusion

Understanding patient preferences is an important component in delivering patient-centered care; however, the measurement and use of patient-preference data relevant to PC CDS remains limited in clinical care. This report describes an Inventory of patient preference measurement tools and instruments used in clinical practice to capture patients' preferences in several areas relevant to PC CDS. This Inventory can support informaticians, researchers, and developers of PC CDS in identifying measurement tools to collect patient-preference data for use in healthcare decision making. Additionally, we describe several considerations for measuring patient preferences and critical gaps in the measurement of patient preferences.

Appendix A. Taxonomy of Patient Preferences: Domains and Subdomains

Table A1. Taxonomy of Patient Preferences

Domain	Subdomain (if applicable)	Example Concepts	Relevance to PC CDS
Personal Characteristics		• Title (e.g., Mr., Mrs., Dr., etc.) • Preferred name • Language	• Allows for personalization of PC CDS-related communication with patients. • Demonstrates respect for the individual. • Builds trust between PC CDS clinician and patient. • Increases likelihood that PC CDS will be considered, adopted, and adhered to.
Communication		• Timing (e.g., time of day, time in relation to clinical visit/care, etc.) • Mode (e.g., verbal, e-questionnaire, paper questionnaire, phone call, text, email, smartphone applications, patient portal) • Frequency (e.g., once a month, every 6 months) • Use of communication tools (e.g., option to discontinue use of communication tools such as messaging with healthcare organizations through the patient portal)	• Allows for naturally integrating PC CDS into patient lifeflow. • Facilitates engaging patients in a convenient and comfortable manner.
Access and Care Experience	Accessibility	• Timeliness of care • Location for clinical care • Location for health services (e.g., pharmacy, lab, imaging site)	• Shapes the delivery and receipt of PC CDS to improve patients' overall experience. • Ensures that PC CDS reach patients by methods they prefer.
	IT-enabled support tools	• Telehealth access • Self-scheduling (e.g., web/mobile appointment manager) • Support access (e.g., secure messaging, Online chatting) • Notifications and reminders (e.g., appointment reminders)	

Domain	Subdomain (if applicable)	Example Concepts	Relevance to PC CDS
	Interpersonal / Relational	• Clinician relationship (e.g., prior relationship, established trust, etc.)	
	Clinician / System	• Clinician qualifications/skills • Clinician identity factors • Access to spiritual/religious care (presence/use of prayer, clergy, talk of death)	
Engagement	Information seeking	• Mode (how the patient prefers to receive information related to their care or condition, e.g., verbal, written, email, video, portal, etc.) • 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") • Tailored health data feedback and education	• Increases the likelihood of generating personally-relevant recommendations that yield patient engagement in their care. • Increases patient understanding of guidance offered by PC CDS tools. • Improves patient ability to interact with, understand, and adopt PC CDS.
	Decision making	• Degree (level of patient responsibility in making decisions around treatment, care, etc.) • Inclusion of others in decisions (e.g., caregiver/family involvement) • Use of decision aids/tools	
	Self-management	• 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.) • Access to community of peer support (e.g., access to "patients like me" for support in managing one's health condition)	

Domain	Subdomain (if applicable)	Example Concepts	Relevance to PC CDS
Data	Access	• Patient access to their own data • Clinician access (e.g., coordination, health information exchange) • Designee access (e.g., family member) • Research access (e.g., consent processes to share data for research) • Level of access (e.g., whole record vs. granular control of sharing one's EHR data) • Duration of access (e.g., expiration of access agreement)	• Enhances the relevance and accuracy of PC CDS recommendations and interventions. • Mitigates potential safety implications of omitting patient health data from PC CDS.
	Use of data	• Personal use (e.g., use within PHR or other tool as a self-maintained, self-controlled complete record of health information) • Research/clinical trial use (e.g., data used to research new ways to prevent cancer) • Healthcare quality improvement (e.g., data used to evaluate how well your doctor provides care)	
Healthcare Services	Prevention	• Receipt of preventive services, treatments, or programs (e.g., vaccines)	• Prioritizes care based on patient preferences (e.g., goals, situation, values) over a clinician's preferences.
	Receipt of results	• Type of tests (e.g., screening tests, genetic tests, follow up) • Return of results (e.g., receipt of genetic testing results)	
	Treatment	• 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) • Receipt of treatment (preferences around whether or not a patient would like to receive or undergo a specific treatment option)	

Domain	Subdomain (if applicable)	Example Concepts	Relevance to PC CDS
	Advance Care Directives	• Cardiopulmonary resuscitation • Intubation and ventilation	
	End-of-life care	• End-stage treatment • Alignment with family preferences • Location (location of death)	

Appendix B. Literature Search Strategy

Exhibit B1. Peer-Reviewed Literature Search Terms

String 1: Patient preferences	String 2: Measurement	String 3: Decision making	String 4: exclude DCE	Filter
"Patient preference*"[Majr]	measure*[tiab] OR instrument [tiab] OR tool[tiab]	"decision making"[Mesh] OR "Decision Support Techniques"[MeSH]	NOT "discrete choice experiment"[tiab]	5 years, English

Exhibit B2. Grey Literature Search Terms

Source	Search
Google	"patient preference measures healthcare"
Google	"patient preferences measure clinical decision support"
PhenX Toolkit	Health Care> Health Care Quality, Access, Evaluation > Delivery of Health Care > Access to Health Services / Needs Assessment / Professional-Patient Relations
PhenX Toolkit	Health Care > Health Care Quality, Access, Evaluation > Quality of Health Care
PhenX Toolkit	Health Care > Population Characteristics
PROMIS	PROMIS-Preference Summary score (calculated from the following PROMIS domains: cognitive function abilities, depression, fatigue, pain interference, physical functioning, sleep disturbance and ability to participate in social roles)
ACM Digital Library	"patient preference" AND measure

Exhibit B3. Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Published in past 5 years (2018-2023) Published in English	• Non-English • Does not include human patients (e.g., algorithms or clinician-focused tools that do not involve some element of patient interaction) • Does not describe a measurement tool or instrument that captures patient preferences (e.g., captures patient experience or satisfaction with care) • Uses methods to capture patient preferences that are not replicable within the context of real-world clinical care (e.g., discrete choice experiments, conjoint analysis, qualitative interviews)

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