Outcomes and Objectives Workgroup: Taxonomy of Patient Preferences

Agency for Healthcare Research and Quality
5600 Fishers Lane
Rockville, MD 20857
www.ahrq.gov

Contract No: 75Q80120D00018

Prepared by:
Gil Kuperman, MD, PhD
Karen Nanji, MD, MPH
Elizabeth Cope, PhD, MPH
Prashila M. Dullabh, MD, FAMIA
Priyanka J. Desai, PhD, MSPH
Marley Catlett, MPH
Sarah Weinberg
Sarah Hoyt, MPH
CDSiC Outcomes and Objectives Workgroup

AHRQ Publication No. 23-0038-EF
May 2023

PURPOSE

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

FUNDING STATEMENT

This project was funded under contract number 75Q80120D00018 from the Agency for Healthcare Research and Quality (AHRQ), U.S. Department of Health and Human Services (HHS). The opinions expressed in this document are those of the authors and do not reflect the official position of AHRQ or HHS.

PUBLIC DOMAIN NOTICE

SUGGESTED CITATION

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

Contributors: CDSiC Outcomes and Objectives Workgroup

Members of the Outcomes and Objectives Workgroup are listed below.

Table 1. Members of the CDSiC Outcomes and Objectives Workgroup

Name	Affiliation
Adam Myers, MD	Blue Cross Blue Shield Association
David Dorr, MD, MS	Oregon Health and Science University
Kistein Monkhouse, MPA	Patient Orator
Lipika Samal, MD, MPH	Brigham and Women's Hospital, Harvard University
Mustafa Ozkaynak, PhD, MS	Colorado University
Richard Schreiber, MD, FACP, FAMIA, ABPM-CI	Pennsylvania State University
Tiffani Bright, PhD, FACMI	Cedars-Sinai Center for Artificial Intelligence Research
Victoria Tiase, PhD, RN-BC, FAMIA, FNAP, FAAN	University of Utah
Wayne Liang, MD, MS	Emory University, Children's Healthcare of Atlanta

Table of Contents

Executive Summary

Patient-centered clinical decision support (PC CDS) is CDS specifically designed to support health-related decision making informed by patient-centered factors, such as: patient-centered research, patient-generated or patient-specific data, use of patient-facing tools, or use in shared decision making (SDM).[1-3]

By acknowledging patient preferences, and aligning PC CDS delivery with these, health systems and clinicians can take critical steps toward transforming and improving patient care, experience, and outcomes. Achieving this responsiveness to patient preferences, however, requires a better understanding of the preferences relevant for PC CDS and how these can and should be implemented.

Despite mounting discussions in the literature around the importance of patient preferences in patient-centered care, no standardized definition for patient preferences currently exists. Building on the work of Brennan and Strombom (1998)[4] and the U.S. Food and Drug Administration (FDA),[5] we define 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. Patient preferences provide the basis for how patients wish to interact with their clinician, care system, or personal data; choose a particular course of action over others; or prioritize particular services or effects of healthcare.

This report provides a framework for the incorporation of patient preferences into the delivery of PC CDS with a focus on patients' behavior- or condition-independent preferences. The development of this report was guided by three high-level objectives: (1) summarize the key considerations and current evidence gaps regarding the elicitation and incorporation of patient preferences in PC CDS, (2) create a preliminary taxonomy of patient preference domains and subdomains relevant to PC CDS, and (3) highlight potential opportunities for incorporating the elicitation and subsequent integration of patient preferences into PC CDS.

The information in this report is primarily designed for developers of PC CDS artifacts, evaluators of PC CDS interventions, healthcare organizations looking to make use of PC CDS, and patient advocates.

Methods

The project team, composed of members of the CDS Innovation Collaborative (CDSiC) Outcomes and Objectives Workgroup, first conducted a scoping review of peer-reviewed and grey literature relevant to patient preferences in PC CDS. Preliminary findings were supplemented and validated by subject matter experts and experts by experience through key informant interviews and a focus group. A series of thematic analyses were conducted to analyze the current landscape of patient preferences relevant to the PC CDS context, which informed the development of a preference taxonomy and review of key implementation considerations.

Findings

Findings were synthesized to generate a preliminary Taxonomy of Patient Preferences relevant to PC CDS, including preference domains, subdomains, concept examples, and descriptions of how subdomains and concept examples are relevant to PC CDS (**Table 3**). The six identified preference domains are defined below.

- **Personal Characteristics** encompasses preferences that are captured in a patient profile (e.g., a patient's preferred salutation, name, pronouns, language).
- **Communication** encompasses preferences around the frequency, timing, and methods for the transfer of information between the patient and the clinician or health system. For example, patients may have preferences around the time of day they are contacted, whether they are contacted by phone or email, and how often they receive communication from the provider organization.
- **Access and Care Experience** encompasses preferences around the range of interactions a patient has across the healthcare system: with all doctors, nurses, and staff – in all hospitals, physician practices, and other healthcare settings. For example, patients may have preferences around the perceived timeliness or geographic location of health services, use of technology-based tools in their care, or identity factors of or type of relationship with their clinician.
- **Engagement** encompasses preferences around a patient's desired level of involvement in their care. Engagement preferences fall into three main categories: information seeking, decision making, and self-management. Information seeking refers to preferences around the receipt of information related to a patient's condition or care, as well as the transfer of knowledge and skills needed to self-advocate in shared decision making. Decision making preferences address how healthcare decisions should be made, as well as whom should be involved. Self-management involves preferences related to supporting the patient's ability to manage their symptoms and treatment, as well as physical, psychological, and social consequences of their condition.
- **Data** encompasses patient preferences around access and use of personal health data. Examples include who may access a patient's health data, how much data they can access, the duration of access, and how a patient's data are used— for example, for research purposes.
- **Healthcare Services** refers to patient preferences around interaction with the healthcare system and the outcomes related thereto. Preferences related to prevention, receipt of results, choice of treatment, advance care directives, and palliative care are captured in the Healthcare Services domain.

The relevance of preference domains to PC CDS is shown in the table below.

Domain	Relevance to PC CDS
Personal Characteristics	Acknowledging and honoring these preferences: • Allows for personalization of PC CDS-related communication with patients. • Demonstrates respect for the individual. • Builds trust between PC CDS provider and patients.

Domain	Relevance to PC CDS
	- Increases likelihood that PC CDS will be considered, adopted, and adhered to.
Communication	Acknowledging and honoring these preferences: - Increases the impact of the PC CDS intervention. - Facilitates engaging patients in a convenient and comfortable manner.
Access and Care Experience	Acknowledging and honoring these preferences: - Shapes the delivery and receipt of PC CDS to improve patients' overall experience. - Ensures that PC CDS outputs reach patients by methods they prefer.
Engagement	Acknowledging and honoring these preferences: - Increases the likelihood of presenting recommendations in a format that is meaningful to the patient. - Increases patient understanding of guidance offered by PC CDS tools. - Improves patient ability to interact with, understand, and adopt PC CDS.
Data	Acknowledging and honoring these preferences: - Helps assure that the PC CDS uses data in accordance with the patient's wishes. - Mitigates potential safety implications of omitting patient health data from PC CDS.
Healthcare Services	Acknowledging and honoring these preferences: - Enables prioritization of care based on the patient's goals, beliefs, and values.

The formative nature of the work on patient preferences in PC CDS presents challenges to the operationalization of preferences in care, and highlights the importance of key considerations for collecting and incorporating patient preferences within PC CDS.

> **Stability of Patient Preferences:** Patient preferences may be dynamic, changing over the course of a patient's life or illness, or under different circumstances. Preference stability varies depending on the patient, their health condition, symptom severity, prognosis, and preference domain.[6]
>
> **Capture/Collection of Patient Preferences:** Various methods have been used for the collection of patient preferences. However, most methods have been used only in research settings, and standardized tools exist only for a few preference domains. While tools to capture structured preference data exist for some preferences, most patient-preference data are collected and recorded as unstructured data in patient electronic health records (EHRs). Time constraints, technological limitations for recording or storing unstructured preference data, and lack of training on collecting preferences in a sensitive manner may pose challenges to

capturing patient preferences for healthcare providers.

Use of Patient Preferences: Preferences that are collected should be incorporated into clinical care discussions or otherwise acted upon to avoid frustration and mistrust between patient and clinician. However, few best practices currently exist for implementing patient preferences in healthcare workflows. In addition to the technical and infrastructure challenges noted above, other factors may influence the ability of providers to honor patient preferences, for example, as they manifest in the context of social determinants of health, resources and/or staff available to the provider's practice setting, or discordance with clinical practice guidelines.

Measuring Concordance with Patient Preferences: Current methods of assessing the extent to which actions taken comply with the patient's stated preferences have to-date focused on measures of treatment-preference concordance and decision quality. Treatment-preference concordance refers to "the association between patients' preferences concerning health outcomes and/or medical treatments, and treatment intention or treatment undergone."[7] Separately, decision quality is "the extent to which treatments reflect the considered preferences of well-informed patients and are implemented."[7] Uptake of these measures is limited, and how measures are specified, reported, and interpreted varies significantly among early adopters. These and other challenging questions related to the role of measurement remain to be explored.

Areas for Future Work

Efforts to advance PC CDS will require coordination across a range of stakeholders, such as EHR developers, CDS content and app developers, and healthcare provider organizations. Given the field of patient preferences is relatively nascent, however, a paucity of information exists on preferences in PC CDS and within applied clinical settings more broadly. Further evidence suggests that gaps exist regarding the infrastructure for embedding patient preferences in care and its impact.

Findings from the literature and key informant interviews highlighted six areas for future work:

Importance and Impact: Research into what preference domains have the most significant impact on patient outcomes. This includes examining the impact on patient trust, adherence, and continuity of care of collecting preference information that is not subsequently used in care.

Validity and Reliability: The development of a standardized definition of patient preferences, and examination of how preferences vary by individual and contextual factors. This includes research into the degree to which preferences vary by different factors; what factors trigger changes in preferences; and how preferences change over time by domain, subdomain, and context.

Generalizability: Research into how patients assign levels of priority to different preference domains/subdomains, and to what degree preferences are generalizable across populations and diseases. This includes development of tools or processes for identifying and predicting preferences.

Implementation: Examination and development of best practices for capturing and honoring preferences in clinical workflows. This includes research into the influence of the presentation of information and personalization of PC CDS tools on patient understanding and outcomes of PC CDS.

Information Systems: Expansion of the capabilities of clinical information systems (CIS) in order to capture and store patient-preference data and make these data available for use by both computers and humans., This includes increasing access to preference data and facilitating their (1) use by native and integrated third-party PC CDS tools in a vendor-neutral, interoperable manner; (2) use by human caregivers in times of crisis; and (3) modification by the patient over time.

Measurement: Examination of what metrics are best suited to assess the domains and subdomains of preferences relevant to PC CDS. This includes examining what metrics are best suited for measuring how well patient preferences are considered in care and whether such measures are standardizable across conditions and other contextual factors as well as the impact of incorporating preferences on care processes and outcomes.

Conclusion

Patient preferences are an essential component of the patient voice, and including their elicitation and subsequent use in PC CDS can advance patient-centered care. As PC CDS continues to advance, it is vital that the understanding and incorporation of patient preferences continues to progress in tandem. The preliminary Taxonomy of Patient Preferences presented in this report may play a role in PC CDS, may offer PC CDS developers an organizing framework for identifying the types of preference information that are most relevant to PC CDS, and should be factored into PC CDS tools. This taxonomy can also support healthcare provider organizations in developing workflows to capture patient-preference information and configuring PC CDS tools to support care informed by these preferences. Moving forward, more research will be needed to improve understanding of how to incorporate patient preferences into PC CDS in operational settings. The taxonomy presented in this report provides an organizing framework for the types of patient-preference information most relevant to PC CDS. Finally, this report outlines remaining knowledge gaps and a research agenda to enhance the field’s understanding of incorporating patient preferences into PC CDS in operational settings.

1. Introduction

Clinical decision support (CDS) encompasses tools and processes designed to enable timely decision making and subsequent delivery of evidence-based care.[8] Early development and adoption were typically clinician facing and used to deliver diagnostic and treatment guidance.[9] As the broader movement toward patient-centered care has steadily gained momentum—notably being codified as a national goal in the Affordable Care Act[9]—it has motivated a new focus on the development of patient-centered CDS (PC CDS). Specifically, PC CDS involves tools that support decision making informed by patient-centered factors related to (1) knowledge—findings from patient-centered outcomes research and comparative effectiveness research; (2) data—including patient-generated, patient-reported, and patient-specific data; (3) delivery—incorporation of patient-facing tools [e.g., apps, websites, patient portals, and text messages]; and/or (4) use—particularly in the context of shared decision making (SDM).[1-2,3]

Care is patient centered when it is "respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions."[10-,11,12] As such, the incorporation of patient preference information into health-related decision making has been highlighted as one important component of patient-centered care.[13]

Exploration of how patient-preference information can be incorporated into PC CDS is both timely and responsive to persistent gaps in knowledge and health information technology (IT). Recent proliferation of patient-facing technologies, as well as preference management in consumer technology more generally provides a useful springboard for consideration of how patient-preference information could be operationalized in the context of PC CDS. This report serves as a first step in this PC CDS direction through the development of a preliminary PC CDS-relevant Taxonomy of Patient Preferences. The report provides an assessment of the state of the field and an overview of key issues in the implementation of preference-informed PC CDS at scale.

1.1 Roadmap of Report

The development of this report was guided by three main objectives:

1. Develop a Taxonomy of Patient Preferences tailored to the PC CDS context.
2. Summarize the current state of the field as it relates to elicitation and subsequent use of patient preference information in PC CDS tools and applications.
3. Identify key implementation considerations as well as current gaps in knowledge and infrastructure that may impede widespread adoption of preference-informed PC CDS.

This report is intended to provide an organizing framework for the categorization of patient preferences relevant to PC CDS tools and processes. It specifically focuses on preferences that may have universal applicability to PC CDS design and implementation. In addition to the taxonomy, the report also surfaces knowledge gaps and implementation considerations that need to be addressed to successfully operationalize patient preferences in PC CDS, particularly at scale. This work culminates in a set of guiding principles for incorporation of patient preferences in PC CDS as well as a research agenda for strengthening the evidence-base of patient preferences in PC CDS.

- Section 2, *Background*, details the important contribution PC CDS can make in advancing patient-centered care and the ways care could be strengthened by incorporation of patient preferences.
- Section 3, *Methods*, describes our primary research aims and approaches used for the literature review and semistructured interviews / discussions.
- Section 4, *Results,* presents a summary of key findings and an overview of the consequent Taxonomy of Patient Preferences, including discussion of relevance to PC CDS at the domain and subdomain levels as well as considerations for implementation.
- Section 5, *Discussion*, synthesizes learnings in the context of scalability and field maturity, and includes a set of principles as well as recommended research areas to stimulate discovery of best practices that guide incorporation of patient preferences in PC CDS and—by extension—advance PC CDS contributions to patient-centered care.
- Section 6, *Conclusion,* provides a summary of this work's contribution to the field and potential uses by PC CDS stakeholder perspective.

This report is primarily designed for clinicians and healthcare providers aiming to enhance preference-concordant care recommendations and adopt PC CDS, patient advocates championing the elicitation and subsequent use of preference information at the point of care, developers of PC CDS artifacts, and evaluators of PC CDS interventions. Additional audiences, such as health IT developers, may also find this report useful in framing approaches to patient preferences in adjacent health IT contexts.

2. Background

The six domains of healthcare quality include care that is safe, effective, patient-centered, timely, efficient, and equitable.[14] These domains ground our pursuit of the quintuple aim for healthcare improvement.[15] CDS is one tool that can be used to support health-related decision making and the delivery of high-quality, high-value care by providing diagnostic and treatment guidance based on clinical guidelines and/or the best available evidence.[15] Specifically, PC CDS advances patient-centered care through its utilization of data and tools to identify care plan options tailored to individual patient needs, engagement of patients and caregivers in decision making, and assurance that care decisions are informed by and concordant with individual patient goals and preferences.

Providing care that is respectful of patient preferences promotes patient autonomy and self-determination by empowering patients to have meaningful input and decisional capacity throughout their health journey.[10,16] The literature demonstrates that discussion and consideration of patient preferences as part of decision making is positively associated with improved adherence to prescribed therapies,[17] higher patient satisfaction and more positive patient experiences with care,[18] and improved patient outcomes.[19]

Patient preferences and PC CDS would seem natural partners in the advancement of patient-centered care. To date, however, no work has been done to examine the array of patient-preference types relevant to PC CDS and what it would take conceptually, operationally, and technically to bring this integration to fruition in a standardized, scalable way. Herein, this report offers a first step in the field's journey down this path.

2.1 Defining Patient Preferences

Currently, no standard, consensus definition for patient preferences exists.[4,20,21] Early work in patient preferences was most commonly focused on risk tolerance and preferences for particular medical treatment or development of new therapies and/or medical devices in the context of equipoise—the existence of options where evidence that one leads to comparatively superior outcomes over another is lacking.[22] Furthermore, discovery of promising practices for operationalizing patient preference elicitation and subsequent use in the context of healthcare and decision making remains nascent. Limited uptake may be due to several factors, including but not limited to: (1) the concept of patient preferences is nebulous and standard terms are lacking, (2) consensus understanding related to the types of preferences most relevant in any given context has not been established, and (3) technical approaches for digital tools and clinical workflows to systematize and routinize capture of patient-preference information in formats accessible to subsequent recall and use have not been defined.[4,6,20,21]

In recognition of the multidimensional nature of patient-centered care and the relative importance of patient preferences in the delivery of patient-centered care, we apply a broader conceptualization of patient preferences to frame our taxonomy development.

Exhibit 1. Exemplar Definitions of Patient Preferences

BRENNAN & STROMBOM: "…patient preferences are statements made by individuals regarding the relative desirability of a range of health experiences, treatment options, or health states."[4]

FDA: "Patient-preference information (PPI) captures the value that patients place on aspects of the medical device. PPI accounts for differing patient perspectives on benefits and risks that come with using that device or treating the condition. PPI is not the same as patient-reported outcomes which are part of a clinical trial and measure how patients feel and function."[5]

We combined elements of patient-preference definitions from Brennan and Strombom (1998) and the U.S. Food and Drug Administration (FDA) (**Exhibit 1**), to establish our working definition of patient preferences.[4,5] **We define patient preferences as the relative desirability or acceptability to patients of specified alternatives or choices among structures, processes, outcomes, or experiences of interactions with the healthcare delivery system**. In other words, patient preferences provide the basis for how patients wish to (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.[5,23,24] Our assessment surfaced grey areas when considering the boundary between preference and consent. We recognize that some preferences may be expressed as consents (e.g., participation in health information exchange or how health data may be used), but not all consents reflect preferences (e.g., consent for a surgical procedure).

3. Methods

A scoping review of peer-reviewed and grey literature was conducted, and findings were supplemented by qualitative interviews and a focus group to fill gaps, enrich our understanding of salient issues, and aid in elucidating specific relevance to PC CDS. Following initial drafting of the taxonomy, we conducted a second round of qualitative interviews coupled with informal discussions to validate interpretation of findings as well as the organizing framework undergirding the draft taxonomy. A brief summary of our methods is presented below; detailed descriptions of study research questions, search strings, and inclusion and exclusion criteria are provided in the **Appendix.**

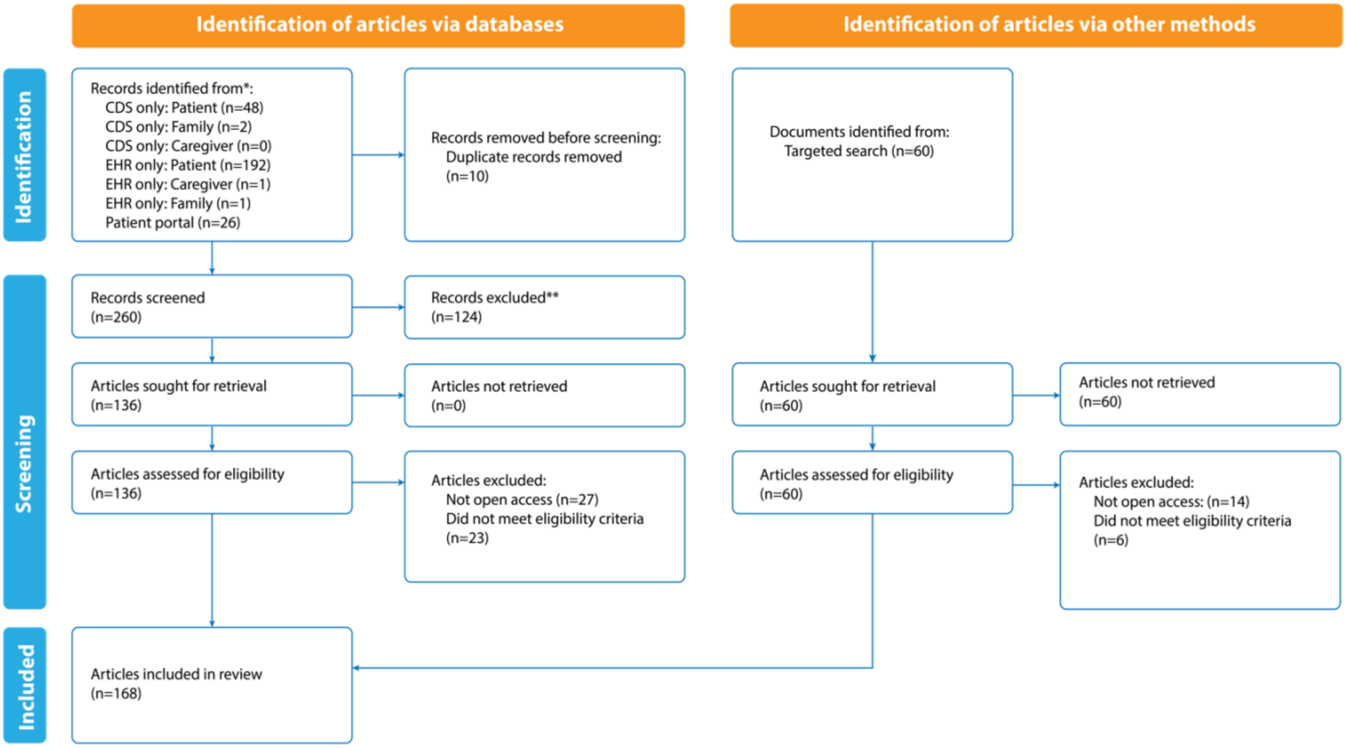
3.1 Literature Review

We conducted a scoping review on patient preferences in the context of PC CDS, beginning with seminal articles shared by Clinical Decision Support Innovation Collaborative (CDSiC) Outcomes and Objectives Workgroup members in addition to a PubMed search to identify peer-reviewed literature. Given the formative nature of work on patient preferences within PC CDS and our recognition that evidence on this topic is limited, we expanded our search to identify literature on patient preferences with electronic health records (EHRs); this involved multiple searches (see **Appendix**) for evidence on patient preferences within health IT and clinical encounters apart from the CDS context. To access grey literature, we utilized Google and Google Scholar search engines.

Our initial searches yielded 270 peer-reviewed articles in PubMed. We then conducted two levels of screening: a title/abstract review of 260 articles, and a full-text review of 136 articles. For each level, we assessed whether the articles met our eligibility criteria (see **Appendix**) and marked them as *eligible, ineligible, or uncertain.* Articles were deemed eligible if they: (1) mentioned patient or consumer preferences, (2) were published in the last 10 years (2012-present), and (3) were in English. Articles deemed *eligible* or *uncertain* at the title/abstract level were screened again during the full-text review.

After the initial round of qualitative interviews (section 3.2), we conducted a series of targeted searches to further investigate key themes and ideas surfaced by informants; this involved searches for evidence on the stability of patient preferences, social determinants of health (SDOH) and equity issues related to patient preferences, and additional searches related to preferences in health IT. We conducted a title/abstract review of 60 articles from peer-reviewed and grey literature, 40 of which advanced to full-text review. In total, we included 128 articles from our systematic searches and 40 articles from other targeted searches in our review (n=168).

Exhibit 2. PRISMA flow diagram for the literature review. Adapted from Page et al. (2021)[25]



3.2 Qualitative Data / Interviews

To supplement our literature review, we conducted a series of qualitative interviews and discussions, including: preliminary key informant interviews (KIIs), a patient perspective focus group, validation KIIs, and iterative engagement with the Outcomes and Objectives Workgroup.

Purposive and snowball sampling was used to identify candidate interviewees and focus group participants. The project team identified three relevant categories of perspectives *a priori*, including: patient/patient advocate, clinical information experts, and consumer technology developers. Specific recommendations were solicited from the Outcomes and Objectives Workgroup members. A total of 17 individuals participated in qualitative data collection activities. A summary of key informant and focus group participants is provided in **Table 2**. Additional details are provided in the sections below.

Table 2. Key Informants and Focus Group Participants by Stakeholder Perspective

Stakeholder Type	Number Participated
Preliminary KIIs	
Clinical Information Systems	**6**

Stakeholder Type	Number Participated
Consumer Technology	**1**
Focus Group	
Patient Advocacy	**2**
Patient-Centered Care	**1**
Validation KIIs	
Clinical Information Systems	**6**
Patient-Centered Care	**1**
Total	**17**

3.2.1 Preliminary Key Informant Interviews

We conducted a series of preliminary key informant interviews to explore potential domains and subdomains for inclusion in the taxonomy, surface implementation considerations, understand current evidence gaps, and solicit recommendations for additional hand searches of the literature. A total of seven (n=7) preliminary KIIs were conducted between September and October 2022, representing two stakeholder perspectives: experts in clinical information systems (n=6) and experts in consumer technology (n=1; see **Table 2**).

Semistructured discussion guides were developed for each stakeholder type to probe in areas tailored to their expertise. Interviews were approximately 45 minutes in duration, conducted via Zoom, and video and audio recorded. Insights garnered through the KIIs prompted supplemental searches of the literature to build out new concepts related to patient preferences.

3.2.2 Patient Perspective Focus Group

To ground our understanding of the types of preference information most important to patients and relevant to the PC CDS context from their perspective, we conducted a three-person focus group with leaders in patient-centered care and patient advocacy in October 2022. This discussion also explored participant perspectives on how patient preferences should be elicited and incorporated into PC CDS as well as the development of preference-informed care plans.

A semistructured discussion guide was developed to prompt discussion of priority preferences, current experiences related to preference elicitation and subsequent concordance with care plans, and recommendations for prioritizing preference information incorporation in PC CDS. The virtual focus group was approximately 90 minutes in duration, conducted via Zoom, and video and audio were recorded. Recommended resources were solicited, and insights shared during the focus group also prompted supplemental literature searches to further investigate points raised by participants.

3.2.3 Validation Key Informant Interviews

A series of key informant dyad interviews were conducted between December 2022 and February 2023, following preliminary development of the PC CDS Taxonomy of Patient Preferences. Distinct from the preliminary KIIs, the purpose of these interviews was to prompt review of the preliminary taxonomy, assess face validity, and solicit feedback to inform refinement. For these interviews, key informants were interviewed in pairs to prompt a richer discussion informed by social sensemaking. Validation informants represented the following stakeholder perspectives: clinical information systems representatives (n=6) and patient-centered care leader / patient advocate (n=1).

A semi-structured discussion guide was developed to solicit general feedback as well as probe in domains where concepts or structural organization was uncertain. Interviews were approximately 60 minutes in duration, conducted via Zoom, and video and audio recorded.

3.2.4 Outcomes and Objectives Workgroup Members

Workgroup members (**Table 1**) were engaged in validation efforts during monthly Workgroup meetings and through asynchronous feedback between November 2022 and February 2023. Targeted discussion questions regarding domain categorization, quality of content, utility of the taxonomy, and relevance to PC CDS were presented for their reflections and contributions.

3.3 Analysis and Synthesis

To assess the current landscape of patient preferences and develop the preliminary Taxonomy of Patient Preferences, we utilized thematic approaches in the analysis of KIIs, the focus group, and the literature. Relevant text excerpts were extracted from 128 articles from the literature review and coded for analysis. Text excerpts were hand coded by team members. Qualitative data from KIIs and the focus group were reviewed by team members to identify key themes within and across interviews.

The development of the taxonomy was a highly iterative process. In order to organize preferences within domains in the taxonomy, examples of related preferences identified in the literature were grouped together. These groups, which ultimately formed domains and subdomains, were developed both by examining how related preferences were described or explored in the literature, and by identifying themes surfaced in the literature and KIIs that tied specific preferences together. The taxonomy functioned as an organizing framework of different domains, subdomains, and examples of patient preferences that we identified in the literature, which were supplemented by informant remarks.

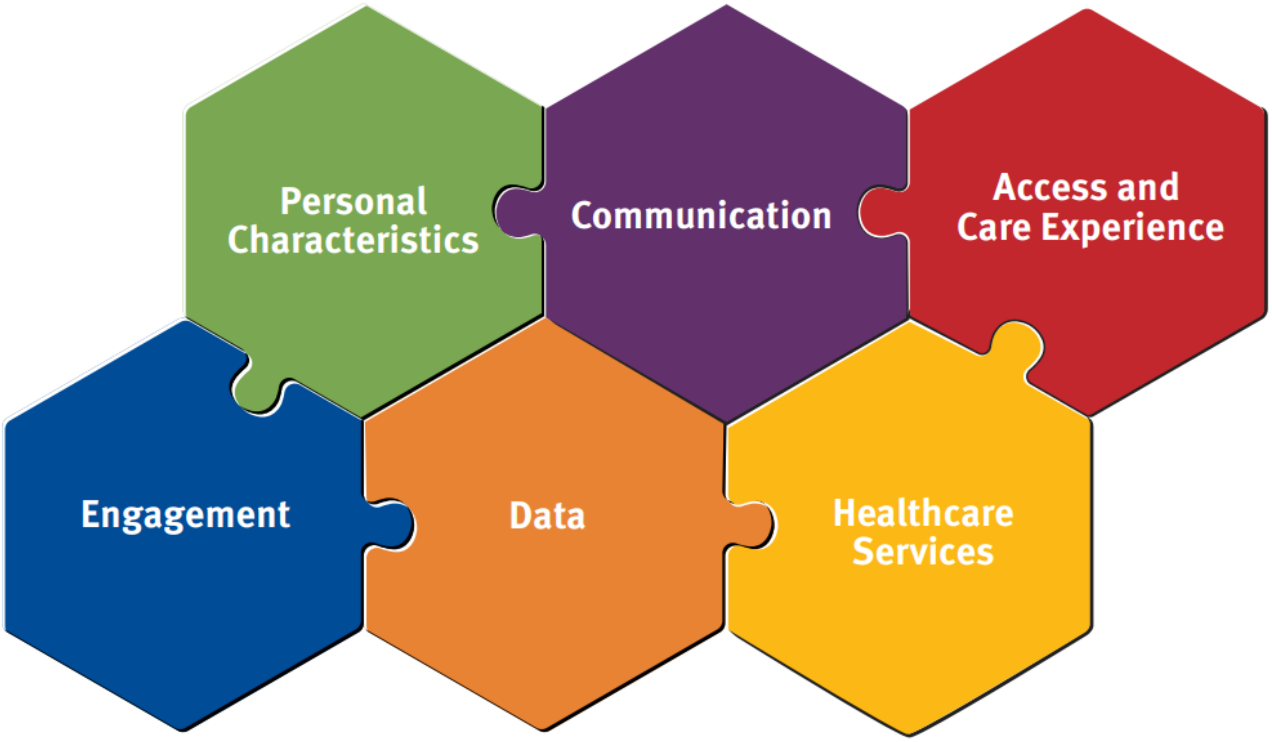
4. Results

Findings from the literature review and KIIs are presented below. We begin by presenting the taxonomy of patient preferences relevant to PC CDS. This includes discussion of each domain, its affiliated subdomains, and particular relevance to the PC CDS context. Considerations for operationalizing the taxonomy in real-world care settings are subsequently reviewed.

4.1 Taxonomy of Patient Preferences

As illustrated in **Exhibit 3**, a total of six preference domains relevant to PC CDS were identified: Personal Characteristics, Communication, Access and Care Experience, Engagement, Data, and Healthcare Services. **Table 3** presents each domain, associated subdomains (if applicable), example concepts, and a brief summary of particular relevance to the PC CDS context.

Exhibit 3. Domains of Patient Preferences



In real-world health interactions, several preferences may be relevant at the same point in time and, as such, there may be a significant amount of interplay among preference domains. Finally, we note that the taxonomy considers all preference types potentially relevant to PC CDS. We did not differentiate among the domains with respect to the potential of the preferences to impact processes or outcomes of care, nor did we differentiate on the feasibility or complexity of capturing the preferences integrating the use of the preferences into care processes. Practical considerations are reviewed in section 4.2 (Preference Implementation Considerations).

Table 3. Taxonomy of Patient Preferences Relevant to PC CDS

Domain	Subdomain (if applicable)	Example Concepts	Relevance to PC CDS
Personal Characteristics		• Title (e.g., Mr., Mrs., Mx., Dr., etc.) • Preferred name • Pronouns • Language	Acknowledging and honoring these preferences: • Allows for personalization of PC CDS-related communication with patients. • Demonstrates respect for the individual. • Builds trust between PC CDS provider and patient. • Increases likelihood that PC CDS will be considered, adopted and adhered to.
Communication[ᵻ]		• Timing (e.g., time of day, time in relation to clinical visit/care, etc.)[26-,27,28] • Mode (e.g., verbal, e-questionnaire, paper questionnaire, phone call, text, email, smartphone applications, patient portal)[29-,30,31,32,33,34,35,36,37,38] • Frequency (e.g., once a month, every 6 months)[39,40] • Use of communication tools (e.g., option to discontinue use of communication tools such as messaging with provider organizations through the patient portal)	Acknowledging and honoring these preferences: • Allows for naturally integrating PC CDS into patient life flow. • Facilitates engaging patients in a convenient and comfortable manner.
Access and Care Experience[ᵻ]	Accessibility	• Timeliness of care[39,41] • Location for clinical care[34,39,42-,43,44] • Location for health services (e.g., pharmacy, lab, imaging site)	Acknowledging and honoring these preferences: • 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[36,37,45-,46,47,48,49] • Self-scheduling (e.g., web/mobile appointment manager)[31,33,44] • Support access (e.g., secure messaging, Online chatting)[48] • Notifications and reminders (e.g., appointment reminders)[40,50]	

Domain	Subdomain (if applicable)	Example Concepts	Relevance to PC CDS
	Interpersonal / Relational	• Provider relationship (e.g., prior relationship, established trust, etc.)[33,51,52]	
	Provider / System	• Provider qualifications / skills (skills and qualifications of the clinician)[39,53,54] • Provider identity factors (e.g., gender-/racial-/ethnic identity, etc.)[42,54,55] • Access to spiritual/religious care (presence/use of prayer, clergy, talk of death)[56,57]	
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.)[29,48,58-,59,60,61,62,63,64,65,66,67,68] • 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”)[43,47,66,69-,70,71,72,73,74] • Tailored health data feedback and education[71,75]	Acknowledging and honoring these preferences: • 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.)[33,44,51,52,71,73,74,76-,77,78,79] • Inclusion of others in decisions (e.g., caregiver/family involvement)[43,69,71,80-,81,82] • Use of decision aids/tools[83]	
	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.)[34,36,37,40,44,47,50,66,77,84-,85,86] • Access to community of peer support (e.g., access to “patients like me” for support in managing one’s health condition)[28,47,87]	

Domain	Subdomain (if applicable)	Example Concepts	Relevance to PC CDS
Data	Access	• Patient access to their own data [50,51,75,76,85,88-,89,90] • Clinician access (e.g., coordination, health information exchange)[33,51,77,91-,92,93,94,95,96,97,98,99] • Designee access (e.g., family member)[93,97,98] • Research access (e.g., consent processes to share data for research)[28,89,91-,92,93,97,98,100-,101,102] • Level of access (e.g., whole record vs. granular control of sharing one's electronic health record)[51,77,91,93-,94,95,96,98,103,104] • Duration of access (e.g., expiration of access agreement)	Acknowledging and honoring these preferences: • 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)[41,85,103] • Research/clinical trial use (e.g., data used to research new ways to prevent cancer)[41,92,97,103,105] • Healthcare quality improvement (e.g., data used to evaluate how well your doctor provides care)[41,92,103]	
Healthcare Services	Prevention	• Receipt of preventive services, treatments, or programs[59] (e.g., vaccines)	Acknowledging and honoring these preferences: • Prioritizes care based on patient's preferences (e.g., goals, situation, values) over a clinician's.
	Receipt of results	• Type of tests (e.g., screening tests, genetic tests, follow-up) • Return of results (e.g., receipt of genetic testing results)[70]	
	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)[4,47,54,59,82,106-,107,108,109,110,111,112,113,114,115,116,117]	

Domain	Subdomain (if applicable)	Example Concepts	Relevance to PC CDS
		• Receipt of treatment (Preferences around whether or not a patient would like to receive or undergo a specific treatment option)[27]	
	Advance Care Directives	• Cardiopulmonary resuscitation (CPR)[81,118] • Intubation and ventilation[56,60,81,118]	
	Palliative care	• End stage treatment[56,116,119-,120,121] • Alignment with family preferences • Location (Location of death)[56,119]	

[†] Communication, Access and Care Experience, and Engagement are interrelated domains.

4.1.1 Personal Characteristics

The promotion of patient-centered care begins with respecting the individual who has contacted the delivery system in pursuit of services. Inclusive, identity-affirming care creates safe environments and builds trust between the patient and clinician.[122] "Seeing" patients for the individual humans they are and in a manner consistent with how they prefer to be seen is a basic—but often overlooked—form of respect that can be disarming and ultimately enable more accurate and efficient discovery of healthcare needs and goals.[123] Though not exhaustive, example identity components for capture and use include title, preferred name/nickname, pronouns, and language.

Several informants indicated that the elicitation and use of Personal Characteristic preferences should be considered the first step in building a safe space for patients, in which their dignity and humanity are affirmed. When PC CDS developers build in elicitation of Patient Characteristic preferences and then use them in the application's logic and presentation, patients may perceive this as a signal that the clinician and/or delivery system respects and "sees" them. Informants stated that PC CDS recommendations and interventions may be more likely to be considered, adopted, and adhered to by patients if identity-affirming preferences are built into the PC CDS interaction. They noted that lack of this step may decrease the effectiveness of PC CDS and the accurate capture of other preferences. Indeed, multiple informants cited this domain as the most important due to how affirmation can influence trust and patient willingness to be forthcoming about preferences related to care delivery. As an informant suggested, *"When you don't create that space for people where you're using their preferred name, their preferred pronouns, the language that they're comfortable in, then you're not going to be able to get the rest. That's just the first step at building a safe space for people."* Moreover, informants noted that provider organizations capturing these preferences but failing to honor them may indicate disrespect to the patient. Informants stated that as a result, patients may not trust the clinician administering PC CDS has their best interest in mind or will respect their preferences for their care and treatment.

> *"When you don't create that space for people where you're using their preferred name, their preferred pronouns, the language that they're comfortable in, then you're not going to be able to get the rest. That's just the first step at building a safe space for people."*
>
> – **Key Informant**, regarding the importance of respecting patient preferences surrounding personal characteristics

4.1.2 Communication

The Communication domain encompasses preferences around the mode and channel of information transfer between the patient and the clinician or care delivery system. Notably, this domain does not capture relational or interpersonal elements of communication, nor does it address information needs. These are classified under the Access and Care Experience domain and Engagement domain, respectively. The Communication domain is primarily focused on mechanisms for information exchange.

- **Timing** encompasses patient preferences around the timing of communication with their clinician or provider organization.[26] This may include preferences for the time of day they are contacted,[27] or the time of contact in relation to their clinical visit or receipt of care.[28]

- **Mode** encompasses preferences for the ways in which patients exchange information with the health system. This may include preferences for electronic versus paper documentation.[30,32,35-,36,37,38] For example, some patients may prefer verbal, face-to-face communication with their clinician, while others may prefer electronic communication through phone,[29,33] email, or text.[28,29,33]

- **Frequency** encompasses preferences for how often a patient would like to be contacted by their clinician or provider organization. For example, some patients may prefer to receive monthly communication from their clinician, while others may prefer to be contacted every 6 months.[29,39]

- **Use of communication tools** refers to preferences around whether patients would like to receive communication at all. Informants indicated that patients may have preferences around the use of communication tools and receipt of communication tools, noting that some patients may prefer to discontinue use of tools, such as patient portals, to communicate with their clinician.

Patient adherence to clinical recommendations and resultant care plans is enhanced when the mechanics of information transfer (i.e., communication) conforms to their expectations and preferences.[124,125] Patients respond best when the PC CDS communicates the right information, to the right person, in the right format, via the correct modality, and at the right time in their interaction with the CDS.[126,127]

The channel, mode, timing, and frequency of communication related to PC CDS or its results should be aligned with the patient's preferences. Some patients may be comfortable receiving messages with medical content via text or email, while others may prefer medical communication through secure messages on their patient portal or through the mail. These preferences may be shaped by any number of factors in a patient's life, including comfort and familiarity with technology, privacy concerns, and other preferences such as timing of delivery with respect to receipt of care.

Informants indicated that, in practice, there may be an interplay between a patient's timing, mode, and channel preferences. For example, a patient may state a preference to receive PC CDS content by phone from a healthcare provider outside of the patient's working hours. If the patient completes a symptom questionnaire in their patient portal, and the results of the PC CDS suggest a change in their patient medication, the clinician can use the patient's preferences to deliver the PC CDS at the appropriate time for the patient.

4.1.3 Access and Care Experience

For the purpose of this taxonomy, the Access and Care Experience domain encompasses the range of interactions that patients have with the healthcare system that may be influenced by PC CDS. This includes several aspects of care delivery, such as the ability to obtain timely appointments at nearby locations, access to support tools, and good interpersonal communication with healthcare providers.

By looking at various dimensions of access and care experience, it is possible to assess the extent to which patients are receiving care that is respectful of and responsive to their needs and preferences, thus providing a more complete picture of healthcare quality. Subdomains emerging from our review of the literature and discussions with key informants are provided below, together with considerations related to the PC CDS context:

- **Accessibility** encompasses preferences related to perceived timeliness[39,41] and geographic location of desired healthcare or treatment, such as preferences for the location of health-related services.[34,39,42-,43,44] Incorporation of accessibility preferences could be incorporated into PC CDS via filtering the recommended care options by location.

- **IT-enabled support tools** relate to preferences for access to and/or use of IT-based tools to support the patients' care. This may include telehealth,[36,37,45-,46,47,48,49] support tools (e.g., secure messaging or online chatting with the health system or provider),[48] self-scheduling tools (e.g., mobile appointment managers),[31,34,46] and notifications (e.g., appointment reminders).[35,50] As an example, informants suggested patients may receive PC CDS recommendations or use PC CDS tools within telehealth appointments, and decision support tools may push notifications to patients if they prefer the use of such tools.

- **Interpersonal/Relational** preferences focus on the relationship between the patient and clinician. For example, patients may prefer to receive care from a clinician with whom they have a prior relationship,[51,52] or established trust.[33] Patient experience with and trust in their clinicians can have a significant impact on their quality of care, comfort and willingness to express other preferences, and subsequent adoption of recommendations.[123,128] One informant offered, if a patient prefers emotionally supportive clinicians and feels unheard and invalidated, that patient may be less likely to trust and adhere to PC CDS recommendations.

- **Provider/System** preferences refer to clinician identity factors (e.g., gender identity, racial identity, ethnic identity),[42,55] provider skills or qualifications,[39,53,54] and access to spiritual care (e.g., chaplain, spiritual care team, use of prayer in care).[56,57] As part of eliciting patient preferences, goals, and values, patients indicate a preference for spiritual services as part of their care (e.g., when discussing palliative and/or end-of-life care). These preferences can be factored into PC CDS recommended care plans.

4.1.4 Engagement

We apply the definition provided by Carmen et al. whereby patient engagement refers to a continuum on which patients, families, their representatives, and health professionals work "in active partnership at various levels across the healthcare system… to improve health and healthcare."[129] At an individual level, patient engagement can be characterized by how much information flows between patient and clinician, how active a role the patient has in care decisions, and how involved the patient is in managing their own condition.[129] Subdomains identified in the literature and through KIIs are presented below, along with their specific relevance to PC CDS:

- **Information seeking** refers to preferences for receipt of information related to a patient's condition or care (e.g., test results, prognosis, treatment options), as well as the transfer of knowledge and skills needed to effectively self-advocate in shared decision making and enable self-management.[130,131] Key components include mode, content, and degree.[43,66] Patients may have preferences for the mode in which they receive information related to their care or condition, such as through verbal face-to-face or phone communication,[31] email, video, or the patient portal.[29,48,59,61-,62,63,64,65,66,67] Patient preferences for the mode of information seeking often depend on context, such as the condition or type of care for which the patient is seeking information. For example, patients may find use of the patient portal appropriate when seeking information about routine health needs or tests, whereas, for more serious health concerns and conditions, patients may prefer face-to-face or phone calls from their clinician.[68] Preferences around content refer to the ways in which information is presented to patient, such as through tailored education.[60,71,75] Degree refers to the level or amount of information a patient prefers to receive about their health condition, health state, or treatment options.[47,71,73,74] Some patients may prefer to receive detailed information about their health condition; for example, preferences for receiving all available results of genetic testing.[70] Others may prefer less information, opting to receive only the results of genetics tests for conditions that are preventable.[69,70] Information-seeking preferences, when combined with needs such as health literacy, are important in ensuring that PC CDS content reaches patients in a way that is accessible and optimizes understanding of how to interact with PC CDS and its results. While some patients may prefer to receive extensive information about their health condition, treatment options, or other PC CDS content, others may prefer more limited information. Informants cautioned against always taking a more-is-better approach to information sharing, which may have diminishing returns in a shared decision-making context—as aptly described by Herbert Simon "…. information consumes the attention of its recipients. Hence, a wealth of information creates a poverty of attention."[132] The mode, content, and volume of PC CDS messages should thus align with patients' stated information-seeking preferences to avoid overwhelming patients, while ensuring patients receive enough information to understand, evaluate, and follow (as desired) PC CDS recommendations.

- **Decision-making** preferences address how health and care decisions should be made, as well as whom should be involved. Components include patient degree of involvement in decision making,[33,44,51,52,71-,72,73,74,76-,77,78,79] whether other individuals must be included—such as caregivers or family members[43,69,71,80-,81,82]—and the use of decisions aids or tools to support decisions.[83] Patient degree of involvement refers to preferences around the level of responsibility in healthcare decision making a patient prefers for themselves and their clinician. For example, patients may prefer for their clinician to be solely responsible for making decisions about their course of care;[71] to serve as a member of their care team, sharing the decision making responsibility with their clinician;[71,76,77] or to take on the primary responsibility of making health decisions for themselves. Use in care to support decision making is one of the four defining elements of PC CDS. Accordingly, understanding patient preferences specific to health-related decision making were overwhelmingly considered to be among the most important for PC CDS. These preferences should govern the role PC CDS plays in shaping individual care decisions and the way it interacts with any complementary preferences the patient may have for the decision making process.[69]

Exhibit 4: Case example – developing EHR capability for supporting collection and documentation of patient preferences

Desai et al. developed a central location in the EHR at Memorial Sloan Kettering Cancer Center which contained key information about the patient, including values, goals, and preferences. Additionally, clinicians were given a structured template to collect patient goals and preferences. When clinicians had ready access to information regarding who the patient preferred to be involved in decision making, how much information the patient preferred to receive, and what type of information the patient preferred to receive, they used this information to guide the way care was delivered.

- **Self-management** involves preferences related to supporting the patient's ability to manage symptoms and treatments, as well as the physical, psychological, and social consequences of their condition. This includes use of self-management tools, such as personal health records (PHRs) or health applications,[34,36,44,77,84-,85,86] as well as access to a community of peers for social support in managing one's health condition.[28,47,87] Preferred uses of self-management tools included filling prescriptions,[37] tracking symptoms,[66] accessing health information and guidance,[50] accessing additional resources,[47] and completing health assessments to monitor their health.[47,50] Knowledge of these preferences could meaningfully inform the types of PC CDS tools and applications most likely to have strong patient uptake with subsequent adherence to recommendations.

Informants universally noted Engagement as one of the most important preference domains in the PC CDS context. Elicitation of information seeking, decision making, and self-management preferences provide meaningful context and insights into a patient's degree of health literacy, self-efficacy, and self-determination—providing a useful frame for interpreting how a patient is engaging and/or would like to engage with PC CDS and its recommendations. Furthermore, informants noted that Engagement preferences are likely to be assumed and not explicitly solicited by healthcare providers or teams, which may frustrate or alienate patients when assumed incorrectly, subsequently hindering the effectiveness of PC CDS.

As CDS tools support clinicians in the delivery of information, awareness of decision-making and information-seeking preferences can aid in the delivery of CDS that is patient centered. **Exhibit 4** provides a case example of an approach that could serve as a promising model for PC CDS developers.

4.1.5 Data

With the increased availability of electronic health data—combined with Federal regulations that obligate providers to make data available—preferences around data access and use are important to consider.[133-,134,9] The Data domain encompasses patient preferences related to which individuals and entities can access their personal health data and how those individuals and entities may use those data:

- **Access** refers to preferences regarding what individuals or entities may access an individual patient's health data and to what degree. Patients may have preferences around where, when, and how they can access their own health data.[50,51,75,76,85,88-,89,90] For example, some patients may prefer to receive paper after-visit summaries that provide them with access to health data relevant to a specific health condition or healthcare experience. Other patients may prefer the ability to access their full medical record through their patient portal. Patients may also have preferences around whether and which providers have access to their health information.[33,77,91-,92,93,94,95,96,97,98,99] For example, one study found that patients generally prefer certain members of their health team, such as nurses, residents, medical students, and operational healthcare staff, have limited or no access to their personal health data. However, patients generally preferred that their personal clinician have access to their full medical record.[51] Similarly, patients may have preferences around whether and which designees or caretakers[93,97,98] and researchers or research institutions may access their health data.[28,89,91-,92,93,97,98,100-,101,102] Patients may prefer individuals or entities have varying levels of access to their personal health data. For example, patients may prefer to grant access only to specific parts of their health record, rather than access to the entire record.[51,77,91,93,94,103,104] In fact, several studies have found that patients prefer granular control of their health information, desiring the ability to share or redact specific pieces of health information with various recipients, including clinicians and other health systems staff.[95,96,98] Several studies have found that a majority of patients chose not to limit access to their personal health data for healthcare providers.[93,135] However, in certain situations, some patients may prefer to restrict access to health information based on the type of provider and information shared.[96,136] For example, in a study aimed at designing a system that allowed patients to restrict access to sensitive health information—such as mental health, sexually transmitted disease, and substance use, type of clinician or staff, and for specific patient ages—43% of patients chose to limit access for at least one provider.[91,95,96,98] Patients most commonly preferred restricting access to their health information for nonclinical staff members and nurses, and retaining access for their personal physicians.[95,137] Key informants also noted that a patient with capacity should be able to designate decision making. A patient who lacks capacity should have a designee who can access the patient's health data to make medical decisions in the interest of the patient. The proxy should adhere to the patient's previously declared wishes and preferences, as information from the proxy may be used to inform PC CDS interventions.
- **Data Use** preferences focus on the intended purpose behind accessing personal health data. Patients may prefer to grant differing levels and durations of data access as a function of

intended use, spanning personal care,[41,85,103] research or clinical trials,[41,92,97,103,105] and clinical quality improvement.[41,92,103] Patient preferences around data access and use for research may have implications for the recommendations made by PC CDS tools. For example, studies examining patient preferences around data access and use have found that most patients identify at least one piece of health information in their record that they would not want to share with researchers. In cases where patients have only the option to share the entire medical record, or not share at all, patients may be inclined to withhold all medical information.[101,102] Informants further raised the importance and difficulty in honoring a preference reliably such that a patient's preference for not revealing sensitive information could be intelligently propagated throughout the system without the user needing to understand all potential downstream impacts related to those topics. Currently, data-sharing consent is unable to mine a patient's record for all instances of sensitive information mentioned. Thus, informants noted how a solution is required for patient preferences and consent constraints to exist at a topic/term level. Optimal methods for segmenting data in the electronic record is an evolving domain.

4.1.6 Healthcare services

The Healthcare services domain refers to patient preferences related to care planning, as well as the health consequences that result from any care or care refusal around 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.[137] Subdomains identified in the literature and through KIIs are presented below, followed by discussion of relevance to the PC CDS context:

- **Preventive care** refers to preferences regarding the receipt of preventive services such as vaccines, preventive mastectomy, etc.[59,106]
- **Receipt of results** refers to preferences related to the receipt of diagnostic tests, such as blood work or magnetic resonance imaging (MRI) studies.[70]
- **Treatment** preferences focus on the type of treatment or intervention—primarily related to the actions or ways of treating, or not treating, a patient or condition medically or surgically—and the management and care to prevent, cure, ameliorate, or slow the progression of a condition.[4,47,54,107-,108,109,110,111,112,113,114,115,116,117] For example, when considering treatment options in mental healthcare, patients may have preferences for medication or psychotherapy, for one medication over another, or for one type of psychotherapy over another.[56] Across conditions, treatment preferences may be influenced by a number of treatment-related factors, such as effectiveness of the treatment method, associated side effects, and impact on quality of life.[109,117] For example, in one study, older patients with multimorbidity preferred not to receive, or to stop medication, for a condition due to symptoms associated with that treatment.[116]
- **Advance care directives** encompasses preferences related to end-of-life care and advance care directives, including preferences for receiving CPR,[81,118] intubation, tube feeding, medications, and ventilation.[56,60,81,118]

- **Palliative care** includes preferences specific to the supportive and medical care given during the time surrounding death. Examples of palliative care preferences include end-stage treatment,[56,116,119-,120,121] location of death,[56,119] and alignment of care with family preferences.

Informants noted that clinicians may initiate care planning without an understanding of the patient's preferences for treatment. In this scenario, it is unlikely that patients will receive their preferred treatment options, as a patient's goals for their healthcare may differ from those of the care team. PC CDS may also recommend a treatment or diagnostic test that a patient does not want for various reasons. Thus, eliciting and honoring healthcare services preferences is vital to a PC CDS approach that is truly patient centered. PC CDS rules and recommendations should automatically account for the previously defined preferences relevant to a current decision.

Several informants stated that nothing epitomizes the need to understand and respect patient decision making more than resuscitation and palliative care preferences. For example, if PC CDS algorithms are designed to detect physiological decline and trigger responses at a certain threshold, the algorithm would need to be aware of the patient's preferences for resuscitation, intubation, and cardiopulmonary resuscitation (CPR) to provide the appropriate response. According to key informants, resuscitation and palliative care preferences are considered some of the most formal and well-developed preferences in terms of elicitation and implementation. Medical orders for life sustaining treatment (MOLST) and physician orders for life sustaining treatment (POLST) offer robust processes for capturing resuscitation preferences within healthcare organizations, although challenges remain in operationalization in community-based care settings.

Preferences related to healthcare services can be complex and highly context-dependent, and often are addressed through the process of SDM. A more in-depth discussion of these components, as well as the relationship between SDM and PC CDS, is explored in the Outcomes and Objectives Workgroup companion product *Framework for Understanding the Role of PC CDS in Supporting Shared Decision Making*.

4.2 Preference Implementation Considerations

The taxonomy presented above focused on the typology of patient preferences most salient to the PC CDS context. These were complemented by discussions with key informants who brought professional- and lived-experience perspectives to bear on a formative evidentiary landscape. The creation of the taxonomy explicitly excluded consideration of feasibility or usability (i.e., actionability/honorability) constraints in service of defining all possible preference types that may influence patient engagement/experience with and/or benefit from PC CDS. Informants suggested that having an awareness of the existence of preferences—rather than assuming the preferences do not exist—and considering the potential role that those preferences play, even generally, may prove useful in certain circumstances. At the same time, the literature and key informants surfaced a number of considerations and challenges that will need to be addressed in order to effectively operationalize the taxonomy in PC CDS. These issues fall into the following categories: stability, collection, use, and quality measurement of patient preferences. Below, we describe each category in turn, beginning with our current knowledge on the topic followed by a discussion of the identified gaps and challenges.

4.2.1 Stability of Patient Preferences

Preference stability has been found to vary as a function of patient characteristics, health condition, symptom severity, and prognosis.[6] Such dynamism is further influenced by stage of life course or patient journey, as well as other contextual factors.[6] Below, we summarize what is known about patient-preference stability, what gaps remain, and any implications for implementing preference elicitation and use in the context of PC CDS.

Current knowledge regarding the stability of patient preferences

It has been documented that preferences may vary across individuals as a function of how identity and circumstance come together with human experience to shape how individuals view healthcare, well-being, and the roles of different actors in shaping them.[6] We expect differences in preferences across individuals given the numerous ways these factors can combine and manifest. Indeed, this assumption is foundational to patient-centered care. The challenge in this case is not so much the variability in preferences *across* individuals as it is the variability of preferences *within* individuals and the role of context in shaping them.[6]

Exhibit 5: Major life events that may trigger changes in patients' preferences

- Change in Marital Status
- Having Children
- Changes in Employment
- Changes in Health Status
- Changes in Caregiver Status

For patient preferences to be effectively operationalized in PC CDS, it is crucial to understand the factors that influence stability and variability of these preferences. Those implementing patient preferences in PC CDS cannot necessarily assume that a preference captured at a different time or in a different context applies in the current context. Several informants emphasized how multi-dimensional drivers of preference variability could include the patient's age or life stage, including SDOH, patient/health journey stage (e.g., their emotional readiness to make a decision or a change in their capacity or desire to seek more information), proximity of non-health life events (e.g., child's wedding), or other factors that may influence a patient's preferences at a particular moment. For example, an individual's treatment preferences for a specific health condition and risk tolerance may considerably vary based on their prognosis or progression of disease.[138,139] That is, a risk averse patient may prefer not to undergo therapy for which there may be serious side effects when they have an optimistic prognosis, but they may change their preference for therapy if their prognosis worsens.

Relative stability of preferences, along with their drivers, may vary by preference domain. For example, engagement preferences have been shown to be dynamic based on patient-reported health status, type of health condition/illness, and patient characteristics such as age, gender identity, education level, and health literacy/numeracy.[79] In contrast, some types of preferences may remain relatively stable over time. For example, a patient's preferred name may not change over the course of the patient's life, or a patient's preferred title or salutation may change only once. A systematic review found considerable variability in the stability of patient end-of-life preferences.[140] One explanation for this variability is the influence of translating stated preferences, often assessed in research settings, to applied care settings.

Certain events may also trigger changes in a patient's preference. For example, as noted in **Exhibit 5**, major life events such as marriage, having children, changes in employment, health, and caregiver status can trigger changes in patients' preferences. More specifically, moving may trigger a change in preferred pharmacy, a change in employment may alter preferred timing or method of contact, or onset of a serious illness may change preferences for in-network provider.

Key informants also voiced that, at the time of preference elicitation, patients may not fully realize the implications of their preferences. Thus, a patient's preference may change upon implementation or impending implementation of their stated preference. As such, organizations administering PC CDS may ask patients to review and update preferences on a regular basis to ensure that documented preferences are accurate.

Conditional and consequent preferences

In addition to observed instability within preference types, preference dependencies across types were also highlighted in the literature and interviews. Referred to as "preference hierarchies" by one informant, these refer to the way in which patients may assign more or less importance to certain preference types as a function of one or more other types of preferences. Depending on context, preferences otherwise deemed important may be downplayed or willingly forgone in order to honor a more highly prioritized preference.[141] Sometimes these preferences appear in the form of tradeoffs. For example, a patient may prefer a clinician whose gender identity aligns with their own but select a clinician of a different gender identity in order to see an in-network provider with shorter wait times. Notably, this phenomenon may hold true for some patients and not others, suggesting there may be significant, or at least unpredictable, variability in preference hierarchies across patients. **Table 4** presents a non-exhaustive list of examples of conditional preferences identified in the literature, and from key informants.

Key informants also identified preferences that exist as a direct result of patient characteristics, termed "consequent preferences," such as religion. A patient's religious identity is not a preference itself. However, preferences may arise as a result of the patient's religious identity. For example, a patient who identifies as Jehovah's Witness may prefer not to receive blood transfusions, and a patient who identifies as Jewish may have dietary preferences.

Table 4. Conditional Preferences by Preference Domain

Preference Domain	Subdomain	Conditional Preference Examples
Access and Care Experience	Provider/System	• Insurance coverage • Wait times

Preference Domain	Subdomain	Conditional Preference Examples
		• Healthcare environment (e.g., cleanliness of the healthcare facility, condition of medical equipment, etc.)
	Interpersonal/Relationship	• Clinician personality characteristics (e.g., bedside manner)
Engagement	Self-Management	• Modifiability (the ability of a patient to modify their personal health data within their personal health record)
Healthcare Services	Treatment and Palliative Care	• Longevity • Level of dis/comfort • Side effects • Level of independence • Religious needs/affiliation

Current gaps and challenges related to the stability of patient preferences

A paucity of literature examines patient preferences in the applied care context, with most documented patient preference-assessments occurring in research settings.[39,93,140] However, preference reporting in research settings can be meaningfully different from the clinical setting, which impacts the translatability of research-based learnings. As a result, literature establishing an empirical foundation for how to navigate preference dynamism in a care delivery context is limited. Approaches to assessing preferences in research settings may result in stated preferences that would not align with preferences in real-world settings.[142-,143,144] For example, when asked about their preferences for the inclusion of others in treatment decisions, patients may state a preference for deciding on their own in a low-stakes research setting. However, when faced with a serious health concern in a real-world setting, the same patient may prefer the support and involvement of a family member to help make the decision. Future research is needed in real-world settings to accurately assess the stability of patient preferences and inform the optimal frequency and appropriate timing for reassessing patient preferences.

4.2.2 Collection/Capture of Patient Preferences

Collection of patient preferences as part of routine workflow increases the likelihood that the preference information will be able to support PC CDS. According to informants, standardized methods of preference elicitation and capture will help to assure that elicited preferences are valid and operational across domains and patients. Despite significant discussion of the importance of preferences and the need to capture preferences in the healthcare workflow, the literature reviewed as part of this report revealed limited information on standardized, structured collection of preference information in real-world settings.

Current knowledge on the collection of patient preferences

Informants noted that education level, health literacy and numeracy, digital literacy, access to technology, and access to health information are important factors for patients in the elicitation of their preferences. These challenges often are related to threats to validity and inadequacy of current tools and methods for preference elicitation. We explore these issues below.

Validity of Captured Patient Preferences. A number of factors may influence preference validity, or the alignment of a stated preference with a patient's true preference. For example, patients themselves may not have a full understanding or awareness of their preferences. Stated preferences may be influenced by how information is presented to patients, as well as other external or personal factors, such as a patient's health literacy.[21] Health literacy and numeracy may influence a patient's understanding of their health condition and the matter for which they are providing a preference, impacting the validity of elicited preferences. Furthermore, a patient's level of health literacy and numeracy may influence their understanding of PC CDS recommendations and messages, just as they have been found to influence a patient's desired and actual levels of engagement in their care.[72,145] In unfamiliar, complex, or emotionally taxing health situations, a patient may have poorly formed or non-existent preferences. In these cases, a patient's stated preferences may be influenced by clinicians, family members, and others.[6]

Key informants noted that, in some cases, patients may understand their preferences but may not voice them, due to a lack of trust or comfort in sharing with their provider. In situations in which patients both know and are willing to share their preferences with clinicians, the lack of best practices for the collection of patient preferences may influence preference validity. In addition to the lack of standardized tools for collecting preferences, the infrastructure for storing preferences upon collection is limited, and clinicians may lack the education to successfully elicit and document preferences in care.[81]

Tools and Methods for Capturing Preferences. Patient preferences are not currently widely captured as part of care delivery. While general consensus is that preferences should be assessed prior to or early in the care process and regularly re-assessed to capture changes in patient preference over time, few standard approaches exist for preference collection.[6] Among existing approaches, standardized tools for capturing patient preferences have been developed and implemented for some preferences in the Engagement and Healthcare services domains (**Table 5**).[71,73,146,147]

Table 5. Tools and Methods for Patient Preference Collection

Tool/Method	Description	Domain	Subdomain(s)	Notes
PPET13[71]	Eight-item survey	Engagement	• Information seeking • Decision making • Self-management	
Dowie Approach[73]	Approach in which patients are asked directly about preferences	Engagement	• Information seeking • Decision making	

Tool/Method	Description	Domain	Subdomain(s)	Notes
Degner Scale[73]		Engagement	- Decision making	
Autonomy Preference Index[148]	Two scales used widely in general healthcare	Engagement	- Decision making - Information seeking	Limited in ability to capture full scope of preferences due to one-way flow of information[74]
Control Preference Scale[149]	Measures how patients with life-threatening illness make treatment decisions	Engagement	- Decision making	Proven to be clinically relevant, valid and reliable; captures only degree of decision making preferences[149]
Problem-Solving Decision-Making Scale[150]	Validated scale that measures preferred role of decision making through hypothetical health situations	Engagement	- Decision making	
Outcome Prioritization Tool[116]	Conversation support tool utilizing movable buttons that represent health outcomes on sliding scale of 0 to 100	Healthcare services	- Palliative care	
POLST[147]	Standardized form that converts patient preferences into medical orders	Healthcare services	- Advance care directives - Palliative care	
Code Order[81]	Form that documents patient preferences for the response of medical staff when a patient's heart and breathing stop	Healthcare services	- Advance care directives	

In research settings, preferences have been collected using a variety of methods, including structured or semistructured interviews, focus groups, surveys, web-based tools such as patient decision aids, card sorts, individual assessment questions integrated into patient intake forms/questionnaires, and unstructured conversations between patients and clinicians. However, discussion of the most appropriate methods and best practices for preference collection operationally is largely missing from the literature. Furthermore, key informant interviews revealed an overall lack of information on preference-elicitation methods for specific domains and few examples of preference implementation. A systematic review examined methodological concerns related to patient preferences and found overall low validity and reliability of preference-elicitation methods.[21] In studies found to have incorporated strong methodology, tension often existed between application of these methods and feasibility/scalability of their real-world use (e.g., cognitive burden on patients).

Other Considerations. Key informants noted that the entity and process of eliciting preferences—be they human or automated—need to be trustworthy to promote the validity of patients' stated preferences. Informants additionally emphasized how trust from both patients and clinicians is important in the effective operationalization of patient preferences. Overall, patients want to be seen and heard by their care team as unique individuals. Facilitating a patient's comfort in sharing preferences can benefit the patient, clinician, and healthcare system (e.g., greater adherence to medication schedules), in addition to impacting the success of the patient-provider relationship. To the extent that choices are available and actionable, preferences for seeking care that match the patient's beliefs, needs, and values may be central to helping them feel comfortable and trusting the care organization.

Informants highlighted several key challenges in collecting patient preferences, including clinician time restraints to updating patient information and potential lack of training to capture references in a sensitive manner. Key informants further noted how building trust and comfort between the patient and the individual eliciting preferences may be an important factor in the collection of accurate, valid patient preferences. Cultural concordance between patient and clinician and explaining why preference information is being captured may aid clinicians in building trust with patients.

Key informants described that EHRs currently have tools that can explicitly capture preferred language, gender identity, and patient goals. While additional preference information may be captured in clinical documentation features in the EHR, such data are often unstructured and difficult to operationalize for PC CDS workflows. Furthermore, informants observed that, while some patient preferences may lend themselves to systematic capture as discrete, structured data, many preferences require an unstructured format to capture context and nuance (e.g., in relation to patient goals). Such data might be helpful to a clinician reading the record but would be hard to incorporate into PC CDS. Given advancements in natural language processing (NLP), some of these barriers can be overcome in settings in which NLP can be implemented.[151] Furthermore, for some preference domains, efforts have been made to standardize patient-preference data. For example, some end-of-life and decision-making preferences may be represented with LOINC codes under specific circumstances.[152,153]

Finally, according to key informants, challenges around systematically locating patient preferences in the EHR hinder the ability of clinical teams to ensure preferences are properly documented and updated during subsequent visits. The ability to analyze, interpret, and implement preferences from unstructured data may be limited in care settings due to the resource intensity required to manually extract relevant information. For a PC CDS application to include the patient's preferences in its logic, the application must be able to determine that the relevant preference was captured and also have the ability to include/integrate the stored preference value. The PC CDS application also must "understand" the shared preference value. For example, for a language preference to be correctly operationalized, the application would need to know that “ENG” = English and “MAN” = Mandarin, etc. As the use of preferences in PC CDS increases, the use of standards to represent preference values will become increasingly important.

Current gaps and challenges in the collection of patient preferences

Although a wide variety of methods have been used to collect preferences, consensus on which methods are most appropriate is missing from the literature. Furthermore, standardized tools for the collection of patient preferences exist for only a limited number of specific preferences. Questions remain around how and when preferences that require capture through unstructured data should be incorporated into the care process and included as part of the patient’s record.

4.2.3 Use of (Honoring) Patient Preferences

In practice, PC CDS can best support patients in health-related decisions if preferences are incorporated within proper workflows and according to consensus standards for preference implementation. To date, few existing recommendations or best practices for efficiently and effectively implementing patient preferences in healthcare workflows have been identified. Key considerations are discussed below.

Current knowledge on the use of patient preferences

Preference information should be used if it is captured, when possible. Given the challenges in collecting patient preferences, preference information may be collected at one point in care but not used in subsequent care interactions. If preference information is captured but not used by the PC CDS tool appropriately, frustration and mistrust between the patient and clinician or care team may result. For example, if the patient has expressed a preference to receive alert messages via text but an alert message is sent via email, the patient might lose trust in the application and the health system. However, technical limitations may present challenges to honoring all preferences in PC CDS. For example, if the patient’s preferred language is not English but not all PC CDS content has been translated into the patient’s preferred language, honoring this language preference may not be feasible. Such situations, although unavoidable at times, are undesirable and put the patient’s trust with the PC CDS application at risk. A key informant noted that recognizing and acknowledging patients’ preferences by incorporating them into clinical conversations *even when they cannot be honored*, would be a step forward in promoting patient-centered care.

Patient preferences also may not reflect the choices that are available, but patients are likely to incorrectly perceive that their preference is actionable if they consider it reasonable.[6] For example, a patient may prefer to use a kiosk in a doctor’s office to complete a Patient Health Questionnaire on Depression (PHQ-9) assessment, but the health system may not have kiosks, and may request that patients complete PHQ-9 forms at home. According to informants, preferences around clinician qualifications/skills and clinician identity factors may be more challenging to honor—whether locally or at scale—and careful consideration should be given before incorporating them into PC CDS tools. One informant additionally identified the necessity to have clinicians’ characteristics on file if patients are asked about their preferences around identity factors, which raises questions around clinicians' comfort in revealing some or all those details about themselves. Other challenges may include staff turnover, high labor costs for institutions, and adding more work for clinicians, as noted by the informant.

Several informants further cautioned that patient communication preferences ultimately will require some reconciliation with system policies and regulatory requirements. One example provided included the case where patients must be contacted urgently as part of rapid public health contact tracing program in which confirmed communications are needed to limit spread of reportable infectious agents and to comply with Federal law. Under these conditions, patient preferences may not align with regulatory or policy requirements.

Preference prioritization considerations. Given the current state of preference implementation in PC CDS, and the considerations outlined above, capturing and incorporating every preference for all patients is not currently feasible. In order to identify preference domains that may be prioritized for implementation, informants were asked which preference domains they believed were most important. Key informants noted that the ways in which patients prioritize preference types is unique to the individual, and the relative impact of how patient preferences manifest in care is different across individuals.

One method of prioritization might be to consider the expected impact on patient care experience in combination with the feasibility of operationalizing the preferences, as well as the actionability of honoring them in the current health system. When asked to prioritize domains by anticipated impact on care, as well as feasibility and actionability, three domains were highlighted by key informants: Personal Characteristics, Engagement, and Healthcare services. Additional exploration should be pursued with patients and clinicians to further validate this preliminary prioritization and determine how consistently these same priorities filter to the top across varying communities served.

Current gaps and challenges in the use of patient preferences

Informants reported that, ideally, preferences should be used both in human interactions between patient and provider or care team and in automated interactions. However, informants noted that the infrastructure for preference collection and use in these interactions is lacking. Informants raised the need for improved PC CDS algorithms and systems that use patient information more effectively to provide clinicians with patient preferences at the right time and in the right place to improve clinician understanding of the relevance of preferences within patient encounters.

4.2.4 Measuring Concordance with Patient Preferences

Current knowledge on measurement of preference concordance

Existing literature on the extent to which care aligns with the patient's stated preferences primarily focuses on treatment preferences, measuring treatment-preference concordance, and decision quality. While individual investigators have operationalized preference-concordant care in specific research studies, the field lacks consensus on a "gold standard" or optimal method for its measurement.[118,154,155]

As noted in **Table 6**, preference concordance is often assessed by measuring treatment-preference/-value concordance and/or decision quality.

Table 6. Measurement of Preference Concordance

Measure Concept	Definition
Treatment-preference/ -value concordance	"The association between patients' preferences concerning health outcomes and/or medical treatments, and treatment intention or treatment undergone."[7]
Decision quality	"The extent to which treatments reflect the considered preferences of well-informed patients and are implemented."[7]

A systematic review found that treatment-preference concordance is most commonly calculated using a relationship between preferences for outcomes/attributes (independent variable) and treatment-preference/intention directly assessed (dependent variable).[7] According to Robbins et al. and Morrison, "the ultimate realization of patient-centered end-of-life care is concordance between stated preferences and the care delivered."[156,157] Accordingly, in the context of PC CDS—where patients and clinicians are selecting specific treatment plans based on evidence-based options and elicitation of patient preferences—a measure of treatment-preference concordance is an important measure concept and has the potential to be a proximal outcome measure of the degree to which evidence-based, patient-centered care was achieved.

For the second measure concept—decision quality—two key factors are (1) the extent to which patients are informed about the evidence on clinically appropriate options and outcomes and (2) how well the treatment aligns with the patients' goals or preferences (value concordance).[7] Decision quality is assessed using decision quality instruments (DQIs), which measure the knowledge of and the extent to which patients receive treatments that match their goals. DQIs include multiple choice knowledge items that are used to create a knowledge score and items to assess goals of patients and treatment received, which are ultimately used to create a concordance score reflecting the percentage of patients who receive treatments that match their goals.[158] The usability of DQIs is limited, as the tools are decision-specific (e.g., health condition-specific). Within the context of PC CDS, decision quality could provide insight as to whether patients receive and understand PC CDS messaging around recommended treatment options, and how well these options align with their preferences.

Another measure used to assess preference implementation is decisional regret, measured with the five-item Decision Regret Scale, which assesses the level of distress or remorse a patient feels about a health decision that has been made.[159,160] Informants indicated that measures of decisional regret may be useful in PC CDS, where high decision regret may indicate the need for the clinician administering the PC CDS to revisit other treatment options. While important, this would reflect a mitigation strategy following unsuccessful delivery of preference-concordant care and, as such, should be measured in complement to one or more of the above-described concordance measures.

Current gaps and challenges in the measurement of patient preferences

A paucity of information exists in the literature on measuring the extent to which patient preferences, when collected, are honored. Despite increased reporting of value concordance in the literature, standardization of how concordance is measured, defined, and calculated is lacking.[7,161] Furthermore, the way value concordance is reported varies significantly.[159] This variation suggests the need for future work to establish standards for measuring and reporting concordance. Measures of decision quality may offer another avenue for assessment. However, tools for evaluating decision quality are not applicable across health conditions or decisions, suggesting the need for future work to establish standards for measuring decision quality under context-independent settings.

In addition, how these types of measures should be used is questionable. If patient-centered care is care that is responsive to patient needs, values, and preferences, the field needs to grapple with questions related to who defines patient need and how discordance between patient needs and preferences should be reconciled and still meet the definition of patient-centered care. These and other challenging questions related to the role of measurement remain to be explored.

5. Discussion

Elicitation and subsequent use of patient preferences as part of PC CDS could play an important role in the broader transformation of our health system as a source of patient-centered, high-value care. Given our broad definition of patient preferences as relevant to all potential opportunities for patient choice with respect to their interactions with healthcare, a comprehensive accounting of all preference types could be quite large, with certain types applying to different healthcare interactions. To provide a more actionable resource for the field, we developed a Taxonomy of Patient Preferences relevant to the PC CDS context. This work surfaced a number of implementation considerations and gaps in knowledge and/or consensus that must be addressed to incorporate patient preferences into PC CDS. These considerations are provided in the sections below and include: the immaturity of the field, the need for multistakeholder involvement, and system-/patient-level implementation considerations. Our findings outlined above combined with these considerations culminate in a set of guiding principles and a research agenda for addressing remaining knowledge/consensus gaps.

5.1 The Field of Patient Preferences is Relatively Nascent

While the importance of eliciting and incorporating patient preferences as a signature feature of patient-centered care has been widely acknowledged for decades,[10] our understanding of how we can and should operationalize this in a systematic way that lends itself to quality management and policy incentivization remains limited, and this is particularly true for the context of PC CDS. Most of the current literature identified in our search describes efforts to elicit and use patient-preference information in a research context, with a particular focus on treatment preferences. The evidence base identifies associations between preferences not related to treatment and outcomes such as patient knowledge, experience, and satisfaction,[53,71,102,112] but an empirical understanding of relative impact and implementation best practices remains elusive. Achieving patient preference adoption as part of PC CDS at scale will require standardized terms, definitions, elicitation methods, and quality measures; a more nuanced understanding of hierarchical dimensions and granularity related to types of preferences; and consensus on best practices for embedding preferences in PC CDS tools and applications.

5.2 Coordination of PC CDS Stakeholders is Needed

The PC CDS design and implementation workflow is necessarily a multistakeholder enterprise, bringing diverse end users (patients, clinicians, healthcare provider organizations, etc.) together with health IT, EHR, and PC CDS application developers. Our literature review and KIIs suggest that technology to capture patient-preference information, particularly in structured formats, is limited, and development is occurring in isolated settings using “homegrown” approaches. Dedicated and, ideally, coordinated effort is needed to establish robust and scalable health IT solutions. This may involve enhancements to clinician-facing or nonclinical staff-facing technology at provider organizations since healthcare personnel may act as intermediaries for the capture of preference data. Enhancements to patient-facing technology to capture preferences directly from patients may also be needed. These changes could manifest as enhancements to the broader health IT architecture, where preference information is retrievable by PC CDS tools, or they could involve changes directly to PC CDS applications, where preference data are incorporated as part of their logic or as part of communicating with the PC CDS target. Any modifications to technology would need to be coupled with complementary updates to workflows for eliciting preference information either from healthcare personnel or patients directly. The broad scope of inputs and interacting elements underscores the need for multistakeholder communication and coordination as necessary components for successful incorporation of patient-preference information as part of PC CDS. Further, workflows need to standardize preference-related concepts to allow the use of preference information across multiple systems.

5.3 Considerations for Implementing Patient Preferences in PC CDS

The aim of implementing PC CDS, particularly in regard to using patient-preference information, should be to operationalize care that sees patients in their entirety. The tools and levers available to drive the movement toward health systems capable of delivering patient-centered care typically involve fitting solutions that reduce patients to a sum of their “parts” (e.g., sociodemographic factors, risk factors, etc.). This presents a key challenge for implementing PC CDS that operationalizes care in a manner that considers patients as wholistic entities.

In exploring patient preferences, we uncovered the many ways preferences intersect and interact with the PC CDS context as part of the patient's health journey. For example, conditional and consequent preferences showcase complex dependencies as described above. Key informants also highlighted the heterogeneity in how patients perceive the relative importance, relevance, and actionability of different types of preferences. It is how these factors come together and interact with other elements of the human experience that determines their degree of influence and impact. Understanding nuance is critical if our steps to operationalize this knowledge are likely to lead to large-scale outcomes improvement.

At the same time, scientific questions—particularly those that drive comparative effectiveness research and evaluations of PC CDS—require specificity and the ability to tease apart cause, effect, and sources of bias in pursuit of generalizable knowledge. Below, we delve into key considerations for implementing patient preferences in PC CDS, highlighting some of the tensions uncovered when moving between patient and system levels.

Patient-level considerations

At a patient level, the ability to elicit timely, accurate, and valid preference information is dependent on a range of factors. Formation of preferences and health-related decision making has been found to be associated with a range of motivational factors, cognitive factors, individual differences, emotion and mood, and health beliefs.[145] The authors of that study further identified health literacy, numeracy, and locus of control as the most influential factors in preference awareness and formation.

In addition to the internal factors described above, it is important to consider the impact of inequities on preference opportunity and formation. What represents a choice or preference-sensitive decision for some may not be a choice for all patients, given life circumstance. Broader structural barriers and other contextual factors may constrain decision making and influence whether certain outcomes are more realistic for some patients than others. For example, a patient may prefer a particular treatment option recommended by their clinician; however, the otherwise preferred treatment option may be cost prohibitive due to inadequacy of insurance coverage. Sensitivity to these situations will be important to embed in PC CDS and its mechanisms of elicitation and application.

Adding to the complexity of patient-preference information, individual preferences can differ depending on context and the interaction of multiple aspects that play a role in constructing preferences. As a result, within an individual, preferences may vary as a function of time, life course and/or journey, and patient journey.[6,51,93,104,162] Also, individuals weigh the relative importance or influence of specific preferences differently.[6] Taken together, the unique drivers of preference formation and dynamism suggest the need for individuality-affirming care. This raises a number of considerations related to the feasibility of designing and implementing PC CDS with the flexibility to accommodate variance in perceived importance of specific preferences as well as their potential to change over time.

Not only should preferences be formed by patients, but they also should be accurately conveyed to clinicians if they are to create preference-concordant care plans. This latter step is heavily influenced by the interpersonal patient-provider relationship and the ability to establish environments conducive to trust. Vulnerability and power differentials are two key factors in the concept of trust in healthcare, which is usually defined as a set of expectations that the patient has of their provider related to appropriate services and care, non-exploitation, genuine interest in patient welfare, and transparent disclosure of all information.[163] Recognition of these two factors has motivated a focus on culturally safe care. Cultural safety seeks to achieve better care through being aware of difference, considering power relationships, implementing reflective practice, and allowing the patient to determine whether a clinical encounter is safe.[164] In the absence of safe and supportive environments, patients may be less likely to share—or share honestly—their preferences.

Another consideration related to the discussion of preferences between patient and clinician is the relative ability to honor and act on patient preferences. Explicit elicitation of preferences deemed important by the patient that are not followed by incorporation and/or responsive action risks damaging provider trustworthiness and long-term patient engagement in care. Developers and end users will need to collaborate in determining the specific preference domains that should be captured by given PC CDS tools with potential actionability as one of the inclusion criteria.

Systems-level considerations

Several systems-level considerations are also relevant to the implementation of preference information in PC CDS. Despite their importance in advancing patient-centered care, consensus terminologies and information models—as well as standard approaches for capture and use of patient preferences in PC CDS—are currently lacking. Scalability and measurability will depend critically on the ability to resolve knowledge gaps and introduce standards. Absent this, a scalable PC CDS application designed to make use of patient preferences must either be implemented in a setting in which those preferences are captured, or the application must also be designed to function under conditions of unknown preferences.

Scalable implementation of patient preferences in PC CDS also presents technical and workflow challenges. Technical challenges may include the ability of health IT systems to capture, update, and consider preferences in the delivery of PC CDS. Moreover, these capabilities are likely to vary across health systems, which could exacerbate inequities among communities served by resource-limited providers. Consensus best practices for incorporating elicitation and application of patient preferences as part of clinical and PC CDS workflows have yet to be identified, and the literature addressing this topic is limited. For this reason, promising practices are emerging in isolation. Preferences may be collected at various touchpoints in the clinical workflow and by various types of healthcare providers or staff. This may lead to wide variability in how patient preferences are operationalized across settings and subsequent challenges for measuring quality and impact in the context of PC CDS at scale.

5.4 Principles for Implementing Patient Preferences

The literature review and key informant interviews offer insights into the nascent field of incorporating patient-preference information in PC CDS. This practice can be a reinforcing contributor to the broader health system transformation toward patient-centered, high-value care. Elicitation and subsequent use of patient preferences in PC CDS is one way clinicians and patients can work to ensure health-related decisions and care delivery are responsive to and concordant with patient preferences. In developing policies and practices for systems seeking to codify the incorporation of patient preferences in PC CDS, we offer the following guiding principles:

- **Equity-Oriented:** The implementation of patient preferences as part of PC CDS should bolster adoption of equity-oriented healthcare (EOHC). Fundamentally, EOHC is care that is trauma- and violence-informed, culturally safe, and contextually tailored. EOHC emphasizes creating a safe and respectful environment that counters the frequent mismatches between dominant approaches to care and the needs of people who are most affected by inequities.[165] Such supportive experiences can lead to greater comfort in care-seeking and confidence that care received will be helpful, in turn creating a sense of mutual respect and trust. In the context of PC CDS, this means developing approaches for elicitation and use that recognize: (1) what may be a choice for some is not necessarily a choice for all, (2) there may be differences in the ability to honor patient preferences depending on individual circumstance, and (3) the manner in which preferences are elicited and applied should be intentionally designed to avoid re-traumatization.

- **Patient-Centered:** It is important to recognize that individual patients may prioritize types of preferences differently, and that their specific preferences for a given choice (e.g., type of treatment, information seeking) may vary over time, life/patient journey stage, and context. PC CDS applications that embed features to elicit, confirm, and apply patient preference information must be designed to accommodate these variances if they are to be truly patient-centered. Developers should account for the process and timing of preference reassessment within PC CDS tools, while clinicians should remain aware of the need to reassess patient preferences over the course of a patient's health journey and account for this process within their workflows.

- **Impactful:** Preference types incorporated into PC CDS should be prioritized by their potential to influence health-related decisions and the degree to which they are actionable. Elicitation of preferences perceived by patients as relatively trivial in the absence of influential preferences may decrease a patient's confidence that the clinician's recommendations are fit to their goals and needs. Further, elicitation of preferences that may be influential from the patient's perspective but are not actionable on the part of the provider may jeopardize trust and, in some cases, risk re-traumatization. PC CDS and health IT developers need to work closely with clinicians and the communities they serve to ensure tools and technologies are designed to capture preferences that are actionable in the context of healthcare and influential in decision making from the patient perspective.

- **Co-Design:** Co-design is a process that draws on the shared creativity and knowledge of developers and those not trained in PC CDS development working together. To this end, attention must be given to involving end users and ensuring that their input as experts through experience is central to the design process and that their specific needs are understood and met. Co-design offers an important way to ensure that new PC CDS tools are usable, acceptable, and tailored toward the patients and clinicians they aim to support. Engagement and collaboration among PC CDS application developers, health IT vendors, healthcare providers, and patients is needed to enhance tools with respect to intuitive design, usability, and integration within clinician workflows.

5.5 Research Agenda

The importance of patient preference information as a necessary component of patient-centered care has been described in the sections above. The literature review and KIIs presented herein revealed meaningful gaps in the current research landscape as it relates to patient preference information and PC CDS. **Table 7** outlines potential priorities for filling knowledge gaps and advancing the integration of patient preferences in PC CDS. Focus areas for research include: importance and impact, validity and reliability, generalizability (relevant to scaling), implementation, information systems, and measurement.

Table 7. Research Needed to Address Knowledge Gaps Related to Use of Patient Preferences in PC CDS

Focus Area	Research Topics
Importance and Impact	• Which preferences or types of preferences do patients consider to be the most important and/or influential? To what degree do these rankings differ by patient characteristics (e.g., sociodemographic factors, stage of patient journey, condition severity, etc.)? • What preference domains/subdomains have the largest impact on patient outcomes (experience, engagement, outcomes, equity, etc.)? • What is the impact on the patient of collecting preference information that is not actionable or possible to honor? How does this impact trust, recommendation adherence, and patient continuity in care? • What is the impact on the patient of collecting preference information on topics where the patient does not perceive a choice (versus other patients who may have the privilege of choice)? What, if any, impact does this have on inequities in care experience, engagement, and outcomes?
Validity and Reliability	• What are the elements of a standardized definition of patient preferences, as distinct from patient goals, values, and needs? • To what degree do preferences vary across patient characteristics (e.g., sociodemographic factors, stage of patient journey, condition severity, etc.)? • How do preferences change over time by domain, subdomain, and context (i.e., knowledge, condition, stage of patient journey, etc.)? • What factors influence preference change, and how predictive of preference change are these factors?
Generalizability	• How consistently do different patients prioritize types of preferences in the same way? How might inability to generalize across patients impact technical and workflow solutions for the incorporation of patient preferences in PC CDS?
Implementation	• What are best practices for eliciting preference information in clinical settings? • What is the optimal timing and setting for reassessment of preferences? How often do preferences need to be updated? • What workflows optimize the capture of patient preference by setting and context? In what ways do they vary by preference domain/subdomain? • How does tailoring or personalization of a PC CDS tool based on patient preferences impact a participant's understanding of their healthcare and outcomes? • How do outcomes differ when participants are presented with information in different formats (e.g., scenario-based interactive tool versus traditional text-based tool)? • What, if any, legal protections need to be considered so that preferences cannot be used to discriminate against them (e.g., by health insurance providers, homeowner's insurance policies that pay out upon death, etc.)?
Information Systems	• What is the best way to operationalize the standard definition of patient preferences in clinical information systems and workflows (e.g., for elicitation)?

Focus Area	Research Topics
	• What is the best way to store key patient preferences in clinical information systems? • What preference domains/sub-domains should be prioritized for standardization and why? • What algorithms and other system tools are needed to ensure preference information can be retrieved on demand by patients and clinicians for incorporation in PC CDS? • What is the best way to ensure patient preference information can be made available for use by native and integrated third-party PC CDS tools in a vendor-neutral, interoperable manner? • To what extent could FHIR be leveraged to develop patient preference profiles (e.g., application of "use contexts" to accommodate context-dependent preferences)?
Measurement	• What is the role of quality and performance measurement as it relates to the elicitation and subsequent use of patient preference information? • How should metrics that assess care plan concordance with patient preferences be developed and used? • What is the best way to measure if patient preferences are being considered in clinical decision making (e.g., by preference concordance or decision quality) and having an impact on patient outcomes? ○ What is the best way to measure if this is being done well (i.e., how do we measure if this is happening? how do we measure if this is happening with the desired level of quality)? • What are the elements of a standardized, operationalizable definition for preference concordance (or equivalent construct) to facilitate quality measurement at scale? • Can measures of preference concordance (or equivalent construct) be developed as context-independent or must they be tailored to specific contexts (e.g., condition-specific)?

5.6 Strengths and Limitations

To our knowledge, this is the first comprehensive examination of the role of patient preferences in PC CDS. Despite broad consensus that incorporation of patient preferences is a necessary component of patient-centered care, a paucity of literature examines precisely what types of preferences should be prioritized and how their capture and subsequent use should be operationalized. Based on a series of scoping literature searches and KIIs representing diverse perspectives staged to inform development and validation, our taxonomy has the potential to help clarify important domains and subdomains of patient preferences relevant to PC CDS. In addition, it offers guidance to developers and end users alike to inform design and implementation considerations.

Notable limitations of this work include the immaturity of the field of patient preferences and the lack of standardized terms and definitions for key concepts. Most of the evidence base related to patient preferences has been in the context of drug/device development, selection of preferred treatment plans in the context of risk and uncertainty, and advance care planning. Taxonomy domains/subdomains relevant to these contexts demonstrate greater specificity and clarity with respect to definitions and examples. A number of preference domains, however, were identified through limited discussion in the literature, in turn necessitating a greater reliance on KIIs to elucidate meaning and examples. More research is needed to strengthen our empirical understanding of domain/subdomain relevance and potential for impact. Finally, as noted above, the boundaries between related concepts—such as goals, values, beliefs, and preferences—are fuzzy. The field currently lacks consensus definitions and consistent terminology usage. Therefore, it is possible that our literature searches missed conceptually relevant articles due to variations in terminology. Iterative searches with varied string combinations were employed to mitigate this risk, but it is possible that some relevant articles were not identified.

Given the nascency of our understanding related to operationalizing patient preferences in the context of PC CDS, this Taxonomy of Patient Preferences offers an initial glimpse into the process of bringing care that is aware of, informed by, and responsive to patient preferences to fruition. It offers a starting point on which future work may build as we develop more nuanced understandings of preferences and best practices related to implementation begin to accumulate.

6. Conclusion

Patient preferences are an essential component of the patient voice and including their elicitation and subsequent use in PC CDS can be an important contributor to the delivery of patient-centered care. Recent proliferation of patient-facing technologies—as well as tools designed to capture and incorporate consumer preferences in adjacent fields—offer a fertile landscape for the exploration of patient preference information in the context of PC CDS, including identification of relevant types of preferences, as well as consideration of key factors relevant to practical implementation. The Taxonomy of Patient Preferences presented in this report provides an organizing framework for the types of patient preference information most relevant to PC CDS. It may be used by developers of PC CDS as a starting point for identifying the types of preference information that can be factored into PC CDS tools. The taxonomy also can be used by healthcare provider organizations as they develop workflows to capture patient preference information and configure PC CDS tools to support care. This report also highlights a set of guiding principles that should frame the development of PC CDS tools that capture and subsequently use patient preference information. Finally, this report outlines remaining knowledge gaps and a research agenda to enhance the field's understanding of incorporating patient preferences into PC CDS in operational settings.

7. Appendix

Table A1. Research Questions

Research Questions
1. What categories and types of patient preferences are currently in use in PC CDS tools/ applications?
2. How are patient preferences currently operationalized in PC CDS tools/applications?

Table A2. Key Search Terms

Search terms for PubMed Search		
CDS Search:	*EHR Search:*	*Patient Portal Search:*
(Decision Support Systems, Clinical[mesh] OR "clinical decision support"[tiab])	((“electronic health records”[MeSH] OR “electronic health record*”[tiab] OR “electronic medical records”[tiab] OR “medical records systems, computerized”[MeSH])	((“patient portal”[tiab])
AND	AND	
(“patient preference”[MeSH] OR “patient preference*”[tw] OR “client preference*”[tw] OR “consumer preference*”[tw]) OR (“family preference*”[tw]) OR (“caregiver preference*”[tw])	(“patient preference”[MeSH] OR “patient preference*”[tw] OR “client preference*”[tw] OR “consumer preference*”[tw]) OR (“family preference*”[tw]) OR (“caregiver preference*”[tw])	(“patient preference”[MeSH] OR “patient preference*”[tw] OR “client preference*”[tw] OR “consumer preference*”[tw])
AND		
2012 - present		

Table A3. Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
• Published in past 10 years (2012-2022) • Published in English language	• Does not include human patients (e.g., veterinary studies; algorithms or clinician-focused tools that do not involve some element of patient interaction)

References

[1] Agency for Healthcare Research and Quality. Patient-Centered Clinical Decision Support. Accessed February 3, 2023. Retrieved from https://cds.ahrq.gov/cdsic/patientcentered

[2] Dullabh P, Heaney-Huls K, Lobach DF, et al. The technical landscape for patient-centered CDS: progress, gaps, and challenges. *J Am Med Inform Assoc*. 2022;29(6):1101-1105. doi:10.1093/jamia/ocac029

[3] Marcial LH, Richardson JE, Lasater B, et al. The Imperative for Patient-Centered Clinical Decision Support. *EGEMS (Wash DC)*. 2018;6(1):12. Published 2018 May 30. doi:10.5334/egems.259

[4] Brennan PF, Strombom I. Improving health care by understanding patient preferences: the role of computer technology. *J Am Med Inform Assoc*. 1998;5(3):257-262. doi:10.1136/jamia.1998.0050257

[5] FDA. Patient Preference Information (PPI) in Medical Device Decision-Making. Accessed February 3, 2023. Retrieved from https://www.fda.gov/about-fda/cdrh-patient-science-and-engagement-program/patient-preference-information-ppi-medical-device-decision-making

[6] Street RL Jr, Elwyn G, Epstein RM. Patient preferences and healthcare outcomes: an ecological perspective. *Expert Rev Pharmacoecon Outcomes Res.* 2012 Apr;12(2):167-80. doi:10.1586/erp.12.3.

[7] Winn K, Ozanne E, Sepucha K. Measuring patient-centered care: An updated systematic review of how studies define and report concordance between patients' preferences and medical treatments. *Patient Educ Couns.* 2015;98(7):811-821. doi:10.1016/j.pec.2015.03.012.

[8] Agency for Healthcare Research and Quality. Clinical Decision Support. Accessed February 3, 2023. Retrieved from https://www.ahrq.gov/cpi/about/otherwebsites/clinical-decision-support/index.html

[9] U.S. Congress. Patient Protection and Affordable Care Act, H.R. 3590. Public Law 111- 148. 111th Cong., March 23, 2010.

[10] Institute of Medicine. *Crossing The Quality Chasm: A New Health System for the 21st Century.* Washington DC: National Academy Press; 2001.

[11] Tzelepis F, Sanson-Fisher RW, Zucca AC, Fradgley EA. Measuring the quality of patient-centered care: why patient-reported measures are critical to reliable assessment. *Patient Prefer Adherence.* 2015;9:831-5. Published 2015 Jun 24. doi:10.2147/PPA.S81975.

[12] NEJM Catalyst. What Is Patient-Centered Care? Accessed February 3, 2023. Retrieved from: https://catalyst.nejm.org/doi/full/10.1056/CAT.17.0559

[13] Dullabh P, Sandberg SF, Heaney-Huls K, et al. Challenges and opportunities for advancing patient-centered clinical decision support: findings from a horizon scan. *J Am Med Inform Assoc*. 2022;29(7):1233-1243. doi:10.1093/jamia/ocac059

[14] Agency for HealthCare Research and Quality. Six Domains of Healthcare. Accessed February 3, 2023. Retrieved from https://www.ahrq.gov/talkingquality/measures/six-domains.html

[15] Nundy S, Cooper LA, Mate KS. The Quintuple Aim for Health Care Improvement: A New Imperative to Advance Health Equity. *JAMA.* 2022;327(6):521–522. doi:10.1001/jama.2021.25181

[16] Scarlet S, Jonhson-Mann CN, Hoffman MR, Horn C, Shipper III, ES. Respect for whose autonomy? Communicating with patients regarding trainee involvement. 2018 Aug 1. In: Bulletin of the American College of Surgeons [Internet].

[17] Losi S, Berra CCF, Fornengo R, Pitocco D, Biricolti G, Federici MO. The role of patient preferences in adherence to treatment in chronic disease: a narrative review. *Drug Target Insights.* 2021;15:13-20. Published 2021 Nov 8. doi:10.33393/dti.2021.2342

[18] Cheraghi-Sohi S, Bower P, Mead N, McDonald R, Whalley D, Roland M. What are the key attributes of primary care for patients? Building a conceptual 'map' of patient preferences. *Health Expect.* 2006;9(3):275-284. doi: 10.1111/j.1369-7625.2006.00395.x.

[19] Ruland CM. Improving patient outcomes by including patient preferences in nursing care. *Proc AMIA Symp.* 1998:448-52.

[20] Bastemeijer CM, Voogt L, van Ewijk JP, Hazelzet JA. What do patient values and preferences mean? A taxonomy based on a systematic review of qualitative papers. *Patient Educ Couns.* 2017100(5):871-881. doi:10.1016/j.pec.2016.12.019.

[21] Janssens R, Huys I, van Overbeeke E, et al. Opportunities and challenges for the inclusion of patient preferences in the medical product life cycle: a systematic review. *BMC Med Inform Decis Mak.* 2019;19(1):189. Published 2019 Oct 4. doi:10.1186/s12911-019-0875-z.

[22] Elwyn G, Frosch D, Rollnick S. Dual equipoise shared decision making: definitions for decision and behaviour support interventions. *Implementation Sci.* 2009;4(75). https://doi.org/10.1186/1748-5908-4-75

[23] Adaptation of Brennan PF, Strombom I. Improving health care by understanding patient preferences: the role of computer technology. *J Am Med Inform Assoc*. 1998;5(3):257-262. doi:10.1136/jamia.1998.0050257

[24] FDA. Focus Area: Patient and Consumer Preferences and Perspectives. Accessed February 3, 2023. Retrieved from https://www.fda.gov/science-research/focus-areas-regulatory-science-report/focus-area-patient-and-consumer-preferences-and-perspectives

[25] Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi:10.1136/bmj.n71. For more information, visit: http://www.prisma-statement.org/

[26] Simón M, Colussi G, Sommer J, Bruchanski L, Plazzotta F. Designing a Patient-Centered Notification System into a PHR. *Stud Health Technol Inform*. 2020;270:931-935. doi:10.3233/SHTI200298.

[27] Butler JM, Gibson B, Lewis L, et al. Patient-centered care and the electronic health record: exploring functionality and gaps. *JAMIA Open.* 2020;3(3):360-368. Published 2020 Oct 29. doi:10.1093/jamiaopen/ooaa044.

[28] Coathup V, Finlay T, Teare HJ, et al. Making the most of the waiting room: Electronic patient engagement, a mixed methods study. *Digit Health*. 2018;4:2055207617751304. Published 2018 Jan 10. doi:10.1177/2055207617751304

[29] Tashkandi E, BaAbdullah M, Zeeneldin A, et al. Optimizing the Communication with Cancer Patients During the COVID-19 Pandemic: Patient Perspectives. *Patient Prefer Adherence*. 2020;14:1205-1212. Published 2020 Jul 20. doi:10.2147/PPA.S263022

[30] Pincus T, Castrejon I, Riad M, Obreja E, Lewis C, Krogh NS. Reliability, Feasibility, and Patient Acceptance of an Electronic Version of a Multidimensional Health Assessment Questionnaire for Routine Rheumatology Care: Validation and Patient Preference Study. *JMIR Form Res*. 2020;4(5):e15815. Published 2020 May 27. doi:10.2196/15815

[31] Ramsey A, Lanzo E, Huston-Paterson H, Tomaszewski K, Trent M. Increasing Patient Portal Usage: Preliminary Outcomes From the MyChart Genius Project. *J Adolesc Health*. 2018;62(1):29-35. doi:10.1016/j.jadohealth.2017.08.029

[32] Langerman SD, Badolato GM, Goyal MK. Attitudes Toward Electronic Sexual Health Assessments Among Adolescents in the Emergency Department. *Pediatr Emerg Care*. 2021;37(12):e1164-e1167. doi:10.1097/PEC.0000000000001947

[33] Yarborough BJH, Stumbo SP. Patient perspectives on acceptability of, and implementation preferences for, use of electronic health records and machine learning to identify suicide risk. *Gen Hosp Psychiatry*. 2021;70:31-37. doi:10.1016/j.genhosppsych.2021.02.008

[34] Wentink MM, Prieto E, de Kloet AJ, Vliet Vlieland TPM, Meesters JJL. The patient perspective on the use of information and communication technologies and e-health in rehabilitation. *Disabil Rehabil Assist Technol*. 2018;13(7):620-625. doi:10.1080/17483107.2017.1358302

[35] SR Health. Patient Communication Preferences in 2021. Accessed February 3, 2023. Retrieved from https://f.hubspotusercontent30.net/hubfs/2332687/SRH-Patient-Communication-Preferences-2021-survey.pdf

[36] Alexander KE, Ogle T, Hoberg H, Linley L, Bradford N. Patient preferences for using technology in communication about symptoms post hospital discharge. *BMC Health Serv Res*. 2021;21(1):141. Published 2021 Feb 15. doi:10.1186/s12913-021-06119-7

[37] Lee JL, Choudhry NK, Wu AW, Matlin OS, Brennan TA, Shrank WH. Patient Use of Email, Facebook, and Physician Websites to Communicate with Physicians: A National Online Survey of Retail Pharmacy Users. *J Gen Intern Med*. 2016;31(1):45-51. doi:10.1007/s11606-015-3374-7

[38] Garcia I, Portugal C, Chu LH, Kawatkar AA. Response rates of three modes of survey administration and survey preferences of rheumatoid arthritis patients. *Arthritis Care Res (Hoboken)*. 2014;66(3):364-370. doi:10.1002/acr.22125

[39] Mühlbacher AC, Bethge S, Reed SD, Schulman KA. Patient Preferences for Features of Health Care Delivery Systems: A Discrete Choice Experiment. *Health Serv Res*. 2016;51(2):704-727. doi:10.1111/1475-6773.12345

[40] MyPreferences Functionality. PossibleNOW. Accessed February 3, 2023. Retrieved from https://www.possiblenow.com/features-functionality#functionality.

[41] Lim D, Norman R, Robinson S. Consumer preference to utilise a mobile health app: A stated preference experiment. *PLoS One.* 2020;15(2):e0229546. Published 2020 Feb 21. doi: 10.1371/journal.pone.0229546.

[42] Liu J, Li C, Xu J, Wu H. A patient-oriented clinical decision support system for CRC risk assessment and preventative care. *BMC Med Inform Decis Mak.* 2018;18(Suppl 5):118. Published 2018 Dec 7. doi: 10.1186/s12911-018-0691-x.

[43] Lambooij MS, Veldwijk J, van Gils PF, Suijkerbuijk AWM, Struijs JN. Trading patients' choice in providers for quality of maternity care? A discrete choice experiment amongst pregnant women. *PLoS One*. 2020;15(4):e0232098. Published 2020 Apr 24. doi:10.1371/journal.pone.0232098

[44] Dirmaier J, Härter M, Weymann N. A tailored, dialogue-based health communication application for patients with chronic low back pain: study protocol of a randomised controlled trial. *BMC Med Inform Decis Mak*. 2013;13:66. Published 2013 Jun 14. doi:10.1186/1472-6947-13-66

[45] Yue H, Mail V, DiSalvo M, Borba C, Piechniczek-Buczek J, Yule AM. Patient Preferences for Patient Portal-Based Telepsychiatry in a Safety Net Hospital Setting During COVID-19: Cross-sectional Study. *JMIR Form Res*. 2022;6(1):e33697. Published 2022 Jan 26. doi:10.2196/33697

[46] Silhavy P, Silhavy R, Prokopova Z. Patients' perspective of the design of provider-patients electronic communication services. *Int J Environ Res Public Health*. 2014;11(6):6231-6245. Published 2014 Jun 12. doi:10.3390/ijerph110606231

[47] Richards R, Kinnersley P, Brain K, Staffurth J, Wood F. The Preferences of Patients With Cancer Regarding Apps to Help Meet Their Illness-Related Information Needs: Qualitative Interview Study. *JMIR Mhealth Uhealth*. 2019;7(7):e14187. Published 2019 Jul 31. doi:10.2196/14187

[48] Ospina-Pinillos L, Davenport TA, Navarro-Mancilla AA, et al. Involving End Users in Adapting a Spanish Version of a Web-Based Mental Health Clinic for Young People in Colombia: Exploratory Study Using Participatory Design Methodologies. *JMIR Ment Health*. 2020;7(2):e15914. Published 2020 Feb 8. doi:10.2196/15914

[49] Lau G, Ho J, Lin S, Yeoh K, Wan T, Hodgkinson M. Patient and clinician perspectives of an integrated electronic medication prescribing and dispensing system: A qualitative study at a multisite Australian hospital network. *Health Inf Manag*. 2019;48(1):12-23. doi:10.1177/1833358317720601

[50] Lehmann J, Buhl P, Giesinger JM, et al. Using the Computer-based Health Evaluation System (CHES) to Support Self-management of Symptoms and Functional Health: Evaluation of Hematological Patient Use of a Web-Based Patient Portal. *J Med Internet Res*. 2021;23(6):e26022. Published 2021 Jun 8. doi:10.2196/26022

[51] Sanyer O, Butler JM, Fortenberry K, Webb-Allen T, Ose D. Information sharing via electronic health records in team-based care: the patient perspective. *Fam Pract*. 2021;38(4):468-472. doi:10.1093/fampra/cmaa145

[52] Farin E, Gramm L, Schmidt E. Taking into account patients' communication preferences: instrument development and results in chronic back pain patients. *Patient Educ Couns.* 2012;86(1):41-8. doi:10.1016/j.pec.2011.04.012.

[53] Foster MM, Earl PE, Haines TP, Mitchell GK. Unravelling the concept of consumer preference: implications for health policy and optimal planning in primary care. *Health Policy.* 2010;97(2-3):105-12. doi:10.1016/j.healthpol.2010.04.005.

[54] Swift JK, Mullins RH, Penix EA, Roth KL, Trusty WT. The importance of listening to patient preferences when making mental health care decisions. *World Psychiatry.* 2021;20(3):316-317. doi: https://doi.org/10.1002/wps.20912

[55] Chekijian S, Kinsman J, Taylor RA, et al. Association between patient-physician gender concordance and patient experience scores. Is there gender bias?. *Am J Emerg Med*. 2021;45:476-482. doi:10.1016/j.ajem.2020.09.090

[56] Litzelman DK, Inui TS, Schmitt-Wendholt KM, et al. Clarifying Values and Preferences for Care Near the End of Life: The Role of a New Lay Workforce. *J Community Health*. 2017;42(5):926-934. doi:10.1007/s10900-017-0336-5

[57] Armstrong MJ, Mullens CD. Value Assessment at the Point-of-care: Incorporating Patient Values Throughout Care Delivery and a Draft Taxonomy of Patient Values. *Value in Health.* 2017; 20(2)292-295. doi:10.1016/j.jval.2016.11.008.

[58] Woolen SA, Kazerooni EA, Steenburg SD, et al. Optimizing Electronic Release of Imaging Results through an Online Patient Portal. *Radiology*. 2019;290(1):136-143. doi:10.1148/radiol.2018180883

[59] W Seidel R, Pardo KA, A Estabrooks P, et al. Beginning a patient-centered approach in the design of a diabetes prevention program. *Int J Environ Res Public Health*. 2014;11(2):2003-2013. Published 2014 Feb 14. doi:10.3390/ijerph110202003

[60] Monchis M, Martin C, DiDiodato G. Evaluation of a program using a physician assistant and an electronic patient-provider communication tool to facilitate discussions about goals of care in older adults in hospital: a pilot study. *CMAJ Open*. 2020;8(3):E577-E584. Published 2020 Sep 14. doi:10.9778/cmajo.20200022

[61] Glasgow RE, Kwan BM, Matlock DD. Realizing the full potential of precision health: The need to include patient-reported health behavior, mental health, social determinants, and patient preferences data. *J Clin Transl Sci*. 2018;2(3):183-185. doi:10.1017/cts.2018.31

[62] Federman AD, Sanchez-Munoz A, Jandorf L, Salmon C, Wolf MS, Kannry J. Patient and clinician perspectives on the outpatient after-visit summary: a qualitative study to inform improvements in visit summary design. *J Am Med Inform Assoc*. 2017;24(e1):e61-e68. doi:10.1093/jamia/ocw106

[63] LaRocque JR, Davis CL, Tan TP, D'Amico FJ, Merenstein DJ. Patient Preferences for Receiving Reports of Test Results. *J Am Board Fam Med*. 2015;28(6):759-766. doi:10.3122/jabfm.2015.06.150030

[64] Choudhry A, Hong J, Chong K, et al. Patients' preferences for biopsy result notification in an era of electronic messaging methods. *JAMA Dermatol*. 2015;151(5):513-521. doi:10.1001/jamadermatol.2014.5634

[65] Caggiano NM, Fegley MW, Matullo KS. Patients' preferences regarding the delivery of health care in a hand surgical practice. *Hand (NY)*. 2015;10(4):785-788. doi:10.1007/s11552-015-9763-x

[66] Gefen R, Bruno MA, Abujudeh HH. Online Portals: Gateway to Patient-Centered Radiology. *AJR Am J Roentgenol*. 2017;209(5):987-991. doi:10.2214/AJR.17.18291

[67] Wildenbos GA, Horenberg F, Jaspers M, Peute L, Sent D. How do patients value and prioritize patient portal functionalities and usage factors? A conjoint analysis study with chronically ill patients. *BMC Med Inform Decis Mak*. 2018;18(1):108. Published 2018 Nov 21. doi:10.1186/s12911-018-0708-5

[68] Bruno B, Steele S, Carbone J, Schneider K, Posk L, Rose SL. Informed or anxious: patient preferences for release of test results of increasing sensitivity on electronic patient portals. *Health Technol (Berl)*. 2022;12(1):59-67. doi:10.1007/s12553-021-00628-5

[69] Desai AV, Michael CL, Kuperman GJ, et al. A Novel Patient Values Tab for the Electronic Health Record: A User-Centered Design Approach. *J Med Internet Res*. 2021;23(2):e21615. Published 2021 Feb 17. doi:10.2196/21615

[70] Prows CA, Marsolo K, Myers MF, Nix J, Hall ES. Adapting Clinical Systems to Enable Adolescents' Genomic Choices. *ACI open*. 2020;4(2):e126-e131. doi:10.1055/s-0040-1718747

[71] Jerofke-Owen TA, Zielinski A, Brown RL. Mixed Methods Study of Nurse Assessment of Patient Preferences for Engagement During Hospitalization. *Nurs Res*. 2021;70(5):366-375. doi:10.1097/NNR.0000000000000526

[72] Goggins KM, Wallston KA, Nwosu S, et al. Health literacy, numeracy, and other characteristics associated with hospitalized patients' preferences for involvement in decision making. *J Health Commun*. 2014;19 Suppl 2(0 2):29-43. doi:10.1080/10810730.2014.938841

[73] Robinson A, Thomson R. Variability in patient preferences for participating in medical decision making: implication for the use of decision support tools. *Qual Health Care*. 2001;10 Suppl 1(Suppl 1):i34-i38. doi:10.1136/qhc.0100034.

[74] Flynn KE, Smith MA, Vanness D. A typology of preferences for participation in healthcare decision making. *Soc Sci Med.* 2006;63(5):1158-69. doi: 10.1016/j.socscimed.2006.03.030.

[75] Ramar P, Roellinger DL, Merrick RF, Ebbert JO, Philpot LM. Helpfulness of Clinical Visit Summary Content From Multi-Specialty Care: A Mixed-Methods Assessment. *Health Serv Res Manag Epidemiol*. 2020;7:2333392820950909. Published 2020 Aug 26. doi:10.1177/2333392820950909

[76] Risling T, Martinez J, Young J, Thorp-Froslie N. Defining Empowerment and Supporting Engagement Using Patient Views From the Citizen Health Information Portal: Qualitative Study. *JMIR Med Inform*. 2018;6(3):e43. Published 2018 Sep 10. doi:10.2196/medinform.8828

[77] Rijken M, Stüssgen R, Leemrijse C, Bogerd MJL, Korevaar JC. Priorities and preferences for care of people with multiple chronic conditions. *Health Expect*. 2021;24(4):1300-1311. doi:10.1111/hex.13262

[78] Seo J, Goodman MS, Politi M, Blanchard M, Kaphingst KA. Effect of Health Literacy on Decision-Making Preferences among Medically Underserved Patients. *Med Decis Making*. 2016;36(4):550-556. doi:10.1177/0272989X16632197

[79] Hölzel LP, Kriston L, Härter M. Patient preference for involvement, experienced involvement, decisional conflict, and satisfaction with physician: a structural equation model test. *BMC Health Serv Res*. 2013;13:231. Published 2013 Jun 25. doi:10.1186/1472-6963-13-231

[80] Bosco JL, Halpenny B, Berry DL. Personal preferences and discordant prostate cancer treatment choice in an intervention trial of men newly diagnosed with localized prostate cancer. *Health Qual Life Outcomes.* 2012;10:123. doi: 10.1186/1477-7525-10-123.

[81] Walker E, McMahan R, Barnes D, Katen M, Lamas D, Sudore R. Advance Care Planning Documentation Practices and Accessibility in the Electronic Health Record: Implications for Patient Safety. *J Pain Symptom Manage*. 2018;55(2):256-264. doi:10.1016/j.jpainsymman.2017.09.018

[82] Holt JM, Cusatis R, Winn A, et al. The Impact of Previsit Contextual Data Collection on Patient-Provider Communication and Patient Activation: Study Protocol for a Randomized Controlled Trial. *JMIR Res Protoc*. 2020;9(9):e20309. Published 2020 Sep 23. doi:10.2196/20309

[83] Hogden A, Crook A. Patient-centered decision making in amyotrophic lateral sclerosis: where are we? *Neurodegener Dis Manag.* 2017 Dec;7(6):377-386. doi: 10.2217/nmt-2017-0026.

[84] Van den Bulck SA, Hermens R, Slegers K, Vandenberghe B, Goderis G, Vankrunkelsven P. Designing a Patient Portal for Patient-Centered Care: Cross-Sectional Survey. *J Med Internet Res*. 2018;20(10):e269. Published 2018 Oct 1. doi:10.2196/jmir.9497

[85] Fuji KT, Abbott AA, Galt KA. A qualitative study of how patients with type 2 diabetes use an electronic stand-alone personal health record. *Telemed J E Health*. 2015;21(4):296-300. doi:10.1089/tmj.2014.0084

[86] Determann D, Lambooij MS, Gyrd-Hansen D, et al. Personal health records in the Netherlands: potential user preferences quantified by a discrete choice experiment. *J Am Med Inform Assoc*. 2017;24(3):529-536. doi:10.1093/jamia/ocw158

[87] Frost J, Vermeulen IE, Beekers N. Anonymity versus privacy: selective information sharing in online cancer communities. *J Med Internet Res*. 2014;16(5):e126. Published 2014 May 14. doi:10.2196/jmir.2684

[88] Hägglund M, McMillan B, Whittaker R, Blease C. Patient empowerment through online access to health records. *BMJ*. 2022;378:e071531. Published 2022 Sep 29. doi:10.1136/bmj-2022-071531

[89] Esmaeilzadeh P, Mirzaei T. The Potential of Blockchain Technology for Health Information Exchange: Experimental Study From Patients' Perspectives. *J Med Internet Res*. 2019;21(6):e14184. Published 2019 Jun 20. doi:10.2196/14184

[90] Harle CA, Golembiewski EH, Rahmanian KP, et al. Patient preferences toward an interactive e-consent application for research using electronic health records. *J Am Med Inform Assoc*. 2018;25(3):360-368. doi:10.1093/jamia/ocx145

[91] Tierney WM, Alpert SA, Byrket A, et al. Provider responses to patients controlling access to their electronic health records: a prospective cohort study in primary care. *J Gen Intern Med*. 2015;30 Suppl 1(Suppl 1):S31-S37. doi:10.1007/s11606-014-3053-0

[92] Grande D, Mitra N, Shah A, Wan F, Asch DA. Public preferences about secondary uses of electronic health information. *JAMA Intern Med*. 2013;173(19):1798-1806. doi:10.1001/jamainternmed.2013.9166

[93] Caine K, Hanania R. Patients want granular privacy control over health information in electronic medical records. *J Am Med Inform Assoc*. 2013;20(1):7-15. doi:10.1136/amiajnl-2012-001023

[94] Dhopeshwarkar RV, Kern LM, O'Donnell HC, Edwards AM, Kaushal R. Health care consumers' preferences around health information exchange. *Ann Fam Med*. 2012;10(5):428-434. doi:10.1370/afm.1396

[95] Leventhal JC, Cummins JA, Schwartz PH, Martin DK, Tierney WM. Designing a system for patients controlling providers' access to their electronic health records: organizational and technical challenges. *J Gen Intern Med*. 2015;30 Suppl 1(Suppl 1):S17-S24. doi:10.1007/s11606-014-3055-y

[96] Schwartz PH, Caine K, Alpert SA, Meslin EM, Carroll AE, Tierney WM. Patient preferences in controlling access to their electronic health records: a prospective cohort study in primary care. *J Gen Intern Med*. 2015;30 Suppl 1(Suppl 1):S25-S30. doi:10.1007/s11606-014-3054-z

[97] Patil S, Lu H, Saunders CL, Potoglou D, Robinson N. Public preferences for electronic health data storage, access, and sharing - evidence from a pan-European survey. *J Am Med Inform Assoc*. 2016;23(6):1096-1106. doi:10.1093/jamia/ocw012

[98] Soni H, Grando A, Murcko A, et al. State of the art and a mixed-method personalized approach to assess patient perceptions on medical record sharing and sensitivity. *J Biomed Inform*. 2020;101:103338. doi:10.1016/j.jbi.2019.103338

[99] Yu E, Adams-Clark A, Riehm A, et al. Perspectives on illness-related stigma and electronically sharing psychiatric health information by people with multiple sclerosis. *J Affect Disord*. 2021;282:840-845. doi:10.1016/j.jad.2020.12.167

[100] Kim H, Bell E, Kim J, et al. iCONCUR: informed consent for clinical data and bio-sample use for research. *J Am Med Inform Assoc*. 2017;24(2):380-387. doi:10.1093/jamia/ocw115

[101] Kim J, Kim H, Bell E, et al. Patient Perspectives About Decisions to Share Medical Data and Biospecimens for Research. *JAMA Netw Open*. 2019;2(8):e199550. Published 2019 Aug 2. doi:10.1001/jamanetworkopen.2019.9550

[102] Daniel C, Kalra D; Section Editors for the IMIA Yearbook Section on Clinical Research Informatics. Clinical Research Informatics: Contributions from 2017. *Yearb Med Inform*. 2018;27(1):177-183. doi:10.1055/s-0038-1641220

[103] Esmaeilzadeh P, Sambasivan M. Patients' support for health information exchange: a literature review and classification of key factors. *BMC Med Inform Decis Mak*. 2017;17(1):33. Published 2017 Apr 4. doi:10.1186/s12911-017-0436-2

[104] Bernaerdt J, Moerenhout T, Devisch I. Vulnerable patients' attitudes towards sharing medical data and granular control in patient portal systems: an interview study. *J Eval Clin Pract*. 2021;27(2):429-437. doi:10.1111/jep.13465

[105] Wagner L, Frisch M, Turner-Brown L, et al. Preferences for the research use of electronic health records among young adults with fragile X syndrome or autism spectrum disorder. *Disabil Health J*. 2020;13(4):100927. doi:10.1016/j.dhjo.2020.100927

[106] Schultz CL, Bocarro JN, Hipp JA, Bennett GJ, Floyd MF. Prescribing Time in Nature for Human Health and Well-Being: Study Protocol for Tailored Park Prescriptions. *Front Digit Health*. 2022;4:932533. Published 2022 Jul 19. doi:10.3389/fdgth.2022.932533

[107] Sarraju A, Coquet J, Zammit A, et al. Using deep learning-based natural language processing to identify reasons for statin nonuse in patients with atherosclerotic cardiovascular disease. *Commun Med (Lond)*. 2022;2:88. Published 2022 Jul 15. doi:10.1038/s43856-022-00157-w

[108] Kerr EA, Hayward RA. Patient-centered performance management: enhancing value for patients and health care systems. *JAMA*. 2013;310(2):137-138. doi:10.1001/jama.2013.6828

[109] Hollin IL, Dimmock AE, Bridges JF, Danoff SK, Bascom R. Collecting patient preference information using a Clinical Data Research Network: demonstrating feasibility with idiopathic pulmonary fibrosis. *Patient Prefer Adherence*. 2019;13:795-804. Published 2019 May 16. doi:10.2147/PPA.S201632

[110] Scalia P, Durand MA, Forcino RC, et al. Implementation of the uterine fibroids Option Grid patient decision aids across five organizational settings: a randomized stepped-wedge study protocol. *Implement Sci*. 2019;14(1):88. Published 2019 Sep 2. doi:10.1186/s13012-019-0933-z

[111] Lenert L, Dunlea R, Del Fiol G, Hall LK. A model to support shared decision making in electronic health records systems. *Med Decis Making*. 2014;34(8):987-995. doi:10.1177/0272989X14550102

[112] Ruland, CM, Bakken, S. Representing Patient Preference-Related Concepts for Inclusion in Electronic Health Records. *J Biomed Inform*. 2001;34(6):415-22. doi: 10.1006/jbin.2002.1035.

[113] Mangin D, Stephen G, Bismah V, Risdon C. Making patient values visible in healthcare: a systematic review of tools to assess patient treatment priorities and preferences in the context of multimorbidity. *BMJ Open*. 2016;6(6):e010903. Published 2016 Jun 10. doi:10.1136/bmjopen-2015-010903

[114] Lambin P, Roelofs E, Reymen B, et al. 'Rapid Learning health care in oncology' - an approach towards decision support systems enabling customised radiotherapy'. *Radiother Oncol*. 2013;109(1):159-164. doi:10.1016/j.radonc.2013.07.007

[115] Wilk S, Michalowski M, Michalowski W, Rosu D, Carrier M, Kezadri-Hamiaz M. Comprehensive mitigation framework for concurrent application of multiple clinical practice guidelines. *J Biomed Inform.* 2017;66:52-71. doi:10.1016/j.jbi.2016.12.002.

[116] van Summeren JJ, Schuling J, Haaijer-Ruskamp FM, Denig P. Outcome prioritisation tool for medication review in older patients with multimorbidity: a pilot study in general practice. *Br J Gen Pract*. 2017;67(660):e501-e506. doi:10.3399/bjgp17X690485

[117] Dima A, Lewith GT, Little P, Moss-Morris R, Foster NE, Bishop FL. Identifying patients' beliefs about treatments for chronic low back pain in primary care: a focus group study. *Br J Gen Pract.* 2013;63(612):e490-8. doi:10.3399/bjgp13X669211.

[118] Unroe KT, Hickman SE, Torke AM; AAHPM Research Committee Writing Group. Care Consistency With Documented Care Preferences: Methodologic Considerations for Implementing the "Measuring What Matters" Quality Indicator. *J Pain Symptom Manage*. 2016;52(4):453-458. doi:10.1016/j.jpainsymman.2016.04.015

[119] Kuusisto A, Saranto K, Korhonen P, Haavisto E. Accessibility of information on patients' and family members' end-of-life wishes in advance care planning. *Nurs Open*. 2022;9(1):428-436. doi:10.1002/nop2.1081

[120] Nakagawa S, Clark EM, Cobbs EL, et al. Promoting advance care planning documentation for veterans through an innovative electronic medical record template. *J Am Geriatr Soc*. 2014;62(9):1811-1813. doi:10.1111/jgs.13008

[121] Turley M, Wang S, Meng D, Kanter MH, Garrido T. An information model for automated assessment of concordance between advance care preferences and care delivered near the end of life. *J Am Med Inform Assoc*. 2016;23(e1):e118-e124. doi:10.1093/jamia/ocv149

[122] Apaydin KZ, Fontenot HB, Shtasel D, et al. Facilitators of and barriers to HPV vaccination among sexual and gender minority patients at a Boston community health center. *Vaccine*. 2018;36(26):3868-3875. doi:10.1016/j.vaccine.2018.02.043

[123] Dang BN, Westbrook RA, Njue SM, Giordano TP. Building trust and rapport early in the new doctor-patient relationship: a longitudinal qualitative study. *BMC Med Educ*. 2017;17(1):32. Published 2017 Feb 2. doi:10.1186/s12909-017-0868-5

[124] Gandapur Y, Kianoush S, Kelli HM, et al. The role of mHealth for improving medication adherence in patients with cardiovascular disease: a systematic review. *Eur Heart J Qual Care Clin Outcomes*. 2016;2(4):237-244. doi:10.1093/ehjqcco/qcw018

[125] Hamine S, Gerth-Guyette E, Faulx D, Green BB, Ginsburg AS. Impact of mHealth chronic disease management on treatment adherence and patient outcomes: a systematic review. *J Med Internet Res*. 2015;17(2):e52. Published 2015 Feb 24. doi:10.2196/jmir.3951

[126] American Health Information Management Association. The Five Rights of Clinical Decision Support: CDS Tools Helpful for Meeting Meaningful Use. Accessed February 17, 2023. Retrieved from: https://library.ahima.org/doc?oid=300027#.YL6EuPlKjIU

[127] Osheroff JA, Teich JA, D Levick, et al. *Improving Outcomes with Clinical Decision Support: An Implementer's Guide*. 2nd ed. Chicago, IL: HIMSS; 2012.

[128] Duke Center for Personalized Health Care. The Importance of Physician-Patient Relationships Communication and Trust in Health Care - Duke Personalized Health Care. Accessed February 3, 2022. Retrieved from https://dukepersonalizedhealth.org/2019/03/the-importance-of-physician-patient-relationships-communication-and-trust-in-health-care/

[129] Carman KL, Dardess P, Maurer M, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Aff (Millwood)*. 2013;32(2):223-231. doi:10.1377/hlthaff.2012.1133

[130] McCabe PJ, Stuart-Mullen LG, McLeod CJ, et al. Patient activation for self-management is associated with health status in patients with atrial fibrillation. *Patient Prefer Adherence*. 2018;12:1907-1916. Published 2018 Sep 25. doi:10.2147/PPA.S172970

[131] Alegría M, Carson N, Flores M, et al. Activation, self-management, engagement, and retention in behavioral health care: a randomized clinical trial of the DECIDE intervention. *JAMA Psychiatry*. 2014;71(5):557-565. doi:10.1001/jamapsychiatry.2013.4519

[132] The Economist. Herbert Simon. Accessed February 3, 2023. Retrieved from https://www.economist.com/news/2009/03/20/herbert-simon

[133] Public Law 114-255. 114th Congress. 2016. Retrieved from: https://www.govinfo.gov/content/pkg/PLAW-114publ255/pdf/PLAW-114publ255.pdf

[134] 21st Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification Program, 85 Fed. Reg. 25642-25961. May 1, 2020. Retrieved from https://www.federalregister.gov/documents/2020/05/01/2020-07419/21st-century-cures-act-interoperability-information-blocking-and-the-onc-health-it-certification

[135] Teixeira PA, Gordon P, Camhi E, Bakken S. HIV patients' willingness to share personal health information electronically. *Patient Educ Couns.* 2011;84(2):e9–12. doi:10.1016/j.pec.2010.07.013.

[136] Whiddett R, Hunter I, Engelbrecht J, Handy J. Patients' attitudes towards sharing their health information*. Int J Med Inform.* 2006;75(7):530–41. doi:10.1016/j.ijmedinf.2005.08.009.

[137] Lee A, Leung S. Health Outcomes. In: Michalos AC, eds. *Encyclopedia of Quality of Life and Well-Being Research.* Springer, Dordrecht; 2014:2730-2735.

[138] Sahm CR. How Much Does Risk Tolerance Change?. *Q J Finance*. 2012;2(4):1250020. doi:10.1142/S2010139212500206

[139] Nanna MG, Peterson ED, Wu A, et al. Age, knowledge, preferences, and risk tolerance for invasive cardiac care. *Am Heart J*. 2020;219:99-108. doi:10.1016/j.ahj.2019.09.008

[140] Auriemma CL, Nguyen CA, Bronheim R, et al. Stability of end-of-life preferences: a systematic review of the evidence. *JAMA Intern Med*. 2014;174(7):1085-1092. doi:10.1001/jamainternmed.2014.1183

[141] Oliver D, Deal K, Howard M, Qian H, Agarwal G, Guenter D. Patient trade-offs between continuity and access in primary care interprofessional teaching clinics in Canada: a cross-sectional survey using discrete choice experiment. *BMJ Open*. 2019;9(3):e023578. Published 2019 Mar 23. doi:10.1136/bmjopen-2018-023578

[142] Ostermann J, Brown DS, de Bekker-Grob EW, Mühlbacher AC, Reed SD. Preferences for Health Interventions: Improving Uptake, Adherence, and Efficiency. *Patient*. 2017;10(4):511-514. doi:10.1007/s40271-017-0251-y

[143] Lambooij MS, Harmsen IA, Veldwijk J, de Melker H, Mollema L, van Weert Y, de Wit GA. Consistency between stated and revealed preferences: a discrete choice experiment and a behavioural experiment on vaccination behaviour compared. *BMC Medical Research Methodology.* 2015;15:19.

[144] Salampessy BH, Veldwijk J, Schuit AJ, van den Brekel-Dijkstra K, Neslo EJ, de Wit GA, Lambooij MS. The Predictive Value of Discrete Choice Experiments in Public Health: An Exploratory Application. *The Patient.* 2015;8(6):521–529.

[145] Russo S, Jongerius C, Faccio F, et al. Understanding Patients' Preferences: A Systematic Review of Psychological Instruments Used in Patients' Preference and Decision Studies. *Value Health*. 2019;22(4):491-501. doi:10.1016/j.jval.2018.12.007

[146] Fried TR, Tinetti M, Agostini J, Iannone L, Towle V. Health outcome prioritization to elicit preferences of older persons with multiple health conditions. *Patient Educ Couns.* 2011;83(2):278-82. doi:10.1016/j.pec.2010.04.032.

[147] Hickman SE, Nelson CA, Perrin NA, Moss AH, Hammes BJ, Tolle SW. A comparison of methods to communicate treatment preferences in nursing facilities: traditional practices versus the physician orders for life-sustaining treatment program. *J Am Geriatr Soc*. 2010;58(7):1241-1248. doi:10.1111/j.1532-5415.2010.02955.x

[148] Bonfils KA, Adams EL, Mueser KT, Wright-Berryman JL, Salyers MP. Factor structure of the autonomy preference index in people with severe mental illness. *Psychiatry Res*. 2015;228(3):526-530. doi:10.1016/j.psychres.2015.06.004

[149] Degner LF, Sloan JA, Venkatesh P. The Control Preferences Scale. *Can J Nurs Res*. 1997;29(3):21-43.

[150] Gregório M, Teixeira A, Páscoa R, Baptista S, Carvalho R, Martins C. The Problem-Solving Decision-Making scale-translation and validation for the Portuguese language: a cross-sectional study. *BMJ Open*. 2020;10(6):e033625. Published 2020 Jun 28. doi:10.1136/bmjopen-2019-033625

[151] Khanbhai M, Anyadi P, Symons J*,* et al. Applying natural language processing and machine learning techniques to patient experience feedback: a systematic review. *BMJ Health & Care Informatics.* 2021;28**:**e100262. doi: 10.1136/bmjhci-2020-100262

[152] LOINC. Patient Goals, preferences, and priorities for care experience. Accessed September 21, 2022. Retrieved from: https://loinc.org/81338-6/

[153] LOINC. Patient Goals, preferences, and priorities under certain health conditions. Accessed September 22, 2022. Retrieved from: https://loinc.org/81336-0/

[154] Dy SM, Kiley KB, Ast K, et al. Measuring what matters: top-ranked quality indicators for hospice and palliative care from the American academy of hospice and palliative medicine and hospice and palliative nurses association. *J Pain Symptom Manage* 2015;49(4):773–781. doi:10.1016/j.jpainsymman.2015.01.012

[155] Ernecoff NC, Wessell KL, Bennett AV, Hanson LC. Measuring Goal-Concordant Care in Palliative Care Research. *J Pain Symptom Manage*. 2021;62(3):e305-e314. doi:10.1016/j.jpainsymman.2021.02.030

[156] Robbins AJ, Ingraham NE, Sheka AC, et al. Discordant Cardiopulmonary Resuscitation and Code Status at Death. *J Pain Symptom Manage*. 2021;61(4):770-780.e1. doi:10.1016/j.jpainsymman.2020.09.015

[157] Sean Morrison R. Advance Directives/Care Planning: Clear, Simple, and Wrong. *J Palliat Med*. 2020;23(7):878-879. doi:10.1089/jpm.2020.0272

[158] Sepucha KR, Scholl I. Measuring shared decision making: a review of constructs, measures, and opportunities for cardiovascular care. *Circ Cardiovasc Qual Outcomes.* 2014;7(4):620-6. doi:10.1161/CIRCOUTCOMES.113.000350.

[159] Becerra Pérez, MM, Menear M, Brehaut JC, Légaré F. Extent and Predictors of Decision Regret about Health Care Decisions: A Systematic Review. *Medical decision making : an international journal of the Society for Medical Decision Making*. 2016;36(6):777–790. https://doi.org/10.1177/0272989X16636113

[160] Brehaut JC, O'Connor AM, Wood TJ, et al. Validation of a decision regret scale. *Med Decis Making*. 2003;23(4):281-292. doi:10.1177/0272989X03256005

[161] Sepucha K, Ozanne EM. How to define and measure concordance between patients' preferences and medical treatments: A systematic review of approaches and recommendations for standardization. *Patient Educ Couns.* 2010;78(1):12-23. doi: 10.1016/j.pec.2009.05.011.

[162] Adler-Milstein J, Nong P. Early experiences with patient generated health data: health system and patient perspectives. *J Am Med Inform Assoc.* 2019;26(10):952-959. doi:10.1093/jamia/ocz045.

[163] Caterinicchio RP. Testing plausible path models of interpersonal trust in patient-physician treatment relationships. *Soc Sci Med Med Psychol Med Sociol*. 1979;13A(1):81-99. doi:10.1016/0160-7979(79)90011-0

[164] Curtis E, Jones R, Tipene-Leach D, et al. Why cultural safety rather than cultural competency is required to achieve health equity: a literature review and recommended definition. *Int J Equity Health*. 2019;18(1):174. Published 2019 Nov 14. doi:10.1186/s12939-019-1082-3

[165] Ford-Gilboe M, Wathen CN, Varcoe C, et al. How Equity-Oriented Health Care Affects Health: Key Mechanisms and Implications for Primary Health Care Practice and Policy. *Milbank Q*. 2018;96(4):635-671. doi:10.1111/1468-0009.12349