

Measurement and Outcomes Workgroup: Patient Prioritization of Measurement Areas for Patient- Centered Clinical Decision Support

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

Contract No: 75Q80120D00018

Prepared by:

Rachel T. Kurtzman, PhD
Priyanka J. Desai, PhD, MSPH
Mustafa Ozkaynak, PhD, MS
Polina Kukhareva, PhD, MPH
Frances Jiménez, MPH
Ruth Nwefo, MPH
Prashila M. Dullabh, MD, FAMIA
CDSiC Measurement and Outcomes Workgroup

AHRQ Publication No. 24-0069-2
July 2024



PURPOSE

The Clinical Decision Support Innovation Collaborative (CDSiC) aims to advance the design, development, dissemination, implementation, use, measurement, and evaluation of evidence-based, shareable, interoperable, and publicly available patient-centered clinical decision support (PC CDS) to improve health outcomes of all patients by creating a proving ground of innovation. The Measurement and Outcomes Workgroup supports the measurement of PC CDS implementation and effectiveness to ensure that PC CDS works as intended. The Workgroup is comprised of 8 eight experts representing diverse perspectives related to CDS. This report is intended for those interested in collecting and measuring patient preferences that are relevant to PC CDS. All qualitative research activities conducted by the CDSiC are reviewed by the NORC at the University of Chicago Institutional Review Board (FWA00000142).

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

This document is in the public domain and may be used and reprinted without permission in the United States unless materials are clearly noted as copyrighted in the document. No one may reproduce copyrighted materials without the permission of the copyright holders. Users outside the United States must get permission from AHRQ to reprint or translate this product. Anyone wanting to reproduce this product for sale must contact AHRQ for permission. Citation of the source is appreciated.

SUGGESTED CITATION

Kurtzman RT, Desai PJ, Ozkaynak M, Kukhareva P, Jiménez F, Nwefo R, Dullabh PM, and CDSiC Measurement and Outcomes Workgroup. Patient Prioritization of Measurement Areas for Patient-Centered Clinical Decision Support. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 24-0069-2. Rockville, MD: Agency for Healthcare Research and Quality; July 2024.

Contributors: CDSiC Measurement and Outcomes Workgroup

Members of the Measurement and Outcomes Workgroup who contributed to this report are listed below.

| Name | Affiliation |
|--|---|
| Jonathan Einbinder, MD, MPH | Harvard University School of Public Health |
| Ben Hamlin, DrPH | Liaison to Federal Agencies and HL7 Communities |
| Wayne Liang, MD, MS | Emory University, Children's Healthcare of Atlanta |
| Scott MacDonald, MD, FACP, FAMIA | University of California Davis Health |
| Kistein Monkhouse, MPA | Patient Orator |
| Richard Schreiber, MD, FACP, FAMIA, ABPM-CI | Pennsylvania State University |
| Karen Sepucha, PhD | Harvard Medical School, Mass General Research Institute |
| Dean Sittig, PhD | University of Texas |

Table of Contents

- Executive Summary.....1
- 1. Introduction.....5
 - 1.1 Report Roadmap.....6
- 2. Methods7
 - 2.1 Initial Ranking of Importance.....7
 - 2.2 Virtual Panel Discussion7
 - 2.3 Final Prioritization7
- 3. Findings.....8
 - 3.1 Findings from the Initial Ranking of Importance.....8
 - 3.2 Findings from the Discussion Panel9
 - 3.2.1 Key Themes9
 - 3.2.2 Top 3 to 5 Measurement Areas12
 - 3.3 Findings from Final Ranking.....12
- 4. Discussion.....13
 - 4.1 Implications for PC CDS Measurement.....14
 - 4.2 Future Directions.....15
 - 4.3 Limitations.....16
- 5. Conclusions.....16
- Appendix A. Measurement Areas Definitions.....17
- References.....18

Executive Summary

Outcome measurement is key to determining if patient-centered clinical decision support (PC CDS) is achieving its intended purpose. PC CDS measurement should assess how and if CDSit influences outcomes important to patients. This requires identifying what process and outcome measures patients find important. Previously, the Clinical Decision Support Innovation Collaborative (CDSiC) identified patient health journey measures relevant to PC CDS. Measures of the patient health journey assess 15 areas related to patients' lived experiences across three domains: patient decision making, patient engagement, and patient care. This report summarizes preliminary work to identify what measurement areas within the patient health journey are essential to patients when assessing PC CDS and why. This report can be used by PC CDS researchers and implementers, as well as healthcare organizations to inform what patient-centered measurement areas should be included in PC CDS assessments.

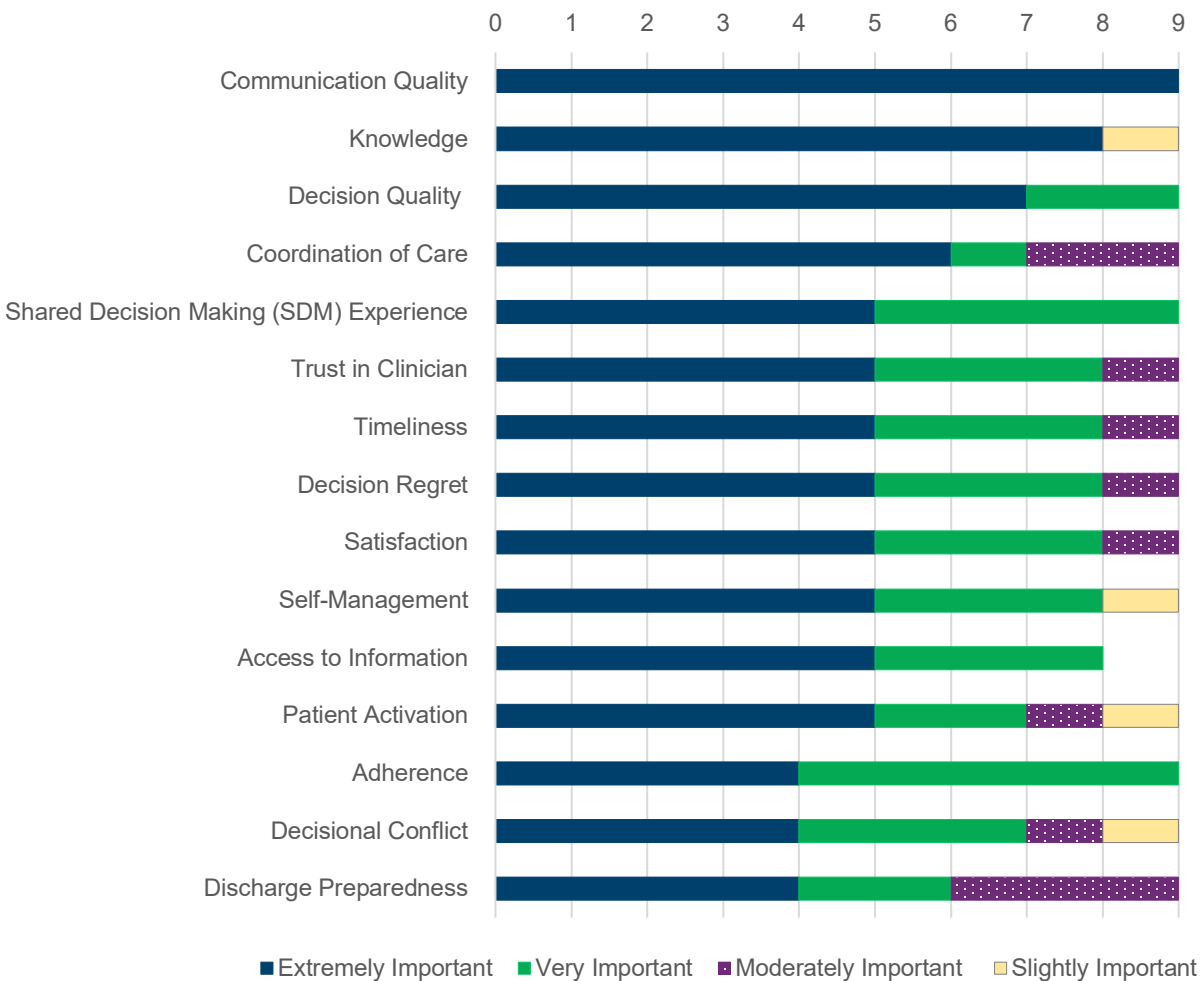
Methods

To understand what areas within the patient health journey were most important to patients, we conducted a modified Delphi panel to elicit patient and patient advocate feedback. We recruited nine patients and patient advocates to participate in three rounds of a prioritization activity. In the first round, participants completed an online form indicating the importance of each of the 15 patient health journey measurement areas using a five-point Likert scale from "Extremely Important" to "Not Important." In the second round, participants were invited to participate in a virtual 2-hour panel discussing results from the initial ranking, and the importance of the measurement areas. Following the virtual panel discussion, participants were invited to complete a final activity ranking all 15 measurement areas in order of importance.

Findings

Nine participants completed the first round of the prioritization activity. All participants indicated that communication quality was extremely important. Communication quality is whether the right information was shared at the right time in the right way by the clinician and whether patients were able to ask questions and engage with their healthcare clinicians. Other areas ranked highly in terms of importance included knowledge, decision quality, coordination of care, and shared decision making experience. No areas were ranked as "Not Important" (Figure 1).

Figure 1. Results from Round 1 Importance Ranking



Eight participants attended the virtual discussion panel. Five of these participants reported they were cancer survivors and worked with cancer advocacy or cancer research organizations; two participants worked with rare disease patient advocacy organizations; and one participant was a patient partner for multiple chronic conditions. Several participants noted their involvement in previous research and patient engagement work. During the panel, three overarching themes were identified:

- **The role of context.** Participants discussed how the importance of measurement areas depends on context. This could be a time-dependent context, such as time since diagnosis; personal factors, such as whether the patient has caregiving responsibilities that influence their own care; who the patient is interacting with in a healthcare setting; and the involvement of caregivers in decision making.
- **The connections between measurement areas.** Participants noted there are connections between measurement areas, and there may be dependencies between these areas. Specifically, participants discussed that many of the measurement areas, including shared decision making and knowledge, are impacted by communication quality and trust in clinician.

- **The importance of measuring other areas that impact the patient health journey.** Participants highlighted three additional areas they felt were critical to measure from a patient perspective: cost, access to care, and social determinants of health (SDOH) or health-related social needs (HRSN). These areas were noted not necessarily as patient health journey outcomes, but rather as inputs into healthcare decision making that influence other outcomes.

Seven participants were engaged in the third round of the prioritization activity and ranked the relative importance of each measurement area. The final prioritized ranking is noted below (Figure 2).

Figure 2. Patient Health Journey Measurement Areas Rankings

| Final Ranking | Measurement Area | Patient Health Journey Domain |
|---------------|-----------------------------------|-------------------------------|
| 1 | Communication Quality | Patient Care |
| 2 | Trust in Clinician | Patient Engagement |
| 2 | Access to Information | Patient Care |
| 3 | Knowledge | Patient Engagement |
| 4 | Shared Decision Making Experience | Patient Decision Making |
| 5 | Decision Quality | Patient Decision Making |
| 5 | Decisional Conflict | Patient Decision Making |
| 6 | Timeliness | Patient Care |
| 7 | Patient Activation | Patient Engagement |
| 8 | Adherence | Patient Engagement |
| 8 | Coordination of Care | Patient Care |
| 9 | Self-Management | Patient Engagement |
| 10 | Satisfaction | Patient Care |
| 11 | Decision Regret | Patient Decision Making |
| 12 | Discharge Preparedness | Patient Engagement |

Discussion

The findings from this prioritization activity have several implications for the measurement of PC CDS. This activity highlights the value of understanding what outcomes patients find important, as these may not be the areas researchers and implementers first think to assess for PC CDS. Many PC CDS studies assess patient satisfaction or adherence, but participants did not prioritize these areas. Participants also noted several additional areas that impact the importance of patient health journey measurement areas, including the involvement of

caregivers, SDOH, and HRSN. The impact of caregivers on outcome measurement in PC CDS is an emerging area, as caregivers represent an additional stakeholder. It is unknown how measurement instruments can best be deployed when caregivers are involved. Additionally, while there is a growing body of evidence that SDOH and HRSN significantly impact outcomes, more research is needed to understand how these factors can impact outcomes in PC CDS.

The findings further highlight several important areas for future work in PC CDS. Specifically, future work should focus on identifying appropriate instruments for the prioritized patient health journey measurement areas. Additionally, there are potentially evolving measurement needs related to access to information, and further investigation is needed to identify the context-specific importance of measurement areas.

Conclusion

This report outlines the patient health journey measurement areas prioritized through a modified Delphi panel and highlights important findings noted by participants. The results from this activity further point to several areas for future work, including emergent fields in PC CDS related to SDOH and HRSN, the importance of context in measuring these concepts, and the need to identify instruments for the prioritized areas.

1. Introduction

Patient-centered clinical decision support (PC CDS) helps provide timely information that can inform healthcare decision making for clinicians, patients, and other healthcare partners such as caregivers.¹

PC CDS assessments can be used to understand how PC CDS workflows can be improved, if PC CDS needs to be modified or adapted, and if it is functioning as intended.^{3,4,5} Measuring outcomes is key to determining if PC CDS is achieving its intended purpose of supporting patient-centered care delivery, and ultimately improving health outcomes. As PC CDS is intended to support patients' decision making, it is essential to identify measures that assess if and how PC CDS influences outcomes important to patients.^{3,4} In reviews and studies, outcomes assessed in CDS have primarily focused on implementation (uptake, workflow, acceptance) and systems-level factors like cost.^{6,7} However, there are gaps in the literature regarding how relevant outcomes and indicators are identified. Assessment of patient and clinician-specific outcomes has been limited, often focused on adherence of the clinician to recommended practices.⁷

PC CDS encompasses a spectrum of decision making tools that significantly incorporate patient-centered factors related to knowledge, data, delivery, and use.²

- *Knowledge* refers to the use of comparative effectiveness research or patient-centered outcomes research (PCOR) findings.
- *Data* focuses on the incorporation of patient-generated health data, patient preferences, social determinants of health (SDOH), and other patient-specific information.
- *Delivery* refers to directly engaging patients and/or caregivers across different settings.
- *Use* focuses on facilitating bi-directional information exchange in support of patient-centered care, including shared decision making.

There has also been limited measurement of the impact of PC CDS on patient engagement in care. This is a critical gap; engaging patients in healthcare decision making has significant benefits, and patients report higher satisfaction with care, increased knowledge, and more realistic expectations about benefits and harms when they are effectively engaged.⁸ Given that PC CDS can support patients in making health care decisions, improve engagement, and ultimately improve the patient care experience, measurement of PC CDS should assess how and if PC CDS influences the outcomes important to patients.³ This requires the identification of what is important to patients.² Previously, the Clinical Decision Support Innovation Collaborative (CDSiC) identified patient health journey measures relevant to PC CDS. These measures include both process and outcome measures. It is important to measure both process and outcome measures to identify if PC CDS is truly impacting care processes.⁵ This prior work defined the patient health journey as the range of experiences a patient has accessing and receiving healthcare, including interactions and engagement with clinicians and systems, as well as their experience living with a health condition(s). Measures of the patient health journey

assess 15 areas related to patients’ lived experiences across three domains: patient decision making, patient engagement, and patient care (Exhibit 1).³

Exhibit 1. Patient Health Journey Domains and Measurement Areas

| Patient Health Journey Domain ⁱ | Patient Decision Making | Patient Engagement | Patient Care |
|--|---|---|--|
| Measurement Areas | <ul style="list-style-type: none"> • Decision Quality • Decision Regret • Shared Decision Making Experience • Decisional Conflict | <ul style="list-style-type: none"> • Knowledge • Activation • Adherence • Self-Management • Discharge Preparedness • Trust in Clinician | <ul style="list-style-type: none"> • Timeliness • Information Access • Communication Quality • Coordination • Satisfaction (Care) |

As PC CDS advances, it is important to understand not just what areas within the patient health journey we can measure, but also which areas are most important to patients. Identifying important areas for patients could inform standardizing PC CDS measurement. This report summarizes preliminary work in the process of identifying what is important to patients when assessing PC CDS, and why. It also identifies potential gaps that should be priority areas for measure development to meet the needs of patients.

1.1 Report Roadmap

This report describes the methods and results from a prioritization activity for patient health journey measurement areas. The report includes the following sections:

- *Methods.* This section summarizes our approach to conducting a modified Delphi prioritization activity.
- *Findings.* This section summarizes the key findings from the three rounds of the prioritization activity and outlines the prioritized measurement areas.
- *Discussion.* This section presents our discussion about the key findings and their implications, highlighting existing knowledge gaps and areas of future work.
- *Conclusions.* This section summarizes the conclusions from this modified Delphi prioritization activity.

This report can be used by PC CDS researchers and implementers as well as healthcare organizations to inform what patient-centered measurement areas should be included in PC CDS assessments. The prioritized list of measurement areas can support the standardization of measurement of the patient health journey for PC CDS.

ⁱ We note that the Agency for Healthcare Research and Quality (AHRQ) Consumer Assessment of Healthcare Providers and Systems (CAHPS) uses the term “[patient experience](#),” which broadly encompasses the entire patient health journey and includes measurement areas in all three domains.

2. Methods

Selecting outcomes of interest to patients should involve patient engagement.⁸ To understand the areas within the patient health journey that are most important to patients, we conducted a modified Delphi panel to elicit patient and patient advocate feedback. Modified Delphi studies are a method for building consensus among participants and have been used for various purposes including prioritization of measures and outcomes.⁹⁻¹¹ For this modified Delphi panel, we conducted three rounds, including two ranking activities and a discussion panel, to prioritize the measurement areas. We recruited nine patients and patient advocates, hereafter referred to as participants, for these activities. Potential participants were identified through snowball sampling and included individuals from throughout the United States. We elaborate on the methods below.

2.1 Initial Ranking of Importance

In the first round of the prioritization activity, participants completed an online form asking them to rank the importance of each of the 15 patient health journey measurement areas identified in Exhibit 1. For each measurement area, participants were provided a definition (Appendix A), and asked about the importance of each area on a 5-point Likert scale from “Extremely Important” to “Not at all Important.” We included a response option of “I don’t know,” acknowledging that individuals may be uncertain about some areas. Items were not ranked in relation to each other, but rather individuals were asked to indicate the importance of each item. To analyze results, we aggregated ratings of importance for all 15 areas and developed stacked bar charts to observe patterns in responses.

2.2 Virtual Panel Discussion

In the second round of this prioritization activity, the participants were invited to participate in a virtual 2-hour panel discussion. This panel was held via Zoom and recorded with participant consent. Before the meeting we developed a brief discussion guide focused on We developed a brief discussion guide prior to the meeting, focusing on first presenting the results from the initial ranking of importance, discussing further the importance of the measurement areas, and ending with a round-robin question asking participants to rank the measurement areas they found most important. Two CDSiC team members took notes during the panel, which were verified for accuracy with the panel recording. To derive qualitative findings, the panel notes were analyzed using qualitative content analysis to explore connections between measurement areas, understand emergent measurement areas, and identify potential considerations for when specific measurement areas may be of greater importance.¹²

2.3 Final Prioritization

Following the virtual panel discussion, the participants were invited to complete the final ranking. Participants were asked to rank all 15 measurement areas against each other in order of importance using a drag-and-drop function (1 as most important and 15 as least important). In addition, we included two open-response questions based on the discussion during the virtual

panel. The first asked if participants' rankings would change if a caregiver was involved in patient care. The second asked about the emergent measurement areas identified during the panel, specifically cost of care, access to care, and SDOH. Ranking responses were analyzed in Excel and visually examined. Qualitative responses were analyzed separately to identify themes.

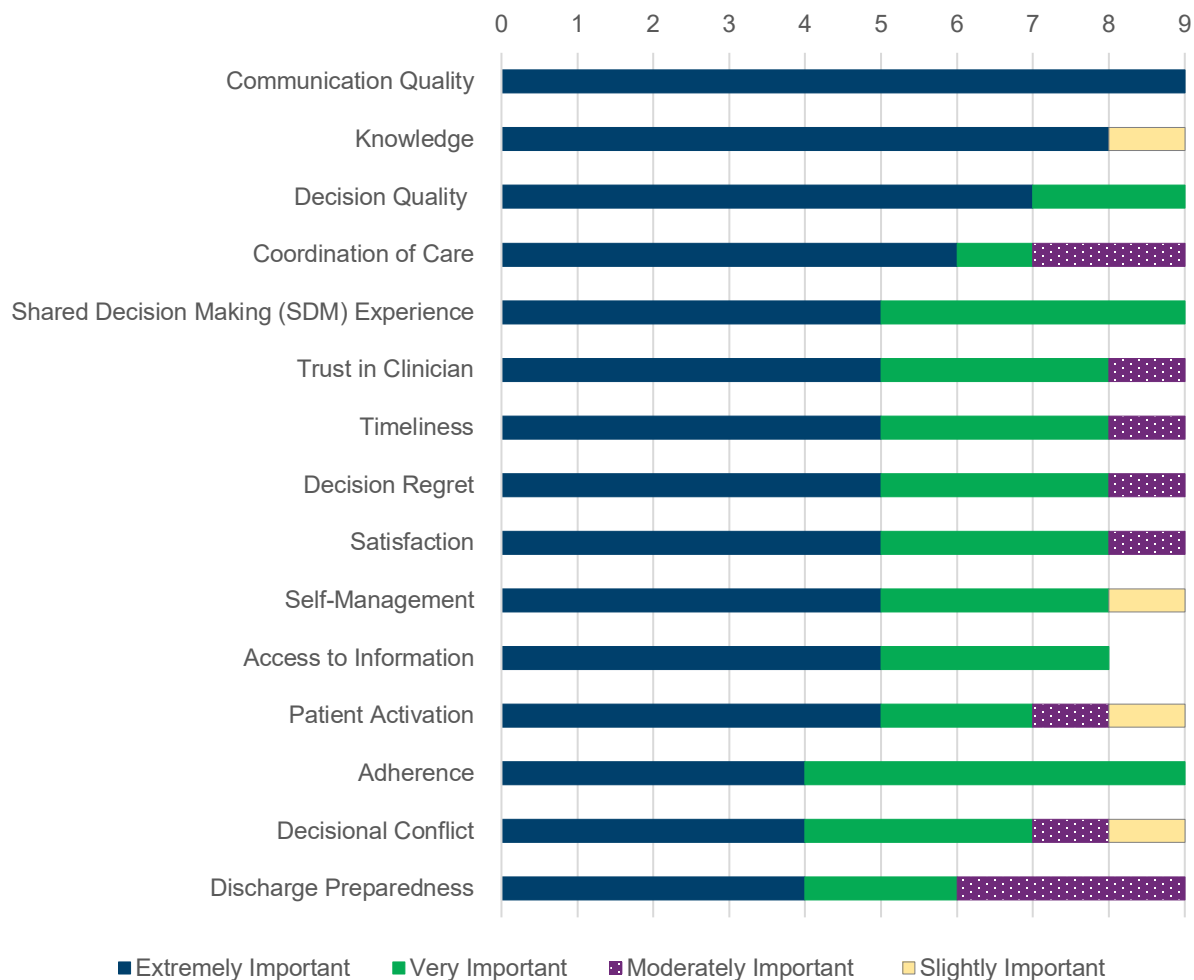
3. Findings

The following sections summarize the findings from the three rounds of the prioritization activity and details the final measurement area prioritized by participants.

3.1 Findings from the Initial Ranking of Importance

There were nine participants in the first round of the prioritization activity. All measures were ranked between “Extremely Important” and “Slightly Important;” no measures were ranked as “Not Important” (**Exhibit 2**). Twelve of the 15 measurement areas were indicated to be “Extremely Important” by at least half of the participants.

Exhibit 2. Summary of Round 1 Importance Rankings



Communication quality was the only measurement area ranked as “Extremely Important” by all nine participants. Other areas ranked highly in terms of importance included knowledge, decision quality, coordination of care, and shared decision making experience. For items ranked in the middle, trust in clinician, timeliness, decision regret, and satisfaction were all ranked the same. Self-management and access to care were also in the middle in terms of rankings, with the same number of participants ranking these as “Extremely Important” and “Very Important.” However, self-management was ranked as “Slightly Important” by one participant. Access to information was the only area where a participant chose the response option “I don’t know.” The areas ranked lowest in importance included patient activation, adherence, decisional conflict, and hospital discharge preparedness. Adherence, decisional conflict, and discharge preparedness were the only measurement areas where less than half of participants selected “Extremely Important.”

We did not observe any trends in terms of importance and patient health journey domains. The top measurement areas fell across all three domains—communication quality and coordination of care within patient experience, knowledge within patient engagement, and decision quality and shared decision making experience within patient decision making. The areas ranked as the least important fell within two domains: patient decision making and patient engagement.

3.2 Findings from the Discussion Panel

Eight participants attended the virtual discussion panel.ⁱⁱ Five participants reported they were cancer survivors and work with cancer advocacy or cancer research organizations; two participants work with rare disease patient advocacy organizations; and one participant is a patient partner for multiple chronic conditions. Several participants noted their involvement in previous research and patient engagement work.

3.2.1 Key Themes

Participants noted that the importance of measurement areas depends on context. This could be time-dependent contexts, such as time since diagnosis, personal factors such as if the patient has caregiving responsibilities influencing their own care, who the patient is interacting with in a healthcare setting, and the involvement of caregivers. Participants discussed how patient needs can vary over the course of an illness, from initial diagnosis to ongoing management. When a patient is newly diagnosed, their needs may be related more to knowledge and understanding of their disease, rather than making decisions or advocating for their healthcare choices. Another

“I think that we also need to be aware that at different times another could be more important. So, when you first start out, you first get your diagnosis communication and knowledge and shared decision making. All that can be very important. But it could also change over time depending on where you are in a process.”

ⁱⁱ One individual who participate in the original ranking did not attend the virtual panel.

participant noted that knowledge can be situational; it implies there is knowledge of the disease or condition, but with rare diseases or complex situations, knowledge may not be available.

The importance of some measurement areas may also vary depending on who the patient is engaging with. As a participant mentioned, patients may have different expectations for trust and communication quality from their primary care clinician or specialist compared to an emergency department physician. When a patient sees a specialist or primary care clinician, they expect the clinician to have prior information about their health and access to their records, but do not necessarily expect that in an emergency department. These different expectations can impact communication quality, which, when lower than expected, can reduce trust in decision making. The importance of ensuring clinicians have consistent access to healthcare information and records throughout medical systems to improve communication was raised by a participant. In addition, the length of the relationship with the clinician can impact the importance of these measurement areas, as patients may have different expectations for trust in a clinician they have seen for some time versus a newer clinician.

Participants discussed the impact of caregivers and social support systems in healthcare decision making, and noted these individuals can influence many factors of a patient's health journey. As one participant noted, patients with more limited social support systems may make different decisions about where they receive treatment or what types of treatments they receive. This support was noted as a particular issue when discussing discharge preparedness, as caregivers can be particularly important in this context. Another participant discussed how the opinion of a caregiver can be very important during decision making. If the caregiver trusts the clinician, they may be inclined to agree with them and can push a decision onto the patient. A participant shared that in their experience, decisions are very often influenced by the caregiver, and ultimately, some of the choices made do not reflect the decision the patient would make for themselves. Alternatively, if a clinician does not communicate with a patient's caregiver or support system, this can foster distrust.

Participants also noted connections and dependencies among the measurement areas.

Specifically, participants discussed that many of the measurement areas are impacted by communication quality and trust in clinician. They said communication quality influences shared decision making, and shared decision making is difficult to achieve without trusting the clinician. Additionally, participants flagged that trust could impact decision conflict and satisfaction with your decision. They emphasized the connection between communication quality and knowledge: when communication quality is poor, patients do not get the information they need. In discussing how communication quality influences knowledge, participants provided examples of overly complex language used during clinical encounters and incomplete information about diagnoses or treatments shared by clinicians. In these cases, poor communication quality can negatively influence patient knowledge. As one participant shared, *"We see this come up often that conflict, because the education and the*

"When there's trust, there's also other factors that go with it. You know, satisfaction, timeliness. You're not going to have that if you don't have trust in the clinician."

knowledge isn't there, so they don't really trust what the doctors are saying, because they don't really understand what's going on." Another participant reiterated, *"but it's not the language of patients, and very often the patient is hesitant to either interrupt the doctor to ask, or to appear, you know, not smart enough."*

Some participants discussed how definitions of these measurement areas can be complex due to these dependencies and connections. For example, the definition of adherence was viewed as being particularly complex, as it should include if there was a mutually established plan for care and the factors that can prevent patients from adhering to a plan. A participant noted that sometimes a plan is developed without patient input, and then patients are non-adherent as they did not mutually agree to the plan. This implies that without shared decision making, patients and clinicians may have different expectations about adherence to a care plan, which could influence the measurement of adherence. Another participant added there should be *"recognition of the outside influence[s] that prevent the patient from adhering... things like family interactions, transportation, cost of medication or so many things outside the influence other than the interaction between patients and a doctor."*

Participants highlighted three other areas that they felt were critical to measure from a patient perspective: cost, access to care, and health-related social needs (HRSN). Several participants noted that cost is not explicitly mentioned in any of the patient health journey measurement areas, but cost influences access to care, decision making, adherence, and many other factors. For example, when clinicians make recommendations, they should consider the cost

"[If] you go into a room, and you know somebody has stated that they're having trouble paying their rent, or they're having trouble buying medications don't recommend a \$400 medication... I think it's more about knowing the person, what their needs, are because they might not want to say out loud."

of recommended treatments or procedures and other factors, like transportation to the treatment, that could hinder an individual's ability to choose a treatment. As a participant noted, *"[If] the social determinants of health are understood by the clinician when they walk in [and] that becomes part of the communication and decision making."* Likewise, access to care can be extremely important to consider for rural patients who may have to travel to appointments or not have access to the same services. Participants also raised the topic of HRSN, which can play an important role in communication and decision making. HRSN are the individual-level factors that affect a person's ability to maintain their health.¹³ These areas were seen not necessarily as patient health journey outcomes, but rather as inputs into healthcare decision making that influence other outcomes. While participants acknowledged difficulties in defining and capturing HRSN information in healthcare settings, they reiterated that clinicians should consider these factors before making recommendations to patients. A participant also noted they are aware of two measures of SDOH currently used in healthcare related to housing and food insecurity.

3.2.2 Top 3 to 5 Measurement Areas

At the end of the panel, participants were asked what they thought were the top three to five measurement areas. Communication quality, trust in clinician, and access to information were ranked as the most important areas to measure by most participants, with all participants ranking communication quality in the top and seven of eight participants ranking trust in clinician in their top measurement areas. In the initial ranking of importance, access to information and trust in clinician were not ranked among the top measurement areas. However, the importance of these areas and how they relate to other measurement areas was a major discussion point during the panel. Also ranked in the top five, though by fewer participants, were: patient activation, shared decision making, and coordination of care (each noted by three participants); self-management and access to information (each noted by two participants); and knowledge, timeliness, and discharge preparedness (each noted by one participant). Four participants also included SDOH and cost in their top measurement areas.

3.3 Findings from Final Ranking

Seven participants ranked the relative importance of each measurement area. The top five measurement areas identified were: 1) communication quality, 2) trust in clinician and access to information (tied), 3) knowledge, and 4) shared decision making. Items at the bottom of the rankings included decisional conflict, timeliness, adherence, self-management, and discharge preparedness. Exhibit 3 details the measurement rankings from Round 3.

Exhibit 3. Patient Health Journey Measurement Areas Rankings

| Final Ranking | Measurement Area | Patient Health Journey Domain |
|---------------|-----------------------------------|-------------------------------|
| 1 | Communication Quality | Patient Care |
| 2 | Trust in Clinician | Patient Engagement |
| 2 | Access to Information | Patient Care |
| 3 | Knowledge | Patient Engagement |
| 4 | Shared Decision Making Experience | Patient Decision Making |
| 5 | Decision Quality | Patient Decision Making |
| 5 | Decisional Conflict | Patient Decision Making |
| 6 | Timeliness | Patient Care |
| 7 | Patient Activation | Patient Engagement |
| 8 | Adherence | Patient Engagement |
| 8 | Coordination of Care | Patient Care |
| 9 | Self-Management | Patient Engagement |

| Final Ranking | Measurement Area | Patient Health Journey Domain |
|---------------|------------------------|-------------------------------|
| 10 | Satisfaction | Patient Care |
| 11 | Decision Regret | Patient Decision Making |
| 12 | Discharge Preparedness | Patient Engagement |

Of the measurement areas viewed as most important in the first round, communication quality remained the most important measurement area in the third round. Knowledge and shared decision making also remained in the top measurement areas, but trust in clinician and access to information, both of which were originally in ranked the middle, moved up in the final ranking. Participants initially viewed both coordination of care and decision quality as “Extremely Important” or “Very Important” during the first exercise. However, these were ranked as lower priority when compared to other measurement areas in the final round. Decision regret, satisfaction, and self-management received mixed ratings of importance ranging from “Extremely Important” to “Slightly Important” in the first round. When compared to other areas of measurement, these were viewed as lower priority. Within measurement areas originally indicated as being of lower importance, the only item that remained consistently viewed as such in the final round was discharge preparedness. Three areas originally considered of lower importance (adherence, patient activation, and decisional conflict) moved up to the middle in the final ranking.

Four participants provided additional responses regarding the importance of caregivers and the emergent areas identified during the panel. Regarding the importance of caregivers and if including caregivers would influence their rankings, results were mixed. Two participants said that involving a caregiver would not change how they ranked the measurement areas, and two participants reported it would change how they ranked specific measurement areas such as knowledge, self-management, and trust. This was echoed in the conversation during the discussion panel regarding how caregivers and other family members can impact trust in a clinician and the knowledge an individual gained from their clinician. Regarding the emergent areas of SDOH, cost, and access to care, two participants noted SDOH as one of the biggest barriers to good healthcare. A participant highlighted that while there may be trust, good communication, and shared decision making, patients may still not have access or be able to afford care.

4. Discussion

During the three rounds of this modified Delphi prioritization activity, participants assessed the importance of previously identified patient health journey measurement areas. In the final ranking, the top five items were communication quality, trust in clinician, access to information, knowledge, and shared decision making experience. During the discussion panel, participants reaffirmed the importance of communication quality, shared decision making and knowledge, and discussed the interconnected nature of these areas. Participants also discussed how these

areas related to trust and clinician and access to information, which may have contributed to their increased ranking in the final round. These top measurement areas vary a little from those noted by participants during the ranking activity at the panel's close. When completing the final ranking participants may have reflected on the conversation during the panel, which may have contributed to the higher ranking of access to information seen in the final round.

4.1 Implications for PC CDS Measurement

This activity highlights the value of understanding what outcomes patients find important, as these may not be the areas researchers and implementers first think to assess for PC CDS. Many PC CDS studies assess patient satisfaction with CDS recommendations or outcomes related to adherence.^{2,14,15} The research used to guide PC CDS and clinical guidelines often focuses on desirable behaviors clinicians would like to see, such as medication adherence.² However, these may not be important outcomes to patients or caregivers, and neither satisfaction nor adherence were prioritized as top measurement areas by participants in this activity. After the final ranking, satisfaction was ranked as one of the lowest importance areas. Furthermore, panel participants noted adherence is a complex issue interconnected with access to care, cost, and SDOH. Adherence is also related to communication and trust in clinicians, as patients may not adhere to a plan they do not understand or if they do not trust their clinician. This complexity can be challenging to measure. Adherence outcomes that do not capture this intricacy may miss important elements impacting patients' adherence to treatments or recommendations. The final rankings from this activity suggest researchers and implementers should consider other outcomes more important to patients when assessing PC CDS.

Additional topics noted by participants as impacting the importance of patient health journey measurement areas included the importance of caregivers. Caregivers can be an important partner in healthcare decision making and impact the relationship between the patient and clinician in both positive and negative ways. Research on the impact of caregivers in various clinical contexts—such as end-of-life and cancer care—has found concordance and discordance between patients and caregivers is related to a host of factors including awareness of patient preferences, quality of communication, and family roles.^{16,17} Many studies capturing outcomes with caregivers are narrowly focused on care coordination,^{16,18} but participants noted that the involvement of caregivers can impact many areas, including trust, knowledge, and self-management. The impact of caregivers on outcome measurement in PC CDS is an emerging area of study, as caregivers represent an additional partner. It is unknown how measurement instruments can best be deployed when caregivers are involved.

In the discussion of emergent areas, participants additionally discussed cost, access to care, and HRSN as factors that influence decision making and potentially other outcomes. Participants noted that neither cost nor access to care are explicit in the patient health journey measurement areas; however, they influence many of these factors. A growing body of evidence suggests HRSNs significantly impact healthcare outcomes, and there is ongoing work to incorporate HRSNs and SDOH factors into PC CDS.^{19,20} However, SDOH could

be individual or contextual, there is no agreed-upon categorization of these factors, and U.S. healthcare systems currently capture and manage SDOH data in different ways.²⁰ A review discussing SDOH categorizations found variable definitions of SDOH, ranging from five to 19 factors.¹⁹ Evolving terminology standards for SDOH can support the standardized collection of SDOH data for use in CDS.²⁰⁻²² The lack of agreed-upon categorization of SDOH factors also creates measurement issues, as measurement requires an understanding of the concept being measured.²³ While HRSN are the individual-level factors that affect an individual's ability to maintain their health,¹³ these can be the result of community-level SDOH factors, and there is ongoing work regarding the capture and measurement of these SDOH factors.²⁴ The impact of SDOH and HRSNs is a developing area, and more work is needed to understand how these factors can impact PC CDS outcomes, as well as how best to measure these outcomes.

4.2 Future Directions

Our findings highlight several important areas for future work in PC CDS:

- **Addressing emerging areas for PC CDS measurement.** As discussed, emerging areas identified by panel participants included cost, access to care, and SDOH/HRSN. These are important areas in PC CDS, and more work is needed to understand how these areas can be integrated into measurement as inputs potentially influencing other outcomes.
- **Identifying measurement instruments.** Several measurement instruments have been developed for the prioritized measurement areas, and a vital next step is understanding what instruments are most applicable or appropriate. The CDSiC previously developed a measurement inventory that includes specific instruments used in PC CDS studies for the measurement of prioritized areas, such as the Shared Decision-Making Process Scale and Trust in Clinician Scale, but these measures may not be applicable in all situations or valid for use with certain populations. Prior work also highlights the dearth of instruments for certain measurement areas, including communication quality and access to information.³ Most previously identified instruments used in PC CDS studies have focused on aspects of patient care (e.g., communication quality) or assessed satisfaction, and there were no measures used to assess communication quality.³ While various measures focused on specific elements of communication exist,²⁵ communication quality is complex, and measures that encompass the various facets of this area are needed.³
- **Examining context-specific importance of measurement areas.** There are important considerations for how and when these measures should be collected. As participants noted, the importance of some of these measurement areas depends on the disease stage or where an individual is in their health journey (e.g., if they are newly diagnosed), and where they are receiving care (e.g., at a specialists). These are important considerations that could be further explored. Researchers and health systems could consult with patient partners or advisory groups to implement similar exercises for specific PC CDS to identify measures important to patients.

- **Understanding evolving measurement of access to information.** Participants in the final round of this activity ranked access to information highly. Access to information has also been identified as a priority area in the Office of that National Coordinator for Health Information Technology Final Rule on information blocking and the Centers for Medicare & Medicaid Services rules on patient access to information.^{26,27} As health systems develop and implement programs that allow patients to access their health information, there may be an increased need for measurement to understand whether these systems or policies allow patients to access information in ways that are clear, accessible, and available when needed.

4.3 Limitations

This was preliminary work with a small sample of patients and patient advocates, who may not speak to all the experiences patients utilizing PC CDS have. Specifically, a number of these individuals were cancer survivors, and they may not represent the views of newly diagnosed individuals or individuals receiving care for other conditions. Additionally, there was slight attrition of participants in this study. There are also a few limitations due to the modified Delphi panel study design. Unlike a traditional Delphi panel, a modified Delphi panel does not typically involve continuous rounds until consensus is achieved. To that end, further rounds of ranking could have elicited additional clarification on the ranking of measurement areas.

5. Conclusions

This report outlines the patient health journey measurement areas prioritized through this modified Delphi panel, and highlights important areas noted by participants related to these areas. Specifically, participants prioritized areas of communication quality, access to information, trust in clinician, knowledge, and shared decision making experience. These areas were noted to be interconnected by participants. These prioritized areas fell across all three domains (patient decision making, patient engagement, and patient care) within the patient health journey, highlighting the importance to patients of assessing multiple domains. The results from this activity further point to several areas for future work, including emergent areas in PC CDS related to SDOH, the importance of context in the measurement of these patient health journey areas, and the need to identify instruments for these prioritized areas.

Appendix A. Measurement Areas Definitions

| Patient Health Journey Measurement Area | Definition ⁱⁱⁱ |
|---|---|
| Decision Quality | The extent to which healthcare decisions reflect the preferences of a patient who is well informed about their options. |
| Decision Regret | A patient's regret or distress over a decision. |
| Shared Decision Making (SDM) Experience | A patient's experience with participating in healthcare decision making (e.g., selecting tests, treatment options, or care plans) in collaboration with their doctor or other healthcare providers. |
| Decisional Conflict | A patient's uncertainty about what course of action to take when making a healthcare decision (e.g., being unsure of what treatment to select or what the right next steps are). |
| Knowledge | What patients know about their disease or condition, including how to manage and monitor it, recommended activities, and how to navigate the healthcare system. |
| Activation | The extent to which patients work with their doctor to make decisions and manage their care when they have knowledge, skills, and access to care. |
| Adherence | The extent to which patients follow the care plan established with their doctor or other healthcare providers (e.g. taking medication on time, changing behaviors). |
| Self-Management | The activities or behaviors patients take to control their disease or condition (e.g., getting exercise, making follow-up appointments). |
| Discharge Preparedness | The extent to which a patient thinks they're ready to leave the hospital. |
| Trust in Clinician | How much trust a patient has in their doctor or other healthcare providers. |
| Timeliness | If a patient was able to get appointments, medication, or care when they needed it. |
| Access to Information | The extent to which information shared with a patient by their doctor is clear, accessible, and available when needed. |
| Communication Quality | If the right information was shared at the right time in the right way by the doctor, and if patients were able to ask questions and engage with their healthcare providers. |
| Coordination of Care | How organized the delivery of patient care is across different healthcare systems, doctors, etc. |
| Satisfaction | The extent to which patients feel the care they receive meets their expectations and preferences. |

ⁱⁱⁱDefinitions have been adapted from “Outcomes and Objectives Workgroup: Patient-Focused Outcome Measures for Patient-Centered Clinical Decision Support.”

References

1. Clinical Decision Support. Accessed March 18, 2024. <https://www.ahrq.gov/cpi/about/otherwebsites/clinical-decision-support/index.html>
2. 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 JAMIA*. 2022;29(7):1233-1243. doi:10.1093/jamia/ocac059
3. Kuperman G, Nanji K, Cope E, et al. *Outcomes and Objectives Workgroup: Patient-Focused Outcome Measures for Patient Centered Clinical Decision Support*. Prepared under Contract No. 75Q80120D00018; 2023.
4. Sittig DF, Boxwala A, Wright A, et al. A lifecycle framework illustrates eight stages necessary for realizing the benefits of patient-centered clinical decision support. *J Am Med Inform Assoc JAMIA*. 2023;30(9):1583-1589. doi:10.1093/jamia/ocad122
5. Office of the National Coordinator for Health Information. *Measure Effects and Refine CDS Interventions*. <https://www.healthit.gov/sites/default/files/3-4-5-measure-effects-and-refine-cds-interv.pdf>
6. Kawamoto K, Fiol GD, Lobach DF, Jenders RA. Standards for Scalable Clinical Decision Support: Need, Current and Emerging Standards, Gaps, and Proposal for Progress. *Open Med Inform J*. 2010;4:235. doi:10.2174/1874431101004010235
7. Van de Velde S, Heselmans A, Delvaux N, et al. A systematic review of trials evaluating success factors of interventions with computerised clinical decision support. *Implement Sci*. 2018;13(1):114. doi:10.1186/s13012-018-0790-1
8. Krist AH, Tong ST, Aycock RA, Longo DR. Engaging patients in decision-making and behavior change to promote prevention. *Stud Health Technol Inform*. 2017;240:284-302.
9. Verweij LPE, Sierevelt IN, Baden DN, et al. A modified Delphi study to identify which items should be evaluated in shoulder instability research: a first step in developing a core outcome set. *JSES Int*. 2023;7(6):2304-2310. doi:10.1016/j.jseint.2023.06.012
10. Hernan AL, Giles SJ, O'Hara JK, Fuller J, Johnson JK, Dunbar JA. Developing a primary care patient measure of safety (PC PMOS): a modified Delphi process and face validity testing. *BMJ Qual Saf*. 2016;25(4):273-280. doi:10.1136/bmjqs-2015-004268
11. Woodcock T, Adeleke Y, Goeschel C, Pronovost P, Dixon-Woods M. A modified Delphi study to identify the features of high quality measurement plans for healthcare improvement projects. *BMC Med Res Methodol*. 2020;20(1):8. doi:10.1186/s12874-019-0886-6
12. Erlingsson C, Brysiewicz P. A hands-on guide to doing content analysis. *Afr J Emerg Med*. 2017;7(3):93-99. doi:10.1016/j.afjem.2017.08.001
13. U.S. Department of Health and Human Services (HHS). *Addressing Health-Related Social Needs in Communities Across the Nation*.; 2023. <https://aspe.hhs.gov/sites/default/files/documents/3e2f6140d0087435cc6832bf8cf32618/hhs-call-to-action-health-related-social-needs.pdf>
14. Bright TJ, Wong A, Dhurjati R, et al. Effect of clinical decision-support systems: a systematic review. *Ann Intern Med*. 2012;157(1):29-43. doi:10.7326/0003-4819-157-1-201207030-00450

15. Peering into the black box: a meta-analysis of how clinicians use decision aids during clinical encounters | Implementation Science | Full Text. Accessed March 18, 2024. <https://implementationscience.biomedcentral.com/articles/10.1186/1748-5908-9-26>
16. Symmons SM, Ryan K, Aoun SM, et al. Decision-making in palliative care: patient and family caregiver concordance and discordance—systematic review and narrative synthesis. *BMJ Support Palliat Care*. 2023;13(4):374-385. doi:10.1136/bmjspcare-2022-003525
17. Martin C, Shrestha A, Burton M, Collins K, Wyld L. How are caregivers involved in treatment decision making for older people with dementia and a new diagnosis of cancer? *Psychooncology*. 2019;28(6):1197-1206. doi:10.1002/pon.5070
18. Levoy K, Rivera E, McHugh M, Hanlon A, Hirschman K, Naylor M. Caregiver Engagement Enhances Outcomes among Randomized Control Trials of Transitional Care Interventions: A Systematic Review and Meta-Analysis. *Med Care*. 2022;60(7):519-529. doi:10.1097/MLR.0000000000001728
19. He Z, Pfaff E, Guo SJ, et al. Enriching Real-world Data with Social Determinants of Health for Health Outcomes and Health Equity: Successes, Challenges, and Opportunities. *Yearb Med Inform*. 2023;32(1):253-263. doi:10.1055/s-0043-1768732
20. Office of the National Coordinator for Health Information Technology (ONC). *Social Determinants of Health (SDOH) Clinical Decision Support (CDS) Feasibility Brief.*; 2023.
21. Thomas Craig KJ, Fusco N, Gunnarsdottir T, Chamberland L, Snowdon JL, Kassler WJ. Leveraging Data and Digital Health Technologies to Assess and Impact Social Determinants of Health (SDoH): a State-of-the-Art Literature Review. *Online J Public Health Inform*. 2021;13(3):E14. doi:10.5210/ojphi.v13i3.11081
22. Craven CK, Highfield L, Basit M, et al. Toward standardization, harmonization, and integration of social determinants of health data: A Texas Clinical and Translational Science Award institutions collaboration. *J Clin Transl Sci*. 2024;8(1):e17. doi:10.1017/cts.2024.2
23. National Committee for Quality Assurance (NCQA). *Social Determinants of Health: Resource Guide.*; 2020. https://www.ncqa.org/wp-content/uploads/2020/10/20201009_SDOH-Resource_Guide.pdf
24. Patient-Centered Primary Care Home Program. *Health-Related Social Needs vs. The Social Determinants of Health*. Oregon Health <https://www.oregon.gov/oha/HPA/dsi-pcpch/AdditionalResources/Health-related%20Social%20Needs%20vs%20the%20Social%20Determinants%20of%20Health.pdf>
25. *HCAHPS Survey.*; 2023. https://www.hcahpsonline.org/globalassets/hcahps/quality-assurance/2023_survey-instruments_english_mail.pdf
26. CMS Interoperability and Patient Access Final Rule (CMS-9115-F) | CMS. Accessed May 10, 2024. <https://www.cms.gov/priorities/key-initiatives/burden-reduction/interoperability/policies-and-regulations/cms-interoperability-and-patient-access-final-rule-cms-9115-f>
27. ONC's Cures Act Final Rule | HealthIT.gov. Accessed May 10, 2024. <https://www.healthit.gov/topic/oncs-cures-act-final-rule>