

Trust and Patient-Centeredness Workgroup: Capturing Patient Preferences for Patient-Centered Clinical Decision Support Within Patient Lifeflows and Clinical Workflows

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Prepared by:

Prashila Dullabh, MD, FAMIA and Jessica Ancker, PhD, MPH, FACMI

Caroline Peterson, MPH

Lindsay Abdulhay, MPH

Avantika Shah, MPH

Angela Dobes, MPH

Priyanka J. Desai, PhD, MSPH

CDSiC Trust and Patient-Centeredness Workgroup

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PURPOSE

The Clinical Decision Support Innovation Collaborative (CDSiC) aims to advance the design, development, dissemination, implementation, use, measurement, and evaluation of evidence-based, shareable, interoperable, and publicly available patient-centered clinical decision support (PC CDS) to improve health outcomes of all patients by creating a proving ground of innovation. The Trust and Patient-Centeredness Workgroup is charged with supporting the design, implementation, and uptake of PC CDS to enhance trust, foster shared decision-making, and engage patients and clinicians as partners alongside all members of the care team. The Workgroup is composed of 13 experts and stakeholders who represent diverse perspectives within the CDS community. This report is intended to share strategies for capturing patient preferences for PC CDS within patient lifeflows and clinical workflows. All CDSiC qualitative research activities are reviewed by the NORC at the University of Chicago Institutional Review Board (FWA00000142).

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Contributors: CDSiC Trust and Patient-Centeredness Workgroup

Members of the Trust and Patient-Centeredness Workgroup who contributed to this report are listed below.

Table 1. CDSiC Trust and Patient-Centeredness Workgroup Members

Name	Affiliation
Karim Hanna, MD, FAAFP	University of South Florida
Kevon-Mark Jackman, DrPH, MPH	Johns Hopkins University School of Medicine
Sarah Krug, MS	Cancer 101
Elizabeth Oehrlein, PhD, MS	Applied Patient Experience
Jodyn Platt, PhD, MPH	University of Michigan
Joshua Richardson, PhD, MS, MLIS, FAMIA	Research Triangle Institute
Danny Sands, MD, MPH	Consultant

Executive Summary

This report provides a summary of illustrative approaches to the collection and integration of patient preferences into patient-centered clinical decision support (PC CDS), along with swimlane diagrams tailored to specific clinical scenarios. The report also shares key considerations for optimizing the collection and use of patient preferences for PC CDS to reduce patient and clinician burden, as well as short- and long-term opportunities to advance the incorporation of patient preferences into PC CDS.

Introduction

Patients interact with the health system in different ways, presenting multiple opportunities for their preferences to be collected. These preferences can then influence the care they receive. The discussion and consideration of patient preferences in healthcare decision-making can enhance patient satisfaction, improve health outcomes, promote patient autonomy, and support patient adherence to clinical recommendations. One potential method to address patient preferences in patient, caregiver, and care team decision making is to integrate preferences into PC CDS, which encompasses a spectrum of decision-making tools that significantly incorporate patient-centered factors related to knowledge, data, delivery, and use.

Methods

We conducted a literature review and a series of key informant interviews to identify the methods for collecting and using patient preferences for PC CDS. Our literature review included peer-reviewed articles identified through a PubMed search, as well as articles on patient preference measures that were identified in a previous Clinical Decision Support Innovation Collaborative (CDSiC) scoping review. We conducted two distinct sets of qualitative key informant interviews to supplement our literature review findings. Five preliminary key informant interviews were conducted to identify current methods for the collection and integration of patient preferences in clinical workflows. Four additional key informant interviews were conducted to review and obtain feedback on workflow diagrams representing the collection of different types of patient preferences based on specific clinical scenarios.

We then abstracted data from the final list of 63 publications included in our literature review and synthesized findings from that abstracted data to identify common timepoints, methods, and challenges with collecting patient preferences in clinical care, as well as considerations for reducing patient and clinician burden.

Key Findings: When and How Patient Preference Data Are Collected

Patient preferences vary in how routinely they are collected from patients, and there is no standard, optimal timepoint or method for collecting preference information. While there are several validated tools that aim to collect patient preferences, there is a gap in terms of implementing and testing these validated tools in routine clinical care.

We identified three timepoints when patient preference data are typically collected: before a clinical visit (e.g., through an app or the patient portal in the days before a clinical visit), during a clinical visit (i.e., a

healthcare encounter, such as being in the waiting room, during a face-to-face interaction with the care team, or during hospitalization), and after a clinical visit (i.e., in the weeks or months after the clinical visit and often at home). Key informants shared that different types of patient preference data may be more appropriate, important, or feasible to capture at different times. Further, they emphasized the value in providing patients with opportunities to reassess their preferences at multiple points over time, given that preferences often change over the course of a condition.

Literature review findings and key informant interviews indicated that several methods are used to collect patient preferences, both in patient lifeflows and in clinical workflows. In patient lifeflows, which include a patient's daily activities that take place outside of a clinical setting, patient-facing technologies are often used to collect patient preferences without the direct involvement of the clinician. In clinical workflows, key informants emphasized the centrality of face-to-face discussions between clinicians and patients that occur during a clinical visit to the collection of patient preferences. These discussions give patients the opportunity to openly share their preferences and yield a significant amount of information the clinician can then use to determine next steps.

Further, a “funneled” approach to the collection of patient preferences was recommended to ensure a broader reach among patients, as patients would have multiple opportunities to share their preferences over time. With this approach, clinical teams first use automated patient-facing technologies to capture patient preferences, and then shift to more targeted approaches, such as phone calls or face-to-face discussions, to collect information from patients who did not respond to the automated methods.

Illustrative Swimlane Diagrams for Collecting Patient Preferences

We developed a series of swimlane diagrams that visualize opportunities within patient lifeflows and clinical workflows for collecting and documenting patient preferences. Swimlane diagrams are tools for representing healthcare-related workflows. These swimlane diagrams (on pages 12–17 of this report) focus on four distinct clinical scenarios: 1) collecting administrative preferences before a clinical visit, 2) collecting preferences related to health maintenance and preventive care, 3) discussing medication therapy choices, and 4) discussing treatment options for breast cancer.

Considerations for Optimizing the Collection and Use of Patient Preferences for PC CDS

Findings from our literature review and key informant interviews suggest there are several opportunities to improve the collection and integration of patient preferences into PC CDS by ensuring these processes fit into clinicians' workflows and patients' lifeflows. These include encouraging patients to provide preference information, gathering preferences that are important to patients' care, delegating the collection of patient preference information to other care team members, such as medical assistants or nurses, and ensuring patient preference data are easily accessible to clinicians. These opportunities hold promise for reducing burden on both patients and clinicians.

Discussion

Our literature review and key informant interview findings provide suggestions for capturing patient preferences within patient lifeflows and clinician workflows for PC CDS, including short-term and long-term opportunities in this area. Short-term opportunities include promoting the importance of including patient preferences in PC CDS tools and educating clinical staff to better recognize and accommodate diverse patient preferences. Long-term opportunities include exploring clinical workflows and patient lifeflows that accommodate changes in patient preferences over time, as well as prioritizing the implementation of robust tools and methodologies for gathering patient preferences for use in routine clinical care.

Conclusion

Collecting and incorporating patient preferences for PC CDS are vital for personalized care, treatment adherence, and collaborative patient-provider relationships, leading to improved health outcomes and addressing care disparities. This report describes the timepoints and various methods for capturing different types of patient preference data and visualizes these within patient lifeflows and clinical workflows through four distinct clinical use cases. It also offers considerations to reduce patient and clinician burden. Health system stakeholders and PC CDS developers seeking to optimize the collection and utilization of patient preference information for PC CDS may find valuable insights in this report.

1. Introduction

Patients have a variety of preferences that influence how they would like to interact with the healthcare system and receive health services. These can include patients' preferences about communication or interaction with their clinician, approaches to healthcare decision-making, and engagement with healthcare services.¹ Patient preferences are formally defined 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.”¹ The discussion and consideration of patient preferences in healthcare decision-making can enhance patient satisfaction, improve health outcomes, promote patient autonomy, and support patient adherence to clinical recommendations.^{2,3}

One potential way to address patient preferences in patient, caregiver, and care team decision-making is to integrate preferences into patient-centered clinical decision support (PC CDS) tools. PC CDS encompasses a spectrum of decision-making tools that significantly incorporate patient-centered factors related to knowledge, data, delivery, and use. Knowledge refers to the use of comparative effectiveness research (CER) or patient-centered outcomes research (PCOR) findings. Data focuses on the incorporation of patient-generated health data, patient preferences, social determinants of health, and other patient-specific information. Delivery refers to directly engaging patients and/or caregivers across different settings. Finally, use focuses on facilitating bi-directional information exchange in support of patient-centered care, including shared decision-making (SDM).^{4,5}

Previously, the Clinical Decision Support Innovation Collaborative (CDSiC) created an organizing framework that identified and categorized patient preferences using six domains relevant to PC CDS: 1) personal characteristics, 2) communication, 3) access and care experience, 4) engagement, 5) data, and 6) healthcare services. However, gaps remain in our understanding of how and when these data are currently collected and used in clinical workflows and patient lifeflows to facilitate PC CDS. A clinical workflow is a series of steps required to perform a specific clinical activity or task. Patient lifeflows are activities both within and outside of healthcare encounters that impact an individual's health.⁶

This report builds on previous CDSiC work to explore how and when patient preferences are collected and integrated into patient lifeflows and clinical workflows for PC CDS, including considerations for reducing patient and clinician burden.

1.1. Report Roadmap

This report includes a summary of common methods and timepoints for the collection and integration of patient preferences into PC CDS. Additionally, the report includes swimlane diagrams tailored to specific clinical scenarios that illustrate workflows for the collection and use of patient preferences. The roadmap of the subsequent sections of the report is below.

- Section 2, *Methods*, describes our research aims and the approaches used for the literature review and key informant interviews, including participant recruitment, data collection, and analysis.
- Section 3, *Key Findings: When and How Patient Preference Data Are Collected*, summarizes our findings related to how and when patient preferences are being collected.

- Section 4, *Illustrative Swimlane Diagrams for Collecting Patient Preferences*, depicts workflows for collecting and integrating patient preferences in patient lifeflows and clinical workflows.
- Section 5, *Considerations for Optimizing the Collection and Use of Patient Preferences for PC CDS to Reduce Burden*, presents a list of considerations specific to patients and clinicians to reduce burden when collecting and integrating patient preferences in PC CDS.
- Section 6, *Discussion*, describes the significance of our findings, future areas of work related to the collection and integration of patient preferences in PC CDS, and limitations.
- Section 7, *Conclusion*, summarizes the key takeaways and implications of our findings.

2. Methods

We conducted a literature review and a series of key informant interviews to identify the methods for collecting and using patient preferences for PC CDS.

2.1. Literature Review

Our literature review included peer-reviewed articles identified through a PubMed search (see Appendix A), as well as articles on patient preference measures that were identified in a previous CDSiC scoping review.¹ The review was conducted in two stages—1) title and abstract screening, and 2) full-text review—with records assessed for eligibility (e.g., eligible, ineligible, or uncertain) at each stage.

Records were deemed eligible after the title and abstract screening if they were: 1) published in the past 10 years, 2) published in English, and 3) included human patients (e.g., were not veterinary studies, algorithms, or clinician-focused tools that did not involve some element of patient engagement). Records that were deemed uncertain after the title/abstract screening were included in the full-text review to confirm eligibility. Of the 67 articles identified from our searches and previous CDSiC reviews, 63 were deemed eligible after both stages of screening and included in the final list of records for data abstraction.

2.2. Key Informant Interviews

We conducted two distinct sets of qualitative key informant interviews (nine interviews total) to supplement our literature review findings. Preliminary key informant interviews were conducted to identify current timepoints and methods for the collection and integration of patient preferences in clinical workflows and patient lifeflows. A second round of key informant interviews were conducted to review and obtain feedback on workflow diagrams representing the collection of different types of patient preferences based on specific clinical scenarios. Exhibit 1 summarizes the types of key informants that participated in the interviews.

All interviews were conducted via Zoom and audio and video recorded. An experienced CDSiC team facilitator led each interview while a designated notetaker produced detailed notes.

Exhibit 1. Key Informant Types

Key Informant Type	Preliminary Key Informant Interviews	Workflow Diagram-Focused Key Informant Interviews
Researcher	4	2
Internist/Clinical Informaticist	1	1
Patient Advocate	0	1

Preliminary Key Informant Interviews

For the preliminary interviews, we developed a semi-structured interview guide focused on eliciting findings related to current timepoints and methods for collecting patient preferences in clinical care, as well as exploring the optimal frequency, methods, and timing for collecting patient preference information. Informants were also asked to provide feedback on strategies to reduce patient and provider burden when collecting and implementing patient preferences in PC CDS. These interviews lasted approximately 60 minutes.

Workflow Diagram-Focused Key Informant Interviews

For these interviews, a semi-structured interview guide was used to elicit feedback on the overall design and readability of the swimlane diagrams, key timepoints depicted for the collection of patient preferences, possible steps or information needed to accurately represent the patient experience, and additional strategies to reduce patient burden. Four workflow diagram-focused interviews were conducted: three with key informants who participated in a preliminary interview and one with a patient advocate. The interviews with prior participants lasted 30 minutes, while the interview with the patient advocate lasted 60 minutes to receive patient-specific feedback on methods and timepoints for the collection of preference.

2.3. Analysis and Synthesis

We abstracted data from the final list of papers included in our literature review, including: 1) how and when patient preferences were collected, 2) challenges with collecting and using this information, 3) how patient preference data were incorporated into PC CDS, 4) methods or best practices used or needed to reduce patient and clinician burden, and 5) future opportunities or research areas to improve this process. We synthesized findings from data abstracted from the literature review to identify common timepoints, methods, and challenges with collecting patient preferences in clinical care, as well as considerations for reducing patient and clinician burden. Rapid qualitative content analysis was used to identify key themes and insights that emerged from both rounds of key informant interviews.⁷

The interview guides facilitated deductive and inductive coding to analyze themes related to how and when patient preference data are collected and strategies to enhance these processes to reduce patient and clinician burden.

2.4. Development of Swimlane Diagrams

Using findings from our literature review, we developed a series of preliminary swimlane diagrams detailing the process for collecting patient preferences in clinical workflows and patient lifeflows. Swimlane diagrams are flowcharts that map out a process using “lanes” that can be delineated by time, people/job functions, and tasks/actions.⁸ Our diagrams focused on the collection of patient preferences by the patient and clinician before, during, and after the clinical encounter, as well as the methods of data collection. Based on the literature and feedback from key informants, we adapted the swimlane diagrams to focus on four different clinical scenarios. Diagrams were iteratively reviewed and revised based on ongoing feedback from the Trust and Patient-Centeredness Workgroup and findings from our initial key informant interviews.

As described above, the final set of diagrams were validated during our workflow diagram-focused discussions. Key informants provided feedback on the overall clarity, accuracy, and completeness of the depicted processes.

3. Key Findings: When and How Patient Preference Data Are Collected

Our literature review and key informant interviews yielded information on several topics relevant to the collection of patient preferences: the current state of patient preference collection in clinical care, including common timepoints for collecting patient preferences, as well as methods for collecting patient preferences in patient lifeflows and clinical workflows. Below we describe key findings on these topics.

3.1. Patient Preference Collection in Clinical Care

A range of patient preferences can be collected in clinical practice. Available preference measurement tools support the capture of communication preferences, such as how a patient prefers to be contacted by their clinician;⁹ engagement preferences, such as the amount of information a patient prefers to receive about their health condition;¹⁰ data-related preferences, such as a patient’s willingness to have their health data used for research;¹¹ and healthcare services preferences, such as the type of treatment or intervention a patient will pursue.¹²

Patient Preference Collection in Clinical Care. Patient preferences vary in how routinely they are collected by clinicians, and there is no standard timepoint or method for collecting preference information. While there are several validated tools that aim to collect patient preferences, there is a gap in terms of implementing and testing these validated tools in routine clinical care. The majority of the literature included in our review focused on patient preference collection for research purposes.

Overall, key informants confirmed this gap and emphasized that the capture of patient preferences in clinical care is still not routinely conducted. Key informants shared that “administrative preferences” (e.g., personal characteristics, methods of communication, receipt of test/laboratory results) are more easily captured on a routine basis, such as through a pre-visit questionnaire shared through a patient portal. However, key informants noted that the collection of certain patient preferences is part of patient-clinician discussions during visits, especially those crucial for progressing with care decisions (e.g., treatment preferences). Further, how often preferences are captured varies depending on the

specific disease and its severity. For instance, a key informant shared that clinicians are more accustomed to soliciting a patient's preferences when there are multiple valid treatment options. In contrast, clinicians may not frequently seek patient's input when they feel a certain treatment is the best choice.

Other preferences, such as those related to communication style, learning needs, and involvement in decision-making, are not well integrated or comprehensively collected during clinical encounters.

“Certain things, I think, lend themselves much more to incorporating patient preferences. If a patient is making a true preference-sensitive decision, whether or not to get breast reconstruction, for example, it has to be part of the conversation ... If [you] have a genomic test that suggests that you’re [going to] benefit from chemotherapy, there’s less preference assessment going on because the provider feels like that’s the best thing for them to do.” – Key Informant

Timepoints for Patient Preference Collection. We identified three timepoints when patient preference data are typically collected: before a clinical visit (e.g., outside of a clinical setting, through an app or the patient portal in the days before a clinical visit), during a clinical visit (i.e., during a healthcare encounter), and after a clinical visit (i.e., in the weeks or months after the clinical visit and often at home).^{13,14,15}

For outpatient care, patient preference data are collected at timepoints such as in a waiting room before interacting with the care team or during a face-to-face interaction with the care team. For inpatient care, patient preferences may be collected during hospital admission, hospitalization, and on the day of hospital discharge.^{9, 16,17} Patient preference data gathered after a clinical visit, often while the patient is at home, is collected at various timepoints, including 1 month, 3 months, and 6 months post-visit.^{18,19,20}

Key informants shared that different types of patient preference data may be more appropriate, important, or feasible to capture at different times. They noted that patient preferences focused on the administrative aspects of care are often collected before a clinical encounter, which allows more of the encounter to focus on essential discussions between the patient and clinician. Key informants also saw value in patients having the opportunity to provide this preference information before arriving at a clinical visit. There can be a level of stress associated with being required to document preferences in the waiting room before the appointment begins, since patients may feel that they need to rush to complete it before the actual interaction with the clinician.

Patient preferences related to more complex aspects of clinical care—such as the choice of a medication regimen or surgical treatment—are more often collected during the clinical encounter itself. This allows patients to directly share their thoughts and preferences and facilitates SDM. Key informants emphasized that for some more significant treatments, such as the choice of breast cancer surgery, patients would optimally be given time to reflect on their preferences following a clinical visit, especially given the many factors that can make it challenging to identify and express preferences during the actual visit.

“Optimally ... [the patient] then would have some time to reflect afterwards on ... ‘What are my real values and preferences with the decisions at hand, and...which option best aligns with that?’ ... it’s hard to take in a lot of information, process that, and then think about what are your values and preferences about that when you’re in a short encounter with a doctor and trying to figure it out and then also trying to speak up for yourself.” – Key Informant

Key informants also recognized the value in providing patients with opportunities to reassess their preferences at multiple points over time, given that preferences understandably change as patients live with and learn more about their condition.

“Those preferences change: at diagnosis, you feel one way, and three months in, once you’ve got your feet under you again, and you kind of understand what these different terms mean, your preferences change for very real and valid reasons. And then they change again, as you’ve been on this ... journey for seven, eight years ... So I think it’s always very fluid.” – Key Informant

3.2. Methods for Collecting Patient Preferences

Literature review findings and key informant interviews indicated that several methods are used to collect patient preferences, both in patient lifeflows and in clinical workflows.

Patient Lifeflows. In patient lifeflows, which include a patient’s daily activities that take place outside of a clinical setting, patient-facing technologies are often used to capture patient preferences. Key informants discussed how the patient portal has been the main modality for collecting patient preference information. They noted that the automated collection of patient preference information through the patient portal uses minimal resources, is less time-consuming for clinical teams, and will likely capture a significant number of patients.

Other methods include patient-facing apps, surveys shared via email, and text message exchanges.^{19,21} These methods are accessible to many patients and allow patients to share information at a time that is convenient for them. Key informants noted that care teams should be equipped to use different methods to capture preference data from patients with varied life circumstances. As one key informant highlighted, this is especially relevant for patients who are less able to use technology and individuals who do not respond to automated patient portal requests.

One key informant recommended using a “funneled” approach for capturing data, in which clinical teams first use automated methods to capture patient preferences, and then shift to more targeted approaches—such as phone calls or face-to-face discussions—to collect information from patients who did not respond to the automated methods. This approach would ideally ensure a broader reach among patients, as patients would have more than one opportunity to share their preferences.

“I think the approach really needs to start first from really understanding who an individual is in their life circumstances, and then [make] the way in which we might collect the information about the patient preferences more attuned to their needs. This technology is great. Maybe it captures a lot of people, but it’s not [going to] capture everyone.” – Key Informant

Clinical Workflows. Key informants shared the centrality of face-to-face discussions between clinicians and patients that occur during a clinical visit to the collection of patient preferences. These discussions give patients the opportunity to openly share their preferences and yield a significant amount of information the clinician can then use to determine next steps.

Additional methods to collect preferences in clinical settings include waiting room kiosks and electronic and paper surveys, which allow patients to share preferences while at their clinician’s office, often while in the waiting room.^{9, 22,23}

4. Illustrative Swimlane Diagrams for Collecting Patient Preferences

As previously mentioned, prior CDSiC work found that there are varied types of patient preferences relevant to PC CDS.¹ Our literature review and key informant interviews revealed that, given the varied preference data that can be collected and the myriad reasons why a patient may initiate a clinical visit, preferences can be collected at different points in a patient’s interaction with the healthcare system.

In response, we developed a series of swimlane diagrams that visualize opportunities within patient lifeflows and clinical workflows for collecting and documenting patient preferences. Swimlane diagrams are tools for representing healthcare-related workflows. These workflows which must be examined to promote the efficient and effective implementation of new processes or interventions.²⁴ Our swimlane diagrams focus on four distinct clinical scenarios: 1) collecting administrative preferences before a clinical visit, 2) collecting preferences related to health maintenance and preventive care, 3) discussing anticoagulation choices, and 4) discussing surgical options for breast cancer.

Patient and Clinician Swimlanes. The swimlane diagrams include five distinct “lanes,” each representing a different “actor” in the clinical scenario. These lanes represent both the current state of collecting patient preferences, as well as potential opportunities or methods that could further strengthen this process, especially with regard to the use of decision support tools. The activities in each lane are aligned to three major timepoints: pre-visit, during visit, and post-visit. These lanes are defined in the example swimlane diagram below (Exhibit 2).

Exhibit 2. Example Swimlane Diagram with Lane Definitions

	Pre-Visit	During Visit	Post-Visit
Patient/ Caregiver	The patient who is seeking and receiving healthcare and providing their preferences, along with any caregivers who are involved in the patient's care. The patient's/caregiver's activities also include receiving information and summaries shared by the patient-facing technology (see green lane below).		
Patient- Facing Technology	An online patient portal or patient-facing app that can be used as a PC CDS tool that facilitates communication, shares information with patients/caregivers, and/or allows patients/caregivers to input information related to health and preferences. The information shared by the patient/caregiver can then be accessed and reviewed by the care team.		
Patient/ Caregiver & Care Team Interaction	The clinical visit where the patient and care team directly interact. Several members of the care team may be involved in the collection of patient preferences, including physicians, nurses, and medical assistants.		
Care Team- Facing Technology	A clinical decision support (CDS) tool for use by care team members, such as the electronic health record (EHR) or online-based decision support tools.		
Care Team	The clinical team members who have direct contact with and are responsible for the healthcare of the patient.		

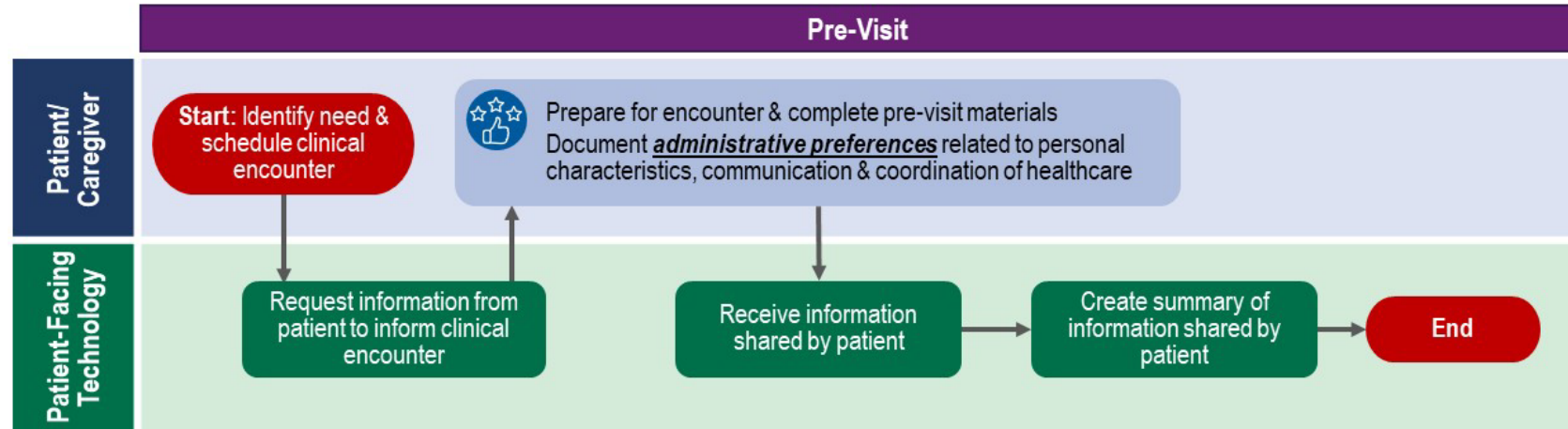
Types of Patient Preferences. Conversations with key informants focused on three types of preferences that are generally collected in conjunction with a clinical visit. These preferences are the focus of the illustrative clinical scenarios.


- **Administrative Preferences:** Patients' general preferences that guide their overall care, such as those related to their personal characteristics, pronouns, preferred methods of communication, or desire to receive lab results via a patient portal.
- **Health Maintenance and Preventive Care Preferences:** Patients' preferences related to more routine healthcare, such as vaccinations, family planning, or diagnostic screenings.
- **Treatment Preferences:** Patients' preferences on the course of treatment they will receive (e.g., choice of medication or care management strategy, choice of surgery or chemotherapy for cancer patients) as well as the factors that may inform that decision (e.g., the patient's ability to self-manage their symptoms).

4.1. Clinical Scenario 1: Collecting Administrative Preferences Before a Clinical Visit

Exhibit 3 illustrates a clinical scenario in which **administrative preferences** are collected before the clinical visit via a patient-facing technology. These administrative preferences could include personal characteristics, such as the patient's preferred name, pronouns, or language, as well as communication preferences, such as their preferred method of communicating with their care team or the time of day they prefer to be contacted.

Exhibit 3. Collecting Administrative Preferences Before a Clinical Visit



 Indicates points where patient preferences could be collected.

In this scenario, after scheduling a clinical visit, the patient-facing technology sends a request to the patient to provide some preference information before the clinical visit. The patient then inputs their administrative preferences, which are received and summarized by the patient-facing technology.

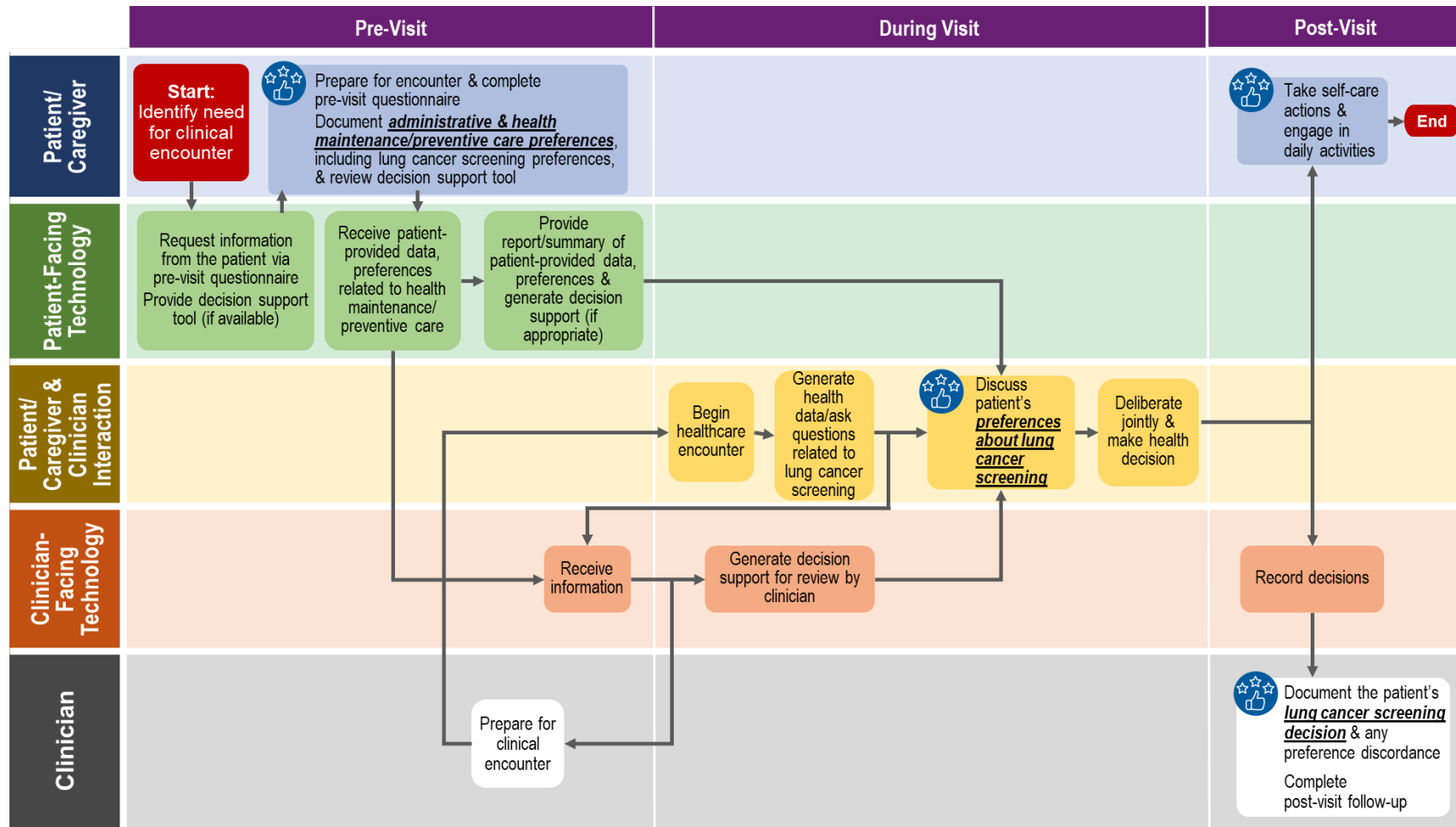
Key informants emphasized that these administrative preferences are best collected pre-visit. This approach has several benefits, including allowing the preferences to inform the clinical visit itself; helping to reserve more time during the visit for clinical concerns that can only be discussed during the visit; and supporting the clinician in reassessing and confirming patient preferences at multiple timepoints, which is a critical step in ensuring the continued accuracy and relevance of this data.


4.2. Clinical Scenario 2: Collecting Preferences Related to Health Maintenance and Preventive Care

Key informants agreed that some patient preferences may only emerge or be captured during a conversation between the patient and their clinician during a clinical visit. These may include **preferences related to preventive care**, such as receiving a lung cancer screening.

Exhibit 4 illustrates a scenario in which a patient is attending a primary care visit to discuss routine health maintenance or preventive care activities, such as receiving a lung cancer screening. Here, the patient can share routine **administrative preferences**, such as preferences related to their personal identifiers, before the clinical visit via a patient-facing technology, as described in Scenario 1. In addition, the patient may also provide general **preferences focused on preventive health**, such as their desire to receive a specific screening at their next visit, via the patient-facing technology.

Exhibit 4. Collecting Preferences Related to Health Maintenance/Preventive Care



 Indicates points where patient preferences could be collected.

If available and applicable to the focus of the clinical encounter, the patient-facing technology can also provide a decision support tool to the patient before the clinical visit. The patient-facing technology receives the information shared by the patient and shares the data with a clinician-facing technology, which the clinician can review before the healthcare encounter. The patient-facing technology then uses the preference information shared by the patient to create a summary and, if applicable, generates a corresponding decision support.

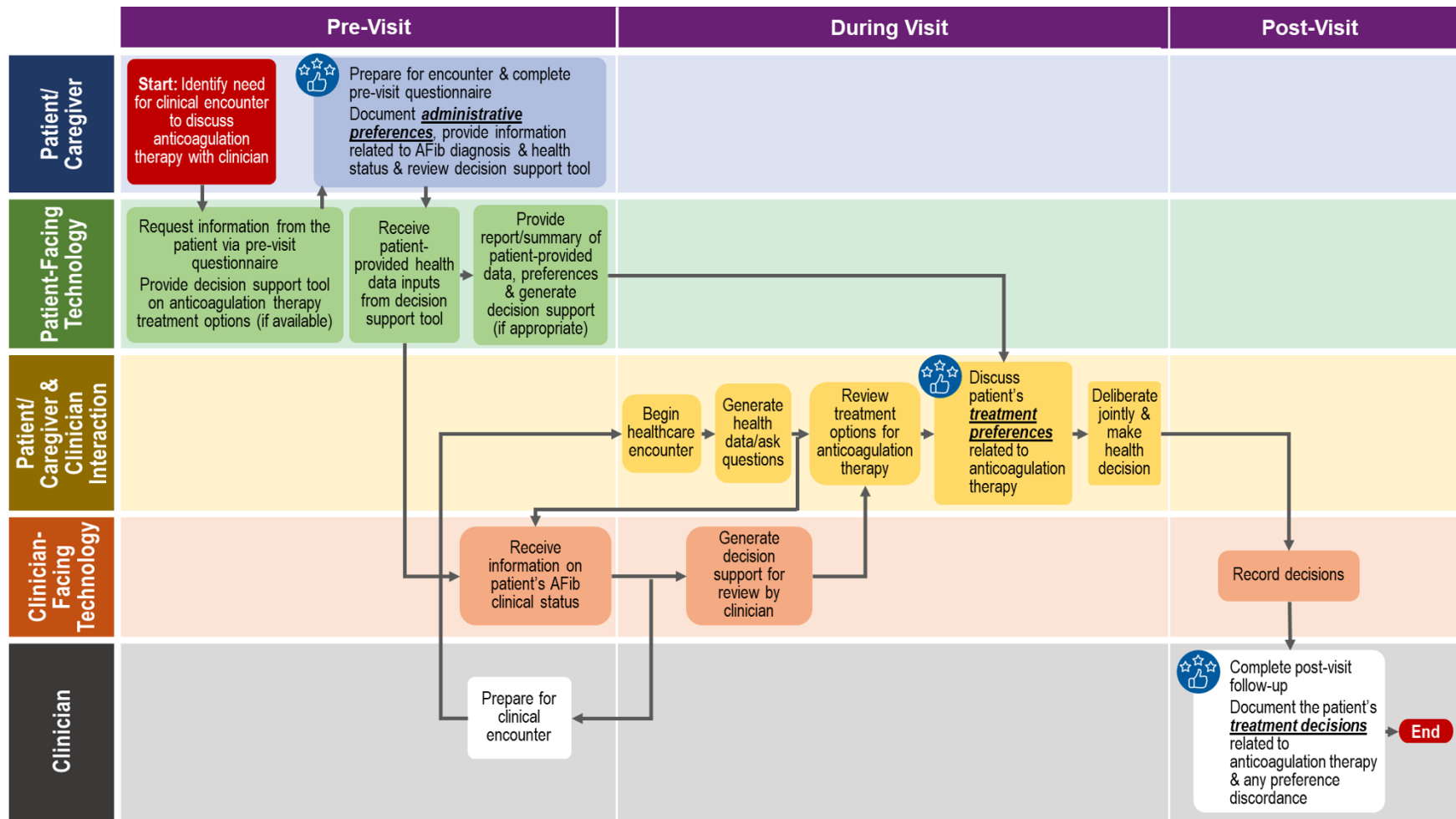
Once the healthcare encounter begins, additional data provided by the patient during the visit will also be added to the clinician-facing technology. The clinician-facing technology will use this information to generate decision support. The patient and clinician can use this decision support, as well as the summary or decision support generated by the *patient*-facing technology, to inform a discussion of the patient's vaccination preferences. After the visit, the clinician-facing technology records the decision(s) made, and the clinician documents the patient's final decision(s) and any discordance.


4.3. Clinical Scenario 3: Discussing Medication Therapy Choices

As noted above, key informants shared that some preferences are best discussed and captured during the clinical visit. These often include **treatment preferences**, as determining a course of treatment is a complex process, and SDM is essential to ensure patient perspectives and circumstances are understood and integrated into the decision-making process.⁵ The discussion of treatment preferences may also include preferences related to engagement, such as the patient's preferences related to supporting their ability to self-manage their condition.

Exhibit 5 illustrates a scenario in which a patient with atrial fibrillation (AFib) discusses treatment and engagement preferences related to anticoagulation therapy with their clinician. Anticoagulation therapy helps reduce the risk of ischemic stroke in AFib patients and is a real-world application of CDS.^{25,26}

Exhibit 5. Discussing Medication Therapy Choices



 Indicates points where patient preferences could be collected.

As shown in the previous swimlane diagrams, the patient can share **administrative preferences** before the clinical visit. The patient-facing technology can also provide a decision support tool focused on anticoagulation therapy options to the patient before the clinical visit. The patient-facing technology then receives the preference information shared by the patient and shares the data with a clinician-facing technology, which the clinician can review to prepare for the healthcare encounter. The patient-facing technology also uses the preference information shared by the patient to create a summary and, if applicable, generate patient-facing decision support.

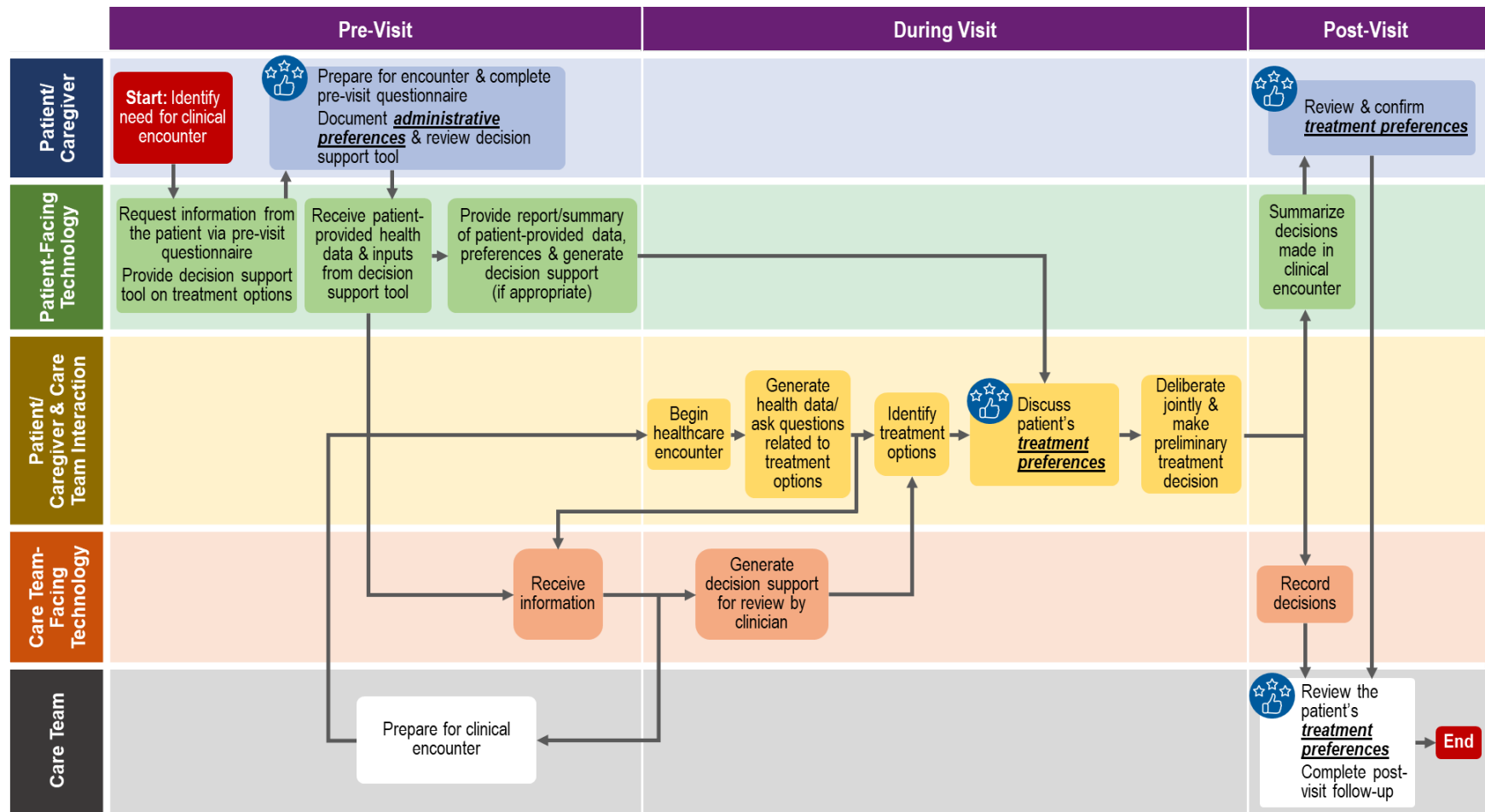
Once the healthcare encounter begins, additional health and preference data provided by the patient during the visit will also be added to the clinician-facing technology. The clinician-facing technology will use this information, along with the evidence-based recommendations, to generate decision support for review by the clinician during the encounter, which can be used to explain the evidence to the patient and facilitate a discussion of available options for anticoagulation therapy. The patient and clinician then discuss the patient's preferences for anticoagulation therapy. Following joint deliberation, the patient and clinician will either make or defer the treatment decision. Following the visit, the clinician-facing technology records the decisions made, and the clinician documents the patient's final treatment decision and any preference discordance.


4.4. Clinical Scenario 4: Discussing Treatment Options for Breast Cancer

The final swimlane diagram focuses on a clinical scenario in which a patient needs to make a complex clinical decision related to their ongoing treatment, which could involve selecting from a range of treatment options. While our scenario focuses on a particular condition, these processes could be applied to other scenarios in which patients would express preferences related to their treatment.

In this specific scenario, illustrated in Exhibit 6, a patient with breast cancer initiates a clinical visit to discuss complex treatment options with their clinician. Like in clinical scenario 3, SDM is critical to ensuring that patient values, goals, preferences, and circumstances are considered alongside the evidence to inform treatment choice. Here, a patient may consider several possible treatment methods, including radiation, chemotherapy, hormone therapy, immunotherapy, surgery, or a combination of these methods.²⁷

Exhibit 6. Discussing Treatment Options for Breast Cancer



 Indicates points where patient preferences could be collected.

In this scenario, the patient can share **administrative preferences** before the clinical visit, as in the prior scenarios. Here, clinicians can also provide patients with a decision support tool on breast cancer treatment options via a patient-facing technology that patients can review and use to provide information before a clinical visit. Patients can use these decision aids to inform their initial **treatment preferences**, which can then form the basis of a subsequent discussion with their clinician during a visit. Key informants noted that often patients need some advance information or education prior to identifying their preferences about a certain topic, especially complex clinical decisions.

Similar to Scenarios 2 and 3, the patient-facing technology receives the preference information provided by the patient and shares the data with a clinician-facing technology, which the clinician can review to prepare for the healthcare encounter. The patient-facing technology also uses the preference information shared by the patient to create a summary and, if applicable, generate patient-facing decision support.

With the start of the healthcare encounter, additional health data provided by the patient during the visit will also be added to the clinician-facing technology. The clinician-facing technology will use this information to generate decision support for review by the clinician during the encounter, which can be used to identify treatment options. The patient and clinician then discuss the patient's breast cancer treatment preferences within the context of available evidence and the care team's knowledge and experience. The summary or patient-facing CDS generated by the patient-facing technology can be used to further inform this discussion.

Following joint deliberation, the patient and clinician make a preliminary treatment decision. Post-visit, while the clinician-facing technology records the decisions made, the patient is able to review and confirm their treatment preferences via the patient-facing technology, such as an online preference collection tool. The clinician then reviews these preferences from the patient and proceeds with the appropriate follow-up. Given the significance of this type of decision, key informants emphasized that patients should have the opportunity to reflect on and adjust their clinical preferences related to treatment options, as well as determine next steps such as the need for a follow-up appointment, after the clinical visit.

5. Considerations for Optimizing the Collection and Use of Patient Preferences for PC CDS to Reduce Burden

Findings from our literature review and key informant interviews suggest there are several opportunities to improve the collection and integration of patient preferences by ensuring these processes fit into clinician workflows and patient lifeflows.^{15,28,29,30} Informants provided several considerations to reduce burden and improve the capture of patient preferences for PC CDS.

5.1. Reducing Burden for Patients

Most informants emphasized that reducing burden on patients when collecting patient preference information requires considerations for diverse patient experiences, levels of comfort with technology, and health priorities. Key informants suggested several considerations to help reduce burden and support the sharing of preferences in patient lifeflows.

Encourage patients to provide this information. A few informants noted that patients are often asked to complete multiple forms and questionnaires related to their clinical care. They noted the importance of communicating the purpose and value of preference information to motivate patients to complete preference collection instruments within the patient lifeflow. Additionally, some informants emphasized that health systems need to demonstrate how preference information was actually used to tailor the care that patients receive.

“Obviously we can’t just ask patients to fill out these questions and then not have the conversation [to] follow up on them ... otherwise they’ll think it was [just] one more thing they were asked to do. So, it definitely needs to be something that is discussed. Especially maybe when they’re kind of trying to come up with their treatment plan or talking about the different decisions that need to be made.” – Key Informant

Gather preferences that are important to patients’ care. Most informants recognized that certain preferences may not be important to all patients. Thus, patients should be allowed to provide information for the preferences that are most important to them and opt out of providing information on those that are not. As an example, one informant suggested that patients could first rank the preferences that are most important to them. Follow-up questions could then be tailored to the patient’s specific priority areas to save time when completing preference-collection instruments.

“We ask them to rank what’s most important, and then based on what’s most important to them, they get questions about their preferences for those areas so that we’re really focused on what’s the most important to the patient and ... they’re not going to get exhausted by answering all these questions.” – Key Informant

Enable designated family members and caregivers to provide preference information on behalf of patients. Some informants noted that it may be difficult to collect preference information from certain patients, such as those experiencing a serious illness. One informant recommended that designated family members and caregivers should be allowed to provide this information on behalf of their loved one. This would ensure that a patient’s preferences are still captured, but they are not burdened by the data collection process while facing health concerns.

“I know [it’s] hard to be able to delegate this out, if it’s needed, to other family members, because there’s just not that capacity for some patients to do that. Or if you’re really sick ... just making it easier to be able to allow family members, or whomever you’ve designated as that decision maker, to be able to provide those patient preferences.”
– Key Informant

Use a “funneled” approach to collect patient preference information. Most informants described the potential challenges with reaching all patients when collecting preference information. They noted that methods that rely on digital health technologies may exclude patients with low digital literacy or limited experience using technology. As one informant suggested, a “funneled” approach (e.g., using online, automated data collection via the patient portal and then following up with non-responders using other methods, such as a phone call) offers multiple layers and modes of data collection and may improve the capture of this information across the patient population.

5.2. Reducing Burden for Clinicians

All informants emphasized factors such as limited bandwidth and inefficient processes that can create burden and interfere with the collection of patient preferences in clinical workflows. Additionally, most key informants shared that when patient preferences are discussed during clinical encounters, documentation of this information in the EHR is inconsistent and unstandardized, complicating its integration in clinical care. Informants provided several suggestions for reducing burden on clinicians to better support the capture and use of patient preferences.

Use a care team approach to the collection of patient preference information. Informants noted that multiple members of the care team, such as physicians, nurses, and medical assistants, may be involved in the collection of patient preferences. Additionally, some care team members may be better suited to collect certain types of preferences due to their bandwidth and level of professional experience. As a result, the full care team can be involved in this process to reduce the burden on any one clinician and ensure effective coordination.

Ensure patient preference data are easily accessible to clinicians. All informants emphasized that patient preference information should be readily available to clinicians to support its use in clinical care. For example, an informant suggested a summary of patient preferences be located in a designated tab in the EHR to establish a standardized space for recording and reviewing preference information.

Some informants suggested that specific preferences be displayed to the clinician when reviewing related information in the EHR (e.g., patient-provided preferences about vaccination when reviewing their vaccination history) so the timing of their review and discussion of preferences during the clinical encounter is appropriate. Additionally, a few informants noted that current patient preference collection systems are often housed separately from the EHR, requiring clinicians to navigate to different online platforms to review preference information. They recommended enhancing interoperability between patient preference collection systems and the EHR to support integration and streamline workflows when accessing this information.

“Ideally, when those preferences are collected, they would go somewhere in the EHR that’s easy to get to. I mean, a lot of things in the EHR are kind of hidden in certain tabs and not all providers know where to go to find them, and they don’t even know they’re there. So, I think it is best to kind of have it go into some central place, maybe where the patient demographics are, where people go to look to see.” – Key Informant

6. Discussion

Identifying patient preferences and integrating them into PC CDS has emerged as a crucial effort.¹ By identifying and filling some existing gaps in the knowledge regarding the timing and methods for capturing patient preferences, this report lays the groundwork for future research and practical applications in real-world clinical settings. The report provides an overview of the various timepoints and methods employed in collecting different types of patient preference data for PC CDS. The visual representations provided in the report offer an overview of the steps involved in collecting and integrating patient preference data, serving as a valuable resource for health system leaders and information technology (IT) developers seeking to optimize PC CDS tools and workflows. Additionally, they can help to empower patients, emphasizing the centrality of their preferences to healthcare decision-making and recognizing that they are deserving of this type of collaborative, patient-centered care. This report can facilitate ongoing dialogue and collaboration among stakeholders to advance the integration of patient preferences into PC CDS and ultimately improve patient-centered care outcomes.

6.1. Areas for Future Work

Our literature review and key informant interview findings provide suggestions for incorporating patient preferences into PC CDS, highlighting this as an area ripe for exploration and development. Below are some short- and long-term opportunities that emerged for consideration.

Short-Term Opportunities

Promote the importance of including patient preferences in PC CDS tools. Some informants discussed the inherent power differential in the patient-clinician relationship and how it presents challenges for patients in having their voices heard. Care teams should be aware of how this power dynamic could limit patients' willingness to share their preferences. Future efforts can aim to empower patients by emphasizing that healthcare decision-making should be driven by their preferences, thereby fostering a more collaborative approach to care.

Educate clinical staff to better recognize and accommodate diverse patient preferences. The collection and discussion of patient preferences offer avenues for enhancing cultural understanding within healthcare settings. Some informants suggested that future initiatives should prioritize educating clinical staff to enhance their ability to identify and accommodate a wide range of patient preferences, ultimately fostering stronger trust between patients and clinicians.

Explore the use of mixed modes of data collection to capture patient preferences comprehensively. All informants noted that while patient preference collection systems should be easy to use and analyze, preferences do not always fit into discrete or binary categories, and there needs to be a balance between standardization and free text capture. To allow for a more comprehensive understanding of patients' preferences, informants suggested testing options for inputting non-discrete data in patient preference collection systems (e.g., free-text boxes in online surveys).

Identify and implement best practices for patients to view and access their own patient preference data. Some informants emphasized the pressing need to enhance patients' access to their

own medical data. They underscored the significance of this process in identifying best practices, particularly in facilitating the management of patient preference information. Access to their preference information will enable patients to validate and update data regularly, ensuring its accuracy and relevance.

Long-Term Opportunities

Investigate clinical workflows and patient lifeflows that can be leveraged to capture changes in patient preferences over time. Most informants highlighted the dynamic nature of patient preferences and how they can evolve over time and/or with changes in the patient's disease progression or lifestyle. Future work should focus on developing adaptable best practices for integrating evolving patient preferences into healthcare delivery.

Prioritize the implementation of robust tools and methodologies for gathering patient preferences for use in routine clinical care. Despite continued efforts to make healthcare more patient-centered, a significant gap persists in the routine, comprehensive collection of patient preferences within clinical practice. Based on the findings of this report, most existing efforts pertaining to patient preference measures and tools have been in the realm of research. Moving forward, it is imperative to prioritize the implementation of robust tools and methodologies aimed at gathering and seamlessly integrating patient preferences into routine clinical workflows.

Leveraging artificial intelligence (AI) to automate the collection and aggregation of patient preference information for PC CDS. As AI becomes increasingly integrated into healthcare systems, there is an opportunity to automate the collection and summarization of patient preference data for PC CDS. For example, natural language processing methods have been used to extract unstructured patient-generated health data from clinical notes³¹ and could be used to synthesize free-text patient-provided information. AI technologies are being leveraged for precision medicine and CDS by tailoring recommendations based on unique patient characteristics.³² Most informants mentioned that leveraging AI technologies to streamline the patient preference integration process for PC CDS could ultimately reduce burden for both clinicians and patients. It could also help clinicians improve their understanding and use of this data in clinical care.

6.2. Limitations

There are some limitations to the findings outlined in this report. First, it is important to note that the timepoints designated for patient preference data collection, the methods utilized for capturing this data, and the steps outlined in the swimlane diagrams are not exhaustive. The field of patient preference data integration into PC CDS is still in its early stages. As such, the swimlane diagrams are primarily derived from key informant interview findings.

The report illustratively outlines how patient preference data is currently (or could be) collected and integrated into PC CDS workflows and lifeflows using four example clinical scenarios. The steps identified across these scenarios may not account for or visually represent all nuances. Additionally, these may not necessarily be applicable to all clinical scenarios. Therefore, the swimlane diagrams will need to be revisited as health systems progressively integrate patient preference data into routine clinical care for different use cases.

7. Conclusion

Collecting and incorporating patient preferences for PC CDS is vital for personalized care, treatment adherence, and collaborative patient-provider relationships, and can lead to improved health outcomes and address care disparities.^{33,34} This report describes the timepoints and various methods for capturing different types of patient preference data and visualizes these within patient lifeflows and clinical workflows through four distinct clinical use cases. It also offers considerations to reduce patient and clinician burden. Additional approaches to enhance the clinical utility of patient preferences identified in the report include communicating value to patients, using multiple modes of data collection, ensuring easy clinician access to these data, and potentially leveraging AI for automatic entry and analysis. Health system stakeholders and PC CDS developers seeking to optimize the collection and utilization of patient preference information for PC CDS may find valuable insights in this report.

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