Innovation Center: Framework and Inventory of Patient Engagement Measures for PC CDS

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Clinical Decision Support Innovation Collaborative

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. This report presents an inventory of measures that can be used to assess patient engagement across the lifecycle of PC CDS, spanning the generation of evidence, the translation of that evidence into CDS tools, and the use of those tools in clinical decision making.

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Executive Summary

Patient engagement is essential to high-quality, patient-centered healthcare, and can empower patients and caregivers to actively participate in treatment decisions. Engaged patients typically experience greater satisfaction with their care, stronger trust in providers, better treatment adherence, and improved health outcomes. As defined by Carman et al., patient engagement is “the active partnership between patients, their families, representatives, and healthcare professionals working across the health care system.” This partnership exists on a continuum—from basic patient input to deeper involvement through shared decision making and collaborative care partnerships.

Patient-centered clinical decision support (PC CDS) encompasses digital technologies that are designed to provide patients, caregivers, and clinicians evidence-based, patient-specific clinical guidance to inform care decisions. Throughout the PC CDS lifecycle—spanning the generation of evidence, the translation of that evidence into CDS tools, and the use of those tools in clinical decision making—engagement manifests in various forms, from patients contributing data and perspectives to actively codesigning and implementing PC CDS tools in their care.

The Clinical Decision Support Innovation Collaborative (CDSiC) has examined patient engagement metrics across several reports, finding that measurement in PC CDS remains limited and largely formative. Current measures primarily assess basic engagement forms rather than the full continuum. More meaningful engagement aspects—particularly partnership and shared leadership—remain significantly under-measured. Without comprehensive metrics, effectively evaluating patient engagement impact and identifying meaningful involvement best practices will continue to be challenging.

This report introduces a first of its kind framework and inventory of measures capturing patient engagement throughout the PC CDS lifecycle. Rather than providing an exhaustive catalog of measurements for selection, we present illustrative examples designed to help researchers and evaluators understand the framework’s core aspects and potential applications.

Methods

We conducted a targeted literature review to identify PC CDS patient engagement measures and held key informant interviews to validate the measures we found, identify gaps in our findings, and provide perspectives on challenges and opportunities within the measurement of patient engagement. We also shared key findings and collected feedback from a seven-member Expert Planning Committee.

About the Inventory of Patient Engagement Measures

The Patient Engagement Inventory contains measures reported in the literature to assess patient engagement in PC CDS. The measures correspond to the continuum of roles that patients can have when engaging in the PC CDS lifecycle:

- As **contributors, collaborators, or partners** in research, guideline development, and the codesign and codeployment of PC CDS technologies.
- As **end users** who leverage PC CDS technologies to support informed decision making.

How the Inventory Is Organized. The inventory is organized into three parts that represent different levels where patients can be engaged as contributors, collaborators, partners, and/or end users in the PC CDS lifecycle (ES Exhibit 1):

- **Phases**: The broad stages of Knowledge Generation, CDS, and Healthcare Delivery outlined in the PC CDS lifecycle framework.
- **Steps:** The key points within each phase where patients can be engaged.
- **Activities:** The specific activities patients engage in within each step.

Measures in the Inventory are mapped to a specific activity, step, or entire phase as applicable, depending on their scope.

ES Exhibit 1. Key steps and outcomes of patient engagement across the PC CDS lifecycle

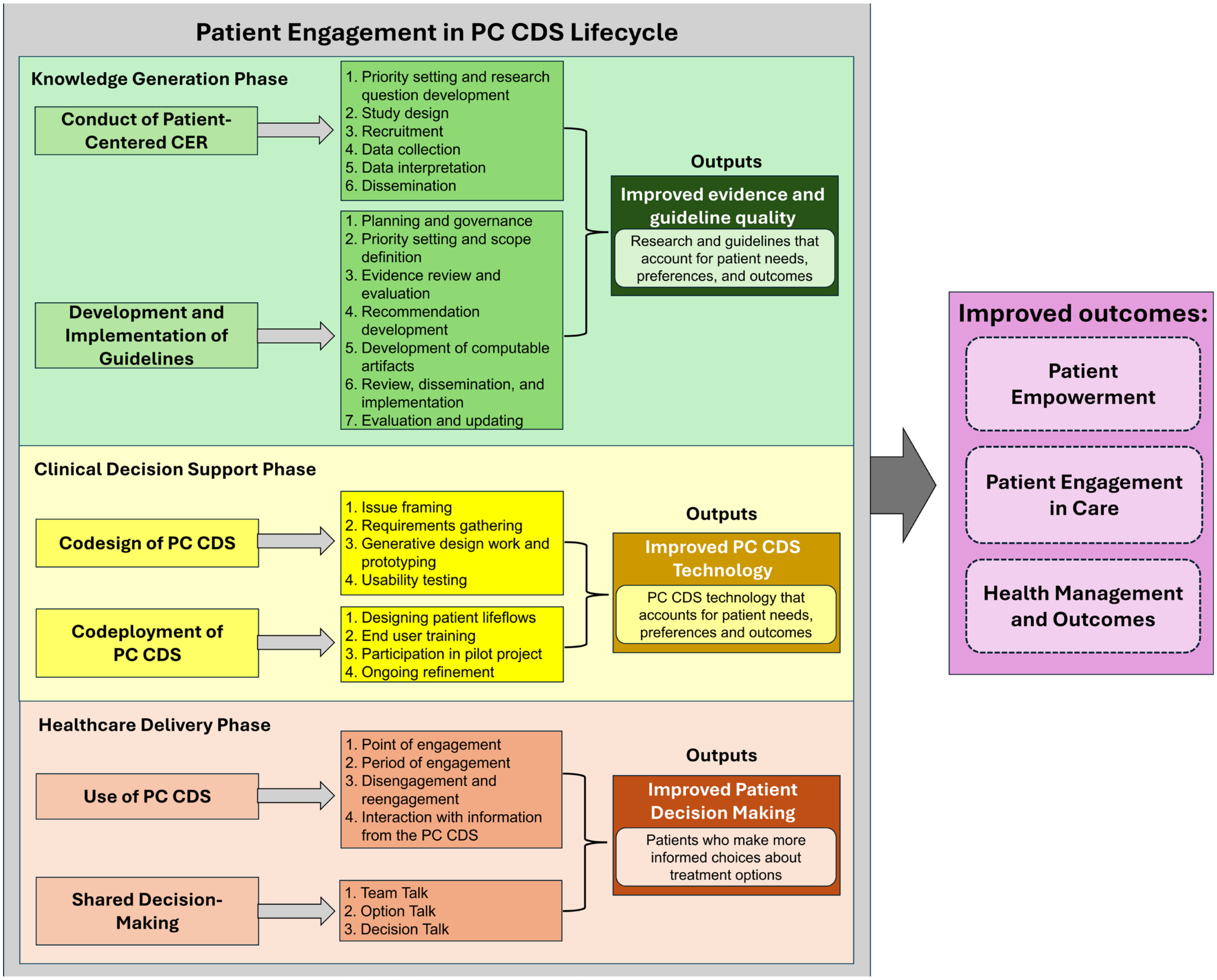
PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**How Patients Are Engaged**
Knowledge Generation	1. Conduct of Patient-Centered Outcomes Research (PCOR)	Patients are involved as **contributors, collaborators, or partners** in the design, conduct, and dissemination of PCOR studies.
	2. Development and Implementation of Evidence-Based Guidelines	Patients are involved as **contributors, collaborators, or partners** in the identification of priorities, review of evidence, and formulation of recommendations.
Clinical Decision Support	1. Design and Development of PC CDS	Patients are involved as **contributors, collaborators, or partners** in identifying needs, shaping tool features, and ensuring solutions align with their preferences and real-world experiences.
	2. Implementation of PC CDS	Patients are involved as **contributors, collaborators, or partners** in the design and conduct of pilots, as well as **users** through participation in pilots.
	3. Use of PC CDS	Patients are involved as **end users** by leveraging PC CDS tools to share and receive information about their condition.

PC CDS Lifecycle Phase	Steps Where Patients Are Engaged	How Patients Are Engaged
Healthcare Delivery	1. Shared Decision Making	Patients are involved as **end users** by leveraging PC CDS tools to collaborate with clinicians on their care.
Outcomes of Engagement	1. Patient Engagement in Care	PC CDS technologies that successfully enhance patient engagement in care can lead to more informed choices.
	2. Health Management	PC CDS technologies that successfully enhance patient engagement in care can lead to greater adherence to treatment plans and self-management behaviors.
	3. Patient Empowerment	PC CDS technologies that successfully enhance patient engagement in care can lead to greater feelings of self-efficacy in managing health.

Discussion

The inventory of measures for patient engagement in PC CDS contains measures to assess the structures, processes, meaningfulness, and outputs of patient engagement across the PC CDS lifecycle. ES Exhibit 2 provides a framework for users of the inventory to understand how patient engagement occurs throughout the lifecycle and ultimately contributes to improvements in important end goals in healthcare delivery, namely more empowered and engaged patients and better overall health management. Please reference the full inventory of measures in **Appendix C**.

ES Exhibit 2. Framework for patient engagement measurement across the PC CDS lifecycle



Challenges and Opportunities

- **Lack of measures that capture meaningful patient engagement.** Overall, our findings revealed that there is a need to move beyond structure and process measures of engagement and identify sophisticated measures that truly assess meaningful patient engagement. Future measures could borrow from and build on those used in research to include assessments of how patients want to be engaged, their perceptions of their involvement, their trust in the project team, their decision-making authority or power sharing throughout the process, and the impact of patient contributions on final products.

- **Lack of measures to assess PC CDS codesign and codeployment.** While patient engagement in codesign and codeployment is emerging, there is a significant gap in measures in this area. Future research is needed to determine whether measures identified in the Knowledge Generation phase could apply to codesign and codeployment.
- **Difficulty connecting engagement in PC CDS to behavioral changes or health outcomes.** While improving patient engagement across the PC CDS lifecycle is important, its value remains challenging to demonstrate due to significant evidence gaps. Future activities should focus on assessing how different levels and types of patient engagement influence outputs and outcomes; they should also focus on developing and validating more robust outcome measures of engagement in PC CDS.
- **No gold standard exists to measure engagement.** Despite the attention on capturing preferences for engagement with PC CDS, there are currently few reliable and valid means to measure the meaningfulness of engagement with PC CDS across the lifecycle. More work is needed across the steps in the PC CDS lifecycle to develop standardized measurements for assessing the meaningful participation of patients to allow for comparisons across projects and within projects over time.

Conclusion

To maximize patient-centered clinical decision support tools' benefits, we need better measures of patient engagement across the PC CDS lifecycle. Current measurement approaches predominantly focus on structure and process metrics, with few tools assessing meaningful engagement. Future work should prioritize developing measures for patient codesign and codeployment, validating measurement tools, and establishing clear connections between process measures and healthcare outcomes.

1. Introduction

Patient engagement is essential to delivering high-quality, patient-centered healthcare, as it empowers patients and caregivers to actively participate in decisions that impact their treatment and health. Engaged patients are more likely to feel satisfied with their decisions and care, trust their healthcare provider, adhere to treatment plans, and ultimately experience better health outcomes.[1] [2] [3] Digital technologies, such as wearable devices and mobile apps, support patient engagement by providing patients with the tools, resources, and connectivity needed to actively participate in their healthcare.[4]

Patient-centered clinical decision support (PC CDS) encompasses digital technologies that are designed to provide patients, caregivers, and clinicians evidence-based, patient-specific clinical guidance to inform care decisions.[5] PC CDS technologies 1) incorporate evidence-based knowledge from patient-centered outcomes research (PCOR) or comparative effectiveness research; 2) incorporate patient-generated health data, patient preferences, social determinants of health (SDOH), and other patient-specific information; 3) facilitate bidirectional information exchange in support of patient-centered care, including shared decision making; and 4) directly engage patients and/or caregivers across different settings.[6]

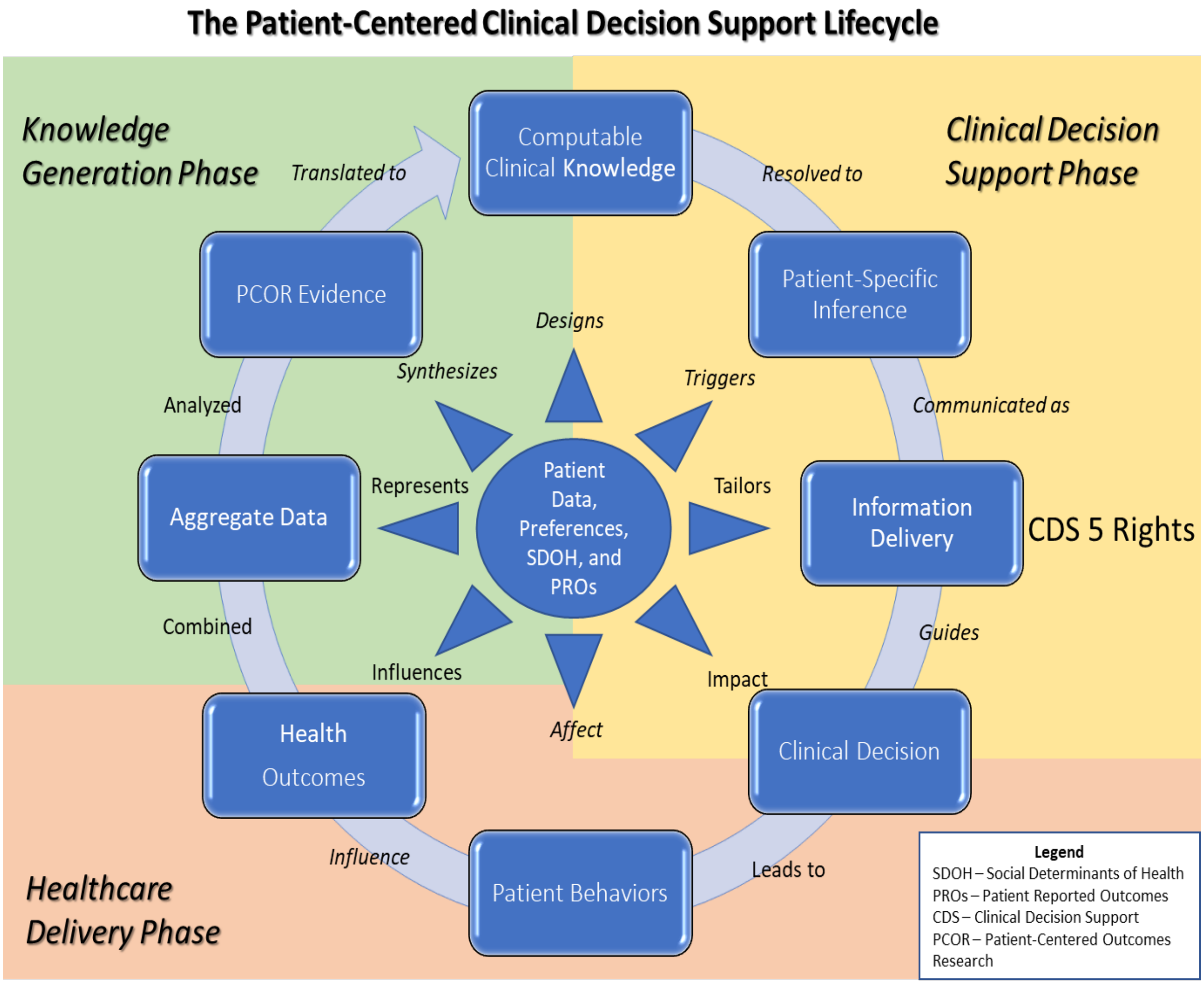
This report draws upon Carman et al.'s definition of patient engagement: “the active partnership between patients, their families, representatives, and healthcare professionals working across the health care system.” This occurs on a continuum that ranges from soliciting input from patients to deeper forms of involvement, such as shared decision making and partnership.[7] Within the PC CDS lifecycle—spanning the generation of evidence, the translation of that evidence into CDS tools, and the use of those tools in clinical decision making—engagement can take different forms, from contributing data and perspectives to actively shaping and using PC CDS in care. This report presents a framework and an inventory of measures that encapsulate patient engagement across the PC CDS lifecycle.

2. Background

In 2023, the CDSiC developed the PC CDS lifecycle framework (Exhibit 1) to guide performance measurement of PC CDS.[8] The lifecycle is separated into three phases:

1) **Knowledge generation phase.** This phase involves the conduct of PCOR or comparative effectiveness research and the development of evidence-based guidelines.[9]
2) **Clinical decision support (CDS) phase.** This phase involves the transformation of evidence-based guidelines into computable logic that can be used to generate and deliver trusted, high-quality, accurate, timely, reliable, comprehensible, and patient-specific recommendations to patients, their caregivers and care teams, and/or their clinicians.
3) **Healthcare delivery phase.** This phase encompasses clinical decision making, which follows from clinician, patient, and caregiver interactions with PC CDS technology.

Exhibit 1. The PC CDS lifecycle framework



Patients can be engaged in the PC CDS lifecycle as: 1) contributors, collaborators, or partners involved in research, guideline development, and the design and development of PC CDS technologies; and 2) end users of PC CDS technology, where their use of these tools to contribute data and inform decisions represents an active role in healthcare delivery. Engaging patients as contributors, collaborators, or partners drives the development of high-quality evidence and guidelines, and better aligns PC CDS technologies with patient needs, preferences, and values. Engagement with high quality PC CDS technologies in turn drives greater engagement with care, ultimately leading to improved patient experience, more informed decision making, and higher-quality care.[10]

The CDSiC has explored measures of patient engagement in several products including the PC CDS Performance Measurement Inventory User Guide,[11] the Inventory of Patient Preference Measurement Tools for PC CDS Report,[12] Measuring PC CDS Performance: A Unified Framework,[13] and the Real-World Performance Measurement of Patient-Centered Clinical Decision Support Tools.[14] Overall, the findings from these reports indicate that measurement of patient engagement in PC CDS is limited and remains largely formative. Existing measures primarily assess more basic forms of engagement rather than capturing the full continuum. Deeper forms of engagement, such as partnership and shared leadership,[15] remain particularly under-measured. Without more comprehensive measures, it will remain difficult to evaluate the impact of patient engagement and identify best practices that support meaningful involvement. As a result, patients risk being engaged in only limited ways, preventing PC CDS technologies from fully reflecting their needs and ultimately inhibiting adoption and effectiveness.

To support better measurement, this report and accompanying inventory detail the findings from a targeted literature review and key informant interviews identifying measures that assess patient engagement across the PC CDS lifecycle. To capture the full continuum of how patients can be engaged as either collaborators in PC CDS development or use, we identified both measures of how engagement occurred (i.e., structure and process-based measures) as well as measures that can provide insight into whether patients were meaningfully engaged, such as through insight into their power and decision-making authority,[16] or the extent to which they actively used PC CDS technology to inform their care decisions. Given that PC CDS is an emerging field, the inventory and the measures highlighted in the report are not a prescriptive or exhaustive set of metrics. Rather, they serve as illustrative examples within a comprehensive framework for measuring patient engagement across the PC CDS lifecycle.

The intended audience of the report and inventory are PC CDS developers, implementers, and evaluators that specialize across all phases of the PC CDS lifecycle. The objectives are as follows:

1) Describe key measurement areas for patient engagement in each phase of the PC CDS lifecycle.
2) Identify both existing patient engagement measures and identify areas where measures are currently lacking.
3) Describe challenges and opportunities to advance PC CDS patient engagement measurement in research and practice.

2.1. Report Roadmap

The report includes the following sections:

- ***Methods.*** This section summarizes our approach to 1) conducting a targeted literature review to identify PC CDS patient engagement measures; 2) holding key informant interviews to validate the measures we found, identify gaps in our findings, and provide perspectives on challenges and opportunities within the measurement of patient engagement; and 3) collecting feedback from a seven-member Expert Planning Committee.
- ***About the Inventory of Patient Engagement Measures for PC CDS.*** This section introduces the purpose, intended audiences, and potential uses of the inventory. It describes the content of the inventory and how it is organized.
- ***Measurement Concepts Across the PC CDS Lifecycle.*** This section outlines the areas to measure patient engagement in each phase of the lifecycle: knowledge generation, clinical decision

support, and healthcare delivery. Within each section, there is a summary of the measures included in the inventory that we identified from the literature review and key informants. In addition, there is a section describing the outcomes to be expected from patient engagement.

- ***Discussion.*** This section provides an overall framework for PC CDS engagement measurement and a summary of key challenges with and opportunities for advancing patient engagement measurement.
- ***Appendix.*** This section provides the full inventory (Appendix C), along with a user guide (Appendix A) and codebook (Appendix B) to support use.

3. Methods

To inform this report and accompanying inventory, we undertook 1) a targeted literature review of CDSiC resources and other published literature on patient engagement measurement; 2) a validation process involving eight key informant interviews with patient engagement researchers, and 3) feedback from a seven-member Expert Planning Committee of CDS developers, clinical informaticists, and a patient representative.

3.1. Literature Review

To complete the initial literature review, we conducted a targeted scan of CDSiC resources that discuss patient engagement measurement in PC CDS (Exhibit 2).

Exhibit 2. CDSiC resources included in literature review

CDSiC Resources That Discuss Patient Engagement Measurement
Measurement and Outcomes Workgroup: Patient Prioritization of Measurement Areas for Patient-Centered Clinical Decision Support[17]
Implementation, Adoption, and Scaling Workgroup: Exploring Challenges and Opportunities for Patient Engagement, Implementation, Adoption, and Scaling Through PC CDS Case Studies[18]
Trust & Patient-Centeredness Workgroup: An Introductory Handbook for Patient Engagement Throughout the Patient-Centered Clinical Decision Support Lifecycle[19]
Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory[20]
Measurement and Outcomes Workgroup: Inventory of Patient Preference Measurement Tools for PC CDS Report[21]
Outcomes and Objectives Workgroup: Patient-Focused Outcome Measures for Patient-Centered Clinical Decision Support[22]
Measuring PC CDS Performance: A Unified Framework[23]
Real-World Performance Measurement of Patient-Centered Clinical Decision Support Tools: AHRQ Project Assessment[24]

The NORC team reviewed the full text of each resource, extracted patient engagement measures, and mapped the measures to the phases of the PC CDS lifecycle framework and their associated steps (e.g., conduct of patient-centered outcomes research in the Knowledge Generation Phase). After this initial mapping, we conducted a targeted review for each step of the PC CDS lifecycle, resulting in inclusion of 86 additional peer-reviewed publications. Lastly, we added 11 peer-reviewed publications shared by our key informants. **Appendix D** includes the full list of data abstraction domains from the targeted review.

3.2. Key Informant Interviews

NORC conducted 60-minute interviews with eight key informants to 1) review and validate the patient engagement measures the team identified, and 2) discuss potential measurement gaps, challenges, and perspectives on how to improve patient engagement measurement. Informants included researchers, informaticians, and guideline developers (Appendix B). Two senior members of the Innovation Center Core 1 team led the discussions, and a research associate recorded transcript-style notes and key takeaways. Two senior members of the Innovation Center Core 1 team reviewed all notes to ensure key points were captured. After all the interviews were completed, the team conducted a thematic analysis to identify key themes, including any inventory gaps and/or needed modifications.

3.3. Expert Planning Committee

The Innovation Center operates an Expert Planning Committee comprising seven thought leaders in the CDS field, including clinical informaticists, PC CDS developers, a payor, and a patient. We sought input on the preliminary findings of the patient engagement inventory and incorporated their perspectives.

4. About the Inventory of Patient Engagement Measures for PC CDS

The Patient Engagement Inventory (**Appendix C**) contains measures reported in the literature to assess patient engagement in PC CDS. The measures correspond to the continuum of roles that patients can have when engaging in the PC CDS lifecycle:

1) As **contributors, collaborators, or partners** in research, guideline development, and the codesign and codeployment of PC CDS technologies.
2) As **end users** who leverage PC CDS technologies to support informed decision making.

How the Inventory Is Organized. The inventory is organized into three parts that represent different levels where patients can be engaged as contributors, collaborators, partners, and/or end users in the PC CDS lifecycle:

1) **Phases**: The broad stages of Knowledge Generation, CDS, and Healthcare Delivery outlined in the PC CDS lifecycle framework.

2) **Steps:** The key points within each phase where patients can be engaged.
3) **Activities:** The specific activities patients engage in within each step.

Measures in the inventory are mapped to a specific activity, step, or entire phase as applicable, depending on their scope.

While we acknowledge the importance of understanding the full impact of patient engagement in the PC CDS lifecycle, the inventory does not include measures of outcomes, such as changes in health management or clinical outcomes. Given the complexity of definitively linking engagement in PC CDS to these types of outcomes, our inventory focuses on measures that assess the extent, nature, and meaningfulness of patient involvement in the development, implementation, and use of PC CDS technologies. To support the evaluation of outcomes that may be related to patient engagement in PC CDS, the CDSiC has developed a separate inventory of patient-focused outcome measures.[25] This report provides a high-level overview of these outcomes and key areas for measurement.

Intended audience. The primary purpose of the inventory is to help PC CDS developers, implementers, and evaluators track and assess patient engagement within their relevant phase of the PC CDS lifecycle. While the inventory is not exhaustive, by collating existing measures in one place, it aims to improve awareness and standardization of measures of patient engagement in PC CDS. Importantly, the inventory is not intended to be a prescriptive checklist—users should select measures that best align with their specific objectives rather than attempt to use all available measures. Potential uses of the inventory include the following:

- Assisting PC CDS designers, developers, implementers, and evaluators in selecting measures that align with their objectives and creating meaningful ways to measure patient engagement; and
- Supporting healthcare organizations and clinicians to evaluate how well their existing PC CDS tools facilitate patient participation in care decisions and identify gaps in patient engagement.

In this report, we summarize the steps and activities of the PC CDS lifecycle where patients can be engaged and associated measures reported in the inventory to assess their engagement.

5. Measurement Concepts Across the PC CDS Lifecycle

Exhibit 3 describes six steps across each phase of the PC CDS lifecycle where patient engagement is essential, and three outcomes associated with effective patient engagement.

Exhibit 3. Key steps and outcomes of patient engagement across the PC CDS lifecycle

PC CDS Lifecycle Phase	Steps Where Patients Are Engaged	How Patients Are Engaged
Knowledge Generation	1. Conduct of Patient-Centered Outcomes Research (PCOR)	Patients are involved as **contributors, collaborators, or partners** in the design, conduct, and dissemination of PCOR studies.
	2. Development and Implementation of Clinical Practice Guidelines	Patients are involved as **contributors, collaborators, or partners** in the identification of priorities, review of evidence, and formulation of recommendations.
Clinical Decision Support	1. Design and Development of PC CDS	Patients are involved as **contributors, collaborators, or partners** in identifying needs, shaping tool features, and ensuring solutions align with their preferences and real-world experiences.
	2. Implementation of PC CDS	Patients are involved as **contributors, collaborators, or partners** in the design and conduct of pilots, as well as **users** through participation in pilots.
	3. Use of PC CDS	Patients are involved as **end users** by leveraging PC CDS tools to share and receive information about their condition.
Healthcare Delivery	1. Shared Decision Making	Patients are involved as **end users** by leveraging PC CDS tools to collaborate with clinicians on their care.
Outcomes of Engagement	1. Patient Engagement in Care	PC CDS technologies that successfully enhance patient engagement in care can lead to more informed choices.
	2. Health Management	PC CDS technologies that successfully enhance patient engagement in care can lead to greater adherence to treatment plans and self-management behaviors.
	3. Patient Empowerment	PC CDS technologies that successfully enhance patient engagement in care can lead to greater feelings of self-efficacy in managing health.

Below, we describe patient engagement in each step and outcome in more detail. For each step, we provide example measures from the inventory.

5.1. Knowledge Generation Phase

Patients can be engaged as contributors, collaborators, and/or partners in two key steps of the Knowledge Generation Phase: 1) the conduct of patient-centered outcomes research (PCOR) and 2) the development and implementation of clinical practice guidelines (CPGs).

5.1.1. Involvement in Patient-Centered Outcomes Research

According to the Patient-Centered Outcomes Research Institute's framework,[26] patient engagement in PCOR supports the generation of evidence that is more relevant and aligned with patient needs and preferences.[27] Patient engagement in PCOR encompasses involvement in the following activities[28]:

1. **Priority setting and research question development:** Patients can help identify research priorities, participate in research governance, and shape study questions to ensure they address real-world concerns and patient-centered outcomes.
2. **Study design:** Patients can help refine study methodologies, outcome measures, and meaningful endpoints that reflect their lived experiences.
3. **Recruitment:** Patients can support the development of outreach strategies to improve study participation, ensuring representative samples.
4. **Data collection:** Patients can assist in designing patient-friendly data collection methods.
5. **Data interpretation:** Patients can help to contextualize findings, ensuring that conclusions reflect patient priorities and lived experiences.
6. **Dissemination:** Patients can help translate and communicate study results in accessible formats for broader audiences, including patient communities and policymakers, as well as encouraging uptake and implementation of research.

Summary of Measures. A wide range of measures exist in the literature to assess patient engagement in research, capturing both the structures and processes of engagement as well as the extent to which engagement was meaningful. Most measures evaluate

Exhibit 4. Example Survey Instruments

- **Patient Engagement in Research Scale (PEIRS)[29]:** Measures the degree of meaningful patient engagement in research projects from a patient perspective.
- **Patient and Public Engagement Evaluation Tool (PPEET)[30]:** Measures patient and/or research team perspectives on the meaningfulness and impact of patient and public engagement initiatives in health research and decision making.
- **Final Comprehensive Research Engagement Survey Tool (REST)[31]:** Measures stakeholder perspectives on the extent and meaningfulness of their engagement in research.
- **Ways of Engaging- ENgagement ACtivity Tool (WE-ENACT)[32]:** Measures patient perspectives on the characteristics and meaningfulness of their engagement in research.
- **Person-Centeredness of Research Scale (PCoR)[33]:** Measures the degree of person-centeredness of research products from the perspective of the research team.

engagement across all activities in the research process, though some specifically focus on dissemination.

Measures assessing meaningful engagement examine both patient and research team perspectives on the extent of patient involvement in research, most often through survey instruments (see Exhibit 4 for examples). These measures reflect a range of ways patients can engage, from providing input on specific aspects of the study to full partnership in decision making. Patient-reported measures assess opportunities to share ideas, provide input, take on leadership roles, and influence the project structure, as well as whether they felt like equal partners in the research team.[34] They also capture patient confidence that their input will be used and assurance about the level of influence they had on research activities. Researcher-reported measures focus on their willingness to listen to patient partners and integrate their feedback into the research process. Some research teams also measured the type and extent of patient contributions.

Structural and process-focused measures assessed whether research teams established the necessary infrastructure to support effective engagement. This included assessing the types of patients invited to be partners, data sharing and communication practices, mechanisms for handling disagreements, and whether incentives or other support were offered to support engagement.

Measures focusing specifically on dissemination assess whether patients had sufficient time to contribute meaningfully to research publications. They also capture patient perspectives on whether they received adequate recognition, such as authorship, and whether they could see the impact of their contributions on others. Additionally, measures assess how well research teams involved patient partners in sharing results and whether they provided meaningful opportunities for patients to serve as co-authors.

Several key informants noted that very few survey instruments for measuring patient engagement in PCOR have undergone sufficient reliability and validity testing, raising concerns about their ability to accurately and consistently assess engagement across diverse research settings. They also noted that the use of engagement measures in research remains in its early stages in the United States, with Europe and Canada showing more progress in this area. Researchers often focus on evaluating the structures and processes of engagement rather than assessing the depth and meaningfulness of patient involvement.

Exhibit 5 provides example measures from the inventory for patient engagement in PCOR.

Exhibit 5. Example measures for patient engagement in PCOR

Engagement Activities	Example Measures From Inventory
All research and dissemination activities	**Structure and process of engagement:** • Number of research activities patient was involved in[35] • Demographic composition of patients engaged in the research process (e.g., sex and other demographics, geographic distribution)[36] [37] [38] • Whether financial supports were provided to patients for serving as research partners[39] • How long patient has been working with research organization[40] • Patient perspectives on whether supports they needed to engage were available (e.g., travel, childcare)[41] • How often fair processes are established to manage conflicts or disagreements[42] **Meaningfulness of engagement:** • Patient perspectives on how well research team provides opportunities to share ideas, input, and leadership responsibilities and to share in the determination of the project structure[43] • Patient perspectives on whether they had sufficient opportunities to contribute to the project[44] • Patient perspectives on whether they felt they were an equal partner in the research project team[45] • Patient's level of confidence that input provided will be used by research team[46] • Research team members' perspectives on the extent to which their team demonstrated willingness to listen to patient partners[47] • Whether patient considered themselves a partner on the research project[48] • Patient perspectives on amount of influence they had on each research activity[49] • Extent of patient contributions to research process[50] • Concerns relevant to the population of interest or to patients in general are included or addressed in the research [51]
Dissemination	**Structure and process of engagement:** • Whether patient had sufficient time to make useful contributions to research publications[52] **Meaningfulness of engagement:** • Patient perspectives on whether they received sufficient recognition for their contributions (e.g., authorship)[53] • Patient perspectives on whether they could see how their contributions benefited others[54] • Patient perspectives on how well the research team involved patient partners in activities related to sharing results[55] • Patient perspectives on how well the research team gave partners the opportunity to be coauthors[56]

5.1.2. Involvement in Development and Implementation of Guidelines

Patient engagement in the development and translation of clinical practice guidelines (CPG) increases the likelihood that healthcare recommendations are patient-centered, relevant, and effective.[57] [58] Patient engagement in this process encompasses involvement in the following activities, which draw from the Guidelines International Network (GIN)-McMaster Guideline Development Checklist (GDC) Extension for Engagement.[59] This is a comprehensive checklist of topics and items for engaging interest-holder groups (including patients) throughout the guideline development and implementation process.

1. **Planning and governance.** Patients can help shape group membership, decision-making processes, and conflict-of-interest policies to ensure inclusivity of perspectives and patient-centered planning.
2. **Priority setting and scope definition.** Patients can help identify priority health concerns and gaps in existing guidelines, select relevant clinical questions and audiences, and ensure that CPGs address issues that are meaningful to those affected.
3. **Evidence review and evaluation.** Patients can review and interpret clinical evidence alongside researchers and clinicians, helping to contextualize findings based on lived experience and real-world applicability.
4. **Recommendation development.** Patients can contribute to drafting recommendations by ensuring that language is clear and accessible, and helping assess the balance of benefits, harms, and feasibility based on their values and experiences.
5. **Developing computable artifacts.** Patients can provide input on when and how their contributed data inform clinical decision support to ensure that digital tools maintain usability and relevance for patient care.
6. **Review, dissemination, and implementation.** Patients can be involved in reviewing final guideline drafts to ensure clarity and accessibility, developing consumer-friendly versions, sharing guideline recommendations with broader patient communities, and adapting guidelines for specific healthcare settings.
7. **Evaluation and updating.** Patients can help evaluate how well guidelines improve patient care and outcomes.

Summary of Measures. In the literature, measures of patient engagement in guideline development and implementation primarily assessed involvement in activities prior to their conversion into computable artifacts, and dissemination, implementation, evaluation, and updating of recommendations. Similar to measures of engagement in PCOR, measures aimed to capture both the structures and processes of engagement in guideline development activities as well as the extent to which engagement was meaningful. Measures of engagement meaningfulness assess patient perspectives on how well and how meaningfully they were involved. They also assess the impact and value of patient contributions, both from the patient's perspective and the guideline development team's analysis. Structure and process-focused measures assess who is engaged, including the demographic and disease composition of patient participants, as well as how engagement occurs, such as participation on panels, survey response rates, and meeting duration. Additionally, they capture patient perspectives on the feasibility of engagement, including the ease of using engagement tools, the effort required to participate, the adequacy of information provided, and the availability of necessary supports such as travel and childcare.[60 61]

Unlike patient engagement in PCOR, there were limited survey instruments in the literature specifically for measuring patient engagement in guideline development and implementation. One paper used a custom survey combined with qualitative data collection to measure patient satisfaction and perceived benefits, challenges, and burdens of the guideline development engagement process, as well as ease of use of the online engagement tool employed to gather patient input on scope.[62] One paper tested and validated the use of the Patient and Public Engagement Evaluation Tool (PPEET)[63] for measuring engagement in guideline development, although it is more commonly used to measure engagement in research and healthcare delivery.

We found no measures of patient engagement identified in the literature or via key informant discussions related to later stages in the guideline development process, including development of computable artifacts, review, dissemination, implementation, evaluation, and updating.

Several key informants emphasized the importance of measures that assess the impact of patient engagement on guideline development, including both the development process and the content of the guideline. They noted that these measures are most effective in capturing the meaningfulness of patient engagement.

Exhibit 6 provides examples of engagement activities and measures within the development and implementation of guidelines.

Exhibit 6. Example measures for patient engagement in development and implementation of guidelines

Engagement Activities	Example Measures From Inventory
- Planning and governance - Priority setting and scope definition - Evidence review and evaluation - Recommendation development	**Structure and process of engagement:** • Demographic and disease composition of patients engaged in guideline development[64] [65] [66] • Length of meetings convened to engage patients in guideline question development[67] • Response rate to surveys gathering patient input on guideline development[68] • Patient participation on guideline development panels[69] • Patient perspectives on ease of using guideline development engagement tools[70] • Patient perspectives on amount of effort needed to participate in guideline development[71] • Patient perspectives on how well guideline development team provided necessary information to engage in guideline development process[72] • Patient perspectives on whether supports they needed to engage were available (e.g., travel, childcare)[73] **Meaningfulness of engagement:** • Type and extent of patient contributions to guideline question development[74] • Patient influence over conduct of discussions[75] • Change in recommendations based on patient input[76] • Change in wording of recommendations based on patient input[77] • Whether patient considered themselves a partner in the guideline development process[78] • Patient's level of confidence that input provided will be used by guideline development team[79] • Patient perspectives on whether engagement initiative was a good use of their time[80] • Patient perspectives on whether they were able to express their views[81]

5.2. Clinical Decision Support Phase

The Clinical Decision Support phase encompasses the implementation of CDS artifacts into decision support tools for patients and clinicians. Patients can be involved in this phase as contributors, collaborators, and partners as well as end users to inform the design, development, implementation, and use of PC CDS.

5.2.1. Participation in Design and Development of PC CDS

Engaging patients as partners in the design and development of PC CDS (i.e., “codesign” and “codevelopment”) can ensure that decision support tools contain the right information, at the right time, and in the right format to meet patients’ needs. To effectively engage patients in codesign, PC CDS developers should focus on building a relationship between developers and users, soliciting iterative feedback, and recognizing that patients have their own expertise in design and development.[82] The CDSiC has developed the Methods for Involving End Users in PC CDS Codesign report that details different approaches for engaging patients in this phase, including consultative groups, surveys, focus groups, and empathy interviews.[83] Adapting steps from the Generative Codesign Framework for Healthcare Innovation[84] and the Software Development Life Cycle,[85] patients can be engaged in the following four activities for PC CDS design and development:

1. **Framing the issue.** Patients can help identify priorities, challenges, and gaps that the PC CDS should address, ensuring that the tool is designed to support real-world patient needs and that there is a shared vision for the work.
2. **Requirements gathering.** Patients can help identify the functional and nonfunctional requirements of the PC CDS, such as the type of information it should collect, how that information should be presented, and preferred modes of delivery.
3. **Generative design work and prototyping**. Patients can participate in activities such as persona exercises, storytelling activities, or creative prototyping exercises to express deeper understanding about the underlying root cause of issues identified above. The products generated can be presented and iterated upon through an appreciative inquiry process to expand on ideas and provide feedback on interface design and content.
4. **Usability testing.** Patients can work alongside developers to involve other patients in testing the PC CDS functionality, navigation, and content to have users assess its ease of use and alignment with their expectations, ensuring the tool is both practical and user-friendly. Usability testing includes methods such as think-aloud protocols, heuristic evaluations, card-sorting activities, user interviews, user diaries, direct observation, and specialized surveys like the System Usability Scale.[86]

Summary of Measures. There were few measures in the literature for engaging patients as contributors, collaborators, and/or partners in PC CDS codesign or codevelopment (Exhibit 7). One exemplar is AHRQ’s CDS Connect project, which included patient activists in the agile software development every two weeks and measured their influence on decisions related to features and functionalities.[87] However, most of the measures we identified related to the structure and process of participation in prototyping and usability testing (e.g., number of patients, number of activities), which key informants emphasized did not capture the meaningfulness of engagement. While there are descriptions of several codesign methods in the literature, there is limited evaluation of the codesign process itself.[88] For instance, one study involved stakeholders in a participatory design process called "living labs" where stakeholders were involved in the design of research methodology, requirements gathering, prototyping, and usability testing.[89] Stakeholder input informed the design and development of an electronic system that streamlines elderly patient referrals to community services. However, the study did not use a measurement framework to assess stakeholders' perceptions of engagement.

Exhibit 7. Example measures for patient engagement in design and development of PC CDS

Engagement Activities	Example Measures From Inventory
Requirements gathering	**Structure and process of engagement:** • Number of requirements identified by patients **Meaningfulness of engagement:** • Documentation of decisions influenced by patient input during agile software development[90] • Prioritization of features and functionality based on patient input[91]
Prototyping and usability testing	**Structure and process of engagement:** • Number of design activities patients participated in • Input provided on prototype features, functionalities, and interface design[92] [93] **Meaningfulness of engagement:** • Perspectives on the value of their contributions[94] • Degree to which patients feel comfortable sharing feedback on the technology[95]

5.2.2. Participation in Implementation of PC CDS

Patients can be engaged as contributors, collaborators, and/or partners in the implementation of PC CDS (i.e., in "codeployment"). Patient engagement in implementation can facilitate adoption and acceptance among patients using the tool, as well as ensure that PC CDS is created to support end user needs and fit within patients' lifeflows (i.e., daily activities) outside of the healthcare setting. Patient engagement in implementation of PC CDS encompasses involvement in the following four activities:

1. **Designing patient lifeflows.** Patients can contribute to designing workflows that integrate PC CDS into their daily routines, ensuring the tool aligns with their real-world needs, preferences, and interactions with clinicians.
2. **End user training.** Patients can help develop training materials for other patients and caregivers, ensuring that instructions on using the PC CDS are clear and accessible, effectively communicating key information.

3. **Participation in pilot project.** Patients can take part in pilot implementations of the PC CDS, providing feedback on usability, effectiveness, and real-world application to refine and improve the tool before broader deployment.
4. **Ongoing refinement and evaluation**. Patients can be involved in continuous evaluation and improvement efforts, offering insights on the PC CDS's performance, identifying challenges, and helping to refine features to enhance long-term effectiveness and engagement.

Summary of Measures. We did not identify measures to assess the patient's level of engagement as a collaborator, contributor, and/or partner in codeployment, but there were some measures for patient engagement as a user of PC CDS in pilot projects (Exhibit 8). This may be an evolving area of patient engagement; some organizations have recommended engaging patients in developing pamphlets, flyers, or scripts about why patient-reported outcome (PRO) data are collected and how they are used to inform clinical decision making,[96] yet development of patient engagement measures is still formative.

Exhibit 8. Example measures for patient engagement in implementation of PC CDS

Engagement Activities	Example Measures From Inventory
Participation in pilot projects	**Structure and process of engagement:** • Number of patients recruited for intervention[97] • Percentage of patients who registered/signed up[98] • Number of active users by user type[99]

5.2.3. Use of PC CDS

Engaging patients as end users of the PC CDS allows them to access and understand relevant health information, participate in decision making regarding their care, and contribute their own data to inform clinical decisions. Here, patients engage in bidirectional interactions with the PC CDS technology rather than their clinician or care team (i.e., they provide information to the PC CDS and the PC CDS provides information back). In their conceptual framework, O'Brien and Toms define user engagement with technology as "a quality of user experience characterized by attributes of challenge, positive affect, endurability, aesthetic and sensory appeal, attention, feedback, variety/novelty, interactivity, and perceived user control."[100] Patients can be engaged in use of PC CDS in four distinct stages adapted from O'Brien and Toms[101]:

1. **Point of engagement.** This refers to the extent to which patients log into or otherwise access a PC CDS. They may be motivated by their medical condition, their health goals, and encouragement from caregivers or clinicians.
2. **Period of engagement.** This refers to extent to which patients explore all the tool's available features and maintain their focus on the PC CDS.
3. **Disengagement and reengagement**. Patients may stop their engagement with the PC CDS for a period of time due to internal reasons (e.g., sense of urgency, perceived sense of control over their condition), or external reasons (e.g., lack of time, technological issues) and can return to the PC CDS to restart the engagement process. They may reengage if they have a recurrence of a clinical condition or their condition changes (e.g., stage of hypertension).

4. **Interaction with information from the PC CDS.** This refers to the extent to which patients review the information provided by the PC CDS as well as contribute their own information (e.g., entering symptoms). This includes feedback, or the information communicated from the PC CDS about actions that have occurred and results that were achieved.

Summary of Measures. As shown in Exhibit 9, measures included mostly structure and process measures. In user interface design, structure and process measures can be categorized as user-based metrics (i.e., how users behave with and experience the tool), usage-based metrics (i.e., how deeply and frequently users interact with specific features) and performance metrics (i.e., overall effectiveness of the tool). Overall, key informants said that performance metrics were typically underrepresented in the clinical informatics literature, but key to elucidating why patients engage with PC CDS in certain ways.

We did not identify many measures of the meaningfulness of engagement in the literature, which was validated by our key informants. Key informants said this could be done by measuring engagement in correlation with clinical touchpoints in order to understand whether the behavior is related to the PC CDS. For example, if a patient interacts with a patient portal to schedule an appointment, that metric should be correlated with the point of clinical encounter and any patient portal interactions due to that encounter.

Some key informants also emphasized that measures of use should be reflective of the patient's illness. Patients with chronic diseases may be more engaged with PC CDS tools if it impacts their quality of life (e.g., patients with hypertension, diabetes, or cardiovascular disease), whereas some patients may be less likely to engage if their condition impacts their cognitive or energy levels (e.g., patients with dementia).

Exhibit 9. Example measures for use of PC CDS

Engagement Activities	Example Measures From Inventory
Point of engagement, period of engagement, disengagement, and reengagement	**Structure and process of engagement:** • *User metrics:* – Number of login attempts[102] – Rate and extent of PC CDS uptake[103] • *Usage metrics:* – Percentage of days the PC CDS was used[104] – Amount of time spent on the patient portal or PC CDS (minutes per day or per week)[105] • *Performance metrics:* – Number of help desk requests sent[106] **Meaningfulness of engagement:** • *User metrics:* – Perceptions of usability (screen legibility, dropdown menu functionality)[107] • *Performance metrics:* – User feedback on errors related to usability[108]

Engagement Activities	Example Measures From Inventory
Interaction with information from the PC CDS	**Structure and process of engagement:** • *User metrics:* – Number of alerts accepted over total number of alerts fired[109] – Number of alerts/recommended actions overridden[110] – Frequency of PRO reporting or symptom reporting[111] – Frequency of submitting patient-generated health data (PGHD) – Number of portal messages sent/received[112] – Percentage of users that incorporated all components of the decision aid as intended[113] – Degree of workload burden (demand-capacity ratio) for cognitive, physical, and social-behavioral tasks[114] – Perceptions of alignment of information with patient's daily life[115] • *Usage metrics:* – Amount of time spent interacting with information on decision aids[116] – Whether patients could successfully retrieve all information (e.g., medications) across data categories[117] • *Performance metrics:* – Number of alert malfunctions per month[118] **Meaningfulness of engagement:** • *User metrics:* – Perceptions of usability (ease of finding information, clarity of information, timeliness of information)[119]

5.3. Healthcare Delivery Phase

The Healthcare Delivery phase embodies the shared decision-making process, which is a collaborative process between clinicians and patients/caregivers to make a healthcare decision based on evidence and patient's preferences.[120] The decision is usually between two or more options, and clinicians should bring together patient's values, goals, and preferences with the care team's knowledge and experience using risk communication principles. The CDSiC has developed a report (The Integration of Patient-Centered Clinical Decision Support Into Shared Decision Making) to describe how PC CDS can facilitated shared decision making.[121] It provides a framework integrating the three elements of PC CDS (knowledge, data, delivery) with Elwyn et al.'s three phases of shared decision making (SDM): Team talk, Option talk, and Decision talk.[122] Measurement in this phase can include both the patient's level of engagement as well as how well clinicians engaged patients in shared decision making.

5.3.1. Discussions About Roles and Preferences ("Team Talk")

"Team talk" refers to discussions between clinicians and patients that acknowledge that a healthcare decision needs to be made. Patient engagement in Team talk initiates the shared decision-making process and emphasizes patients' goals as a means of guiding decision making. Patients can be engaged in Team talk in two areas:

1. **Establishment of roles.** Patients can be involved in discussions about the extent to which they want to be involved in the decision making, and whether they want family members or caregivers in involved in the decision making.
2. **Discussion of patient values, preferences, and/or goals.** Patients can be involved in discussions about their goals related to care, quality of life, and outcomes and preferences for various aspects of the decision making (e.g., information seeking, communication).

Exhibit 10. Example Survey Instruments

- **Problem-Solving Decision-Making Scale**[123]**:** Measures problem-solving and decision-making preferences in medical treatment.
- **Control Preferences Scale**[124]**:** Measures how much control individuals want in treatment decisions ranging from individual to physician decision making.
- **Patient Preferences for Engagement Tool (PPET)**[125]**:** Preferences for engagement in healthcare across six key domains.
- **Communication Preferences for Patients with Chronic Illness**[126]**:** The extent of matching between patient communication preferences and physician communication behavior.

Summary of Measures. The majority of measures relate to the structure and process of engaging patients in Team talk. They can be assessed through the patient or clinician's perspective. There are several shared decision-making instruments that gather patients' preferences, including structural components of care (e.g., clinician or health system characteristics), processes of care (e.g., preferred decision-making engagement), and outcomes of care (e.g., length of hospital stay) (see the CDSiC's Inventory of Patient Preference Measurement Tools for PC CDS for a full list of preferences that can be assessed).[127] Exhibit 10 shows a few example instruments. Here, we focus on the measures that assess the patient's level of engagement in sharing their preferences, values, or goals with their clinicians. There are several patient-reported instruments that assess whether patients expressed their preferences with their clinician and whether they want to be involved in the decision making.[128] [129] There are also instruments that assess the extent to which clinicians elicited patients' preferences or identified goals during conversations. The only meaningful measure of engagement that we identified assessed patient's perceptions toward using a patient portal for decision making from the Patient Portal Cross Section Surve (Exhibit 11).[130]

Exhibit 11. Example measures for patient engagement in team talk

Engagement Activities	Examples Measures From Inventory
Establishment of roles in the decision-making process	**Structure and process of engagement:** • Preference for decision-making role and information sharing[131] • Inclusion of family/caregivers in decision-making process[132] • Readiness for engagement in decision-making[133] [134] • Extent to which clinician involved patients in shared decision making[135] [136] • Whether clinician indicated a need for shared decision making[137] [138]

Engagement Activities	Examples Measures From Inventory
Discussion of patient values, preferences, and/or goals	**Structure and process of engagement:** • Whether patients shared their preferences with their clinician • Number of patients that shared their preferences with their clinician • Number of clinician inquiries about patient's preferences • Whether clinician elicited patient's preferences in conversations • Number of preferences that were incorporated in the PC CDS **Meaningfulness of engagement:** • Patient attitudes and expectations toward using a patient portal during decision making[139]

5.3.2. Discussions About Options ("Option Talk")

"Option talk" refers to discussions between clinicians and patients regarding the risks and benefits of all their available treatment or care options. Patient engagement in Option talk ensures that they are making an informed decision that aligns with their goals and values. Clinicians can engage patients in two activities related to Option talk:

1. **Discussion of available options.** Patients can be involved in discussions about the different treatment or care plan options available to them.
2. **Discussion of pros and cons.** Patients can be involved in the consideration of the benefits and risks of each option.

Measurement in this area. Through the literature and key informant interviews, we only identified structure and process measures for clinician's engagement of patients in Option talk, assessed by gathering patient, clinician, or external observer perspectives through survey instruments (Exhibit 12). Instruments assess whether the clinician presented different options and weighed the pros and cons with the patients. They can also measure the effectiveness of the clinician's risk communication from the patient's perspective. Exhibit 13 shows a few example instruments.

Key informants discussed differing opinions on measuring patient understanding of available options. Some believed that the growth of artificial intelligence could provide new methods for assessing level of engagement through verbal patterns and gestures, such as through ambient sensors, speech analysis, or facial recognition. Others believed those were passive measures of engagement that would not be sufficient for measuring meaningful engagement.

Exhibit 12. Example measures for patient engagement in option talk

Engagement Activities	Example Measures From Inventory
Discussion of available options	**Structure and process of engagement:** • Whether clinician presented more than one option[140] [141] • Whether clinician provided enough information about each option available[142]

Engagement Activities	Example Measures From Inventory
Discussion of pros and cons	**Structure and process of engagement:** • Whether clinician explained pros and cons of each option[143] [144] • Whether clinician checked for patient's understanding of the information provided[145] [146]

5.3.3. Discussions About the Decision ("Decision Talk")

"Decision talk" refers to the task of arriving at a healthcare decision. Patient engagement in the Decision talk increases the likelihood that the decision reflects their informed preferences. Clinicians can engage patients in three activities related to Decision talk:

1. **Shared decision making.** Patients can be involved in discussion about the final decision to be made.
2. **Patient-clinician communication.** Patients can provide feedback on the overall quality, quantity, and timeliness of communication from their care team.
3. **Results of the decision.** Patients can share feedback on how they are feeling about the decision, whether the care plan is working, and any challenges they are experiencing with the decision.

Summary of Measures. Measures include structure and process-focused counts of whether Decision talk occurred as well as more meaningful measures that assess patients' perceptions of their involvement in Decision talk (Exhibit 14). Key informants provided suggestions for how to make the identified measures meaningful by soliciting patients' perceptions. For instance, instead of calculating the "time span to make a decision," assessments could ask patients if they had enough time to make a decision. Instead of observers reporting the number of topics raised by patients, they could ask patients if they were able to ask all their questions/concerns.

Exhibit 13. Example survey instruments

- **COMRADE**[147]**:** Measures the effectiveness of risk communication and treatment decision making in consultations.
- **DEEP-SDM**[148]**:** A coding scheme for analyzing SDM in medical encounters. It allows for in-depth analysis of each participant's contributions.
- **MAPPIN-SDM**[149]**:** Assesses SDM behaviors and competencies of clinicians, patients, and the clinician-patient dyad.
- **OPTION Scale**[150]**:** Observer-rated instrument for whether problems are well-defined, options are formulated, information is provided, and patient understanding and role preferences are evaluated.
- **SDM-Q-9**[151]**:** Assesses the implementation of SDM in clinical encounters.
- **Shared Decision-Making Process Scale**[152]**:** Short patient-reported measure for discussions of options, pros and cons, and preferences.
- **SURE Scale**[153]**:** A brief measure of decisional conflict.

We identified several instruments with items related to Decision talk (Exhibit 15). After a clinical encounter, patients can share their perceived level of involvement in decision making or their clinician's level of support and encouragement.[154] They can also share their satisfaction with the decision-making process, the emotional impact of the decision, and their confidence in the decision, which measure the effect of the engagement in Decision talk.[155][156] Clinicians can also share their perspective of engaging patients in the process and documenting followup plans.[157][158] In addition, external observers or clinicians can assess how well clinicians communicated, exhibited empathy, and established relationships with patients.

Exhibit 14. Example Measures for patient engagement in decision talk

Engagement Activities	Example Measures From Inventory
Shared decision-making process	**Structure and process of engagement:** • Time span to make a decision from initial screening[159] • Number of patients/caregivers that participated in shared decision making • Whether clinician provided decision tools during decision making • Whether clinician solicited patient's involvement in decision making • Whether clinician incorporated patient's preferences/values in conversations **Meaningfulness of engagement:** • Perceived level of involvement in decision making (observed or self-report)[160][161] • Effectiveness of decision tools during decision making[162] • Patient level of satisfaction with the decision-making process[163]
Patient-clinician communication	**Structural and process of engagement:** • Number of topics/questions patients raised with their clinician[164] • Number of utterances or decision-making events that families engaged in[165] **Meaningfulness of engagement:** • Patient perspectives regarding whether clinician listened to their inquiries • Patient perspectives regarding whether clinician encouraged their questions
Results of the decision	**Structural and process of engagement:** • Extent to which patients followed through with the treatment decision[166] **Meaningfulness of engagement:** • Patient level of confidence in the decision[167][168]

5.4. Outcomes of Patient Engagement in PC CDS

Patient engagement throughout the PC CDS lifecycle has the potential to enhance patient involvement in their own care, ultimately improving important health-related outcomes. The process begins with patient engagement in research and guideline development, which can strengthen the relevance and applicability of the evidence base and resulting guidelines. Incorporating better evidence and guidelines into PC CDS technology, while engaging patients in codesign and codeployment, can lead to more effective technologies that are better aligned with patient needs and preferences. More effective PC CDS technologies, in turn, could facilitate greater adoption, enabling meaningful shared decision making and more informed healthcare decisions. The cumulative impact of these effects is greater patient empowerment, increased overall engagement in care, and improved health management and outcomes.

In this section, we focus on the cumulative impact of patient engagement across the PC CDS lifecycle. However, attributing outcomes such as improved activation, engagement with care, adherence, and health outcomes, requires an understanding of the meaningfulness of engagement and its effects at each step in the PC CDS lifecycle. PC CDS technology alone does not inherently lead to greater patient engagement in care or better outcomes—these benefits depend on whether the underlying evidence was strengthened by patient input, whether the technology was meaningfully enhanced through codesign, and whether its implementation supports effective access and sustained use.

Below we describe the outcomes associated with engagement across the PC CDS lifecycle and measure constructs typically used to assess them.

Exhibit 15. Example survey instruments

- Clinical Decision Making Involvement and Satisfaction[169]: Measures involvement and satisfaction from patient and staff perspective for use in mental health services.
- CollaboRATE[170]: Patient-reported measures of the process of SDM
- Decisional Conflict Scale[171]: Measures perceptions of uncertainty and modifiable factors of uncertainty.
- Decision Regret Scale[172]: Indicator of health care decision regret at a given point in time.
- Facilitation of Patient Involvement Scale (FPIS)[173]: Nine-item measure to assess the degree to which patients perceive that their clinician actively encouraged or facilitated their involvement in their own healthcare.
- Perceived Involvement in Care Scale[174]: Examines three factors: 1) doctor facilitation of patient involvement, 2) level of information exchange, and 3) patient participation in decision making.

5.4.1. Patient Empowerment

Patient empowerment encompasses patients' perceptions of their agency and self-efficacy as it relates to their health and healthcare providers. Measures used in the literature for assessing how PC CDS impacts patient empowerment cover three areas: 1) knowledge acquisition, 2) trust, and 3) activation. Exhibit 16 describes each of these constructs.

Exhibit 16. Measure constructs for assessing patient empowerment

Measure Construct	Description
Knowledge Acquisition	The degree to which the patient came away with lasting knowledge about their medical situation.[175]
Trust	The degree to which the patient has trust in their healthcare organization and clinicians.[176]
Patient Activation	The extent to which patients have the knowledge, skills, and confidence to manage their health and involve themselves in the decision-making process.[177]

5.4.2. Patient Engagement in Care

Numerous terms and concepts are used interchangeably when discussing patient engagement (e.g., patient activation, treatment adherence), leading to confusion and wide variation in what patient engagement in care is and how it is measured.[178] [179] However, validated instruments developed to measure engagement generally consider it to be a distinct, more holistic concept than patient empowerment, encompassing how patients interact with their health and healthcare systems at multiple levels (i.e., not only at medical visits or at specific points in time).[180] [181] These instruments cover the patient's psychological experience, commitment, navigation, and ownership. Exhibit 17 provides further information about these constructs and what they measure.

Exhibit 17. Measure constructs for assessing patient engagement in care

Measure Construct	Description
Psychological experience	The degree to which a patient's emotional, cognitive, and behavioral states change over time as it relates to their health situation.[182]
Commitment	The degree to which a patient is able to maintain health management behaviors.[183]
Informed Choice	The degree to which a patient makes informed decisions about who they want to treat them.[184]
Navigation	The degree to which a patient feels confident in navigating healthcare systems.[185]
Ownership	The degree to which the patient feels their health situation is their responsibility.[186]

5.4.3. Health Management and Outcomes

Health management and outcomes encompass actions patients take to manage their health and medical conditions, and the impact of those actions on their health status. PC CDS technologies that successfully empower patients and inspire engagement with care have the potential to lead to improved health management and outcomes. Measures used in the literature for assessing how PC CDS impacts health management and outcomes cover three areas: 1) adherence to care plans, 2) behavior change, and 3) clinical outcomes. Exhibit 18 describes each of these constructs.

Exhibit 18. Measure constructs for assessing health management

Measure Construct	Description
Adherence[187]	The degree to which patients follow treatment recommendations.
Behavior change	The degree to which patients engage in activities or behaviors to control their disease or condition (e.g., exercising, making follow-up appointments).[188]
Clinical outcomes	The degree to which the patient experiences a change in health status.[189]

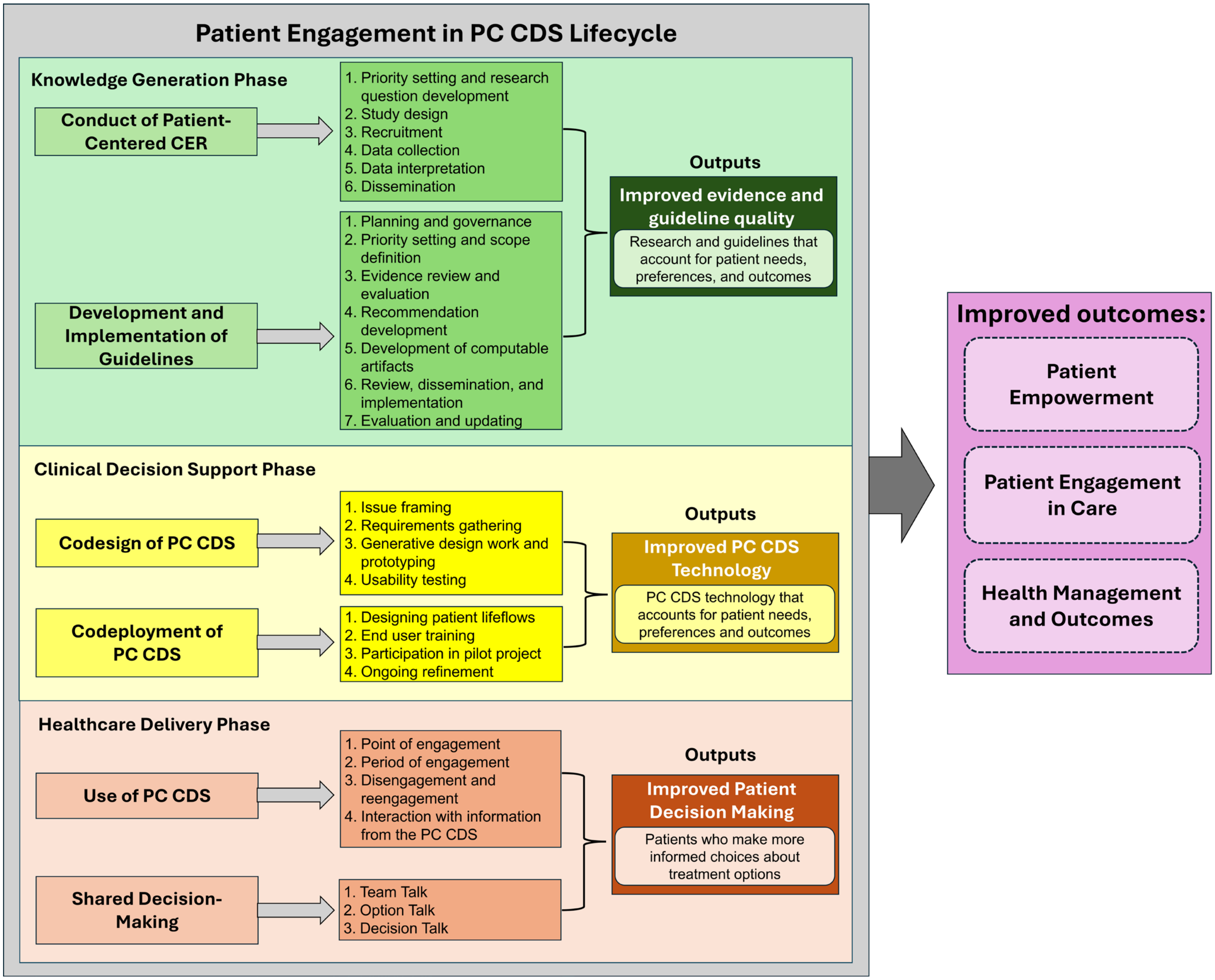
6. Discussion

The inventory of measures for patient engagement in PC CDS contains measures to assess the structures, processes, meaningfulness, and outputs of patient engagement across the PC CDS lifecycle. Exhibit 19 provides a framework for users of the inventory to understand how patient engagement occurs throughout the lifecycle and ultimately contributes to improvements in important end goals in healthcare delivery, namely more empowered and engaged patients and better overall health management. Given the emerging nature of PC CDS, this framework and inventory are not meant to prescribe a fixed set of measures but rather to help evaluators expand their thinking about what to consider when designing their evaluation strategies.

This framework and inventory advance the field of PC CDS patient engagement measurement in three ways:

1) They include measures across the entire PC CDS lifecycle.
2) They differentiate between structure and process measures versus measures of meaningful engagement, which offer insight into the depth and impact of engagement.
3) They distinguish the outputs of engagement—those directly related to PC CDS lifecycle activities—and the outcomes, which reflect PC CDS technology's broader influence on patient empowerment and engagement in care. This distinction provides a blueprint for identifying effects that can be directly attributed to engagement in the PC CDS lifecycle versus those requiring more advanced measurement and attribution methods.

Exhibit 19. Framework for patient engagement measurement across the PC CDS lifecycle



In developing the framework and inventory, we identified several gap areas and opportunities for advancing measurement of patient engagement in PC CDS:

1) **Lack of measures that capture meaningful patient engagement.** Overall, our literature review and key informant interviews revealed that there is a need to move beyond structure and process measures of engagement and identify sophisticated measures that truly assess meaningful patient engagement. While there are several instruments that measure meaningful engagement in the research phase (e.g., PEIRS, REST), there is little guidance for measurement in clinical practice guideline development and PC CDS codesign, and co-implementation. Future measures could borrow from and build on those used in research to include assessments of how patients want to be engaged, their perceptions of their involvement, their trust in the project team, their decision-making authority or power sharing throughout the process, and the impact of patient contributions on final products.
2) **Lack of measures to assess PC CDS codesign and codeployment.** While patient engagement in codesign and codeployment is emerging, there is a significant gap in measures in this area.[190] This limits our understanding of whether the degree of patient involvement is sufficient for developing effective and appropriate PC CDS. It can also lead to developing PC CDS that primarily aligns with the goals of clinicians or health systems rather than patients.[191] Future research is needed to determine whether measures identified in the Knowledge Generation phase could apply to codesign and codeployment.
3) **Difficulty connecting engagement in PC CDS to improved outputs and outcomes.** While improving patient engagement across the PC CDS lifecycle is important, its value remains challenging to demonstrate due to significant evidence gaps.[192] A critical limitation is the scarcity of conclusive research proving that enhanced patient engagement directly translates to improved outputs and outcomes across the PC CDS lifecycle. Apart from the shared decision-making step, many evaluation studies relied on qualitative methods to capture the effects of patient engagement, providing valuable insights but often lacking standardization and limiting the ability to draw clear links to overall engagement in care and health-related outcomes.[193] In addition, there are statistical challenges with linking patient engagement with PC CDS directly to health outcomes due to the multiple factors involved in patient care and the need for longitudinal studies that extend beyond the evaluation phase.[194] Future activities should focus on assessing how different levels and types of patient engagement influence outputs and outcomes, and developing and validating more robust outcome measures of engagement in PC CDS.
4) **No gold standard exists to measure engagement.** Despite the attention on capturing preferences for engagement with PC CDS,[195] there are currently few reliable and valid means to measure the meaningfulness of engagement with PC CDS across the lifecycle. Though several instruments are used to measure patient engagement in research, key informants noted that few have undergone sufficient reliability and validity testing. No formal instruments existed for any of the other steps in the lifecycle. More work is needed across the steps in the PC CDS lifecycle to develop standardized measurements for assessing the meaningful participation of patients to allow for comparisons across projects and within projects over time. Moreover, this measure

development and validation should involve patients to ensure their perceptions of what meaningful engagement is are captured given their unique conditions and other demographic characteristics.[196]

7. Inventory Limitations

We identified three main limitations. First, the literature review was not exhaustive or systematic. Given the nascency of PC CDS, we began with targeted reviews of CDSiC documents followed by a snowball approach to focus on what has already been collected on the topic. Secondly, there is inconsistent terminology in the literature to describe patient engagement. The terms patient empowerment, patient activation, self-efficacy, patient participation, and patient-centeredness are often used interchangeably when discussing patient engagement in care and health IT,[197] [198] and there is no specific MeSH term for patient engagement.[199] In addition, the structure and process of engagement (e.g., number of engaged patients) and the impact of engagement (e.g., influence on design decisions) are often used interchangeably in the literature, and their descriptions are often vague and difficult to interpret.[200] Finally, we did not include information on the validity, reliability, or prevalence of use of the measures or instruments in the report or inventory. Our goal was to outline areas to measure patient engagement and identify gaps and future opportunities for measurement.

8. Conclusion

To realize the benefit of patient-centered clinical decision support tools, a better understanding is needed of relevant measures of patient engagement throughout the PC CDS lifecycle. The current landscape of patient engagement measurement largely focuses on structure and process measures, with limited measures to assess meaningful engagement. Future work in advancing patient engagement in PC CDS should focus on developing measures for patient codesign and codeployment, improving measurement validation, and linking process measures to healthcare outcomes.

9. Appendix

9.1. Appendix A: PC CDS Patient Engagement Measurement Inventory - User Guide

VERSION AND DATE	Version 3_July 22, 2025
PURPOSE	The PC CDS Patient Engagement Measurement Inventory supports PC CDS developers, implementers, and evaluators in identifying key measures of patient engagement across the PC CDS lifecycle, spanning the generation of evidence, the translation of that evidence into PC CDS tools, and the use of those tools in clinical decision making.
WHAT IS IN THE INVENTORY	Measures and associated instruments to assess patient engagement across the PC CDS lifecycle
WHEN TO USE THE INVENTORY	• In the proposal drafting phase, to identify and justify relevant patient engagement measures that demonstrate the project's commitment to patient-centered design and evaluation. • In the planning phase of a PC CDS project, to select appropriate measures that align with project goals and ensure appropriate data are collected from the outset. • In the implementation or evaluation phase of a PC CDS project, to assess the effectiveness and impact of patient engagement strategies used in the development and use of PC CDS tools.
HOW TO USE THE INVENTORY	• To use the inventory effectively, we recommend beginning by identifying the phase of the PC CDS lifecycle you are working in (Knowledge Generation, Clinical Decision Support, and Healthcare Delivery) via the "PC CDS Lifecycle Phase" column. • From there, use the "Steps Where Patients Are Engaged" column to find measures relevant to your specific context. • You can then review further by activity, measure type, data collection approach, and the perspective assessed to find measures that best fit your project's goals and resources. • For additional detail on the structure and definitions of the variables included in the inventory, refer to the second tab ("Codebook"), which provides comprehensive explanations for each column and term used.
CONSIDERATIONS FOR USING THE INVENTORY	• **The inventory is not a comprehensive resource for patient engagement measures across the PC CDS lifecycle,** as the team did not conduct a systematic review in developing it. • **The Inventory does not contain measures that assess the outcomes of engagement**, as there is little conclusive research correlating patient engagement with improved outcomes. • **The Inventory does not include information on the reliability or validity of instruments or tools,** as the information is not readily available/many instruments have not undergone sufficient reliability and validity testing.

9.2. Appendix B: PC CDS Patient Engagement Measurement Inventory - Codebook

Variable Name	Description	Values	Notes
PC CDS Lifecycle Phase	The phase of the PC CDS lifecycle to which the measure is applicable.	• Knowledge Generation Phase • Clinical Decision Support Phase • Healthcare Delivery Phase	Some measures can be used to assess patient engagement in multiple phases of the PC CDS lifecycle. When this is the case, each step that the measure assesses is included in the cell, separated by a semicolon (e.g., Knowledge Generation Phase; Clinical Decision Support Phase; Healthcare Delivery Phase).
Steps Where Patients Are Engaged	The specific step(s) of the PC CDS lifecycle where patients can be engaged, to which the measure is applicable.	• Conduct of Patient-Centered Outcomes Research (PCOR) • Development and Implementation of Guidelines • Design and Development of PC CDS • Implementation of PC CDS • Use of PC CDS • Team Talk • Option Talk • Decision Talk • All steps	Some measures can be used to assess patient engagement in multiple steps. When this is the case, each step that the measure assesses is included in the cell, separated by a semicolon (e.g., Conduct of Patient-Centered Outcomes Research (PCOR); Development and Implementation of Guidelines).

Variable Name	Description	Values	Notes
Activities Where Patients Are Engaged	The specific activity (or activities) within each step of the PC CDS lifecycle in which patients can engage, to which the measure is applicable.	• Research question development • Study design, Recruitment • Data collection • Data interpretation • Dissemination • Planning and governance • Priority setting and scope definition • Evidence review and evaluation • Recommendation development • Developing computable artifacts • Review, dissemination, and implementation • Evaluation and updating • Framing the issue • Requirements gathering • Generative design work and prototyping • Usability testing • Participation in pilot project • Point of engagement • Period of engagement • Disengagement and reengagement • Interaction with information from the PC CD • Establishment of roles • Discussion of patient values, preferences, and/or goals • Discussion of available options • Discussion of pros and cons • Patient-clinician communication • Shared decision making • Results of the decision • All activities	Some measures can be used to assess patient engagement in multiple activities within a single step. In these cases, each activity is listed in the cell and separated by commas. If a measure applies to multiple steps and multiple activities, the activities for each step are grouped and separated by semicolons (e.g., Dissemination; Planning and governance).

Variable Name	Description	Values	Notes
How Patients Are Engaged	The capacity in which patients are engaged in the activity (or activities).	• Contributor/Collaborator/Partner • User	Patients can be engaged in the PC CDS lifecycle as: 1) contributors, collaborators, or partners involved in research, guideline development, and the design and development of PC CDS technologies; and 2) end users of PC CDS technology, where their use of these tools to contribute data and inform decisions represents an active role in healthcare delivery.
Measure	The measure used to assess patient engagement in the activity.	e.g., Extent to which patients shape how discussions are conducted, Percentage of users that incorporate all components of the decision aid as intended	
Measure Type	Whether the measure assessed the structure/process of engagement or the meaningfulness of engagement.	Structure/Process Meaningfulness	Measures that assess the structure/process of engagement focus on observable characteristics or activities (e.g., demographics of patients, number of patients engaged). Measures that assess the meaningfulness of engagement focus on elements such as patients' influence, decision-making authority, and perceived impact within the engagement process.
Perspective Assessed	The perspective from which patient engagement is evaluated by the measure.	Patient Researcher N/A	Because some structure/process measures focus solely on observable characteristics or activities—such as counts or demographics—they do not capture a particular perspective. In these cases, the cell is designated with "N/A".
Data Collection Approach	Whether the measure is collected using qualitative or quantitative methods.	Quantitative Qualitative	
Instrument	The name of the instrument from which the measure is derived.	e.g., Person Centeredness of Research Scale (PCoR), Research Engagement Survey Tool (REST)	For measures that are not derived from a specific instrument, the cell is designated with "N/A".
Source(s)	The AMA-formatted citation(s) for the source(s) from which the measure was derived.	AMA citation	
Link to Instrument	The web link to the instrument from which the measure is derived.	URL	For measures that are not derived from a specific instrument, the cell is designated with "N/A".

9.3. Appendix C: PC CDS Patient Engagement Measurement Inventory

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	Steps Where Patients Are Engaged	Activities Where Patients Are Engaged	How Patients Are Engaged	Measure	Measure Type	Perspective Assessed	Data Collection Approach	Tool	Source(s)	Link to Tool
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Extent to which patients shape how discussions are conducted	Meaningfulness	Researcher	Qualitative	N/A	Armstrong MJ, Mullins CD, Gronseth GS, Gagliardi AR. Impact of patient involvement on clinical practice guideline development: a parallel group study. Implement Sci. 2018;13(1):55. Published 2018 Apr 16. doi:10.1186/s13012-018-0745-6	N/A
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Extent to which patients contribute to setting patient-centered scope	Meaningfulness	Researcher	Qualitative	N/A	Armstrong MJ, Mullins CD, Gronseth GS, Gagliardi AR. Impact of patient involvement on clinical practice guideline development: a parallel group study. Implement Sci. 2018;13(1):55. Published 2018 Apr 16. doi:10.1186/s13012-018-0745-6	N/A
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Extent to which patients' lived experience influenced guideline development	Meaningfulness	Researcher	Qualitative	N/A	Armstrong MJ, Mullins CD, Gronseth GS, Gagliardi AR. Impact of patient involvement on clinical practice guideline development: a parallel group study. Implement Sci. 2018;13(1):55. Published 2018 Apr 16. doi:10.1186/s13012-018-0745-6	N/A
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Extent to which patient partnership was meaningful and effective	Meaningfulness	Researcher	Qualitative	N/A	Armstrong MJ, Mullins CD, Gronseth GS, Gagliardi AR. Impact of patient involvement on clinical practice guideline development: a parallel group study. Implement Sci. 2018;13(1):55. Published 2018 Apr 16. doi:10.1186/s13012-018-0745-6	N/A

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR); Development and Implementation of Guidelines	Research question development; Priority setting and scope definiton, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Extent to which relevant issues that may be overlooked by medical professionals were identified	Meaningfulness	Researcher	Qualitative	N/A	Armstrong MJ, Mullins CD, Gronseth GS, Gagliardi AR. Impact of patient involvement on clinical practice guideline development: a parallel group study. Implement Sci. 2018;13(1):55. Published 2018 Apr 16. doi:10.1186/s13012-018-0745-6	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR); Development and Implementation of Guidelines	Research question development; Priority setting and scope definiton, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Extent to which patient contributions support selection of patient-relevant topics and outcomes	Meaningfulness	Researcher	Qualitative	N/A	Armstrong MJ, Mullins CD, Gronseth GS, Gagliardi AR. Impact of patient involvement on clinical practice guideline development: a parallel group study. Implement Sci. 2018;13(1):55. Published 2018 Apr 16. doi:10.1186/s13012-018-0745-6	N/A
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Extent of patient influence over guideline development/structure	Meaningfulness	Researcher	Qualitative	N/A	Armstrong MJ, Mullins CD, Gronseth GS, Gagliardi AR. Impact of patient involvement on clinical practice guideline development: a parallel group study. Implement Sci. 2018;13(1):55. Published 2018 Apr 16. doi:10.1186/s13012-018-0745-6	N/A
Knowledge Generation Phase	Development and Implementation of Guidelines	Review, dissemination, and implementation	Contributor/ Collaborator/ Partner	Extent of patient involvement in guideline dissemination and implementation	Meaningfulness	Researcher	Qualitative	N/A	Armstrong MJ, Mullins CD, Gronseth GS, Gagliardi AR. Impact of patient involvement on clinical practice guideline development: a parallel group study. Implement Sci. 2018;13(1):55. Published 2018 Apr 16. doi:10.1186/s13012-018-0745-6	N/A

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Length of meetings convened to engage patients in guideline question development	Structure/ Process	N/A	Quantitative	N/A	Armstrong MJ, Mullins CD, Gronseth GS, Gagliardi AR. Impact of patient involvement on clinical practice guideline development: a parallel group study. Implement Sci. 2018;13(1):55. Published 2018 Apr 16. doi:10.1186/s13012-018-0745-6	N/A
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Demographic and disease composition of patients engaged in guideline development	Structure/ Process	N/A	Quantitative	N/A	Armstrong MJ, Mullins CD, Gronseth GS, Gagliardi AR. Impact of patient involvement on clinical practice guideline development: a parallel group study. Implement Sci. 2018;13(1):55. Published 2018 Apr 16. doi:10.1186/s13012-018-0745-6	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	How often the research team provides patients with opportunity to share ideas, input, and leadership responsibilities and to share in the determination of the project structure	Structure/ Process	Patient	Quantitative	Research Engagement Survey Tool (REST)	Bowen, D.J., Ackermann, N., Thompson, V.S. et al. A Study Examining the Usefulness of a New Measure of Research Engagement. J GEN INTERN MED 37 (Suppl 1), 50–56 (2022). https://doi.org/10.1007/s11606-021-06993-1	https://publichealth.nyu.edu/w/casjph/rest
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	How well the research team provides patients with opportunity to share ideas, input, and leadership responsibilities and to share in the determination of the project structure	Meaningfulness	Patient	Quantitative	Research Engagement Survey Tool (REST)	Bowen, D.J., Ackermann, N., Thompson, V.S. et al. A Study Examining the Usefulness of a New Measure of Research Engagement. J GEN INTERN MED 37 (Suppl 1), 50–56 (2022). https://doi.org/10.1007/s11606-021-06993-1	https://publichealth.nyu.edu/w/casjph/rest

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	How often the research team provides opportunity for all patient partners to assist in establishing roles and related responsibilities for the partnership	Structure/ Process	Patient	Quantitative	Research Engagement Survey Tool (REST)	Bowen, D.J., Ackermann, N., Thompson, V.S. et al. A Study Examining the Usefulness of a New Measure of Research Engagement. J GEN INTERN MED 37 (Suppl 1), 50–56 (2022). https://doi.org/10.1007/s11606-021-06993-1	https://publichealth.nyu.edu/w/casjph/rest
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	How well the research team provides opportunity for all patient partners to assist in establishing roles and related responsibilities for the partnership	Meaningfulness	Patient	Quantitative	Research Engagement Survey Tool (REST)	Bowen, D.J., Ackermann, N., Thompson, V.S. et al. A Study Examining the Usefulness of a New Measure of Research Engagement. J GEN INTERN MED 37 (Suppl 1), 50–56 (2022). https://doi.org/10.1007/s11606-021-06993-1	https://publichealth.nyu.edu/w/casjph/rest
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	How often the research team share updates, progress, strategies, and new ideas regularly	Structure/ Process	Patient	Quantitative	Research Engagement Survey Tool (REST)	Bowen, D.J., Ackermann, N., Thompson, V.S. et al. A Study Examining the Usefulness of a New Measure of Research Engagement. J GEN INTERN MED 37 (Suppl 1), 50–56 (2022). https://doi.org/10.1007/s11606-021-06993-1	https://publichealth.nyu.edu/w/casjph/rest
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	How well the research team share updates, progress, strategies, and new ideas regularly	Meaningfulness	Patient	Quantitative	Research Engagement Survey Tool (REST)	Bowen, D.J., Ackermann, N., Thompson, V.S. et al. A Study Examining the Usefulness of a New Measure of Research Engagement. J GEN INTERN MED 37 (Suppl 1), 50–56 (2022). https://doi.org/10.1007/s11606-021-06993-1	https://publichealth.nyu.edu/w/casjph/rest

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	How often fair processes are established to manage conflicts or disagreements	Structure/ Process	Patient	Quantitative	Research Engagement Survey Tool (REST)	Bowen, D.J., Ackermann, N., Thompson, V.S. et al. A Study Examining the Usefulness of a New Measure of Research Engagement. J GEN INTERN MED 37 (Suppl 1), 50–56 (2022). https://doi.org/10.1007/s11606-021-06993-1	https://publichealth.nyu.edu/w/casjph/rest
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	How well fair processes are established to manage conflicts or disagreements	Meaningfulness	Patient	Quantitative	Research Engagement Survey Tool (REST)	Bowen, D.J., Ackermann, N., Thompson, V.S. et al. A Study Examining the Usefulness of a New Measure of Research Engagement. J GEN INTERN MED 37 (Suppl 1), 50–56 (2022). https://doi.org/10.1007/s11606-021-06993-1	https://publichealth.nyu.edu/w/casjph/rest
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	How often the research team continue community-engaged activities beyond an initial project, activity, or study	Structure/ Process	Patient	Quantitative	Research Engagement Survey Tool (REST)	Bowen, D.J., Ackermann, N., Thompson, V.S. et al. A Study Examining the Usefulness of a New Measure of Research Engagement. J GEN INTERN MED 37 (Suppl 1), 50–56 (2022). https://doi.org/10.1007/s11606-021-06993-1	https://publichealth.nyu.edu/w/casjph/rest
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	How well the research team continue community-engaged activities beyond an initial project, activity, or study	Meaningfulness	Patient	Quantitative	Research Engagement Survey Tool (REST)	Bowen, D.J., Ackermann, N., Thompson, V.S. et al. A Study Examining the Usefulness of a New Measure of Research Engagement. J GEN INTERN MED 37 (Suppl 1), 50–56 (2022). https://doi.org/10.1007/s11606-021-06993-1	https://publichealth.nyu.edu/w/casjph/rest

Areas of Patient Engagement Measures					**Measure Specifications**				**Additional Information**	
PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	How often community-engaged activities are continued until the goals (as agreed upon by all patient partners) are achieved	Structure/ Process	Patient	Quantitative	Research Engagement Survey Tool (REST)	Bowen, D.J., Ackermann, N., Thompson, V.S. et al. A Study Examining the Usefulness of a New Measure of Research Engagement. J GEN INTERN MED 37 (Suppl 1), 50–56 (2022). https://doi.org/10.1007/s11606-021-06993-1	https://publichealth.nyu.edu/w/casjph/rest
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	How well community-engaged activities are continued until the goals (as agreed upon by all patient partners) are achieved	Meaningfulness	Patient	Quantitative	Research Engagement Survey Tool (REST)	Bowen, D.J., Ackermann, N., Thompson, V.S. et al. A Study Examining the Usefulness of a New Measure of Research Engagement. J GEN INTERN MED 37 (Suppl 1), 50–56 (2022). https://doi.org/10.1007/s11606-021-06993-1	https://publichealth.nyu.edu/w/casjph/rest
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	How often patient partners have a variety of opportunities to gain new skills or knowledge from their involvement	Structure/ Process	Patient	Quantitative	Research Engagement Survey Tool (REST)	Bowen, D.J., Ackermann, N., Thompson, V.S. et al. A Study Examining the Usefulness of a New Measure of Research Engagement. J GEN INTERN MED 37 (Suppl 1), 50–56 (2022). https://doi.org/10.1007/s11606-021-06993-1	https://publichealth.nyu.edu/w/casjph/rest
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	How well patient partners have a variety of opportunities to gain new skills or knowledge from their involvement	Meaningfulness	Patient	Quantitative	Research Engagement Survey Tool (REST)	Bowen, D.J., Ackermann, N., Thompson, V.S. et al. A Study Examining the Usefulness of a New Measure of Research Engagement. J GEN INTERN MED 37 (Suppl 1), 50–56 (2022). https://doi.org/10.1007/s11606-021-06993-1	https://publichealth.nyu.edu/w/casjph/rest

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	How often the partnership adds value to the work of all patient partners	Structure/ Process	Patient	Quantitative	Research Engagement Survey Tool (REST)	Bowen, D.J., Ackermann, N., Thompson, V.S. et al. A Study Examining the Usefulness of a New Measure of Research Engagement. J GEN INTERN MED 37 (Suppl 1), 50–56 (2022). https://doi.org/10.1007/s11606-021-06993-1	https://publichealth.nyu.edu/w/casjph/rest
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	How well the partnership adds value to the work of all patient partners	Meaningfulness	Patient	Quantitative	Research Engagement Survey Tool (REST)	Bowen, D.J., Ackermann, N., Thompson, V.S. et al. A Study Examining the Usefulness of a New Measure of Research Engagement. J GEN INTERN MED 37 (Suppl 1), 50–56 (2022). https://doi.org/10.1007/s11606-021-06993-1	https://publichealth.nyu.edu/w/casjph/rest
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	How often patient partners can use knowledge generated from the partnership	Structure/ Process	Patient	Quantitative	Research Engagement Survey Tool (REST)	Bowen, D.J., Ackermann, N., Thompson, V.S. et al. A Study Examining the Usefulness of a New Measure of Research Engagement. J GEN INTERN MED 37 (Suppl 1), 50–56 (2022). https://doi.org/10.1007/s11606-021-06993-1	https://publichealth.nyu.edu/w/casjph/rest
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	How well patient partners can use knowledge generated from the partnership	Meaningfulness	Patient	Quantitative	Research Engagement Survey Tool (REST)	Bowen, D.J., Ackermann, N., Thompson, V.S. et al. A Study Examining the Usefulness of a New Measure of Research Engagement. J GEN INTERN MED 37 (Suppl 1), 50–56 (2022). https://doi.org/10.1007/s11606-021-06993-1	https://publichealth.nyu.edu/w/casjph/rest

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	How often the research team involved patient partners in activities related to sharing results	Structure/ Process	Patient	Quantitative	Research Engagement Survey Tool (REST)	Bowen, D.J., Ackermann, N., Thompson, V.S. et al. A Study Examining the Usefulness of a New Measure of Research Engagement. J GEN INTERN MED 37 (Suppl 1), 50–56 (2022). https://doi.org/10.1007/s11606-021-06993-1	https://publichealth.nyu.edu/w/casjph/rest
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	How well the research team involved patient partners in activities related to sharing results	Meaningfulness	Patient	Quantitative	Research Engagement Survey Tool (REST)	Bowen, D.J., Ackermann, N., Thompson, V.S. et al. A Study Examining the Usefulness of a New Measure of Research Engagement. J GEN INTERN MED 37 (Suppl 1), 50–56 (2022). https://doi.org/10.1007/s11606-021-06993-1	https://publichealth.nyu.edu/w/casjph/rest
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	How often the research team gave patient partners the opportunity to be coauthors	Structure/ Process	Patient	Quantitative	Research Engagement Survey Tool (REST)	Bowen, D.J., Ackermann, N., Thompson, V.S. et al. A Study Examining the Usefulness of a New Measure of Research Engagement. J GEN INTERN MED 37 (Suppl 1), 50–56 (2022). https://doi.org/10.1007/s11606-021-06993-1	https://publichealth.nyu.edu/w/casjph/rest
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	How well the research team gave patient partners the opportunity to be coauthors	Meaningfulness	Patient	Quantitative	Research Engagement Survey Tool (REST)	Bowen, D.J., Ackermann, N., Thompson, V.S. et al. A Study Examining the Usefulness of a New Measure of Research Engagement. J GEN INTERN MED 37 (Suppl 1), 50–56 (2022). https://doi.org/10.1007/s11606-021-06993-1	https://publichealth.nyu.edu/w/casjph/rest

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	Steps Where Patients Are Engaged	Activities Where Patients Are Engaged	How Patients Are Engaged	Measure	Measure Type	Perspective Assessed	Data Collection Approach	Tool	Source(s)	Link to Tool
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Size of patient advisory panel(s)	Structure/ Process	N/A	Quantitative	N/A	Clifton J, Adair E, Cheung M, et al. PROGRESS: A patient-centered engagement infrastructure and multi-level approach to enrich diversity, equity, and inclusion in a national randomized online behavioral pain treatment study. J Pain. Published online October 23, 2024. doi:10.1016/j.jpain.2024.104718	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Demographic composition of patient advisory panels	Structure/ Process	N/A	Quantitative	N/A	Clifton J, Adair E, Cheung M, et al. PROGRESS: A patient-centered engagement infrastructure and multi-level approach to enrich diversity, equity, and inclusion in a national randomized online behavioral pain treatment study. J Pain. Published online October 23, 2024. doi:10.1016/j.jpain.2024.104718	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Amount of financial support provided to patient advisory panel members	Structure/ Process	N/A	Quantitative	NA	Clifton J, Adair E, Cheung M, et al. PROGRESS: A patient-centered engagement infrastructure and multi-level approach to enrich diversity, equity, and inclusion in a national randomized online behavioral pain treatment study. J Pain. Published online October 23, 2024. doi:10.1016/j.jpain.2024.104718	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Type of adjustments made to research process and/or materials based on patient contributions	Meaningfulness	Researcher	Qualitative	N/A	Clifton J, Adair E, Cheung M, et al. PROGRESS: A patient-centered engagement infrastructure and multi-level approach to enrich diversity, equity, and inclusion in a national randomized online behavioral pain treatment study. J Pain. Published online October 23, 2024. doi:10.1016/j.jpain.2024.104718	N/A

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Challenges and lessons learned during patient engagement process	Meaningfulness	Researcher	Qualitative	N/A	Clifton J, Adair E, Cheung M, et al. PROGRESS: A patient-centered engagement infrastructure and multi-level approach to enrich diversity, equity, and inclusion in a national randomized online behavioral pain treatment study. J Pain. Published online October 23, 2024. doi:10.1016/j.jpain.2024.104718	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Patient perception on whether they were appropriately engaged	Meaningfulness	Patient	Qualitative	N/A	Concannon, Thomas W. and George Timmins, Measurement of Consumer Engagement in HIV Care Quality Improvement. Santa Monica, CA: RAND Corporation, 2023. https://www.rand.org/pubs/research_reports/RRA2744-1.html.	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	How often meetings occur	Structure/ Process	N/A	Quantitative	N/A	Concannon, Thomas W. and George Timmins, Measurement of Consumer Engagement in HIV Care Quality Improvement. Santa Monica, CA: RAND Corporation, 2023. https://www.rand.org/pubs/research_reports/RRA2744-1.html.	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Depth of engagement activities	Meaningfulness	Patient	Qualitative	N/A	Concannon, Thomas W. and George Timmins, Measurement of Consumer Engagement in HIV Care Quality Improvement. Santa Monica, CA: RAND Corporation, 2023. https://www.rand.org/pubs/research_reports/RRA2744-1.html.	N/A

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PC CDS Lifecycle Phase	Steps Where Patients Are Engaged	Activities Where Patients Are Engaged	How Patients Are Engaged	Measure	Measure Type	Perspective Assessed	Data Collection Approach	Tool	Source(s)	Link to Tool
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Patient composition	Structure/ Process	N/A	Quantitative	N/A	Concannon, Thomas W. and George Timmins, Measurement of Consumer Engagement in HIV Care Quality Improvement. Santa Monica, CA: RAND Corporation, 2023. https://www.rand.org/pubs/research_reports/RRA2744-1.html.	N/A
Knowledge Generation Phase; Clinical Decision Support Phase; Healthcare Delivery Phase	All steps	All activities	Collaborator/ Contributor/Partner; User	Level of satisfaction with engagement	Meaningfulness	Patient	Qualitative	N/A	Concannon, Thomas W. and George Timmins, Measurement of Consumer Engagement in HIV Care Quality Improvement. Santa Monica, CA: RAND Corporation, 2023. https://www.rand.org/pubs/research_reports/RRA2744-1.html.	N/A
Knowledge Generation Phase; Clinical Decision Support Phase; Healthcare Delivery Phase	All steps	All activities	Collaborator/ Contributor/Partner; User	Level of empowerment resulting from engagement	Meaningfulness	Patient	Qualitative	N/A	Concannon, Thomas W. and George Timmins, Measurement of Consumer Engagement in HIV Care Quality Improvement. Santa Monica, CA: RAND Corporation, 2023. https://www.rand.org/pubs/research_reports/RRA2744-1.html.	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Total sum of engagement investments (e.g., time, personnel, material supports) made by the research team to support patient engagement	Structure/ Process	Researcher	Quantitative	N/A	Concannon, Thomas W. and George Timmins, Measurement of Consumer Engagement in HIV Care Quality Improvement. Santa Monica, CA: RAND Corporation, 2023. https://www.rand.org/pubs/research_reports/RRA2744-1.html.	N/A

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PC CDS Lifecycle Phase	Steps Where Patients Are Engaged	Activities Where Patients Are Engaged	How Patients Are Engaged	Measure	Measure Type	Perspective Assessed	Data Collection Approach	Tool	Source(s)	Link to Tool
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Perceived impact of contributions on research	Meaningfulness	Patient	Qualitative	N/A	Crocker JC, Boylan AM, Bostock J, Locock L. Is it worth it? Patient and public views on the impact of their involvement in health research and its assessment: a UK-based qualitative interview study. Health Expect. 2017;20(3):519-528. doi:10.1111/hex.12479	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Self-reported demographic composition of patient partners	Structure/ Process	Patient	Quantitative	N/A	Crocker JC, Boylan AM, Bostock J, Locock L. Is it worth it? Patient and public views on the impact of their involvement in health research and its assessment: a UK-based qualitative interview study. Health Expect. 2017;20(3):519-528. doi:10.1111/hex.12479	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Self-reported role as a research partner (i.e., patient, caregiver, both)	Structure/ Process	Patient	Quantitative	N/A	Crocker JC, Boylan AM, Bostock J, Locock L. Is it worth it? Patient and public views on the impact of their involvement in health research and its assessment: a UK-based qualitative interview study. Health Expect. 2017;20(3):519-528. doi:10.1111/hex.12479	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Self-reported length of involvement in research	Structure/ Process	Patient	Quantitative	N/A	Crocker JC, Boylan AM, Bostock J, Locock L. Is it worth it? Patient and public views on the impact of their involvement in health research and its assessment: a UK-based qualitative interview study. Health Expect. 2017;20(3):519-528. doi:10.1111/hex.12479	N/A

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
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Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Perceived role and mechanism of impact	Meaningfulness	Patient	Qualitative	N/A	Crocker JC, Boylan AM, Bostock J, Locock L. Is it worth it? Patient and public views on the impact of their involvement in health research and its assessment: a UK-based qualitative interview study. Health Expect. 2017;20(3):519-528. doi:10.1111/hex.12479	N/A
Clinical Decision Support Phase	Use of PC CDS	Interaction with information from the PC CDS	User	Number of help desk requests sent	Structure/ Process	Researcher	Quantitative	N/A	Dullabh P, Zott C, Gauthreaux N, Swiger J, Lomotan E, Sittig DF. Validating a performance measurement framework through real-world experience in PC CDS measurement. Poster presented at AMIA 2024 Annual Symposium; November 11, 2024; San Francisco, CA. https://amia.secure-platform.com/symposium/gallery/rounds/82001/details/10747	N/A
Clinical Decision Support Phase	Use of PC CDS	Point of engagement, Period of engagement, Disengagement and reengagement, Interaction with information from the PC CDS	User	Rate of PC CDS uptake	Structure/ Process	Researcher	Quantitative	N/A	Dullabh P, Zott C, Gauthreaux N, Swiger J, Lomotan E, Sittig DF. Validating a performance measurement framework through real-world experience in PC CDS measurement. Poster presented at AMIA 2024 Annual Symposium; November 11, 2024; San Francisco, CA. https://amia.secure-platform.com/symposium/gallery/rounds/82001/details/10747	N/A
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether a patient knows the treatment/screening options that are available to them	Meaningfulness	Patient	Quantitative	Decisional Conflict Scale (DCS)	O'Connor AM. Validation of a decisional conflict scale. Med Decis Making. 1995;15(1):25-30. doi:10.1177/0272989X9501500105	https://decisionaid.ohri.ca/docs/develop/Tools/DCS_English.pdf

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PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Healthcare Delivery Phase	Option Talk	Discussion of pros and cons	User	Whether a patient knows the benefits of each treatment/screening option	Meaningfulness	Patient	Quantitative	Decisional Conflict Scale (DCS)	O'Connor AM. Validation of a decisional conflict scale. Med Decis Making. 1995;15(1):25-30. doi:10.1177/0272989X9501500105	https://decisionaid.ohri.ca/docs/develop/Tools/DCS_English.pdf
Healthcare Delivery Phase	Option Talk	Discussion of pros and cons	User	Whether a patient knows the risks and side effects of each treatment/screening option	Meaningfulness	Patient	Quantitative	Decisional Conflict Scale (DCS)	O'Connor AM. Validation of a decisional conflict scale. Med Decis Making. 1995;15(1):25-30. doi:10.1177/0272989X9501500105	https://decisionaid.ohri.ca/docs/develop/Tools/DCS_English.pdf
Healthcare Delivery Phase	Option Talk	Discussion of pros and cons	User	Whether a patient is clear about which risks and side effects of the treatment/screening option matter the most to them	Meaningfulness	Patient	Quantitative	Decisional Conflict Scale (DCS)	O'Connor AM. Validation of a decisional conflict scale. Med Decis Making. 1995;15(1):25-30. doi:10.1177/0272989X9501500105	https://decisionaid.ohri.ca/docs/develop/Tools/DCS_English.pdf
Healthcare Delivery Phase	Option Talk	Discussion of pros and cons	User	Whether a patient is clear about whether benefits, risks, or side effects of the treatment/screening option are the most important to them	Meaningfulness	Patient	Quantitative	Decisional Conflict Scale (DCS)	O'Connor AM. Validation of a decisional conflict scale. Med Decis Making. 1995;15(1):25-30. doi:10.1177/0272989X9501500105	https://decisionaid.ohri.ca/docs/develop/Tools/DCS_English.pdf
Healthcare Delivery Phase	Decision Talk	Results of the decision	User	Perceived support from others to make a choice about the treatment screening/option	Meaningfulness	Patient	Quantitative	Decisional Conflict Scale (DCS)	O'Connor AM. Validation of a decisional conflict scale. Med Decis Making. 1995;15(1):25-30. doi:10.1177/0272989X9501500105	https://decisionaid.ohri.ca/docs/develop/Tools/DCS_English.pdf
Healthcare Delivery Phase	Decision Talk	Results of the decision	User	Whether a patient perceives they are choosing the treatment/screening option without pressure from others	Meaningfulness	Patient	Quantitative	Decisional Conflict Scale (DCS)	O'Connor AM. Validation of a decisional conflict scale. Med Decis Making. 1995;15(1):25-30. doi:10.1177/0272989X9501500105	https://decisionaid.ohri.ca/docs/develop/Tools/DCS_English.pdf

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Healthcare Delivery Phase	Decision Talk	Results of the decision	User	Whether a patient perceives they have enough advice to make a choice about the treatment/screening option	Meaningfulness	Patient	Quantitative	Decisional Conflict Scale (DCS)	O'Connor AM. Validation of a decisional conflict scale. Med Decis Making. 1995;15(1):25-30. doi:10.1177/0272989X9501500105	https://decisionaid.ohri.ca/docs/develop/Tools/DCS_English.pdf
Healthcare Delivery Phase	Decision Talk	Results of the decision	User	Whether a patient feels clear about the best choice for them about the treatment/screening option	Meaningfulness	Patient	Quantitative	Decisional Conflict Scale (DCS)	O'Connor AM. Validation of a decisional conflict scale. Med Decis Making. 1995;15(1):25-30. doi:10.1177/0272989X9501500105	https://decisionaid.ohri.ca/docs/develop/Tools/DCS_English.pdf
Healthcare Delivery Phase	Decision Talk	Results of the decision	User	Whether a patient feels sure about what to choose for their treatment/screening option	Meaningfulness	Patient	Quantitative	Decisional Conflict Scale (DCS)	O'Connor AM. Validation of a decisional conflict scale. Med Decis Making. 1995;15(1):25-30. doi:10.1177/0272989X9501500105	https://decisionaid.ohri.ca/docs/develop/Tools/DCS_English.pdf
Healthcare Delivery Phase	Decision Talk	Results of the decision	User	Whether a patient perceives that the decision about the treatment/screening option is easy to make	Meaningfulness	Patient	Quantitative	Decisional Conflict Scale (DCS)	O'Connor AM. Validation of a decisional conflict scale. Med Decis Making. 1995;15(1):25-30. doi:10.1177/0272989X9501500105	https://decisionaid.ohri.ca/docs/develop/Tools/DCS_English.pdf
Healthcare Delivery Phase	Decision Talk	Results of the decision	User	Whether the patient feels they made an informed choice about the treatment/screening option	Meaningfulness	Patient	Quantitative	Decisional Conflict Scale (DCS)	O'Connor AM. Validation of a decisional conflict scale. Med Decis Making. 1995;15(1):25-30. doi:10.1177/0272989X9501500105	https://decisionaid.ohri.ca/docs/develop/Tools/DCS_English.pdf
Healthcare Delivery Phase	Decision Talk	Results of the decision	User	Whether a patient expects to stick with the decision about the treatment/screening option	Meaningfulness	Patient	Quantitative	Decisional Conflict Scale (DCS)	O'Connor AM. Validation of a decisional conflict scale. Med Decis Making. 1995;15(1):25-30. doi:10.1177/0272989X9501500105	https://decisionaid.ohri.ca/docs/develop/Tools/DCS_English.pdf
Healthcare Delivery Phase	Decision Talk	Results of the decision	User	Patient's perceived satisfaction with their decision about the treatment/screening option	Meaningfulness	Patient	Quantitative	Decisional Conflict Scale (DCS)	O'Connor AM. Validation of a decisional conflict scale. Med Decis Making. 1995;15(1):25-30. doi:10.1177/0272989X9501500105	https://decisionaid.ohri.ca/docs/develop/Tools/DCS_English.pdf

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PC CDS Lifecycle Phase	Steps Where Patients Are Engaged	Activities Where Patients Are Engaged	How Patients Are Engaged	Measure	Measure Type	Perspective Assessed	Data Collection Approach	Tool	Source(s)	Link to Tool
Healthcare Delivery Phase	Decision Talk	Results of the decision	User	Whether a patient feels that the healthcare decision they made was right	Meaningfulness	Patient	Quantitative	Decision Regret Scale	Brehaut JC, O'Connor AM, Wood TJ, et al. Validation of a decision regret scale. Med Decis Making. 2003;23(4):281-292. doi:10.1177/0272989X03256005	https://decisionaid.ohri.ca/docs/develop/Tools/DCS_English.pdf
Healthcare Delivery Phase	Decision Talk	Results of the decision	User	Whether a patient regrets the healthcare choice they made	Meaningfulness	Patient	Quantitative	Decision Regret Scale	Brehaut JC, O'Connor AM, Wood TJ, et al. Validation of a decision regret scale. Med Decis Making. 2003;23(4):281-292. doi:10.1177/0272989X03256005	https://decisionaid.ohri.ca/docs/develop/Tools/DCS_English.pdf
Healthcare Delivery Phase	Decision Talk	Results of the decision	User	Whether a patient would make the same healthcare choice if they had to do it again	Meaningfulness	Patient	Quantitative	Decision Regret Scale	Brehaut JC, O'Connor AM, Wood TJ, et al. Validation of a decision regret scale. Med Decis Making. 2003;23(4):281-292. doi:10.1177/0272989X03256005	https://decisionaid.ohri.ca/docs/develop/Tools/DCS_English.pdf
Healthcare Delivery Phase	Decision Talk	Results of the decision	User	Whether a patient feels that the healthcare choice caused them a lot of harm	Meaningfulness	Patient	Quantitative	Decision Regret Scale	Brehaut JC, O'Connor AM, Wood TJ, et al. Validation of a decision regret scale. Med Decis Making. 2003;23(4):281-292. doi:10.1177/0272989X03256005	https://decisionaid.ohri.ca/docs/develop/Tools/DCS_English.pdf
Healthcare Delivery Phase	Decision Talk	Results of the decision	User	Whether a patient feels that the healthcare decision they made was wise	Meaningfulness	Patient	Quantitative	Decision Regret Scale	Brehaut JC, O'Connor AM, Wood TJ, et al. Validation of a decision regret scale. Med Decis Making. 2003;23(4):281-292. doi:10.1177/0272989X03256005	https://decisionaid.ohri.ca/docs/develop/Tools/DCS_English.pdf

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Healthcare Delivery Phase	Decision Talk	Results of the decision	User	Extent of effectiveness of decision tools during decision making	Meaningfulness	Patient	Qualitative	N/A	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	N/A
Clinical Decision Support Phase	Use of PC CDS	Interaction with information from the PC CDS	User	How often patients report PROs or symptoms	Structure/ Process	Patient	Quantitative	N/A	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	N/A
Clinical Decision Support Phase	Use of PC CDS	Interaction with information from the PC CDS	User	How often patients submit patient-generated health data (PGHD)	Structure/ Process	Patient	Quantitative	N/A	N/A	N/A

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
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Clinical Decision Support Phase	Use of PC CDS	Interaction with information from the PC CDS	User	Percentage of users that incorporate all components of the decision aid as intended	Structure/ Process	Patient	Quantitative	N/A	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	N/A
Clinical Decision Support Phase	Use of PC CDS	Interaction with information from the PC CDS	User	Perceived mental demand of a task	Meaningfulness	Patient	Quantitative	NASA Task Load Index	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	https://humansystems.arc.nasa.gov/groups/TLX/downloads/TLXScale.pdf

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PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Clinical Decision Support Phase	Use of PC CDS	Interaction with information from the PC CDS	User	Perceived physical demand of a task	Meaningfulness	Patient	Quantitative	NASA Task Load Index	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	https://humansystems.arc.nasa.gov/groups/TLX/downloads/TLXScale.pdf
Clinical Decision Support Phase	Use of PC CDS	Interaction with information from the PC CDS	User	Perceived pace of a task	Meaningfulness	Patient	Quantitative	NASA Task Load Index	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	https://humansystems.arc.nasa.gov/groups/TLX/downloads/TLXScale.pdf

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Clinical Decision Support Phase	Use of PC CDS	Interaction with information from the PC CDS	User	Perceived success in accomplishing a task	Meaningfulness	Patient	Quantitative	NASA Task Load Index	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	https://humansystems.arc.nasa.gov/groups/TLX/downloads/TLXScale.pdf
Clinical Decision Support Phase	Use of PC CDS	Interaction with information from the PC CDS	User	Perceived frustration in performing the task	Meaningfulness	Patient	Quantitative	NASA Task Load Index	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	https://humansystems.arc.nasa.gov/groups/TLX/downloads/TLXScale.pdf

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Clinical Decision Support Phase	Use of PC CDS	Interaction with information from the PC CDS	User	Perceived effort in performing the task	Meaningfulness	Patient	Quantitative	NASA Task Load Index	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	https://humansystems.arc.nasa.gov/groups/TLX/downloads/TLXScale.pdf
Clinical Decision Support Phase	Use of PC CDS	Interaction with information from the PC CDS	User	Whether patients could retrieve all information across data categories	Structure/ Process	Patient	Qualitative	N/A	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	N/A

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Clinical Decision Support Phase	Use of PC CDS	Interaction with information from the PC CDS	User	Perceived usability of PC CDS tool	Meaningfulness	Patient	Qualitative	N/A	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	N/A
Healthcare Delivery Phase	Decision Talk	Patient-clinician communication	User	Number of utterances or decision-making events that families engaged in	Structure/ Process	Patient	Quantitative	N/A	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	N/A

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Healthcare Delivery Phase	Decision Talk	Patient-clinician communication	User	Number of topics/questions patients raised with their clinician	Structure/ Process	Researcher	Quantitative	N/A	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	N/A
Clinical Decision Support Phase	Use of PC CDS	Period of engagement, Interaction with information from the PC CDS	User	Number of alerts/recommended actions overridden	Structure/ Process	Researcher	Quantitative	N/A	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	N/A

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Clinical Decision Support Phase	Use of PC CDS	Interaction with information from the PC CDS	User	Number of CDS alert malfunctions per month	Structure/ Process	Researcher	Quantitative	N/A	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	N/A
Clinical Decision Support Phase	Use of PC CDS	Period of engagement, Interaction with information from the PC CDS	User	Number of alerts accepted over total number fired	Structure/ Process	Researcher	Quantitative	N/A	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	N/A

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	Steps Where Patients Are Engaged	Activities Where Patients Are Engaged	How Patients Are Engaged	Measure	Measure Type	Perspective Assessed	Data Collection Approach	Tool	Source(s)	Link to Tool
Clinical Decision Support Phase	Use of PC CDS	Point of engagement, Period of engagement, Disengagement and reengagement, Interaction with information from the PC CDS	User	Percentage of days the PC CDS was used	Structure/ Process	Researcher	Quantitative	N/A	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	N/A
Clinical Decision Support Phase	Use of PC CDS	Point of engagement, Period of engagement, Disengagement and reengagement, Interaction with information from the PC CDS	User	Amount of time spent on patient portal (minutes/day)	Structure/ Process	Researcher	Quantitative	N/A	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	N/A

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	Steps Where Patients Are Engaged	Activities Where Patients Are Engaged	How Patients Are Engaged	Measure	Measure Type	Perspective Assessed	Data Collection Approach	Tool	Source(s)	Link to Tool
Clinical Decision Support Phase	Use of PC CDS	Interaction with information from the PC CDS	User	Number of portal messages sent/received	Structure/ Process	Researcher	Quantitative	N/A	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	N/A
Clinical Decision Support Phase	Use of PC CDS	Point of engagement, Period of engagement, Disengagement and reengagement, Interaction with information from the PC CDS	User	Amount of time spent interacting with information on decision aid	Structure/ Process	Researcher	Quantitative	N/A	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	N/A

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	Steps Where Patients Are Engaged	Activities Where Patients Are Engaged	How Patients Are Engaged	Measure	Measure Type	Perspective Assessed	Data Collection Approach	Tool	Source(s)	Link to Tool
Clinical Decision Support Phase	Use of PC CDS	Point of engagement	User	Number of login attempts	Structure/ Process	Researcher	Quantitative	N/A	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	N/A
Clinical Decision Support Phase	Design and development of PC CDS	Framing the issue, Requirements gathering, Generative design work and prototyping, Usability testing	Contributor/ Collaborator/ Partner	User feedback on errors related to usability	Meaningfulness	Patient	Qualitative	N/A	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	N/A

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Clinical Decision Support Phase	Design and development of PC CDS	Framing the issue, Requirements gathering, Generative design work and prototyping, Usability testing	Contributor/ Collaborator/ Partner	Perceived usability	Meaningfulness	Patient	Qualitative	N/A	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	N/A
Clinical Decision Support Phase	Design and development of PC CDS	Framing the issue, Requirements gathering, Generative design work and prototyping, Usability testing	Contributor/ Collaborator/ Partner	Perceived satisfaction with specific aspects of the interface	Meaningfulness	Patient	Qualitative	N/A	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	N/A

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Clinical Decision Support Phase	Design and development of PC CDS	Framing the issue, Requirements gathering, Generative design work and prototyping, Usability testing	Contributor/ Collaborator/ Partner	Perceived ease of finding information	Meaningfulness	Patient	Qualitative	N/A	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	N/A
Clinical Decision Support Phase	Implementation of PC CDS	Participation in pilot project	Contributor/ Collaborator/ Partner	Percentage of patients who registered/ signed up for intervention	Structure/ Process	Researcher	Quantitative	N/A	Klarenbeek SE, Weekenstroo HHA, Sedelaar JPM, Fütterer JJ, Prokop M, Tummers M. The Effect of Higher Level Computerized Clinical Decision Support Systems on Oncology Care: A Systematic Review. Cancers (Basel). 2020;12(4):1032. Published 2020 Apr 22. doi:10.3390/cancers12041032	N/A
Clinical Decision Support Phase	Use of PC CDS	Point of engagement, Period of engagement, Disengagement and reengagement, Interaction with information from the PC CDS	User	Level of patient satisfaction	Meaningfulness	Patient	Qualitative	N/A	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	N/A

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	Steps Where Patients Are Engaged	Activities Where Patients Are Engaged	How Patients Are Engaged	Measure	Measure Type	Perspective Assessed	Data Collection Approach	Tool	Source(s)	Link to Tool
Healthcare Delivery Phase	Decision Talk	Shared decision-making	User	Time span to make a decision from initial screening	Structure/ Process	Researcher	Quantitative	N/A	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	N/A
Healthcare Delivery Phase	Team Talk	Discussion of patient values, preferences, and/or goals	User	Patient attitudes and expectations toward using PC CDS during decision making	Meaningfulness	Patient	Qualitative	N/A	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023.	N/A

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PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether clinician presented more than one option	Structure/ Process	Patient	Quantitative	N/A	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023; Elwyn G, Edwards A, Wensing M, Hood K, Atwell C, Grol R. Shared decision making: developing the OPTION scale for measuring patient involvement. Qual Saf Health Care. 2003;12(2):93-99. doi:10.1136/qhc.12.2.93	N/A

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	Steps Where Patients Are Engaged	Activities Where Patients Are Engaged	How Patients Are Engaged	Measure	Measure Type	Perspective Assessed	Data Collection Approach	Tool	Source(s)	Link to Tool
Healthcare Delivery Phase	Option Talk	Discussion of pros and cons	User	Whether clinician explained pros and cons of each option	Structure/ Process	Patient	Quantitative	N/A	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023; Elwyn G, Edwards A, Wensing M, Hood K, Atwell C, Grol R. Shared decision making: developing the OPTION scale for measuring patient involvement. Qual Saf Health Care. 2003;12(2):93-99. doi:10.1136/qhc.12.2.93	N/A

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PC CDS Lifecycle Phase	Steps Where Patients Are Engaged	Activities Where Patients Are Engaged	How Patients Are Engaged	Measure	Measure Type	Perspective Assessed	Data Collection Approach	Tool	Source(s)	Link to Tool
Healthcare Delivery Phase	Option Talk	Discussion of pros and cons	User	Whether clinician checked for patient's understanding of the information provided	Structure/ Process	Patient	Quantitative	N/A	Dullabh PM, Heaney-Huls K, Jiménez F, Ryan S, McCoy AB, Desai PJ, Osheroff JA, CDSiC Scaling, Measurement, and Dissemination of CDS Workgroup. Scaling, Measurement, and Dissemination of CDS Workgroup: PC CDS Performance Measurement Inventory User Guide. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 23-0073. Rockville, MD: Agency for Healthcare Research and Quality; August 2023; Elwyn G, Edwards A, Wensing M, Hood K, Atwell C, Grol R. Shared decision making: developing the OPTION scale for measuring patient involvement. Qual Saf Health Care. 2003;12(2):93-99. doi:10.1136/qhc.12.2.93	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	Patient perception of whether their co-authors understood the importance of having a patient author	Meaningfulness	Patient	Quantitative	Patient Authorship Experience Tool: Patient Author Version	Envision Pharma Group. Powering Patient Voices: Patient Authorship Experience Tool. https://static-content.springer.com/esm/art%3A10.1186%2Fs40900-020-00190-w/MediaObjects/40900_2020_190_MOESM4_ESM.pdf	https://static-content.springer.com/esm/art%3A10.1186%2Fs40900-020-00190-w/MediaObjects/40900_2020_190_MOESM4_ESM.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	Patient perception of whether they were treated with respect during the development of the publication	Meaningfulness	Patient	Quantitative	Patient Authorship Experience Tool: Patient Author Version	Envision Pharma Group. Powering Patient Voices: Patient Authorship Experience Tool. https://static-content.springer.com/esm/art%3A10.1186%2Fs40900-020-00190-w/MediaObjects/40900_2020_190_MOESM4_ESM.pdf	https://static-content.springer.com/esm/art%3A10.1186%2Fs40900-020-00190-w/MediaObjects/40900_2020_190_MOESM4_ESM.pdf

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	Patient perception of whether their ability to access and share information was taken into account by the research team	Meaningfulness	Patient	Quantitative	Patient Authorship Experience Tool: Patient Author Version	Envision Pharma Group. Powering Patient Voices: Patient Authorship Experience Tool. https://static-content.springer.com/esm/art%3A10.1186%2Fs40900-020-00190-w/MediaObjects/40900_2020_190_MOESM4_ESM.pdf	https://static-content.springer.com/esm/art%3A10.1186%2Fs40900-020-00190-w/MediaObjects/40900_2020_190_MOESM4_ESM.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	Patient perception of whether they understood the roles and responsibilities of being an author, as outlined in the written authorship agreement form	Meaningfulness	Patient	Quantitative	Patient Authorship Experience Tool: Patient Author Version	Envision Pharma Group. Powering Patient Voices: Patient Authorship Experience Tool. https://static-content.springer.com/esm/art%3A10.1186%2Fs40900-020-00190-w/MediaObjects/40900_2020_190_MOESM4_ESM.pdf	https://static-content.springer.com/esm/art%3A10.1186%2Fs40900-020-00190-w/MediaObjects/40900_2020_190_MOESM4_ESM.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	Patient perception of whether they had sufficient time to make a useful contribution to the publication	Meaningfulness	Patient	Quantitative	Patient Authorship Experience Tool: Patient Author Version	Envision Pharma Group. Powering Patient Voices: Patient Authorship Experience Tool. https://static-content.springer.com/esm/art%3A10.1186%2Fs40900-020-00190-w/MediaObjects/40900_2020_190_MOESM4_ESM.pdf	https://static-content.springer.com/esm/art%3A10.1186%2Fs40900-020-00190-w/MediaObjects/40900_2020_190_MOESM4_ESM.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	Patient perception of whether they had sufficient insights to make a useful contribution to the publication	Meaningfulness	Patient	Quantitative	Patient Authorship Experience Tool: Patient Author Version	Envision Pharma Group. Powering Patient Voices: Patient Authorship Experience Tool. https://static-content.springer.com/esm/art%3A10.1186%2Fs40900-020-00190-w/MediaObjects/40900_2020_190_MOESM4_ESM.pdf	https://static-content.springer.com/esm/art%3A10.1186%2Fs40900-020-00190-w/MediaObjects/40900_2020_190_MOESM4_ESM.pdf

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	Steps Where Patients Are Engaged	Activities Where Patients Are Engaged	How Patients Are Engaged	Measure	Measure Type	Perspective Assessed	Data Collection Approach	Tool	Source(s)	Link to Tool
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	Patient perception of whether communication among authors was open and honest	Meaningfulness	Patient	Quantitative	Patient Authorship Experience Tool: Patient Author Version	Envision Pharma Group. Powering Patient Voices: Patient Authorship Experience Tool. https://static-content.springer.com/esm/art%3A10.1186%2Fs40900-020-00190-w/MediaObjects/40900_2020_190_MOESM4_ESM.pdf	https://static-content.springer.com/esm/art%3A10.1186%2Fs40900-020-00190-w/MediaObjects/40900_2020_190_MOESM4_ESM.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	Patient perception of whether documents were shared appropriately	Meaningfulness	Patient	Quantitative	Patient Authorship Experience Tool: Patient Author Version	Envision Pharma Group. Powering Patient Voices: Patient Authorship Experience Tool. https://static-content.springer.com/esm/art%3A10.1186%2Fs40900-020-00190-w/MediaObjects/40900_2020_190_MOESM4_ESM.pdf	https://static-content.springer.com/esm/art%3A10.1186%2Fs40900-020-00190-w/MediaObjects/40900_2020_190_MOESM4_ESM.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	Patient perception of wheter they understood the main stages involved in preparing a publication	Meaningfulness	Patient	Quantitative	Patient Authorship Experience Tool: Patient Author Version	Envision Pharma Group. Powering Patient Voices: Patient Authorship Experience Tool. https://static-content.springer.com/esm/art%3A10.1186%2Fs40900-020-00190-w/MediaObjects/40900_2020_190_MOESM4_ESM.pdf	https://static-content.springer.com/esm/art%3A10.1186%2Fs40900-020-00190-w/MediaObjects/40900_2020_190_MOESM4_ESM.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	Patient perception of whether efforts were made to nurture relationships among the authorship group so that future projects could be considered	Meaningfulness	Patient	Quantitative	Patient Authorship Experience Tool: Patient Author Version	Envision Pharma Group. Powering Patient Voices: Patient Authorship Experience Tool. https://static-content.springer.com/esm/art%3A10.1186%2Fs40900-020-00190-w/MediaObjects/40900_2020_190_MOESM4_ESM.pdf	https://static-content.springer.com/esm/art%3A10.1186%2Fs40900-020-00190-w/MediaObjects/40900_2020_190_MOESM4_ESM.pdf

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Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	Patient perception of whether the research reported in the publication could have a positive impact on stakeholders	Meaningfulness	Patient	Quantitative	Patient Authorship Experience Tool: Patient Author Version	Envision Pharma Group. Powering Patient Voices: Patient Authorship Experience Tool. https://static-content.springer.com/esm/art%3A10.1186%2Fs40900-020-00190-w/MediaObjects/40900_2020_190_MOESM4_ESM.pdf	https://static-content.springer.com/esm/art%3A10.1186%2Fs40900-020-00190-w/MediaObjects/40900_2020_190_MOESM4_ESM.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	Patient perception of whether efforts were made to learn from patients about their authorship experiences	Meaningfulness	Patient	Quantitative	Patient Authorship Experience Tool: Patient Author Version	Envision Pharma Group. Powering Patient Voices: Patient Authorship Experience Tool. https://static-content.springer.com/esm/art%3A10.1186%2Fs40900-020-00190-w/MediaObjects/40900_2020_190_MOESM4_ESM.pdf	https://static-content.springer.com/esm/art%3A10.1186%2Fs40900-020-00190-w/MediaObjects/40900_2020_190_MOESM4_ESM.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Whether the research team established shared values, vision, and mission among all parties	Meaningfulness	Researcher	Quantitative	Principles of Partnership Self-Assessment Tool	Frontiers. Principles of Partnership Self-Assessment Tool. Patient-Centered Outcomes Research Institute. https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf	https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Whether the research team engaged in open communication and demonstrated willingness to listen to patient partners	Meaningfulness	Researcher	Quantitative	Principles of Partnership Self-Assessment Tool	Frontiers. Principles of Partnership Self-Assessment Tool. Patient-Centered Outcomes Research Institute. https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf	https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Whether the research team valued differences of patient partners	Meaningfulness	Researcher	Quantitative	Principles of Partnership Self-Assessment Tool	Frontiers. Principles of Partnership Self-Assessment Tool. Patient-Centered Outcomes Research Institute. https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf	https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Whether the research team performed all activities with cultural sensitivity and humility	Meaningfulness	Researcher	Quantitative	Principles of Partnership Self-Assessment Tool	Frontiers. Principles of Partnership Self-Assessment Tool. Patient-Centered Outcomes Research Institute. https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf	https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Whether the research team maintained ongoing participation in meetings and activities	Meaningfulness	Researcher	Quantitative	Principles of Partnership Self-Assessment Tool	Frontiers. Principles of Partnership Self-Assessment Tool. Patient-Centered Outcomes Research Institute. https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf	https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Whether the research team has a clear understanding of patient partners' expertise, strengths, and roles	Meaningfulness	Researcher	Quantitative	Principles of Partnership Self-Assessment Tool	Frontiers. Principles of Partnership Self-Assessment Tool. Patient-Centered Outcomes Research Institute. https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf	https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Whether the research team included patient-relevant objectives and maintained fidelity to associated evaluation plans	Meaningfulness	Researcher	Quantitative	Principles of Partnership Self-Assessment Tool	Frontiers. Principles of Partnership Self-Assessment Tool. Patient-Centered Outcomes Research Institute. https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf	https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Whether the research team informed all patient partners of findings and accomplishments in relevant projects and initiatives	Meaningfulness	Researcher	Quantitative	Principles of Partnership Self-Assessment Tool	Frontiers. Principles of Partnership Self-Assessment Tool. Patient-Centered Outcomes Research Institute. https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf	https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf

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Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Whether the research team built upon identified patient partner strengths and assets	Meaningfulness	Researcher	Quantitative	Principles of Partnership Self-Assessment Tool	Frontiers. Principles of Partnership Self-Assessment Tool. Patient-Centered Outcomes Research Institute. https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf	https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Whether the research team provided learning opportunities for patient partners in identified priority areas	Meaningfulness	Researcher	Quantitative	Principles of Partnership Self-Assessment Tool	Frontiers. Principles of Partnership Self-Assessment Tool. Patient-Centered Outcomes Research Institute. https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf	https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Whether the research team developed opportunities for patients to participate and develop marketable knowledge and skills	Meaningfulness	Researcher	Quantitative	Principles of Partnership Self-Assessment Tool	Frontiers. Principles of Partnership Self-Assessment Tool. Patient-Centered Outcomes Research Institute. https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf	https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	Whether the research team created opportunities for shared authorship in reports and presentations for scientific and community audiences	Meaningfulness	Researcher	Quantitative	Principles of Partnership Self-Assessment Tool	Frontiers. Principles of Partnership Self-Assessment Tool. Patient-Centered Outcomes Research Institute. https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf	https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Recruitment	Contributor/ Collaborator/ Partner	Whether the research team adhered to processes for identifying and inviting new patient partners	Meaningfulness	Researcher	Quantitative	Principles of Partnership Self-Assessment Tool	Frontiers. Principles of Partnership Self-Assessment Tool. Patient-Centered Outcomes Research Institute. https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf	https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf

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Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Whether the research team included periodic feedback and evaluation processes from all patient partners	Meaningfulness	Researcher	Quantitative	Principles of Partnership Self-Assessment Tool	Frontiers. Principles of Partnership Self-Assessment Tool. Patient-Centered Outcomes Research Institute. https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf	https://www.pcori.org/sites/default/files/3894_GPC_Principles-Partnership-Self-Assessment.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Patient perception of whether they were interested in the issue(s) being researched in the project	Meaningfulness	Patient	Quantitative	Patient Engagement in Research Scale (PEIRS)	Hamilton CB, Hoens AM, McQuitty S, et al. Development and pre-testing of the Patient Engagement In Research Scale (PEIRS) to assess the quality of engagement from a patient perspective. PLoS One. 2018;13(11):e0206588. Published 2018 Nov 1. doi:10.1371/journal.pone.0206588	https://pmc.ncbi.nlm.nih.gov/articles/instance/6211727/bin/pone.0206588.s004.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Patient perception of their understanding of the objectives of the project	Meaningfulness	Patient	Quantitative	Patient Engagement in Research Scale (PEIRS)	Hamilton CB, Hoens AM, McQuitty S, et al. Development and pre-testing of the Patient Engagement In Research Scale (PEIRS) to assess the quality of engagement from a patient perspective. PLoS One. 2018;13(11):e0206588. Published 2018 Nov 1. doi:10.1371/journal.pone.0206588	https://pmc.ncbi.nlm.nih.gov/articles/instance/6211727/bin/pone.0206588.s004.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Patient perception of their agreement with the objectives of the project	Meaningfulness	Patient	Quantitative	Patient Engagement in Research Scale (PEIRS)	Hamilton CB, Hoens AM, McQuitty S, et al. Development and pre-testing of the Patient Engagement In Research Scale (PEIRS) to assess the quality of engagement from a patient perspective. PLoS One. 2018;13(11):e0206588. Published 2018 Nov 1. doi:10.1371/journal.pone.0206588	https://pmc.ncbi.nlm.nih.gov/articles/instance/6211727/bin/pone.0206588.s004.pdf

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Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Patient perception of their understanding of how they could contribute to the project	Meaningfulness	Patient	Quantitative	Patient Engagement in Research Scale (PEIRS)	Hamilton CB, Hoens AM, McQuitty S, et al. Development and pre-testing of the Patient Engagement In Research Scale (PEIRS) to assess the quality of engagement from a patient perspective. PLoS One. 2018;13(11):e0206588. Published 2018 Nov 1. doi:10.1371/journal.pone.0206588	https://pmc.ncbi.nlm.nih.gov/articles/instance/6211727/bin/pone.0206588.s004.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Patient perception of whether they had sufficient opportunities to contribute to the project	Meaningfulness	Patient	Quantitative	Patient Engagement in Research Scale (PEIRS)	Hamilton CB, Hoens AM, McQuitty S, et al. Development and pre-testing of the Patient Engagement In Research Scale (PEIRS) to assess the quality of engagement from a patient perspective. PLoS One. 2018;13(11):e0206588. Published 2018 Nov 1. doi:10.1371/journal.pone.0206588	https://pmc.ncbi.nlm.nih.gov/articles/instance/6211727/bin/pone.0206588.s004.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Patient perception of whether they were able to perform tasks for the project	Meaningfulness	Patient	Quantitative	Patient Engagement in Research Scale (PEIRS)	Hamilton CB, Hoens AM, McQuitty S, et al. Development and pre-testing of the Patient Engagement In Research Scale (PEIRS) to assess the quality of engagement from a patient perspective. PLoS One. 2018;13(11):e0206588. Published 2018 Nov 1. doi:10.1371/journal.pone.0206588	https://pmc.ncbi.nlm.nih.gov/articles/instance/6211727/bin/pone.0206588.s004.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Patient perception of whether they participated in making decisions for the project	Meaningfulness	Patient	Quantitative	Patient Engagement in Research Scale (PEIRS)	Hamilton CB, Hoens AM, McQuitty S, et al. Development and pre-testing of the Patient Engagement In Research Scale (PEIRS) to assess the quality of engagement from a patient perspective. PLoS One. 2018;13(11):e0206588. Published 2018 Nov 1. doi:10.1371/journal.pone.0206588	https://pmc.ncbi.nlm.nih.gov/articles/instance/6211727/bin/pone.0206588.s004.pdf

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Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Patient perception of whether the project was worth the time they spent on it	Meaningfulness	Patient	Quantitative	Patient Engagement in Research Scale (PEIRS)	Hamilton CB, Hoens AM, McQuitty S, et al. Development and pre-testing of the Patient Engagement In Research Scale (PEIRS) to assess the quality of engagement from a patient perspective. PLoS One. 2018;13(11):e0206588. Published 2018 Nov 1. doi:10.1371/journal.pone.0206588	https://pmc.ncbi.nlm.nih.gov/articles/instance/6211727/bin/pone.0206588.s004.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Patient perception of whether they had opportunity to provide input into selecting tasks for the project	Meaningfulness	Patient	Quantitative	Patient Engagement in Research Scale (PEIRS)	Hamilton CB, Hoens AM, McQuitty S, et al. Development and pre-testing of the Patient Engagement In Research Scale (PEIRS) to assess the quality of engagement from a patient perspective. PLoS One. 2018;13(11):e0206588. Published 2018 Nov 1. doi:10.1371/journal.pone.0206588	https://pmc.ncbi.nlm.nih.gov/articles/instance/6211727/bin/pone.0206588.s004.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Patient perception of whether they had opportunity to express their views	Meaningfulness	Patient	Quantitative	Patient Engagement in Research Scale (PEIRS)	Hamilton CB, Hoens AM, McQuitty S, et al. Development and pre-testing of the Patient Engagement In Research Scale (PEIRS) to assess the quality of engagement from a patient perspective. PLoS One. 2018;13(11):e0206588. Published 2018 Nov 1. doi:10.1371/journal.pone.0206588	https://pmc.ncbi.nlm.nih.gov/articles/instance/6211727/bin/pone.0206588.s004.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Patient perception of whether they contributed by providing their perspective	Meaningfulness	Patient	Quantitative	Patient Engagement in Research Scale (PEIRS)	Hamilton CB, Hoens AM, McQuitty S, et al. Development and pre-testing of the Patient Engagement In Research Scale (PEIRS) to assess the quality of engagement from a patient perspective. PLoS One. 2018;13(11):e0206588. Published 2018 Nov 1. doi:10.1371/journal.pone.0206588	https://pmc.ncbi.nlm.nih.gov/articles/instance/6211727/bin/pone.0206588.s004.pdf

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Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Patient perception of whether the contributions were a good use of their time	Meaningfulness	Patient	Quantitative	Patient Engagement in Research Scale (PEIRS)	Hamilton CB, Hoens AM, McQuitty S, et al. Development and pre-testing of the Patient Engagement In Research Scale (PEIRS) to assess the quality of engagement from a patient perspective. PLoS One. 2018;13(11):e0206588. Published 2018 Nov 1. doi:10.1371/journal.pone.0206588	https://pmc.ncbi.nlm.nih.gov/articles/instance/6211727/bin/pone.0206588.s004.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Patient perception of whether they shared knowledge within the project team	Meaningfulness	Patient	Quantitative	Patient Engagement in Research Scale (PEIRS)	Hamilton CB, Hoens AM, McQuitty S, et al. Development and pre-testing of the Patient Engagement In Research Scale (PEIRS) to assess the quality of engagement from a patient perspective. PLoS One. 2018;13(11):e0206588. Published 2018 Nov 1. doi:10.1371/journal.pone.0206588	https://pmc.ncbi.nlm.nih.gov/articles/instance/6211727/bin/pone.0206588.s004.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Patient perception of perception on whether they received sufficient recognition for their contributions (e.g., authorship)	Meaningfulness	Patient	Quantitative	Patient Engagement in Research Scale (PEIRS)	Hamilton CB, Hoens AM, McQuitty S, et al. Development and pre-testing of the Patient Engagement In Research Scale (PEIRS) to assess the quality of engagement from a patient perspective. PLoS One. 2018;13(11):e0206588. Published 2018 Nov 1. doi:10.1371/journal.pone.0206588	https://pmc.ncbi.nlm.nih.gov/articles/instance/6211727/bin/pone.0206588.s004.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Patient perception of whether they made an impact on the decisions in the project	Meaningfulness	Patient	Quantitative	Patient Engagement in Research Scale (PEIRS)	Hamilton CB, Hoens AM, McQuitty S, et al. Development and pre-testing of the Patient Engagement In Research Scale (PEIRS) to assess the quality of engagement from a patient perspective. PLoS One. 2018;13(11):e0206588. Published 2018 Nov 1. doi:10.1371/journal.pone.0206588	https://pmc.ncbi.nlm.nih.gov/articles/instance/6211727/bin/pone.0206588.s004.pdf

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Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Patient perception of whether they could see how their contributions benefited others	Meaningfulness	Patient	Quantitative	Patient Engagement in Research Scale (PEIRS)	Hamilton CB, Hoens AM, McQuitty S, et al. Development and pre-testing of the Patient Engagement In Research Scale (PEIRS) to assess the quality of engagement from a patient perspective. PLoS One. 2018;13(11):e0206588. Published 2018 Nov 1. doi:10.1371/journal.pone.0206588	https://pmc.ncbi.nlm.nih.gov/articles/instance/6211727/bin/pone.0206588.s004.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR); Development and Implementation of Guidelines	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination; Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development, Developing computable artifacts, Review, dissemination, and implementation, Evaluation and updating	Contributor/ Collaborator/ Partner	Patient understanding of purpose of engagement initiative	Meaningfulness	Patient	Quantitative	Public and Patient Engagement Evaluation Tool (PPEET)	Abelson, J. Public and Patient Engagement Evaluation Tool (PPEET) – Version 2.0. McMaster University. August 2018. https://ppe.mcmaster.ca/wp-content/uploads/2023/04/PPEET_Version-2.0_Full-Set.pdf	https://ppe.mcmaster.ca/wp-content/uploads/2023/04/PPEET_Version-2.0_Full-Set.pdf

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Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR); Development and Implementation of Guidelines	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination; Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development, Developing computable artifacts, Review, dissemination, and implementation, Evaluation and updating	Contributor/ Collaborator/ Partner	Patient satisfaction with engagement initiative	Meaningfulness	Patient	Quantitative	Public and Patient Engagement Evaluation Tool (PPEET)	Abelson, J. Public and Patient Engagement Evaluation Tool (PPEET) – Version 2.0. McMaster University. August 2018. https://ppe.mcmaster.ca/wp-content/uploads/2023/04/PPEET_Version-2.0_Full-Set.pdf	https://ppe.mcmaster.ca/wp-content/uploads/2023/04/PPEET_Version-2.0_Full-Set.pdf

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR); Development and Implementation of Guidelines	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination; Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development, Developing computable artifacts, Review, dissemination, and implementation, Evaluation and updating	Contributor/ Collaborator/ Partner	How long patient has been working with research organization	Meaningfulness	Patient	Quantitative	Public and Patient Engagement Evaluation Tool (PPEET)	Abelson, J. Public and Patient Engagement Evaluation Tool (PPEET) – Version 2.0. McMaster University. August 2018. https://ppe.mcmaster.ca/wp-content/uploads/2023/04/PPEET_Version-2.0_Full-Set.pdf	https://ppe.mcmaster.ca/wp-content/uploads/2023/04/PPEET_Version-2.0_Full-Set.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR); Development and Implementation of Guidelines	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination; Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development, Developing computable artifacts, Review, dissemination, and implementation, Evaluation and updating	Contributor/ Collaborator/ Partner	Patient perception on whether supports they needed to engage were available (e.g., travel, childcare)	Meaningfulness	Patient	Quantitative	Public and Patient Engagement Evaluation Tool (PPEET)	Abelson, J. Public and Patient Engagement Evaluation Tool (PPEET) – Version 2.0. McMaster University. August 2018. https://ppe.mcmaster.ca/wp-content/uploads/2023/04/PPEET_Version-2.0_Full-Set.pdf	https://ppe.mcmaster.ca/wp-content/uploads/2023/04/PPEET_Version-2.0_Full-Set.pdf

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Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR); Development and Implementation of Guidelines	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination; Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development, Developing computable artifacts, Review, dissemination, and implementation, Evaluation and updating	Contributor/ Collaborator/ Partner	Patient perception that engagement was a good use of time	Meaningfulness	Patient	Quantitative	Public and Patient Engagement Evaluation Tool (PPEET)	Abelson, J. Public and Patient Engagement Evaluation Tool (PPEET) – Version 2.0. McMaster University. August 2018. https://ppe.mcmaster.ca/wp-content/uploads/2023/04/PPEET_Version-2.0_Full-Set.pdf	https://ppe.mcmaster.ca/wp-content/uploads/2023/04/PPEET_Version-2.0_Full-Set.pdf
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Perceived experience in participation on guideline panel	Meaningfulness	Patient	Qualitative	N/A	Khodyakov D, Kinnett K, Denger B, et al. Developing a Process for Getting Patient and Caregiver Input on Clinical Practice Guidelines. Washington (DC): Patient-Centered Outcomes Research Institute (PCORI); June 2020.	N/A
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Perceived benefits and challenges of online discussion	Meaningfulness	Patient	Qualitative	N/A	Khodyakov D, Kinnett K, Denger B, et al. Developing a Process for Getting Patient and Caregiver Input on Clinical Practice Guidelines. Washington (DC): Patient-Centered Outcomes Research Institute (PCORI); June 2020.	N/A

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PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Perceived participation burden	Meaningfulness	Patient	Qualitative	N/A	Khodyakov D, Kinnett K, Denger B, et al. Developing a Process for Getting Patient and Caregiver Input on Clinical Practice Guidelines. Washington (DC): Patient-Centered Outcomes Research Institute (PCORI); June 2020.	N/A
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Perceived areas of improvement for engagement	Meaningfulness	Patient	Qualitative	N/A	Khodyakov D, Kinnett K, Denger B, et al. Developing a Process for Getting Patient and Caregiver Input on Clinical Practice Guidelines. Washington (DC): Patient-Centered Outcomes Research Institute (PCORI); June 2020.	N/A
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Perceived ability to express views	Meaningfulness	Patient	Qualitative	N/A	Khodyakov D, Kinnett K, Denger B, et al. Developing a Process for Getting Patient and Caregiver Input on Clinical Practice Guidelines. Washington (DC): Patient-Centered Outcomes Research Institute (PCORI); June 2020.	N/A
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Perceived usefulness of engagement tool	Meaningfulness	Patient	Qualitative	N/A	Khodyakov D, Kinnett K, Denger B, et al. Developing a Process for Getting Patient and Caregiver Input on Clinical Practice Guidelines. Washington (DC): Patient-Centered Outcomes Research Institute (PCORI); June 2020.	N/A
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Patient satisfaction	Meaningfulness	Patient	Qualitative	N/A	Khodyakov D, Kinnett K, Denger B, et al. Developing a Process for Getting Patient and Caregiver Input on Clinical Practice Guidelines. Washington (DC): Patient-Centered Outcomes Research Institute (PCORI); June 2020.	N/A

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PC CDS Lifecycle Phase	Steps Where Patients Are Engaged	Activities Where Patients Are Engaged	How Patients Are Engaged	Measure	Measure Type	Perspective Assessed	Data Collection Approach	Tool	Source(s)	Link to Tool
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Perceived amount of effort needed to participate	Meaningfulness	Patient	Qualitative	N/A	Khodyakov D, Kinnett K, Denger B, et al. Developing a Process for Getting Patient and Caregiver Input on Clinical Practice Guidelines. Washington (DC): Patient-Centered Outcomes Research Institute (PCORI); June 2020.	N/A
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	How well guideline development team did at providing necessary information to engage in guideline development process	Meaningfulness	Patient	Qualitative	N/A	Khodyakov D, Kinnett K, Denger B, et al. Developing a Process for Getting Patient and Caregiver Input on Clinical Practice Guidelines. Washington (DC): Patient-Centered Outcomes Research Institute (PCORI); June 2020.	N/A
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Perceived ease of using guideline development engagement tools	Meaningfulness	Patient	Qualitative	N/A	Khodyakov D, Kinnett K, Denger B, et al. Developing a Process for Getting Patient and Caregiver Input on Clinical Practice Guidelines. Washington (DC): Patient-Centered Outcomes Research Institute (PCORI); June 2020.	N/A
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Patient perception of whether participation in the study was satisfying	Meaningfulness	Patient	Quantitative	Study-specific Assessment	Khodyakov D, Kinnett K, Denger B, et al. Developing a Process for Getting Patient and Caregiver Input on Clinical Practice Guidelines. Washington (DC): Patient-Centered Outcomes Research Institute (PCORI); June 2020.	N/A
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Patient perception of whether the topic of the study is important	Meaningfulness	Patient	Quantitative	Study-specific Assessment	Khodyakov D, Kinnett K, Denger B, et al. Developing a Process for Getting Patient and Caregiver Input on Clinical Practice Guidelines. Washington (DC): Patient-Centered Outcomes Research Institute (PCORI); June 2020.	N/A

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Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Patient perception of the mechanics of participating distract from the substance of the study	Meaningfulness	Patient	Quantitative	Study-specific Assessment	Khodyakov D, Kinnett K, Denger B, et al. Developing a Process for Getting Patient and Caregiver Input on Clinical Practice Guidelines. Washington (DC): Patient-Centered Outcomes Research Institute (PCORI); June 2020.	N/A
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Patient perception of whether they were able to express views on the study topic	Meaningfulness	Patient	Quantitative	Study-specific Assessment	Khodyakov D, Kinnett K, Denger B, et al. Developing a Process for Getting Patient and Caregiver Input on Clinical Practice Guidelines. Washington (DC): Patient-Centered Outcomes Research Institute (PCORI); June 2020.	N/A
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Patient perception of whether the study will generate useful outcomes	Meaningfulness	Patient	Quantitative	Study-specific Assessment	Khodyakov D, Kinnett K, Denger B, et al. Developing a Process for Getting Patient and Caregiver Input on Clinical Practice Guidelines. Washington (DC): Patient-Centered Outcomes Research Institute (PCORI); June 2020.	N/A
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Patient perception of whether the study met their expectations	Meaningfulness	Patient	Quantitative	Study-specific Assessment	Khodyakov D, Kinnett K, Denger B, et al. Developing a Process for Getting Patient and Caregiver Input on Clinical Practice Guidelines. Washington (DC): Patient-Centered Outcomes Research Institute (PCORI); June 2020.	N/A
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Patient perception of whether participation n the study took a lot of effort	Meaningfulness	Patient	Quantitative	Study-specific Assessment	Khodyakov D, Kinnett K, Denger B, et al. Developing a Process for Getting Patient and Caregiver Input on Clinical Practice Guidelines. Washington (DC): Patient-Centered Outcomes Research Institute (PCORI); June 2020.	N/A

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Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Patient perception of it was tedious to complete rounds of guideline development	Meaningfulness	Patient	Quantitative	Study-specific Assessment	Khodyakov D, Kinnett K, Denger B, et al. Developing a Process for Getting Patient and Caregiver Input on Clinical Practice Guidelines. Washington (DC): Patient-Centered Outcomes Research Institute (PCORI); June 2020.	N/A
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Patient perception of whether discussions in guideline development were informative	Meaningfulness	Patient	Quantitative	Study-specific Assessment	Khodyakov D, Kinnett K, Denger B, et al. Developing a Process for Getting Patient and Caregiver Input on Clinical Practice Guidelines. Washington (DC): Patient-Centered Outcomes Research Institute (PCORI); June 2020.	N/A
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Patient perception of whether they had trouble following discussions in guideline development	Meaningfulness	Patient	Quantitative	Study-specific Assessment	Khodyakov D, Kinnett K, Denger B, et al. Developing a Process for Getting Patient and Caregiver Input on Clinical Practice Guidelines. Washington (DC): Patient-Centered Outcomes Research Institute (PCORI); June 2020.	N/A
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Patient perception of whether they felt overloaded with information during the discussion	Meaningfulness	Patient	Quantitative	Study-specific Assessment	Khodyakov D, Kinnett K, Denger B, et al. Developing a Process for Getting Patient and Caregiver Input on Clinical Practice Guidelines. Washington (DC): Patient-Centered Outcomes Research Institute (PCORI); June 2020.	N/A
Clinical Decision Support Phase	Implementation of PC CDS	Participation in pilot project	Contributor/ Collaborator/ Partner	Number of patients recruited for intervention	Structure/ Process	N/A	Quantitative	N/A	Klarenbeek SE, Weekenstroo HHA, Sedelaar JPM, Fütterer JJ, Prokop M, Tummers M. The Effect of Higher Level Computerized Clinical Decision Support Systems on Oncology Care: A Systematic Review. Cancers (Basel). 2020;12(4):1032. Published 2020 Apr 22. doi:10.3390/cancers12041032	N/A

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
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Clinical Decision Support Phase	Implementation of PC CDS	Participation in pilot project	Contributor/ Collaborator/ Partner	Percentage of patients who registered/signed up	Structure/ Process	N/A	Quantitative	N/A	Klarenbeek SE, Weekenstroo HHA, Sedelaar JPM, Fütterer JJ, Prokop M, Tummers M. The Effect of Higher Level Computerized Clinical Decision Support Systems on Oncology Care: A Systematic Review. Cancers (Basel). 2020;12(4):1032. Published 2020 Apr 22. doi:10.3390/cancers12041032	N/A
Clinical Decision Support Phase	Implementation of PC CDS	Participation in pilot project	Contributor/ Collaborator/ Partner	Number of active users by user type	Structure/ Process	N/A	Quantitative	N/A	Klarenbeek SE, Weekenstroo HHA, Sedelaar JPM, Fütterer JJ, Prokop M, Tummers M. The Effect of Higher Level Computerized Clinical Decision Support Systems on Oncology Care: A Systematic Review. Cancers (Basel). 2020;12(4):1032. Published 2020 Apr 22. doi:10.3390/cancers12041032	N/A
Clinical Decision Support Phase	Design and development of PC CDS	Framing the issue, Requirements gathering, Generative design work and prototyping, Usability testing	Contributor/ Collaborator/ Partner	Patient's understanding of the PC CDS, including its context and ways it can improve	Meaningfulness	Patient	Qualitative	N/A	Lobach D, Heaney-Huls K, Ryan S, Chiao AB, Kawamoto K, Desai PJ, Segal C, Dullabh PM, CDSiC Implementation, Adoption, and Scaling Workgroup. Implementation, Adoption, and Scaling Workgroup: Exploring Challenges and Opportunities for Patient Engagement, Implementation, Adoption, and Scaling through PC CDS Case Studies. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 24-0069-4. Rockville, MD: Agency for Healthcare Research and Quality; August 2024.	N/A

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Clinical Decision Support Phase	Design and development of PC CDS	Framing the issue, Requirements gathering, Generative design work and prototyping, Usability testing	Contributor/ Collaborator/ Partner	Patient perception on the value of their contributions	Meaningfulness	Patient	Qualitative	N/A	Maher LM, Hayward B, Hayward P, Walsh C. Increasing patient engagement in healthcare service design: a qualitative evaluation of a co-design programme in New Zealand. Patient Experience Journal. 2017; 4(1):23-32. doi: 10.35680/2372-0247.1149.	N/A
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development	Contributor/ Collaborator/ Partner	Patient participation on guideline development panels	Structure/ Process	N/A	Quantitative	N/A	Mirza RD, Bolster MB, Johnson SR, et al. Assessing Patient Values and Preferences to Inform the 2023 American College of Rheumatology/American College of Chest Physicians Interstitial Lung Disease Guidelines. Arthritis Care Res (Hoboken). 2024;76(8):1083-1089. doi:10.1002/acr.25346	N/A
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development, Developing computable artifacts, Review, dissemination, and implementation, Evaluation and updating	Contributor/ Collaborator/ Partner	Patient perception of whether their ideas were heard	Meaningfulness	Patient	Quantitative	Patient Engagement and Evaluation Tool (PEET)	Moore A, Wu Y, Kwakkenbos L, et al. The patient engagement evaluation tool was valid for clinical practice guideline development. J Clin Epidemiol. 2022;143:61-72. doi:10.1016/j.jclinepi.2021.11.034 Kennedy ED, McKenzie M, Schmocker S, et al. Patient engagement study to identify and improve surgical experience. Br J Surg. 2021;108(4):435-440. doi:10.1093/bjs/znaa087	https://www.jclinepi.com/article/S0895-4356(21)00392-9/pdf

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Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development, Developing computable artifacts, Review, dissemination, and implementation, Evaluation and updating	Contributor/ Collaborator/ Partner	Patient perception of the ability to clearly express viewpoints	Meaningfulness	Patient	Quantitative	Patient Engagement and Evaluation Tool (PEET)	Moore A, Wu Y, Kwakkenbos L, et al. The patient engagement evaluation tool was valid for clinical practice guideline development. J Clin Epidemiol. 2022;143:61-72. doi:10.1016/j.jclinepi.2021.11.034 Kennedy ED, McKenzie M, Schmocker S, et al. Patient engagement study to identify and improve surgical experience. Br J Surg. 2021;108(4):435-440. doi:10.1093/bjs/znaa087	https://www.jclinepi.com/article/S0895-4356(21)00392-9/pdf
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development, Developing computable artifacts, Review, dissemination, and implementation, Evaluation and updating	Contributor/ Collaborator/ Partner	Patient perception of the equality of opportunity to participate in discussion	Meaningfulness	Patient	Quantitative	Patient Engagement and Evaluation Tool (PEET)	Moore A, Wu Y, Kwakkenbos L, et al. The patient engagement evaluation tool was valid for clinical practice guideline development. J Clin Epidemiol. 2022;143:61-72. doi:10.1016/j.jclinepi.2021.11.034 Kennedy ED, McKenzie M, Schmocker S, et al. Patient engagement study to identify and improve surgical experience. Br J Surg. 2021;108(4):435-440. doi:10.1093/bjs/znaa087	https://www.jclinepi.com/article/S0895-4356(21)00392-9/pdf
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development, Developing computable artifacts, Review, dissemination, and implementation, Evaluation and updating	Contributor/ Collaborator/ Partner	Patient participation of amount of information available to participate knowledgeably	Meaningfulness	Patient	Quantitative	Patient Engagement and Evaluation Tool (PEET)	Moore A, Wu Y, Kwakkenbos L, et al. The patient engagement evaluation tool was valid for clinical practice guideline development. J Clin Epidemiol. 2022;143:61-72. doi:10.1016/j.jclinepi.2021.11.034 Kennedy ED, McKenzie M, Schmocker S, et al. Patient engagement study to identify and improve surgical experience. Br J Surg. 2021;108(4):435-440. doi:10.1093/bjs/znaa087	https://www.jclinepi.com/article/S0895-4356(21)00392-9/pdf

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Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation, Recommendation development, Developing computable artifacts, Review, dissemination, and implementation, Evaluation and updating	Contributor/ Collaborator/ Partner	Patient perceived impact on final product	Meaningfulness	Patient	Quantitative	Patient Engagement and Evaluation Tool (PEET)	Moore A, Wu Y, Kwakkenbos L, et al. The patient engagement evaluation tool was valid for clinical practice guideline development. J Clin Epidemiol. 2022;143:61-72. doi:10.1016/j.jclinepi.2021.11.034 Kennedy ED, McKenzie M, Schmocker S, et al. Patient engagement study to identify and improve surgical experience. Br J Surg. 2021;108(4):435-440. doi:10.1093/bjs/znaa087	https://www.jclinepi.com/article/S0895-4356(21)00392-9/pdf
Knowledge Generation Phase	Development and Implementation of Guidelines	Planning and governance, Priority setting and scope definition, Evidence review and evaluation	Contributor/ Collaborator/ Partner	Response rate to surveys gathering patient input on guideline development	Structure/ Process	Researcher	Quantitative	N/A	Morin SN, Djekic-Ivankovic M, Funnell L, et al. Patient engagement in clinical guidelines development: input from > 1000 members of the Canadian Osteoporosis Patient Network. Osteoporos Int. 2020;31(5):867-874. doi:10.1007/s00198-019-05248-4	N/A
Healthcare Delivery Phase	Team Talk	Discussion of patient values, preferences, and/or goals	User	Whether patients shared their preferences with their clinician	Structure/ Process	Patient	Quantitative	N/A	N/A	N/A
Healthcare Delivery Phase	Team Talk	Discussion of patient values, preferences, and/or goals	User	Number of patients that shared their preferences with their clinician	Structure/ Process	Patient	Quantitative	N/A	N/A	N/A
Healthcare Delivery Phase	Team Talk	Discussion of patient values, preferences, and/or goals	User	Number of clinician inquiries about patient's preferences	Structure/ Process	Patient	Quantitative	N/A	N/A	N/A
Healthcare Delivery Phase	Team Talk	Discussion of patient values, preferences, and/or goals	User	Whether clinician elicited patient's preferences in conversations	Structure/ Process	Patient	Quantitative	N/A	N/A	N/A
Healthcare Delivery Phase	Team Talk	Discussion of patient values, preferences, and/or goals	User	Number of preferences that were incorporated in the PC CDS	Structure/ Process	Patient	Quantitative	N/A	N/A	N/A

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Healthcare Delivery Phase	Decision Talk	Shared decision-making	User	Number of patients/caregivers that participated in shared decision-making	Structure/ Process	Patient	Quantitative	N/A	N/A	N/A
Healthcare Delivery Phase	Decision Talk	Shared decision-making	User	Whether clinician provided decision tools during decision-making	Structure/ Process	Patient	Quantitative	N/A	N/A	N/A
Healthcare Delivery Phase	Decision Talk	Shared decision-making	User	Whether clinician solicited patient's involvement in decision-making	Structure/ Process	Patient	Quantitative	N/A	N/A	N/A
Healthcare Delivery Phase	Decision Talk	Shared decision-making	User	Whether clinician incorporated patient's preferences/values in conversations	Structure/ Process	Patient	Quantitative	N/A	N/A	N/A
Healthcare Delivery Phase	Decision Talk	Shared decision-making	User	Effectiveness of decision tools during decision-making	Meaningfulness	Patient	Qualitative	N/A	N/A	N/A
Healthcare Delivery Phase	Decision Talk	Patient-clinician communication	User	Patient perception regarding whether clinician listened to their inquiries	Meaningfulness	Patient	Qualitative	N/A	N/A	N/A
Healthcare Delivery Phase	Decision Talk	Patient-clinician communication	User	Patient perception regarding whether clinician encouraged their questions	Meaningfulness	Patient	Qualitative	N/A	N/A	N/A
Healthcare Delivery Phase	Team Talk	Establishment of roles	User	Preferences for decision-making roles and information sharing	Structure/ Process	Patient	Qualitative	N/A	Ozkaynak M, Jiménez F, Kurtzman RT, Nwefo R, Kukhareva P, Desai PJ, Dullabh PM, and CDSiC Measurement and Outcomes Workgroup. Inventory of Patient Preference Measurement Tools for PC CDS Report. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 24-0062-1-EF. Rockville, MD: Agency for Healthcare Research and Quality; June 2024.	N/A

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
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Healthcare Delivery Phase	Team Talk	Establishment of roles	User	Inclusion of family/caregivers in decision-making process	Structure/ Process	Patient	Quantitative	N/A	Ozkaynak M, Jiménez F, Kurtzman RT, Nwefo R, Kukhareva P, Desai PJ, Dullabh PM, and CDSiC Measurement and Outcomes Workgroup. Inventory of Patient Preference Measurement Tools for PC CDS Report. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 24-0062-1-EF. Rockville, MD: Agency for Healthcare Research and Quality; June 2024.	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Whether patients were involved in different parts of research	Structure/ Process	Patient	Quantitative	Ways of Engaging-ENgagement ACtivity Tool (WE-ENACT) - Patients and Stakeholders 3.0 Item Pool	Patient-Centered Outcomes Research Institute. Ways of Engaging- ENgagement ACtivity Tool (WE-ENACT) - Patients and Stakeholders 3.0 Item Pool. August 1, 2016. https://www.pcori.org/sites/default/files/PCORI-WE-ENACT-3-0-Patients-Stakeholders-Item-Pool-080916.pdf	https://perc-phc.mcmaster.ca/app/uploads/2022/01/PCORI-Engagement-Inventory-WE-ENACT-.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Number of research activities patient was involved in	Structure/ Process	Patient	Quantitative	Ways of Engaging-ENgagement ACtivity Tool (WE-ENACT) - Patients and Stakeholders 3.0 Item Pool	Patient-Centered Outcomes Research Institute. Ways of Engaging- ENgagement ACtivity Tool (WE-ENACT) - Patients and Stakeholders 3.0 Item Pool. August 1, 2016. https://www.pcori.org/sites/default/files/PCORI-WE-ENACT-3-0-Patients-Stakeholders-Item-Pool-080916.pdf	https://perc-phc.mcmaster.ca/app/uploads/2022/01/PCORI-Engagement-Inventory-WE-ENACT-.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	What the patient did in their involvement	Meaningfulness	Patient	Quantitative	Ways of Engaging-ENgagement ACtivity Tool (WE-ENACT) - Patients and Stakeholders 3.0 Item Pool	Patient-Centered Outcomes Research Institute. Ways of Engaging- ENgagement ACtivity Tool (WE-ENACT) - Patients and Stakeholders 3.0 Item Pool. August 1, 2016. https://www.pcori.org/sites/default/files/PCORI-WE-ENACT-3-0-Patients-Stakeholders-Item-Pool-080916.pdf	https://perc-phc.mcmaster.ca/app/uploads/2022/01/PCORI-Engagement-Inventory-WE-ENACT-.pdf

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PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/Collaborator/Partner	Whether the patient made a difference	Meaningfulness	Patient	Quantitative	Ways of Engaging-ENgagement ACtivity Tool (WE-ENACT) - Patients and Stakeholders 3.0 Item Pool	Patient-Centered Outcomes Research Institute. Ways of Engaging- ENgagement ACtivity Tool (WE-ENACT) - Patients and Stakeholders 3.0 Item Pool. August 1, 2016. https://www.pcori.org/sites/default/files/PCORI-WE-ENACT-3-0-Patients-Stakeholders-Item-Pool-080916.pdf	https://perc-phc.mcmaster.ca/app/uploads/2022/01/PCORI-Engagement-Inventory-WE-ENACT-.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/Collaborator/Partner	Level of perceived influence over different research parts	Meaningfulness	Patient	Quantitative	Ways of Engaging-ENgagement ACtivity Tool (WE-ENACT) - Patients and Stakeholders 3.0 Item Pool	Patient-Centered Outcomes Research Institute. Ways of Engaging- ENgagement ACtivity Tool (WE-ENACT) - Patients and Stakeholders 3.0 Item Pool. August 1, 2016. https://www.pcori.org/sites/default/files/PCORI-WE-ENACT-3-0-Patients-Stakeholders-Item-Pool-080916.pdf	https://perc-phc.mcmaster.ca/app/uploads/2022/01/PCORI-Engagement-Inventory-WE-ENACT-.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/Collaborator/Partner	Level of trust, honesty, transparency, shared-learning, and give-and-take relationships patient felt	Meaningfulness	Patient	Quantitative	Ways of Engaging-ENgagement ACtivity Tool (WE-ENACT) - Patients and Stakeholders 3.0 Item Pool	Patient-Centered Outcomes Research Institute. Ways of Engaging- ENgagement ACtivity Tool (WE-ENACT) - Patients and Stakeholders 3.0 Item Pool. August 1, 2016. https://www.pcori.org/sites/default/files/PCORI-WE-ENACT-3-0-Patients-Stakeholders-Item-Pool-080916.pdf	https://perc-phc.mcmaster.ca/app/uploads/2022/01/PCORI-Engagement-Inventory-WE-ENACT-.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/Collaborator/Partner	Level of preparation to contribute to research project	Structure/Process	Patient	Quantitative	Ways of Engaging-ENgagement ACtivity Tool (WE-ENACT) - Patients and Stakeholders 3.0 Item Pool	Patient-Centered Outcomes Research Institute. Ways of Engaging- ENgagement ACtivity Tool (WE-ENACT) - Patients and Stakeholders 3.0 Item Pool. August 1, 2016. https://www.pcori.org/sites/default/files/PCORI-WE-ENACT-3-0-Patients-Stakeholders-Item-Pool-080916.pdf	https://perc-phc.mcmaster.ca/app/uploads/2022/01/PCORI-Engagement-Inventory-WE-ENACT-.pdf

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Length of time working with researchers	Structure/ Process	Patient	Quantitative	Ways of Engaging-ENgagement ACtivity Tool (WE-ENACT) - Patients and Stakeholders 3.0 Item Pool	Patient-Centered Outcomes Research Institute. Ways of Engaging- ENgagement ACtivity Tool (WE-ENACT) - Patients and Stakeholders 3.0 Item Pool. August 1, 2016. https://www.pcori.org/sites/default/files/PCORI-WE-ENACT-3-0-Patients-Stakeholders-Item-Pool-080916.pdf	https://perc-phc.mcmaster.ca/app/uploads/2022/01/PCORI-Engagement-Inventory-WE-ENACT-.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Study design	Contributor/ Collaborator/ Partner	Whether patients are in key personnel roles	Structure/ Process	Researcher	Quantitative	Principles of Partnership: An Engagement Assessment Tool	PCORNet. Principles of Partnership: An Engagement Assessment Tool. National Patient-Centered Clinical Research Network.	https://www.pcori.org/sites/default/files/1118-PCORnet-Engagement-Committee-Assessment-Tool.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Study design	Contributor/ Collaborator/ Partner	Number and percent of patients in network leadership positions who have decision-making authority	Structure/ Process	Researcher	Quantitative	Principles of Partnership: An Engagement Assessment Tool	PCORNet. Principles of Partnership: An Engagement Assessment Tool. National Patient-Centered Clinical Research Network.	https://www.pcori.org/sites/default/files/1118-PCORnet-Engagement-Committee-Assessment-Tool.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Study design	Contributor/ Collaborator/ Partner	Patient-reported satisfaction with execution of SOPs and conflict resolution processes	Meaningfulness	Patient	Quantitative	Principles of Partnership: An Engagement Assessment Tool	PCORNet. Principles of Partnership: An Engagement Assessment Tool. National Patient-Centered Clinical Research Network.	https://www.pcori.org/sites/default/files/1118-PCORnet-Engagement-Committee-Assessment-Tool.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Patient-reported satisfaction in involvement in the research process and whether they feel adequately informed about the project activities and results	Meaningfulness	Patient	Quantitative	Principles of Partnership: An Engagement Assessment Tool	PCORNet. Principles of Partnership: An Engagement Assessment Tool. National Patient-Centered Clinical Research Network.	https://www.pcori.org/sites/default/files/1118-PCORnet-Engagement-Committee-Assessment-Tool.pdf

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PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Whether patients report that the research was valuable to them and that they have contributed to setting and revising priorities	Meaningfulness	Patient	Quantitative	Principles of Partnership: An Engagement Assessment Tool	PCORNet. Principles of Partnership: An Engagement Assessment Tool. National Patient-Centered Clinical Research Network.	https://www.pcori.org/sites/default/files/1118-PCORnet-Engagement-Committee-Assessment-Tool.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Number of check-ins with patients over project period	Structure/ Process	Researcher	Quantitative	Principles of Partnership: An Engagement Assessment Tool	PCORNet. Principles of Partnership: An Engagement Assessment Tool. National Patient-Centered Clinical Research Network.	https://www.pcori.org/sites/default/files/1118-PCORnet-Engagement-Committee-Assessment-Tool.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Patient-reported satisfaction with participation over time	Meaningfulness	Patient	Quantitative	Principles of Partnership: An Engagement Assessment Tool	PCORNet. Principles of Partnership: An Engagement Assessment Tool. National Patient-Centered Clinical Research Network.	https://www.pcori.org/sites/default/files/1118-PCORnet-Engagement-Committee-Assessment-Tool.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Patient input on use of technology for data collection	Meaningfulness	Patient	Quantitative	Principles of Partnership: An Engagement Assessment Tool	PCORNet. Principles of Partnership: An Engagement Assessment Tool. National Patient-Centered Clinical Research Network.	https://www.pcori.org/sites/default/files/1118-PCORnet-Engagement-Committee-Assessment-Tool.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Recruitment	Contributor/ Collaborator/ Partner	Recruitment rate	Structure/ Process	Researcher	Quantitative	Principles of Partnership: An Engagement Assessment Tool	PCORNet. Principles of Partnership: An Engagement Assessment Tool. National Patient-Centered Clinical Research Network.	https://www.pcori.org/sites/default/files/1118-PCORnet-Engagement-Committee-Assessment-Tool.pdf

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Recruitment	Contributor/ Collaborator/ Partner	Retention rate	Structure/ Process	Researcher	Quantitative	Principles of Partnership: An Engagement Assessment Tool	PCORNet. Principles of Partnership: An Engagement Assessment Tool. National Patient-Centered Clinical Research Network.	https://www.pcori.org/sites/default/files/1118-PCORnet-Engagement-Committee-Assessment-Tool.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Data interpretation	Contributor/ Collaborator/ Partner	Whether feedback from patients integrated into analysis plan	Structure/ Process	Researcher	Quantitative	Principles of Partnership: An Engagement Assessment Tool	PCORNet. Principles of Partnership: An Engagement Assessment Tool. National Patient-Centered Clinical Research Network.	https://www.pcori.org/sites/default/files/1118-PCORnet-Engagement-Committee-Assessment-Tool.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Data interpretation	Contributor/ Collaborator/ Partner	Whether preliminary and final results were shared with stakeholders prior to publication	Structure/ Process	Researcher	Quantitative	Principles of Partnership: An Engagement Assessment Tool	PCORNet. Principles of Partnership: An Engagement Assessment Tool. National Patient-Centered Clinical Research Network.	https://www.pcori.org/sites/default/files/1118-PCORnet-Engagement-Committee-Assessment-Tool.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Number and percent of patient who report feeling satisfied with their participation and/or influential in study decisions (e.g., regarding study question, protocol decisions, recruitment and dissemination strategies)	Structure/ Process	Researcher	Quantitative	Principles of Partnership: An Engagement Assessment Tool	PCORNet. Principles of Partnership: An Engagement Assessment Tool. National Patient-Centered Clinical Research Network.	https://www.pcori.org/sites/default/files/1118-PCORnet-Engagement-Committee-Assessment-Tool.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	Number of abstracts and/or publications on methods used to engage patients	Structure/ Process	Researcher	Quantitative	Principles of Partnership: An Engagement Assessment Tool	PCORNet. Principles of Partnership: An Engagement Assessment Tool. National Patient-Centered Clinical Research Network.	https://www.pcori.org/sites/default/files/1118-PCORnet-Engagement-Committee-Assessment-Tool.pdf

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PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	Whether co-developed dissemination plan was executed	Structure/ Process	Researcher	Quantitative	Principles of Partnership: An Engagement Assessment Tool	PCORNet. Principles of Partnership: An Engagement Assessment Tool. National Patient-Centered Clinical Research Network.	https://www.pcori.org/sites/default/files/1118-PCORnet-Engagement-Committee-Assessment-Tool.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	Whether there are patient-directed publications	Structure/ Process	Researcher	Quantitative	Principles of Partnership: An Engagement Assessment Tool	PCORNet. Principles of Partnership: An Engagement Assessment Tool. National Patient-Centered Clinical Research Network.	https://www.pcori.org/sites/default/files/1118-PCORnet-Engagement-Committee-Assessment-Tool.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	Percent of publications, peer-reviewed, non-peer reviewed with at least one patient co-author	Structure/ Process	Researcher	Quantitative	Principles of Partnership: An Engagement Assessment Tool	PCORNet. Principles of Partnership: An Engagement Assessment Tool. National Patient-Centered Clinical Research Network.	https://www.pcori.org/sites/default/files/1118-PCORnet-Engagement-Committee-Assessment-Tool.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Demographics of patients	Structure/ Process	Researcher	Quantitative	Principles of Partnership: An Engagement Assessment Tool	PCORNet. Principles of Partnership: An Engagement Assessment Tool. National Patient-Centered Clinical Research Network.	https://www.pcori.org/sites/default/files/1118-PCORnet-Engagement-Committee-Assessment-Tool.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Percent of study team meetings involving patients (number of meetings with patient participation each month over total number of study team meetings each month	Structure/ Process	Researcher	Quantitative	Principles of Partnership: An Engagement Assessment Tool	PCORNet. Principles of Partnership: An Engagement Assessment Tool. National Patient-Centered Clinical Research Network.	https://www.pcori.org/sites/default/files/1118-PCORnet-Engagement-Committee-Assessment-Tool.pdf

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	Steps Where Patients Are Engaged	Activities Where Patients Are Engaged	How Patients Are Engaged	Measure	Measure Type	Perspective Assessed	Data Collection Approach	Tool	Source(s)	Link to Tool
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Patient-reported satisfaction with participation in meetings and activities	Meaningfulness	Patient	Quantitative	Principles of Partnership: An Engagement Assessment Tool	PCORNet. Principles of Partnership: An Engagement Assessment Tool. National Patient-Centered Clinical Research Network.	https://www.pcori.org/sites/default/files/1118-PCORnet-Engagement-Committee-Assessment-Tool.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Patient-reported satisfaction with participation and group dynamics	Meaningfulness	Patient	Quantitative	Principles of Partnership: An Engagement Assessment Tool	PCORNet. Principles of Partnership: An Engagement Assessment Tool. National Patient-Centered Clinical Research Network.	https://www.pcori.org/sites/default/files/1118-PCORnet-Engagement-Committee-Assessment-Tool.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Patient-reported satisfaction with opportunities to share feedback	Meaningfulness	Patient	Quantitative	Principles of Partnership: An Engagement Assessment Tool	PCORNet. Principles of Partnership: An Engagement Assessment Tool. National Patient-Centered Clinical Research Network.	https://www.pcori.org/sites/default/files/1118-PCORnet-Engagement-Committee-Assessment-Tool.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Patient-reported satisfaction with cultural humility and sensitivity	Meaningfulness	Patient	Quantitative	Principles of Partnership: An Engagement Assessment Tool	PCORNet. Principles of Partnership: An Engagement Assessment Tool. National Patient-Centered Clinical Research Network.	https://www.pcori.org/sites/default/files/1118-PCORnet-Engagement-Committee-Assessment-Tool.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Number of ideas generated by patients	Structure/ Process	N/A	Quantitative	N/A	Stallings SC, Boyer AP, Joosten YA, et al. A taxonomy of impacts on clinical and translational research from community stakeholder engagement. Health Expect. 2019;22(4):731-742. doi:10.1111/hex.12937	N/A

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	PCOR rating of research abstract or other product	Structure/ Process	N/A	Quantitative	N/A	Stallings SC, Boyer AP, Joosten YA, et al. A taxonomy of impacts on clinical and translational research from community stakeholder engagement. Health Expect. 2019;22(4):731-742. doi:10.1111/hex.12937	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Recruitment and retention rate/improvement	Structure/ Process	N/A	Quantitative	N/A	Stallings SC, Boyer AP, Joosten YA, et al. A taxonomy of impacts on clinical and translational research from community stakeholder engagement. Health Expect. 2019;22(4):731-742. doi:10.1111/hex.12937	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Number and composition of patients on team	Structure/ Process	N/A	Quantitative	N/A	Stallings SC, Boyer AP, Joosten YA, et al. A taxonomy of impacts on clinical and translational research from community stakeholder engagement. Health Expect. 2019;22(4):731-742. doi:10.1111/hex.12937	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Number of patient-identified opportunities	Structure/ Process	N/A	Quantitative	N/A	Stallings SC, Boyer AP, Joosten YA, et al. A taxonomy of impacts on clinical and translational research from community stakeholder engagement. Health Expect. 2019;22(4):731-742. doi:10.1111/hex.12937	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Number of patient participants in grant writing process through focus groups community engagement studios, town halls, meetings	Structure/ Process	N/A	Quantitative	N/A	Stallings SC, Boyer AP, Joosten YA, et al. A taxonomy of impacts on clinical and translational research from community stakeholder engagement. Health Expect. 2019;22(4):731-742. doi:10.1111/hex.12937	N/A

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PC CDS Lifecycle Phase	Steps Where Patients Are Engaged	Activities Where Patients Are Engaged	How Patients Are Engaged	Measure	Measure Type	Perspective Assessed	Data Collection Approach	Tool	Source(s)	Link to Tool
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Number of hours of meetings attended by patients	Structure/ Process	N/A	Quantitative	N/A	Stallings SC, Boyer AP, Joosten YA, et al. A taxonomy of impacts on clinical and translational research from community stakeholder engagement. Health Expect. 2019;22(4):731-742. doi:10.1111/hex.12937	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Number of educational backgrounds represented on study team	Structure/ Process	N/A	Quantitative	N/A	Stallings SC, Boyer AP, Joosten YA, et al. A taxonomy of impacts on clinical and translational research from community stakeholder engagement. Health Expect. 2019;22(4):731-742. doi:10.1111/hex.12937	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Demographic composition of participants in research study	Structure/ Process	N/A	Quantitative	N/A	Stallings SC, Boyer AP, Joosten YA, et al. A taxonomy of impacts on clinical and translational research from community stakeholder engagement. Health Expect. 2019;22(4):731-742. doi:10.1111/hex.12937	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Demographic composition of research participants overall and over time	Structure/ Process	N/A	Quantitative	N/A	Stallings SC, Boyer AP, Joosten YA, et al. A taxonomy of impacts on clinical and translational research from community stakeholder engagement. Health Expect. 2019;22(4):731-742. doi:10.1111/hex.12937	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Presence or absence of opportunity for patients to give feedback on study applicability to multiple study sites	Structure/ Process	N/A	Quantitative	N/A	Stallings SC, Boyer AP, Joosten YA, et al. A taxonomy of impacts on clinical and translational research from community stakeholder engagement. Health Expect. 2019;22(4):731-742. doi:10.1111/hex.12937	N/A

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Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Study design	Contributor/ Collaborator/ Partner	Number of modifications to research protocol made by patients	Structure/ Process	Researcher	Quantitative	N/A	Stallings SC, Boyer AP, Joosten YA, et al. A taxonomy of impacts on clinical and translational research from community stakeholder engagement. Health Expect. 2019;22(4):731-742. doi:10.1111/hex.12937	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Study design	Contributor/ Collaborator/ Partner	Perceived confidence in research protocol	Meaningfulness	Patient	Qualitative	N/A	Stallings SC, Boyer AP, Joosten YA, et al. A taxonomy of impacts on clinical and translational research from community stakeholder engagement. Health Expect. 2019;22(4):731-742. doi:10.1111/hex.12937	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	Diversity in patient responsibilities	Structure/ Process	N/A	Quantitative	N/A	Stallings SC, Boyer AP, Joosten YA, et al. A taxonomy of impacts on clinical and translational research from community stakeholder engagement. Health Expect. 2019;22(4):731-742. doi:10.1111/hex.12937	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Recruitment	Contributor/ Collaborator/ Partner	Patient-initiated suggestions for recruitment/retention that are implemented; recruitment goal achievement	Structure/ Process	N/A	Quantitative	N/A	Stallings SC, Boyer AP, Joosten YA, et al. A taxonomy of impacts on clinical and translational research from community stakeholder engagement. Health Expect. 2019;22(4):731-742. doi:10.1111/hex.12937	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Recruitment	Contributor/ Collaborator/ Partner	Presence or absence of changes to recruitment protocol after patients' contributions	Structure/ Process	N/A	Quantitative	N/A	Stallings SC, Boyer AP, Joosten YA, et al. A taxonomy of impacts on clinical and translational research from community stakeholder engagement. Health Expect. 2019;22(4):731-742. doi:10.1111/hex.12937	N/A

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Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Recruitment	Contributor/ Collaborator/ Partner	Number of participants recruited by patients	Structure/ Process	N/A	Quantitative	N/A	Stallings SC, Boyer AP, Joosten YA, et al. A taxonomy of impacts on clinical and translational research from community stakeholder engagement. Health Expect. 2019;22(4):731-742. doi:10.1111/hex.12937	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Recruitment	Contributor/ Collaborator/ Partner	Change in recruitment rate after patient input implemented	Structure/ Process	N/A	Quantitative	N/A	Stallings SC, Boyer AP, Joosten YA, et al. A taxonomy of impacts on clinical and translational research from community stakeholder engagement. Health Expect. 2019;22(4):731-742. doi:10.1111/hex.12937	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Data collection	Contributor/ Collaborator/ Partner	Presence or absence of changes to data collection protocol after patient feedback	Structure/ Process	N/A	Quantitative	N/A	Stallings SC, Boyer AP, Joosten YA, et al. A taxonomy of impacts on clinical and translational research from community stakeholder engagement. Health Expect. 2019;22(4):731-742. doi:10.1111/hex.12937	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Data interpretation	Contributor/ Collaborator/ Partner	Presence of patients participating in analysis	Structure/ Process	N/A	Quantitative	N/A	Stallings SC, Boyer AP, Joosten YA, et al. A taxonomy of impacts on clinical and translational research from community stakeholder engagement. Health Expect. 2019;22(4):731-742. doi:10.1111/hex.12937	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	Presence of patient authors on manuscript	Structure/ Process	N/A	Quantitative	N/A	Stallings SC, Boyer AP, Joosten YA, et al. A taxonomy of impacts on clinical and translational research from community stakeholder engagement. Health Expect. 2019;22(4):731-742. doi:10.1111/hex.12937	N/A

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	Steps Where Patients Are Engaged	Activities Where Patients Are Engaged	How Patients Are Engaged	Measure	Measure Type	Perspective Assessed	Data Collection Approach	Tool	Source(s)	Link to Tool
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	Presence of patient coauthors	Structure/ Process	N/A	Quantitative	N/A	Stallings SC, Boyer AP, Joosten YA, et al. A taxonomy of impacts on clinical and translational research from community stakeholder engagement. Health Expect. 2019;22(4):731-742. doi:10.1111/hex.12937	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	Number of patient authors in non-scientific publications	Structure/ Process	N/A	Quantitative	N/A	Stallings SC, Boyer AP, Joosten YA, et al. A taxonomy of impacts on clinical and translational research from community stakeholder engagement. Health Expect. 2019;22(4):731-742. doi:10.1111/hex.12937	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	Number of presentations led by patients in non-traditional venues	Structure/ Process	N/A	Quantitative	N/A	Stallings SC, Boyer AP, Joosten YA, et al. A taxonomy of impacts on clinical and translational research from community stakeholder engagement. Health Expect. 2019;22(4):731-742. doi:10.1111/hex.12937	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	Number of companion materials produced and reach of their distribution	Structure/ Process	N/A	Quantitative	N/A	Stallings SC, Boyer AP, Joosten YA, et al. A taxonomy of impacts on clinical and translational research from community stakeholder engagement. Health Expect. 2019;22(4):731-742. doi:10.1111/hex.12937	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	Number of social media shares by non-scientific organizations or individuals	Structure/ Process	N/A	Quantitative	N/A	Stallings SC, Boyer AP, Joosten YA, et al. A taxonomy of impacts on clinical and translational research from community stakeholder engagement. Health Expect. 2019;22(4):731-742. doi:10.1111/hex.12937	N/A

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	Steps Where Patients Are Engaged	Activities Where Patients Are Engaged	How Patients Are Engaged	Measure	Measure Type	Perspective Assessed	Data Collection Approach	Tool	Source(s)	Link to Tool
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Dissemination	Contributor/ Collaborator/ Partner	Number of non-scientific articles which cite the original publications	Structure/ Process	N/A	Quantitative	N/A	Stallings SC, Boyer AP, Joosten YA, et al. A taxonomy of impacts on clinical and translational research from community stakeholder engagement. Health Expect. 2019;22(4):731-742. doi:10.1111/hex.12937	N/A
Clinical Decision Support Phase	Design and development of PC CDS	Framing the issue, Requirements gathering, Generative design work and prototyping, Usability testing	Contributor/ Collaborator/ Partner	Documentation of decisions influenced by patient input during agile software development	Meaningfulness	Researcher	Quantitative	N/A	van Leeuwen D, Mittelman M, Fabian L, Lomotan EA. Nothing for Me or About Me, Without Me: Codesign of Clinical Decision Support. Appl Clin Inform. 2022;13(3):641-646. doi:10.1055/s-0042-1750355	N/A
Clinical Decision Support Phase	Design and development of PC CDS	Framing the issue, Requirements gathering, Generative design work and prototyping, Usability testing	Contributor/ Collaborator/ Partner	Prioritization of features and functionality based on patient input	Meaningfulness	Researcher	Qualitative	N/A	van Leeuwen D, Mittelman M, Fabian L, Lomotan EA. Nothing for Me or About Me, Without Me: Codesign of Clinical Decision Support. Appl Clin Inform. 2022;13(3):641-646. doi:10.1055/s-0042-1750355	N/A
Clinical Decision Support Phase	Implementation of PC CDS	Participation in pilot project	Contributor/ Collaborator/ Partner	Completion of baseline assessment	Structure/ Process	N/A	Quantitative	Study-specific Patient Engagement Assessment	Wickwire EM, Collen J, Capaldi VF, et al. Patient Engagement and Provider Effectiveness of a Novel Sleep Telehealth Platform and Remote Monitoring Assessment in the US Military: Pilot Study Providing Evidence-Based Sleep Treatment Recommendations. JMIR Form Res. 2023;7:e47356. Published 2023 Nov 16. doi:10.2196/47356	N/A

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Clinical Decision Support Phase	Implementation of PC CDS	Participation in pilot project	Contributor/ Collaborator/ Partner	Completion of daily surveys	Structure/ Process	N/A	Quantitative	Study-specific Patient Engagement Assessment	Wickwire EM, Collen J, Capaldi VF, et al. Patient Engagement and Provider Effectiveness of a Novel Sleep Telehealth Platform and Remote Monitoring Assessment in the US Military: Pilot Study Providing Evidence-Based Sleep Treatment Recommendations. JMIR Form Res. 2023;7:e47356. Published 2023 Nov 16. doi:10.2196/47356	N/A
Clinical Decision Support Phase	Implementation of PC CDS	Participation in pilot project	Contributor/ Collaborator/ Partner	Perceived ease of completion of pilot	Meaningfulness	Patient	Quantitative	Study-specific Patient Engagement Assessment	Wickwire EM, Collen J, Capaldi VF, et al. Patient Engagement and Provider Effectiveness of a Novel Sleep Telehealth Platform and Remote Monitoring Assessment in the US Military: Pilot Study Providing Evidence-Based Sleep Treatment Recommendations. JMIR Form Res. 2023;7:e47356. Published 2023 Nov 16. doi:10.2196/47356	N/A
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	The extent to which there is evidence that beliefs relevant to the population of interest or to patients/community members in general are included or addressed in the research.	Meaningfulness	Patient; Researcher	Quantitative	Person Centeredness of Research Scale (PCoR)	Wilkins CH, Villalta-Gil V, Houston MM, et al. Development and validation of the Person-Centeredness of Research Scale. J Comp Eff Res. 2018;7(12):1153-1159. doi:10.2217/cer-2018-0046	https://ccphealth.org/wp-content/uploads/2021/02/Person-Centeredness-of-Research-Scale-Wilkins-et-al-Final-2018.pdf

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PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	The extent to which there is evidence that attitudes relevant to the population of interest or to patients/community members in general are included or addressed in the research.	Meaningfulness	Patient; Researcher	Quantitative	Person Centeredness of Research Scale (PCoR)	Wilkins CH, Villalta-Gil V, Houston MM, et al. Development and validation of the Person-Centeredness of Research Scale. J Comp Eff Res. 2018;7(12):1153-1159. doi:10.2217/cer-2018-0046	https://ccphealth.org/wp-content/uploads/2021/02/Person-Centeredness-of-Research-Scale-Wilkins-et-al-Final-2018.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	The extent to which there is evidence that concerns relevant to the population of interest or to patients/community members in general are included or addressed in the research.	Meaningfulness	Patient; Researcher	Quantitative	Person Centeredness of Research Scale (PCoR)	Wilkins CH, Villalta-Gil V, Houston MM, et al. Development and validation of the Person-Centeredness of Research Scale. J Comp Eff Res. 2018;7(12):1153-1159. doi:10.2217/cer-2018-0046	https://ccphealth.org/wp-content/uploads/2021/02/Person-Centeredness-of-Research-Scale-Wilkins-et-al-Final-2018.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	The extent to which person/community-centered goals and/or outcomes are included or addressed in the research	Meaningfulness	Patient; Researcher	Quantitative	Person Centeredness of Research Scale (PCoR)	Wilkins CH, Villalta-Gil V, Houston MM, et al. Development and validation of the Person-Centeredness of Research Scale. J Comp Eff Res. 2018;7(12):1153-1159. doi:10.2217/cer-2018-0046	https://ccphealth.org/wp-content/uploads/2021/02/Person-Centeredness-of-Research-Scale-Wilkins-et-al-Final-2018.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	The extent to which research priorities of interest to the patient/community are included or addressed in the research.	Meaningfulness	Patient; Researcher	Quantitative	Person Centeredness of Research Scale (PCoR)	Wilkins CH, Villalta-Gil V, Houston MM, et al. Development and validation of the Person-Centeredness of Research Scale. J Comp Eff Res. 2018;7(12):1153-1159. doi:10.2217/cer-2018-0046	https://ccphealth.org/wp-content/uploads/2021/02/Person-Centeredness-of-Research-Scale-Wilkins-et-al-Final-2018.pdf
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	The extent to which the needs of the patient/community are included or addressed in the research.	Meaningfulness	Patient; Researcher	Quantitative	Person Centeredness of Research Scale (PCoR)	Wilkins CH, Villalta-Gil V, Houston MM, et al. Development and validation of the Person-Centeredness of Research Scale. J Comp Eff Res. 2018;7(12):1153-1159. doi:10.2217/cer-2018-0046	https://ccphealth.org/wp-content/uploads/2021/02/Person-Centeredness-of-Research-Scale-Wilkins-et-al-Final-2018.pdf

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PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Knowledge Generation Phase	Conduct of Patient-Centered Outcomes Research (PCOR)	Research question development, Study design, Recruitment, Data collection, Data interpretation, Dissemination	Contributor/ Collaborator/ Partner	The extent to which individuals representing patients and/or communities are engaged in the research as stakeholders, advisors, consultants or team members (beyond serving as research participants or volunteers).	Structure/ Process	Patient; Researcher	Quantitative	Person Centeredness of Research Scale (PCoR)	Wilkins CH, Villalta-Gil V, Houston MM, et al. Development and validation of the Person-Centeredness of Research Scale. J Comp Eff Res. 2018;7(12):1153-1159. doi:10.2217/cer-2018-0046	https://ccphealth.org/wp-content/uploads/2021/02/Person-Centeredness-of-Research-Scale-Wilkins-et-al-Final-2018.pdf
Healthcare Delivery Phase	Team Talk	Establishment of roles	User	Patient's perception of whether they are responsible for managing their own health	Structure/ Process	Patient	Quantitative	Patient Activation Measure (PAM)	Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. Health Serv Res. 2004;39(4 Pt 1):1005-1026. doi:10.1111/j.1475-6773.2004.00269.x	https://www.ncbi.nlm.nih.gov/core/lw/2.0/html/tileshop_pmc/tileshop_pmc_inline.html?title=Click%20on%20image%20to%20zoom&p=PMC3&id=1361049_hesr_269_f2.jpg
Healthcare Delivery Phase	Team Talk	Establishment of roles	User	Patient's level of importance in taking an active role in their healthcare	Structure/ Process	Patient	Quantitative	Patient Activation Measure (PAM)	Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. Health Serv Res. 2004;39(4 Pt 1):1005-1026. doi:10.1111/j.1475-6773.2004.00269.x	https://www.ncbi.nlm.nih.gov/core/lw/2.0/html/tileshop_pmc/tileshop_pmc_inline.html?title=Click%20on%20image%20to%20zoom&p=PMC3&id=1361049_hesr_269_f2.jpg
Healthcare Delivery Phase	Team Talk	Establishment of roles	User	Patient's level of confidence that they can share concerns with their healthcare provider	Meaningfulness	Patient	Quantitative	Patient Activation Measure (PAM)	Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. Health Serv Res. 2004;39(4 Pt 1):1005-1026. doi:10.1111/j.1475-6773.2004.00269.x	https://www.ncbi.nlm.nih.gov/core/lw/2.0/html/tileshop_pmc/tileshop_pmc_inline.html?title=Click%20on%20image%20to%20zoom&p=PMC3&id=1361049_hesr_269_f2.jpg

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Patient's perception of whether the clinician made them aware of the diferent treatments available	Meaningfulness	Patient	Quantitative	COMRADE Scale	Edwards A, Elwyn G, Hood K, et al. The development of COMRADE—a patient-based outcome measure to evaluate the effectiveness of risk communication and treatment decision making in consultations. Patient Educ Couns. 2003;50(3):311-322.	https://www.sciencedirect.com/science/article/pii/S0738399103000557#TBL6
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Patient's perception of whether the clinician gave them a chance to express their opinions about different treatments available	Meaningfulness	Patient	Quantitative	COMRADE Scale	Edwards A, Elwyn G, Hood K, et al. The development of COMRADE—a patient-based outcome measure to evaluate the effectiveness of risk communication and treatment decision making in consultations. Patient Educ Couns. 2003;50(3):311-322.	https://www.sciencedirect.com/science/article/pii/S0738399103000557#TBL7
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Patient's perceptions of whether the clinician gave them the chance to ask for as much information as they needed about the different treatment choices	Meaningfulness	Patient	Quantitative	COMRADE Scale	Edwards A, Elwyn G, Hood K, et al. The development of COMRADE—a patient-based outcome measure to evaluate the effectiveness of risk communication and treatment decision making in consultations. Patient Educ Couns. 2003;50(3):311-322.	https://www.sciencedirect.com/science/article/pii/S0738399103000557#TBL9
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Patient's perceptions of whether the clinician gave them enough information about treatment choices available	Meaningfulness	Patient	Quantitative	COMRADE Scale	Edwards A, Elwyn G, Hood K, et al. The development of COMRADE—a patient-based outcome measure to evaluate the effectiveness of risk communication and treatment decision making in consultations. Patient Educ Couns. 2003;50(3):311-322.	https://www.sciencedirect.com/science/article/pii/S0738399103000557#TBL10
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Patient's perceptions of whether the clinician provided enough explanation of information about treatment choices	Meaningfulness	Patient	Quantitative	COMRADE Scale	Edwards A, Elwyn G, Hood K, et al. The development of COMRADE—a patient-based outcome measure to evaluate the effectiveness of risk communication and treatment decision making in consultations. Patient Educ Couns. 2003;50(3):311-322.	https://www.sciencedirect.com/science/article/pii/S0738399103000557#TBL11

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Patient's perception of whether the information the clinician gave was easy to understand	Meaningfulness	Patient	Quantitative	COMRADE Scale	Edwards A, Elwyn G, Hood K, et al. The development of COMRADE—a patient-based outcome measure to evaluate the effectiveness of risk communication and treatment decision making in consultations. Patient Educ Couns. 2003;50(3):311-322.	https://www.sciencedirect.com/science/article/pii/S0738399103000557#TBL12
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the clinician gave the patient a chance to decide which treatment they perceived was best for them	Meaningfulness	Patient	Quantitative	COMRADE Scale	Edwards A, Elwyn G, Hood K, et al. The development of COMRADE—a patient-based outcome measure to evaluate the effectiveness of risk communication and treatment decision making in consultations. Patient Educ Couns. 2003;50(3):311-322.	https://www.sciencedirect.com/science/article/pii/S0738399103000557#TBL13
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the clinician gave the patient a chance to be involved in decisions during the consultation	Meaningfulness	Patient	Quantitative	COMRADE Scale	Edwards A, Elwyn G, Hood K, et al. The development of COMRADE—a patient-based outcome measure to evaluate the effectiveness of risk communication and treatment decision making in consultations. Patient Educ Couns. 2003;50(3):311-322.	https://www.sciencedirect.com/science/article/pii/S0738399103000557#TBL14
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Patient's satisfaction with the information the clinician gave them	Meaningfulness	Patient	Quantitative	COMRADE Scale	Edwards A, Elwyn G, Hood K, et al. The development of COMRADE—a patient-based outcome measure to evaluate the effectiveness of risk communication and treatment decision making in consultations. Patient Educ Couns. 2003;50(3):311-322.	https://www.sciencedirect.com/science/article/pii/S0738399103000557#TBL15
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the patient agreed with the clinician about which treatment was best for them	Meaningfulness	Patient	Quantitative	COMRADE Scale	Edwards A, Elwyn G, Hood K, et al. The development of COMRADE—a patient-based outcome measure to evaluate the effectiveness of risk communication and treatment decision making in consultations. Patient Educ Couns. 2003;50(3):311-322.	https://www.sciencedirect.com/science/article/pii/S0738399103000557#TBL16

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Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the patient feels that they can easily discuss the condition with their clinician	Meaningfulness	Patient	Quantitative	COMRADE Scale	Edwards A, Elwyn G, Hood K, et al. The development of COMRADE—a patient-based outcome measure to evaluate the effectiveness of risk communication and treatment decision making in consultations. Patient Educ Couns. 2003;50(3):311-322.	https://www.sciencedirect.com/science/article/pii/S0738399103000557#TBL17
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Patient's level of satisfaction with the way in which the decision was made in the consultation	Meaningfulness	Patient	Quantitative	COMRADE Scale	Edwards A, Elwyn G, Hood K, et al. The development of COMRADE—a patient-based outcome measure to evaluate the effectiveness of risk communication and treatment decision making in consultations. Patient Educ Couns. 2003;50(3):311-322.	https://www.sciencedirect.com/science/article/pii/S0738399103000557#TBL18
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the patient felt that the decision made was right for them personally	Meaningfulness	Patient	Quantitative	COMRADE Scale	Edwards A, Elwyn G, Hood K, et al. The development of COMRADE—a patient-based outcome measure to evaluate the effectiveness of risk communication and treatment decision making in consultations. Patient Educ Couns. 2003;50(3):311-322.	https://www.sciencedirect.com/science/article/pii/S0738399103000557#TBL19
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Patient's level of satisfaction that they were adequately informed about the issues important to the decision	Meaningfulness	Patient	Quantitative	COMRADE Scale	Edwards A, Elwyn G, Hood K, et al. The development of COMRADE—a patient-based outcome measure to evaluate the effectiveness of risk communication and treatment decision making in consultations. Patient Educ Couns. 2003;50(3):311-322.	https://www.sciencedirect.com/science/article/pii/S0738399103000557#TBL20
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the patient felt that it was clear which treatment choice is best for them	Meaningfulness	Patient	Quantitative	COMRADE Scale	Edwards A, Elwyn G, Hood K, et al. The development of COMRADE—a patient-based outcome measure to evaluate the effectiveness of risk communication and treatment decision making in consultations. Patient Educ Couns. 2003;50(3):311-322.	https://www.sciencedirect.com/science/article/pii/S0738399103000557#TBL21

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Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the patient is aware of the treatment choices they have	Meaningfulness	Patient	Quantitative	COMRADE Scale	Edwards A, Elwyn G, Hood K, et al. The development of COMRADE—a patient-based outcome measure to evaluate the effectiveness of risk communication and treatment decision making in consultations. Patient Educ Couns. 2003;50(3):311-322.	https://www.sciencedirect.com/science/article/pii/S0738399103000557#TBL22
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the patient feels an informed choice has been made	Meaningfulness	Patient	Quantitative	COMRADE Scale	Edwards A, Elwyn G, Hood K, et al. The development of COMRADE—a patient-based outcome measure to evaluate the effectiveness of risk communication and treatment decision making in consultations. Patient Educ Couns. 2003;50(3):311-322.	https://www.sciencedirect.com/science/article/pii/S0738399103000557#TBL23
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the decision reflects what is most important to the patient	Meaningfulness	Patient	Quantitative	COMRADE Scale	Edwards A, Elwyn G, Hood K, et al. The development of COMRADE—a patient-based outcome measure to evaluate the effectiveness of risk communication and treatment decision making in consultations. Patient Educ Couns. 2003;50(3):311-322.	https://www.sciencedirect.com/science/article/pii/S0738399103000557#TBL24
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the clinician identifies a problem needing a decision making process	Meaningfulness	Patient	Quantitative	OPTION Scale	Elwyn G, Edwards A, Wensing M, Hood K, Atwell C, Grol R. Shared decision making: developing the OPTION scale for measuring patient involvement. Qual Saf Health Care. 2003;12(2):93-99.	https://pmc.ncbi.nlm.nih.gov/articles/instance/1743691/pdf/v012p00093.pdf
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the clinician states that there is more than one way to deal with an identified problem	Meaningfulness	Patient	Quantitative	OPTION Scale	Elwyn G, Edwards A, Wensing M, Hood K, Atwell C, Grol R. Shared decision making: developing the OPTION scale for measuring patient involvement. Qual Saf Health Care. 2003;12(2):93-99.	https://pmc.ncbi.nlm.nih.gov/articles/instance/1743691/pdf/v012p00093.pdf

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Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the clinician lists "options" including the choice of "no action" if feasible	Meaningfulness	Patient	Quantitative	OPTION Scale	Elwyn G, Edwards A, Wensing M, Hood K, Atwell C, Grol R. Shared decision making: developing the OPTION scale for measuring patient involvement. Qual Saf Health Care. 2003;12(2):93-99.	https://pmc.ncbi.nlm.nih.gov/articles/instance/1743691/pdf/v012p00093.pdf
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the clinician explains the pros and cons of options to the patient	Meaningfulness	Patient	Quantitative	OPTION Scale	Elwyn G, Edwards A, Wensing M, Hood K, Atwell C, Grol R. Shared decision making: developing the OPTION scale for measuring patient involvement. Qual Saf Health Care. 2003;12(2):93-99.	https://pmc.ncbi.nlm.nih.gov/articles/instance/1743691/pdf/v012p00093.pdf
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the clinician checks the patient's preferred information format	Meaningfulness	Patient	Quantitative	OPTION Scale	Elwyn G, Edwards A, Wensing M, Hood K, Atwell C, Grol R. Shared decision making: developing the OPTION scale for measuring patient involvement. Qual Saf Health Care. 2003;12(2):93-99.	https://pmc.ncbi.nlm.nih.gov/articles/instance/1743691/pdf/v012p00093.pdf
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the clinician explores the patient's expectations about how the problems are to be managed	Meaningfulness	Patient	Quantitative	OPTION Scale	Elwyn G, Edwards A, Wensing M, Hood K, Atwell C, Grol R. Shared decision making: developing the OPTION scale for measuring patient involvement. Qual Saf Health Care. 2003;12(2):93-99.	https://pmc.ncbi.nlm.nih.gov/articles/instance/1743691/pdf/v012p00093.pdf
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the clinician explores the patient's concerns about how problems are to be managed	Meaningfulness	Patient	Quantitative	OPTION Scale	Elwyn G, Edwards A, Wensing M, Hood K, Atwell C, Grol R. Shared decision making: developing the OPTION scale for measuring patient involvement. Qual Saf Health Care. 2003;12(2):93-99.	https://pmc.ncbi.nlm.nih.gov/articles/instance/1743691/pdf/v012p00093.pdf

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Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the clinician checks that the patient has understood the information	Meaningfulness	Patient	Quantitative	OPTION Scale	Elwyn G, Edwards A, Wensing M, Hood K, Atwell C, Grol R. Shared decision making: developing the OPTION scale for measuring patient involvement. Qual Saf Health Care. 2003;12(2):93-99.	https://pmc.ncbi.nlm.nih.gov/articles/instance/1743691/pdf/v012p00093.pdf
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the clinician provides opportunities for the patient to ask questions	Meaningfulness	Patient	Quantitative	OPTION Scale	Elwyn G, Edwards A, Wensing M, Hood K, Atwell C, Grol R. Shared decision making: developing the OPTION scale for measuring patient involvement. Qual Saf Health Care. 2003;12(2):93-99.	https://pmc.ncbi.nlm.nih.gov/articles/instance/1743691/pdf/v012p00093.pdf
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the clinician asks for the patient's preferred level of involvement in decision making	Meaningfulness	Patient	Quantitative	OPTION Scale	Elwyn G, Edwards A, Wensing M, Hood K, Atwell C, Grol R. Shared decision making: developing the OPTION scale for measuring patient involvement. Qual Saf Health Care. 2003;12(2):93-99.	https://pmc.ncbi.nlm.nih.gov/articles/instance/1743691/pdf/v012p00093.pdf
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether an opportunity for deferring a decision is provided	Meaningfulness	Patient	Quantitative	OPTION Scale	Elwyn G, Edwards A, Wensing M, Hood K, Atwell C, Grol R. Shared decision making: developing the OPTION scale for measuring patient involvement. Qual Saf Health Care. 2003;12(2):93-99.	https://pmc.ncbi.nlm.nih.gov/articles/instance/1743691/pdf/v012p00093.pdf
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether arrangements are made to review the decision	Meaningfulness	Patient	Quantitative	OPTION Scale	Elwyn G, Edwards A, Wensing M, Hood K, Atwell C, Grol R. Shared decision making: developing the OPTION scale for measuring patient involvement. Qual Saf Health Care. 2003;12(2):93-99.	https://pmc.ncbi.nlm.nih.gov/articles/instance/1743691/pdf/v012p00093.pdf

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Healthcare Delivery Phase	Team Talk	Discussion of patient values, preferences, and/or goals	User	Whether the clinician and/or patient should determine what the likely causes of their symptoms	Structure/ Process	Patient	Quantitative	Problem-Solving Decision-Making Scale	Gregório M, Teixeira A, Páscoa R, Baptista S, Carvalho R, Martins C. The Problem-Solving Decision-Making scale-translation and validation for the Portuguese language: a cross-sectional study. BMJ Open. 2020;10(6):e033625. Published 2020 Jun 28. doi:10.1136/bmjopen-2019-033625	https://pmc.ncbi.nlm.nih.gov/articles/PMC7322329/
Healthcare Delivery Phase	Team Talk	Discussion of patient values, preferences, and/or goals	User	Whether the clinician and/or patient should determine what the treatment options are	Structure/ Process	Patient	Quantitative	Problem-Solving Decision-Making Scale	Gregório M, Teixeira A, Páscoa R, Baptista S, Carvalho R, Martins C. The Problem-Solving Decision-Making scale-translation and validation for the Portuguese language: a cross-sectional study. BMJ Open. 2020;10(6):e033625. Published 2020 Jun 28. doi:10.1136/bmjopen-2019-033625	https://pmc.ncbi.nlm.nih.gov/articles/PMC7322329/
Healthcare Delivery Phase	Team Talk	Discussion of patient values, preferences, and/or goals	User	Whether the clinician and/or patient should determine what the risks and benefits for each treatment option are	Structure/ Process	Patient	Quantitative	Problem-Solving Decision-Making Scale	Gregório M, Teixeira A, Páscoa R, Baptista S, Carvalho R, Martins C. The Problem-Solving Decision-Making scale-translation and validation for the Portuguese language: a cross-sectional study. BMJ Open. 2020;10(6):e033625. Published 2020 Jun 28. doi:10.1136/bmjopen-2019-033625	https://pmc.ncbi.nlm.nih.gov/articles/PMC7322329/
Healthcare Delivery Phase	Team Talk	Discussion of patient values, preferences, and/or goals	User	Whether the clinician and/or the patient should determine how likely risks and benefits are to happen	Structure/ Process	Patient	Quantitative	Problem-Solving Decision-Making Scale	Gregório M, Teixeira A, Páscoa R, Baptista S, Carvalho R, Martins C. The Problem-Solving Decision-Making scale-translation and validation for the Portuguese language: a cross-sectional study. BMJ Open. 2020;10(6):e033625. Published 2020 Jun 28. doi:10.1136/bmjopen-2019-033625	https://pmc.ncbi.nlm.nih.gov/articles/PMC7322329/

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Healthcare Delivery Phase	Team Talk	Discussion of patient values, preferences, and/or goals	User	Whether the clinician and/or patient should decide how acceptable of risks and benefits of treatments are	Structure/ Process	Patient	Quantitative	Problem-Solving Decision-Making Scale	Gregório M, Teixeira A, Páscoa R, Baptista S, Carvalho R, Martins C. The Problem-Solving Decision-Making scale-translation and validation for the Portuguese language: a cross-sectional study. BMJ Open. 2020;10(6):e033625. Published 2020 Jun 28. doi:10.1136/bmjopen-2019-033625	https://pmc.ncbi.nlm.nih.gov/articles/PMC7322329/
Healthcare Delivery Phase	Team Talk	Discussion of patient values, preferences, and/or goals	User	Whether the clinician and/or patient should decide what treatment option should be selected	Structure/ Process	Patient	Quantitative	Problem-Solving Decision-Making Scale	Gregório M, Teixeira A, Páscoa R, Baptista S, Carvalho R, Martins C. The Problem-Solving Decision-Making scale-translation and validation for the Portuguese language: a cross-sectional study. BMJ Open. 2020;10(6):e033625. Published 2020 Jun 28. doi:10.1136/bmjopen-2019-033625	https://pmc.ncbi.nlm.nih.gov/articles/PMC7322329/
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the clinician made clear that a decision needs to be made	Meaningfulness	Patient	Quantitative	The 9-item Shared Decision Making Questionnaire (SDM-Q-9)	Kriston L, Scholl I, Hölzel L, Simon D, Loh A, Härter M. The 9-item Shared Decision Making Questionnaire (SDM-Q-9). Development and psychometric properties in a primary care sample. Patient Educ Couns. 2010;80(1):94-99. doi:10.1016/j.pec.2009.09.034	https://www.patient-als-partner.de/media/sdm-q-9_english_version.pdf
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Patient's perception of whether the clinician wanted to know exactly how the patient wanted to be involved in making a healthcare decision	Meaningfulness	Patient	Quantitative	The 9-item Shared Decision Making Questionnaire (SDM-Q-9)	Kriston L, Scholl I, Hölzel L, Simon D, Loh A, Härter M. The 9-item Shared Decision Making Questionnaire (SDM-Q-9). Development and psychometric properties in a primary care sample. Patient Educ Couns. 2010;80(1):94-99. doi:10.1016/j.pec.2009.09.034	https://www.patient-als-partner.de/media/sdm-q-9_english_version.pdf

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PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the clinician told the patient that there are different options for treating their medical condition	Meaningfulness	Patient	Quantitative	The 9-item Shared Decision Making Questionnaire (SDM-Q-9)	Kriston L, Scholl I, Hölzel L, Simon D, Loh A, Härter M. The 9-item Shared Decision Making Questionnaire (SDM-Q-9). Development and psychometric properties in a primary care sample. Patient Educ Couns. 2010;80(1):94-99. doi:10.1016/j.pec.2009.09.034	https://www.patient-als-partner.de/media/sdm-q-9_english_version.pdf
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the doctor helped the patient understand all the information about their treatment option	Meaningfulness	Patient	Quantitative	The 9-item Shared Decision Making Questionnaire (SDM-Q-9)	Kriston L, Scholl I, Hölzel L, Simon D, Loh A, Härter M. The 9-item Shared Decision Making Questionnaire (SDM-Q-9). Development and psychometric properties in a primary care sample. Patient Educ Couns. 2010;80(1):94-99. doi:10.1016/j.pec.2009.09.034	https://www.patient-als-partner.de/media/sdm-q-9_english_version.pdf
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the clinician asked the patient which treatment option they prefer	Meaningfulness	Patient	Quantitative	The 9-item Shared Decision Making Questionnaire (SDM-Q-9)	Kriston L, Scholl I, Hölzel L, Simon D, Loh A, Härter M. The 9-item Shared Decision Making Questionnaire (SDM-Q-9). Development and psychometric properties in a primary care sample. Patient Educ Couns. 2010;80(1):94-99. doi:10.1016/j.pec.2009.09.034	https://www.patient-als-partner.de/media/sdm-q-9_english_version.pdf
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the patient felt that the clinician and them thoroughly weighed different treatment options	Meaningfulness	Patient	Quantitative	The 9-item Shared Decision Making Questionnaire (SDM-Q-9)	Kriston L, Scholl I, Hölzel L, Simon D, Loh A, Härter M. The 9-item Shared Decision Making Questionnaire (SDM-Q-9). Development and psychometric properties in a primary care sample. Patient Educ Couns. 2010;80(1):94-99. doi:10.1016/j.pec.2009.09.034	https://www.patient-als-partner.de/media/sdm-q-9_english_version.pdf

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PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the clinician and patient selected a treatment option together	Meaningfulness	Patient	Quantitative	The 9-item Shared Decision Making Questionnaire (SDM-Q-9)	Kriston L, Scholl I, Hölzel L, Simon D, Loh A, Härter M. The 9-item Shared Decision Making Questionnaire (SDM-Q-9). Development and psychometric properties in a primary care sample. Patient Educ Couns. 2010;80(1):94-99. doi:10.1016/j.pec.2009.09.034	https://www.patient-als-partner.de/media/sdm-q-9_english_version.pdf
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the clinician and patient reached an agreement on how to proceed with their healthcare decision	Meaningfulness	Patient	Quantitative	The 9-item Shared Decision Making Questionnaire (SDM-Q-9)	Kriston L, Scholl I, Hölzel L, Simon D, Loh A, Härter M. The 9-item Shared Decision Making Questionnaire (SDM-Q-9). Development and psychometric properties in a primary care sample. Patient Educ Couns. 2010;80(1):94-99. doi:10.1016/j.pec.2009.09.034	https://www.patient-als-partner.de/media/sdm-q-9_english_version.pdf
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the clinician explained choices to treat the patient's condition	Meaningfulness	Patient	Quantitative	Shared Decision Making Process Scale	Valentine KD, Vo H, Fowler FJ, Brodney S, Barry MJ, Sepucha KR. Development and Evaluation of the Shared Decision Making Process Scale: A Short Patient-Reported Measure. Medical Decision Making. 2021;41(2):108-119. doi:10.1177/0272989X20977878	https://journals.sagepub.com/doi/10.1177/0272989X20977878#supplementary-materials
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the clinician talked about alternate interventions as an option for patients	Meaningfulness	Patient	Quantitative	Shared Decision Making Process Scale	Valentine KD, Vo H, Fowler FJ, Brodney S, Barry MJ, Sepucha KR. Development and Evaluation of the Shared Decision Making Process Scale: A Short Patient-Reported Measure. Medical Decision Making. 2021;41(2):108-119. doi:10.1177/0272989X20977878	https://journals.sagepub.com/doi/10.1177/0272989X20977878#supplementary-materials

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PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the clinician and patient talked about the reasons the patient wants to have an intervention	Meaningfulness	Patient	Quantitative	Shared Decision Making Process Scale	Valentine KD, Vo H, Fowler FJ, Brodney S, Barry MJ, Sepucha KR. Development and Evaluation of the Shared Decision Making Process Scale: A Short Patient-Reported Measure. Medical Decision Making. 2021;41(2):108-119. doi:10.1177/0272989X20977878	https://journals.sagepub.com/doi/10.1177/0272989X20977878#supplementary-materials
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the clinician and patient talked about the reasons the patient does not want to have an intervention	Meaningfulness	Patient	Quantitative	Shared Decision Making Process Scale	Valentine KD, Vo H, Fowler FJ, Brodney S, Barry MJ, Sepucha KR. Development and Evaluation of the Shared Decision Making Process Scale: A Short Patient-Reported Measure. Medical Decision Making. 2021;41(2):108-119. doi:10.1177/0272989X20977878	https://journals.sagepub.com/doi/10.1177/0272989X20977878#supplementary-materials
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the health care provider asked the patient whether or not they wanted to have an intervention	Meaningfulness	Patient	Quantitative	Shared Decision Making Process Scale	Valentine KD, Vo H, Fowler FJ, Brodney S, Barry MJ, Sepucha KR. Development and Evaluation of the Shared Decision Making Process Scale: A Short Patient-Reported Measure. Medical Decision Making. 2021;41(2):108-119. doi:10.1177/0272989X20977878	https://journals.sagepub.com/doi/10.1177/0272989X20977878#supplementary-materials
Healthcare Delivery Phase	Decision Talk	Shared decision-making	User	Patient's perception of how much effort the clinician made to help the patient understand their health issues	Meaningfulness	Patient	Quantitative	CollaboRATE Measure	Elwyn G, Barr PJ, Grande SW, Thompson R, Walsh T, Ozanne EM. Developing CollaboRATE: a fast and frugal patient-reported measure of shared decision making in clinical encounters. Patient Educ Couns. 2013;93(1):102-107. doi:10.1016/j.pec.2013.05.009	https://www.glynelwyn.com/uploads/2/4/0/4/24040341/collaborate_for_patients_5_anchor_point_scale.pdf

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	Steps Where Patients Are Engaged	Activities Where Patients Are Engaged	How Patients Are Engaged	Measure	Measure Type	Perspective Assessed	Data Collection Approach	Tool	Source(s)	Link to Tool
Healthcare Delivery Phase	Decision Talk	Shared decision-making	User	Patient's perception of how much effort the clinician made to listen to what matters most to the patient	Meaningfulness	Patient	Quantitative	CollaboRATE Measure	Elwyn G, Barr PJ, Grande SW, Thompson R, Walsh T, Ozanne EM. Developing CollaboRATE: a fast and frugal patient-reported measure of shared decision making in clinical encounters. Patient Educ Couns. 2013;93(1):102-107. doi:10.1016/j.pec.2013.05.009	https://www.glynelwyn.com/uploads/2/4/0/4/24040341/collaborate_for_patients_5_anchor_point_scale.pdf
Healthcare Delivery Phase	Decision Talk	Shared decision-making	User	Patient's perception of how much effort the clinician made to include what matters most to the patient in choosing what to do next	Meaningfulness	Patient	Quantitative	CollaboRATE Measure	Elwyn G, Barr PJ, Grande SW, Thompson R, Walsh T, Ozanne EM. Developing CollaboRATE: a fast and frugal patient-reported measure of shared decision making in clinical encounters. Patient Educ Couns. 2013;93(1):102-107. doi:10.1016/j.pec.2013.05.009	https://www.glynelwyn.com/uploads/2/4/0/4/24040341/collaborate_for_patients_5_anchor_point_scale.pdf
Healthcare Delivery Phase	Decision Talk	Patient-clinician communication	User	How often the clinician gives the patient all the information that they need to make the decisions that are right for them	Meaningfulness	Patient	Quantitative	The Facilitation of Patient Involvement Scale (FPIS)	Martin LR, DiMatteo MR, Lepper HS. Facilitation of patient involvement in care: development and validation of a scale. Behav Med. 2001;27(3):111-120. doi:10.1080/08964280109595777	https://www.tandfonline.com/doi/10.1080/08964280109595777?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%200pubmed
Healthcare Delivery Phase	Decision Talk	Patient-clinician communication	User	How often the clinician ignores the patient's opinion about treatment options	Meaningfulness	Patient	Quantitative	The Facilitation of Patient Involvement Scale (FPIS)	Martin LR, DiMatteo MR, Lepper HS. Facilitation of patient involvement in care: development and validation of a scale. Behav Med. 2001;27(3):111-120. doi:10.1080/08964280109595777	https://www.tandfonline.com/doi/10.1080/08964280109595777?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%200pubmed

Areas of Patient Engagement Measures					Measure Specifications				Additional Information	
PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Healthcare Delivery Phase	Decision Talk	Patient-clinician communication	User	How often the clinician asks the patient if they have any questions about newly prescribed medications and possible side effects	Meaningfulness	Patient	Quantitative	The Facilitation of Patient Involvement Scale (FPIS)	Martin LR, DiMatteo MR, Lepper HS. Facilitation of patient involvement in care: development and validation of a scale. Behav Med. 2001;27(3):111-120. doi:10.1080/08964280109595777	https://www.tandfonline.com/doi/10.1080/08964280109595777?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%200pubmed
Healthcare Delivery Phase	Decision Talk	Patient-clinician communication	User	How often the clinician discourages the patient's questions	Meaningfulness	Patient	Quantitative	The Facilitation of Patient Involvement Scale (FPIS)	Martin LR, DiMatteo MR, Lepper HS. Facilitation of patient involvement in care: development and validation of a scale. Behav Med. 2001;27(3):111-120. doi:10.1080/08964280109595777	https://www.tandfonline.com/doi/10.1080/08964280109595777?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%200pubmed
Healthcare Delivery Phase	Decision Talk	Patient-clinician communication	User	How often the clinician explains all treatment options to the patient so that they can make an informed choice	Meaningfulness	Patient	Quantitative	The Facilitation of Patient Involvement Scale (FPIS)	Martin LR, DiMatteo MR, Lepper HS. Facilitation of patient involvement in care: development and validation of a scale. Behav Med. 2001;27(3):111-120. doi:10.1080/08964280109595777	https://www.tandfonline.com/doi/10.1080/08964280109595777?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%200pubmed
Healthcare Delivery Phase	Decision Talk	Patient-clinician communication	User	How often the clinician strongly encourages the patient to express all of their concerns about the prescribed treatment	Meaningfulness	Patient	Quantitative	The Facilitation of Patient Involvement Scale (FPIS)	Martin LR, DiMatteo MR, Lepper HS. Facilitation of patient involvement in care: development and validation of a scale. Behav Med. 2001;27(3):111-120. doi:10.1080/08964280109595777	https://www.tandfonline.com/doi/10.1080/08964280109595777?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%200pubmed
Healthcare Delivery Phase	Decision Talk	Patient-clinician communication	User	How often the clinician discourages the patient from expressing their personal opinion about their medical condition	Meaningfulness	Patient	Quantitative	The Facilitation of Patient Involvement Scale (FPIS)	Martin LR, DiMatteo MR, Lepper HS. Facilitation of patient involvement in care: development and validation of a scale. Behav Med. 2001;27(3):111-120. doi:10.1080/08964280109595777	https://www.tandfonline.com/doi/10.1080/08964280109595777?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%200pubmed

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PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Healthcare Delivery Phase	Decision Talk	Patient-clinician communication	User	How often the clinician's office staff makes it difficult for the patient to be involved in their own medical care	Meaningfulness	Patient	Quantitative	The Facilitation of Patient Involvement Scale (FPIS)	Martin LR, DiMatteo MR, Lepper HS. Facilitation of patient involvement in care: development and validation of a scale. Behav Med. 2001;27(3):111-120. doi:10.1080/08964280109595777	https://www.tandfonline.com/doi/10.1080/08964280109595777?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%200pubmed
Healthcare Delivery Phase	Decision Talk	Patient-clinician communication	User	How often the clinician makes it difficult for the patient to communicate their concerns about treatment decisions	Meaningfulness	Patient	Quantitative	The Facilitation of Patient Involvement Scale (FPIS)	Martin LR, DiMatteo MR, Lepper HS. Facilitation of patient involvement in care: development and validation of a scale. Behav Med. 2001;27(3):111-120. doi:10.1080/08964280109595777	https://www.tandfonline.com/doi/10.1080/08964280109595777?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%200pubmed
Healthcare Delivery Phase	Decision Talk	Shared decision-making	User	Patient perception of whether their clinician provided them choices and options	Meaningfulness	Patient	Quantitative	Health Care Climate Questionnaire (HCCQ)	Williams, G. C., Grow, V. M., Freedman, Z. R., Ryan, R. M., & Deci, E. L. (1996). Health Care Climate Questionnaire (HCCQ) [Database record]. APA PsycTests. https://doi.org/10.1037/t68628-000	https://scales.arabpsychology.com/s/the-health-care-climate-questionnaire-hccq/
Healthcare Delivery Phase	Decision Talk	Shared decision-making	User	Patient perception of whether they feel understood by their clinician	Meaningfulness	Patient	Quantitative	Health Care Climate Questionnaire (HCCQ)	Williams, G. C., Grow, V. M., Freedman, Z. R., Ryan, R. M., & Deci, E. L. (1996). Health Care Climate Questionnaire (HCCQ) [Database record]. APA PsycTests. https://doi.org/10.1037/t68628-000	https://scales.arabpsychology.com/s/the-health-care-climate-questionnaire-hccq/
Healthcare Delivery Phase	Decision Talk	Shared decision-making	User	Patient perception of whether they are open with their clinician at their meetings	Meaningfulness	Patient	Quantitative	Health Care Climate Questionnaire (HCCQ)	Williams, G. C., Grow, V. M., Freedman, Z. R., Ryan, R. M., & Deci, E. L. (1996). Health Care Climate Questionnaire (HCCQ) [Database record]. APA PsycTests. https://doi.org/10.1037/t68628-000	https://scales.arabpsychology.com/s/the-health-care-climate-questionnaire-hccq/

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Healthcare Delivery Phase	Decision Talk	Shared decision-making	User	Patient perception of their clinician conveys confidence in their ability to make change	Meaningfulness	Patient	Quantitative	Health Care Climate Questionnaire (HCCQ)	Williams, G. C., Grow, V. M., Freedman, Z. R., Ryan, R. M., & Deci, E. L. (1996). Health Care Climate Questionnaire (HCCQ) [Database record]. APA PsycTests. https://doi.org/10.1037/t68628-000	https://scales.arabpsychology.com/s/the-health-care-climate-questionnaire-hccq/
Healthcare Delivery Phase	Decision Talk	Shared decision-making	User	Patient's perception of whether their clinician accepts them	Meaningfulness	Patient	Quantitative	Health Care Climate Questionnaire (HCCQ)	Williams, G. C., Grow, V. M., Freedman, Z. R., Ryan, R. M., & Deci, E. L. (1996). Health Care Climate Questionnaire (HCCQ) [Database record]. APA PsycTests. https://doi.org/10.1037/t68628-000	https://scales.arabpsychology.com/s/the-health-care-climate-questionnaire-hccq/
Healthcare Delivery Phase	Decision Talk	Shared decision-making	User	Patient's perception of whether their clinician has made sure they really understand their condition and how to manage it	Meaningfulness	Patient	Quantitative	Health Care Climate Questionnaire (HCCQ)	Williams, G. C., Grow, V. M., Freedman, Z. R., Ryan, R. M., & Deci, E. L. (1996). Health Care Climate Questionnaire (HCCQ) [Database record]. APA PsycTests. https://doi.org/10.1037/t68628-000	https://scales.arabpsychology.com/s/the-health-care-climate-questionnaire-hccq/
Healthcare Delivery Phase	Decision Talk	Shared decision-making	User	Patient's perception of whether their clinician encourages them to ask questions	Meaningfulness	Patient	Quantitative	Health Care Climate Questionnaire (HCCQ)	Williams, G. C., Grow, V. M., Freedman, Z. R., Ryan, R. M., & Deci, E. L. (1996). Health Care Climate Questionnaire (HCCQ) [Database record]. APA PsycTests. https://doi.org/10.1037/t68628-000	https://scales.arabpsychology.com/s/the-health-care-climate-questionnaire-hccq/
Healthcare Delivery Phase	Decision Talk	Shared decision-making	User	Patient's perception of whether they feel a lot of trust in their clinician	Meaningfulness	Patient	Quantitative	Health Care Climate Questionnaire (HCCQ)	Williams, G. C., Grow, V. M., Freedman, Z. R., Ryan, R. M., & Deci, E. L. (1996). Health Care Climate Questionnaire (HCCQ) [Database record]. APA PsycTests. https://doi.org/10.1037/t68628-000	https://scales.arabpsychology.com/s/the-health-care-climate-questionnaire-hccq/

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PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Healthcare Delivery Phase	Decision Talk	Shared decision-making	User	Patient's perception of whether their clinician answers their questions fully and carefully	Meaningfulness	Patient	Quantitative	Health Care Climate Questionnaire (HCCQ)	Williams, G. C., Grow, V. M., Freedman, Z. R., Ryan, R. M., & Deci, E. L. (1996). Health Care Climate Questionnaire (HCCQ) [Database record]. APA PsycTests. https://doi.org/10.1037/t68628-000	https://scales.arabpsychology.com/s/the-health-care-climate-questionnaire-hccq/
Healthcare Delivery Phase	Decision Talk	Shared decision-making	User	Patient's perception of whether their clinician listens to how they would like to do things	Meaningfulness	Patient	Quantitative	Health Care Climate Questionnaire (HCCQ)	Williams, G. C., Grow, V. M., Freedman, Z. R., Ryan, R. M., & Deci, E. L. (1996). Health Care Climate Questionnaire (HCCQ) [Database record]. APA PsycTests. https://doi.org/10.1037/t68628-000	https://scales.arabpsychology.com/s/the-health-care-climate-questionnaire-hccq/
Healthcare Delivery Phase	Decision Talk	Shared decision-making	User	Patient's perception of whether their clinician handles people's emotions very well	Meaningfulness	Patient	Quantitative	Health Care Climate Questionnaire (HCCQ)	Williams, G. C., Grow, V. M., Freedman, Z. R., Ryan, R. M., & Deci, E. L. (1996). Health Care Climate Questionnaire (HCCQ) [Database record]. APA PsycTests. https://doi.org/10.1037/t68628-000	https://scales.arabpsychology.com/s/the-health-care-climate-questionnaire-hccq/
Healthcare Delivery Phase	Decision Talk	Shared decision-making	User	Patient's perception of whether their clinician cares about them as a person	Meaningfulness	Patient	Quantitative	Health Care Climate Questionnaire (HCCQ)	Williams, G. C., Grow, V. M., Freedman, Z. R., Ryan, R. M., & Deci, E. L. (1996). Health Care Climate Questionnaire (HCCQ) [Database record]. APA PsycTests. https://doi.org/10.1037/t68628-000	https://scales.arabpsychology.com/s/the-health-care-climate-questionnaire-hccq/
Healthcare Delivery Phase	Decision Talk	Shared decision-making	User	Patient's perception of how they feel about the way their clinician talks to them	Meaningfulness	Patient	Quantitative	Health Care Climate Questionnaire (HCCQ)	Williams, G. C., Grow, V. M., Freedman, Z. R., Ryan, R. M., & Deci, E. L. (1996). Health Care Climate Questionnaire (HCCQ) [Database record]. APA PsycTests. https://doi.org/10.1037/t68628-000	https://scales.arabpsychology.com/s/the-health-care-climate-questionnaire-hccq/

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Healthcare Delivery Phase	Decision Talk	Shared decision-making	User	Patient's perception of whether their clinician tries to understand how they see things before suggesting a new way to do things	Meaningfulness	Patient	Quantitative	Health Care Climate Questionnaire (HCCQ)	Williams, G. C., Grow, V. M., Freedman, Z. R., Ryan, R. M., & Deci, E. L. (1996). Health Care Climate Questionnaire (HCCQ) [Database record]. APA PsycTests. https://doi.org/10.1037/t68628-000	https://scales.arabpsychology.com/s/the-health-care-climate-questionnaire-hccq/
Healthcare Delivery Phase	Decision Talk	Shared decision-making	User	Patient's perception of whether they were able to share their feelings with their clinician	Meaningfulness	Patient	Quantitative	Health Care Climate Questionnaire (HCCQ)	Williams, G. C., Grow, V. M., Freedman, Z. R., Ryan, R. M., & Deci, E. L. (1996). Health Care Climate Questionnaire (HCCQ) [Database record]. APA PsycTests. https://doi.org/10.1037/t68628-000	https://scales.arabpsychology.com/s/the-health-care-climate-questionnaire-hccq/
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Patient's perception of whether the concrete medical problem that requires a decision-making process is clear to them	Meaningfulness	Patient	Quantitative	Mappin'SDM	Kasper J, Hoffmann F, Heesen C, Köpke S, Geiger F. MAPPIN'SDM–The Multifocal Approach to Sharing in Shared Decision Making. PLoS One. 2012;7(4):e34849.	https://pmc.ncbi.nlm.nih.gov/articles/instance/3325952/bin/pone.0034849.s003.doc
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Patient's perception of whether they are convinced that from a medical point of view there is not only one correct way to deal with their problem and several basically equivalent ways are conceivable	Meaningfulness	Patient	Quantitative	Mappin'SDM	Kasper J, Hoffmann F, Heesen C, Köpke S, Geiger F. MAPPIN'SDM–The Multifocal Approach to Sharing in Shared Decision Making. PLoS One. 2012;7(4):e34849.	https://pmc.ncbi.nlm.nih.gov/articles/instance/3325952/bin/pone.0034849.s003.doc

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Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Patient's perception of whether the way they exchanged information with the clinician during the consultation suited both parties and contributed towards a mutual understanding	Meaningfulness	Patient	Quantitative	Mappin'SDM	Kasper J, Hoffmann F, Heesen C, Köpke S, Geiger F. MAPPIN'SDM–The Multifocal Approach to Sharing in Shared Decision Making. PLoS One. 2012;7(4):e34849.	https://pmc.ncbi.nlm.nih.gov/articles/instance/3325952/bin/pone.0034849.s003.doc
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Patient's perception of the role distribution during the consultation matched their preferences	Meaningfulness	Patient	Quantitative	Mappin'SDM	Kasper J, Hoffmann F, Heesen C, Köpke S, Geiger F. MAPPIN'SDM–The Multifocal Approach to Sharing in Shared Decision Making. PLoS One. 2012;7(4):e34849.	https://pmc.ncbi.nlm.nih.gov/articles/instance/3325952/bin/pone.0034849.s003.doc
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Patient's awareness of all the options for dealing with their current problem	Meaningfulness	Patient	Quantitative	Mappin'SDM	Kasper J, Hoffmann F, Heesen C, Köpke S, Geiger F. MAPPIN'SDM–The Multifocal Approach to Sharing in Shared Decision Making. PLoS One. 2012;7(4):e34849.	https://pmc.ncbi.nlm.nih.gov/articles/instance/3325952/bin/pone.0034849.s003.doc
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether patients know the pros and cons of the different decision options	Meaningfulness	Patient	Quantitative	Mappin'SDM	Kasper J, Hoffmann F, Heesen C, Köpke S, Geiger F. MAPPIN'SDM–The Multifocal Approach to Sharing in Shared Decision Making. PLoS One. 2012;7(4):e34849.	https://pmc.ncbi.nlm.nih.gov/articles/instance/3325952/bin/pone.0034849.s003.doc
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Patient's perceptions of whether their personal expectations and fears went into the decision	Meaningfulness	Patient	Quantitative	Mappin'SDM	Kasper J, Hoffmann F, Heesen C, Köpke S, Geiger F. MAPPIN'SDM–The Multifocal Approach to Sharing in Shared Decision Making. PLoS One. 2012;7(4):e34849.	https://pmc.ncbi.nlm.nih.gov/articles/instance/3325952/bin/pone.0034849.s003.doc

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Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether it became clear to the patient what the medical information and recommendations from their clinician are based on	Meaningfulness	Patient	Quantitative	Mappin'SDM	Kasper J, Hoffmann F, Heesen C, Köpke S, Geiger F. MAPPIN'SDM–The Multifocal Approach to Sharing in Shared Decision Making. PLoS One. 2012;7(4):e34849.	https://pmc.ncbi.nlm.nih.gov/articles/instance/3325952/bin/pone.0034849.s003.doc
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the patient understood the information the clinician gave them	Meaningfulness	Patient	Quantitative	Mappin'SDM	Kasper J, Hoffmann F, Heesen C, Köpke S, Geiger F. MAPPIN'SDM–The Multifocal Approach to Sharing in Shared Decision Making. PLoS One. 2012;7(4):e34849.	https://pmc.ncbi.nlm.nih.gov/articles/instance/3325952/bin/pone.0034849.s003.doc
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Patient's perception of whether the clinician understood their viewpoint	Meaningfulness	Patient	Quantitative	Mappin'SDM	Kasper J, Hoffmann F, Heesen C, Köpke S, Geiger F. MAPPIN'SDM–The Multifocal Approach to Sharing in Shared Decision Making. PLoS One. 2012;7(4):e34849.	https://pmc.ncbi.nlm.nih.gov/articles/instance/3325952/bin/pone.0034849.s003.doc
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the patient clarified the questions and aspects they had not fully understood during the discussion with their clinician	Meaningfulness	Patient	Quantitative	Mappin'SDM	Kasper J, Hoffmann F, Heesen C, Köpke S, Geiger F. MAPPIN'SDM–The Multifocal Approach to Sharing in Shared Decision Making. PLoS One. 2012;7(4):e34849.	https://pmc.ncbi.nlm.nih.gov/articles/instance/3325952/bin/pone.0034849.s003.doc
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the clinician cleared up the questions and aspects they had not fully understood during the discussion with their patient	Meaningfulness	Patient	Quantitative	Mappin'SDM	Kasper J, Hoffmann F, Heesen C, Köpke S, Geiger F. MAPPIN'SDM–The Multifocal Approach to Sharing in Shared Decision Making. PLoS One. 2012;7(4):e34849.	https://pmc.ncbi.nlm.nih.gov/articles/instance/3325952/bin/pone.0034849.s003.doc
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the decision-making strategy is clear to the patient	Meaningfulness	Patient	Quantitative	Mappin'SDM	Kasper J, Hoffmann F, Heesen C, Köpke S, Geiger F. MAPPIN'SDM–The Multifocal Approach to Sharing in Shared Decision Making. PLoS One. 2012;7(4):e34849.	https://pmc.ncbi.nlm.nih.gov/articles/instance/3325952/bin/pone.0034849.s003.doc

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Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether it was clear to the patient why and which decision was taken at the end of a consultation with their clinician	Meaningfulness	Patient	Quantitative	Mappin'SDM	Kasper J, Hoffmann F, Heesen C, Köpke S, Geiger F. MAPPIN'SDM–The Multifocal Approach to Sharing in Shared Decision Making. PLoS One. 2012;7(4):e34849.	https://pmc.ncbi.nlm.nih.gov/articles/instance/3325952/bin/pone.0034849.s003.doc
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether it is clear to the patient how their problem will in the future be dealt with	Meaningfulness	Patient	Quantitative	Mappin'SDM	Kasper J, Hoffmann F, Heesen C, Köpke S, Geiger F. MAPPIN'SDM–The Multifocal Approach to Sharing in Shared Decision Making. PLoS One. 2012;7(4):e34849.	https://pmc.ncbi.nlm.nih.gov/articles/instance/3325952/bin/pone.0034849.s003.doc
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether reference was made to a rationale for treatment or a reason why the patient should pursue the discussed treatment option	Meaningfulness	Researcher	Quantitative	DEEP-SDM	Clayman ML, Makoul G, Harper MM, Koby DG, Williams AR. Development of a shared decision making coding system for analysis of patient-healthcare provider encounters. Patient Educ Couns. 2012;88(3):367-372. doi:10.1016/j.pec.2012.06.011	https://pmc.ncbi.nlm.nih.gov/articles/PMC3417351/
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the clinician provided a description of the treatment option or procedure	Meaningfulness	Researcher	Quantitative	DEEP-SDM	Clayman ML, Makoul G, Harper MM, Koby DG, Williams AR. Development of a shared decision making coding system for analysis of patient-healthcare provider encounters. Patient Educ Couns. 2012;88(3):367-372. doi:10.1016/j.pec.2012.06.011	https://pmc.ncbi.nlm.nih.gov/articles/PMC3417351/
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the clinician gave a description of the procedure by which this treatment option is delivered	Meaningfulness	Researcher	Quantitative	DEEP-SDM	Clayman ML, Makoul G, Harper MM, Koby DG, Williams AR. Development of a shared decision making coding system for analysis of patient-healthcare provider encounters. Patient Educ Couns. 2012;88(3):367-372. doi:10.1016/j.pec.2012.06.011	https://pmc.ncbi.nlm.nih.gov/articles/PMC3417351/

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Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether there was reference of possible risks, side-effects, or decreased quality of life associated with the discussed treatment option	Meaningfulness	Researcher	Quantitative	DEEP-SDM	Clayman ML, Makoul G, Harper MM, Koby DG, Williams AR. Development of a shared decision making coding system for analysis of patient-healthcare provider encounters. Patient Educ Couns. 2012;88(3):367-372. doi:10.1016/j.pec.2012.06.011	https://pmc.ncbi.nlm.nih.gov/articles/PMC3417351/
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether there was reference to possible benefits or increased quality of life associated with treatment option	Meaningfulness	Researcher	Quantitative	DEEP-SDM	Clayman ML, Makoul G, Harper MM, Koby DG, Williams AR. Development of a shared decision making coding system for analysis of patient-healthcare provider encounters. Patient Educ Couns. 2012;88(3):367-372. doi:10.1016/j.pec.2012.06.011	https://pmc.ncbi.nlm.nih.gov/articles/PMC3417351/
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether there was reference to or mention of patient perceived self-efficacy or ability to adhere to the decision	Meaningfulness	Researcher	Quantitative	DEEP-SDM	Clayman ML, Makoul G, Harper MM, Koby DG, Williams AR. Development of a shared decision making coding system for analysis of patient-healthcare provider encounters. Patient Educ Couns. 2012;88(3):367-372. doi:10.1016/j.pec.2012.06.011	https://pmc.ncbi.nlm.nih.gov/articles/PMC3417351/
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether the clinician mentioned their own preferences/values briefly OR makes it clear that they would/would not consider this to be a good option	Meaningfulness	Researcher	Quantitative	DEEP-SDM	Clayman ML, Makoul G, Harper MM, Koby DG, Williams AR. Development of a shared decision making coding system for analysis of patient-healthcare provider encounters. Patient Educ Couns. 2012;88(3):367-372. doi:10.1016/j.pec.2012.06.011	https://pmc.ncbi.nlm.nih.gov/articles/PMC3417351/

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Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether reference was made to patient outcome expectations or concerns	Meaningfulness	Researcher	Quantitative	DEEP-SDM	Clayman ML, Makoul G, Harper MM, Koby DG, Williams AR. Development of a shared decision making coding system for analysis of patient-healthcare provider encounters. Patient Educ Couns. 2012;88(3):367-372. doi:10.1016/j.pec.2012.06.011	https://pmc.ncbi.nlm.nih.gov/articles/PMC3417351/
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether reference was made to patient’s understanding, or it is clear that the patient’s understanding is sufficient based on her comments	Meaningfulness	Researcher	Quantitative	DEEP-SDM	Clayman ML, Makoul G, Harper MM, Koby DG, Williams AR. Development of a shared decision making coding system for analysis of patient-healthcare provider encounters. Patient Educ Couns. 2012;88(3):367-372. doi:10.1016/j.pec.2012.06.011	https://pmc.ncbi.nlm.nih.gov/articles/PMC3417351/
Healthcare Delivery Phase	Option Talk	Discussion of available options	User	Whether reference to a plan for follow-up regarding the discussed treatment option was made	Meaningfulness	Researcher	Quantitative	DEEP-SDM	Clayman ML, Makoul G, Harper MM, Koby DG, Williams AR. Development of a shared decision making coding system for analysis of patient-healthcare provider encounters. Patient Educ Couns. 2012;88(3):367-372. doi:10.1016/j.pec.2012.06.011	https://pmc.ncbi.nlm.nih.gov/articles/PMC3417351/
Healthcare Delivery Phase	Option Talk	Discussion of pros and cons	User	Whether the patient feels sure about the best healthcare choice for them	Meaningfulness	Patient	Quantitative	SURE Scale	Légaré F, Kearing S, Clay K, et al. Are you SURE?: Assessing patient decisional conflict with a 4-item screening test. Can Fam Physician. 2010;56(8):e308-e314.	https://decisionaid.ohri.ca/docs/develop/Tools/DCS_SURE_English.pdf
Healthcare Delivery Phase	Option Talk	Discussion of pros and cons	User	Whether the patient knows the benefits and risks of each healthcare option	Meaningfulness	Patient	Quantitative	SURE Scale	Légaré F, Kearing S, Clay K, et al. Are you SURE?: Assessing patient decisional conflict with a 4-item screening test. Can Fam Physician. 2010;56(8):e308-e314.	https://decisionaid.ohri.ca/docs/develop/Tools/DCS_SURE_English.pdf

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Healthcare Delivery Phase	Option Talk	Discussion of pros and cons	User	Whether the patient is clear about which benefits and risks of the healthcare option is best for them	Meaningfulness	Patient	Quantitative	SURE Scale	Légaré F, Kearing S, Clay K, et al. Are you SURE?: Assessing patient decisional conflict with a 4-item screening test. Can Fam Physician. 2010;56(8):e308-e314.	https://decisionaid.ohri.ca/docs/develop/Tools/DCS_SURE_English.pdf
Healthcare Delivery Phase	Option Talk	Discussion of pros and cons	User	Whether the patient feels they have enough suppoty and advice to make a healthcare choice	Meaningfulness	Patient	Quantitative	SURE Scale	Légaré F, Kearing S, Clay K, et al. Are you SURE?: Assessing patient decisional conflict with a 4-item screening test. Can Fam Physician. 2010;56(8):e308-e314.	https://decisionaid.ohri.ca/docs/develop/Tools/DCS_SURE_English.pdf
Healthcare Delivery Phase	Team Talk	Discussion of patient values, preferences, and/or goals	User	Whether the clinician weighed advantages and disadvantages of different treatment options with the patient	Meaningfulness	Patient	Quantitative	Communication Preferences for Patients with Chronic Illness	Farin E, Gramm L, Schmidt E. Taking into account patients' communication preferences: instrument development and results in chronic back pain patients. Patient Educ Couns. 2012;86(1):41-8. doi:10.1016/j.pec.2011.04.012.	https://www.sciencedirect.com/science/article/abs/pii/S073839911100200X?via%3Dihub
Healthcare Delivery Phase	Team Talk	Discussion of patient values, preferences, and/or goals	User	Whether the clinician set treatment and therapy measures in a joint discussion with the patient	Meaningfulness	Patient	Quantitative	Communication Preferences for Patients with Chronic Illness	Farin E, Gramm L, Schmidt E. Taking into account patients' communication preferences: instrument development and results in chronic back pain patients. Patient Educ Couns. 2012;86(1):41-8. doi:10.1016/j.pec.2011.04.012.	https://www.sciencedirect.com/science/article/abs/pii/S073839911100200X?via%3Dihub
Healthcare Delivery Phase	Team Talk	Discussion of patient values, preferences, and/or goals	User	Whether the clinician discussed the treatment plan with the patient	Meaningfulness	Patient	Quantitative	Communication Preferences for Patients with Chronic Illness	Farin E, Gramm L, Schmidt E. Taking into account patients' communication preferences: instrument development and results in chronic back pain patients. Patient Educ Couns. 2012;86(1):41-8. doi:10.1016/j.pec.2011.04.012.	https://www.sciencedirect.com/science/article/abs/pii/S073839911100200X?via%3Dihub

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Healthcare Delivery Phase	Team Talk	Discussion of patient values, preferences, and/or goals	User	Whether the clinician asked the patient how they assessed the results of the treatment	Meaningfulness	Patient	Quantitative	Communication Preferences for Patients with Chronic Illness	Farin E, Gramm L, Schmidt E. Taking into account patients' communication preferences: instrument development and results in chronic back pain patients. Patient Educ Couns. 2012;86(1):41-8. doi:10.1016/j.pec.2011.04.012.	https://www.sciencedirect.com/science/article/abs/pii/S073839911100200X?via%3Dihub
Healthcare Delivery Phase	Team Talk	Discussion of patient values, preferences, and/or goals	User	Whether the clinician explained the procedure of the treatment thoroughly to the patient	Meaningfulness	Patient	Quantitative	Communication Preferences for Patients with Chronic Illness	Farin E, Gramm L, Schmidt E. Taking into account patients' communication preferences: instrument development and results in chronic back pain patients. Patient Educ Couns. 2012;86(1):41-8. doi:10.1016/j.pec.2011.04.012.	https://www.sciencedirect.com/science/article/abs/pii/S073839911100200X?via%3Dihub
Healthcare Delivery Phase	Team Talk	Discussion of patient values, preferences, and/or goals	User	Whether the clinician asked the patient what helped them in their treatment and what did not	Meaningfulness	Patient	Quantitative	Communication Preferences for Patients with Chronic Illness	Farin E, Gramm L, Schmidt E. Taking into account patients' communication preferences: instrument development and results in chronic back pain patients. Patient Educ Couns. 2012;86(1):41-8. doi:10.1016/j.pec.2011.04.012.	https://www.sciencedirect.com/science/article/abs/pii/S073839911100200X?via%3Dihub
Healthcare Delivery Phase	Team Talk	Discussion of patient values, preferences, and/or goals	User	Whether the clinician summarized the results at the end of a discussion with the patient	Meaningfulness	Patient	Quantitative	Communication Preferences for Patients with Chronic Illness	Farin E, Gramm L, Schmidt E. Taking into account patients' communication preferences: instrument development and results in chronic back pain patients. Patient Educ Couns. 2012;86(1):41-8. doi:10.1016/j.pec.2011.04.012.	https://www.sciencedirect.com/science/article/abs/pii/S073839911100200X?via%3Dihub

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Healthcare Delivery Phase	Team Talk	Discussion of patient values, preferences, and/or goals	User	Whether the clinician discussed the next stage of treatment with the patient	Meaningfulness	Patient	Quantitative	Communication Preferences for Patients with Chronic Illness	Farin E, Gramm L, Schmidt E. Taking into account patients' communication preferences: instrument development and results in chronic back pain patients. Patient Educ Couns. 2012;86(1):41-8. doi:10.1016/j.pec.2011.04.012.	https://www.sciencedirect.com/science/article/abs/pii/S073839911100200X?via%3Dihub
Healthcare Delivery Phase	Team Talk	Discussion of patient values, preferences, and/or goals	User	Whether the clinician asked the patient everything about the illness	Meaningfulness	Patient	Quantitative	Communication Preferences for Patients with Chronic Illness	Farin E, Gramm L, Schmidt E. Taking into account patients' communication preferences: instrument development and results in chronic back pain patients. Patient Educ Couns. 2012;86(1):41-8. doi:10.1016/j.pec.2011.04.012.	https://www.sciencedirect.com/science/article/abs/pii/S073839911100200X?via%3Dihub
Healthcare Delivery Phase	Team Talk	Discussion of patient values, preferences, and/or goals	User	Whether the clinician enabled the patient to ask questions	Meaningfulness	Patient	Quantitative	Communication Preferences for Patients with Chronic Illness	Farin E, Gramm L, Schmidt E. Taking into account patients' communication preferences: instrument development and results in chronic back pain patients. Patient Educ Couns. 2012;86(1):41-8. doi:10.1016/j.pec.2011.04.012.	https://www.sciencedirect.com/science/article/abs/pii/S073839911100200X?via%3Dihub
Clinical Decision Support Phase	Use of PC CDS	Point of engagement	User	Percentage of patients that opt out of use of PC CDS technology	Structure/ Process	N/A	Quantitative	N/A	Peterson Health Technology Institute. *Adoption of Artificial Intelligence in Healthcare Delivery Systems: Early Applications and Impacts*. Peterson Health Technology Institute AI Taskforce. March 2025. https://phti.org/wp-content/uploads/sites/3/2025/03/PHTI-Adoption-of-AI-in-Healthcare-Delivery-Systems-Early-Applications-Impacts.pdf	https://phti.org/wp-content/uploads/sites/3/2025/03/PHTI-Adoption-of-AI-in-Healthcare-Delivery-Systems-Early-Applications-Impacts.pdf

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PC CDS Lifecycle Phase	**Steps Where Patients Are Engaged**	**Activities Where Patients Are Engaged**	**How Patients Are Engaged**	**Measure**	**Measure Type**	**Perspective Assessed**	**Data Collection Approach**	**Tool**	**Source(s)**	**Link to Tool**
Clinical Decision Support Phase	Use of PC CDS	Period of engagement	User	Amount of uninterrupted time that patient uses a PC CDS technology	Structure/ Process	N/A	Quantitative	N/A	Peterson Health Technology Institute. *Adoption of Artificial Intelligence in Healthcare Delivery Systems: Early Applications and Impacts*. Peterson Health Technology Institute AI Taskforce. March 2025. https://phti.org/wp-content/uploads/sites/3/2025/03/PHTI-Adoption-of-AI-in-Healthcare-Delivery-Systems-Early-Applications-Impacts.pdf	https://phti.org/wp-content/uploads/sites/3/2025/03/PHTI-Adoption-of-AI-in-Healthcare-Delivery-Systems-Early-Applications-Impacts.pdf
Clinical Decision Support Phase	Use of PC CDS	Interaction with information from the PC CDS	User	Patient perception of whether the PC CDS technology impacted their care experience	Meaningfulness	Patient	Qualitative	N/A	Peterson Health Technology Institute. *Adoption of Artificial Intelligence in Healthcare Delivery Systems: Early Applications and Impacts*. Peterson Health Technology Institute AI Taskforce. March 2025. https://phti.org/wp-content/uploads/sites/3/2025/03/PHTI-Adoption-of-AI-in-Healthcare-Delivery-Systems-Early-Applications-Impacts.pdf	https://phti.org/wp-content/uploads/sites/3/2025/03/PHTI-Adoption-of-AI-in-Healthcare-Delivery-Systems-Early-Applications-Impacts.pdf

9.4. Appendix D: Data Abstraction Domains for Targeted Review

Domain	Abstraction Options
Name of Resource	• [Free text]
American Medical Association (AMA) Citation	• [Free text]
Brief Description	• Free text description of article pulled from the abstract
Patient Engagement Concepts Discussed	• [Free text]
Phase of PC CDS Lifecycle	• Knowledge generation phase • Clinical decision support phase • Healthcare delivery phase
Step in the PC CDS Lifecycle	• Conduct of patient-centered outcomes research • Development and implementation of evidence-based guidelines • Design and development of PC CDS • Implementation of PC CDS • Use of PC CDS • Team talk • Option talk • Decision talk • Outcomes of patient engagement
Specific Measures Mentioned	• [Free text]
Specific Instruments Mentioned	• [Free text]
Description of Guideline Development (if applicable)	• [Free text]
Literature Search String (for supplemental searches)	• [Free text]
Challenges Addressed in Paper	• [Free text]
Notes	• [Free text]

9.5. Appendix E: Key Informants by Type

Stakeholder Type	N
Clinical informaticist	1
Guideline developer	1
Patient representative	1
Researcher	5

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