Outcomes and Objectives Workgroup: Patient-Focused Outcome Measures for Patient-Centered Clinical Decision Support

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PURPOSE

The CDSiC Outcomes and Objectives Workgroup is charged with 1) identifying near- and long-term goals that will advance the translation of Patient-Centered Outcome Research (PCOR)-based evidence into clinical practice through safe and effective patient-centered clinical decision support (PC CDS), 2) developing measurement and effectiveness criteria for assessing the impact of PC CDS on health-related outcomes, and 3) informing the Clinical Decision Support Innovation Collaborative's objectives for advancing PC CDS and the desired impact of the collaborative based on stakeholder input. The Workgroup is composed of six experts and stakeholders representing a diversity of perspectives within the CDS community. Patient-Focused Outcome Measures for PC CDS is intended to be used broadly by those interested in measuring patient outcomes of PC CDS.

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Executive Summary

Patient-centered clinical decision support (PC CDS) is CDS designed to support health-related decision making informed by patient-centered factors, including patient-centered research, patient-generated data, use of patient-facing tools, or use in shared decision making (SDM).[1] Understanding the extent to which PC CDS improves care delivery requires measuring relevant outcomes deemed most important by patients. Existing evidence on CDS reveals limited use of measures for assessing patient-focused outcomes related to patient engagement, experience, and patient-reported outcomes (PROs).

This report takes initial steps to address this gap by offering a preliminary review of patient health journey outcomes and patient-reported health outcomes relevant to PC CDS identified in the literature. The information in this report is primarily designed for stakeholders involved in assessing PC CDS effectiveness, including those developing and deploying PC CDS, as well as quality improvement or embedded research evaluators.

Methods

We conducted a scan of peer-reviewed literature, including systematic reviews that documented use of outcome measures for evaluating CDS. We organized patient-focused outcome measure areas potentially relevant to PC CDS into the following two domains: 1) patient health journey outcomes and 2) patient-reported health outcomes. "Patient health journey" refers to the range of experiences a patient has throughout the course of accessing and receiving healthcare, including interactions and engagement with providers and systems, as well as the patient's experience of living with their health condition(s). Our organizing domains, subdomains, measure topics, and example measures were supplemented and validated through a series of key informant interviews. Three use case scenarios were also developed in consultation with members of the Clinical Decision Support Innovation Collaborative (CDSiC) Outcomes and Objectives Workgroup, and with input from key informants.

Findings

Findings from the literature scan and key informant interviews informed the identification of patient health journey and patient-reported health outcomes for measuring the effectiveness of PC CDS.[2]

Patient Health Journey Outcomes

These outcomes encompass subdomains and measure topics related to patients' lived experience of, and satisfaction with, receiving decision support-assisted care. Fifty-four patient health journey outcomes were compiled and described at the measure level. These outcome measures were identified within three subdomains: decision making, engagement, and care experience.

Decision Making refers to patient involvement in key decisions about their own healthcare. Across patient health journey subdomains, decision making contained the fewest measures identified in the literature. Measure topics were identified in four areas: decision quality, decision regret, SDM experience, and decisional conflict.

- **Decision Quality,** or the extent to which treatment reflects the considered preferences of well-informed patients and are implemented, can provide valuable insight into whether patients receive and understand PC CDS-provided treatment options, and how well these options align with their goals and preferences. Decision quality can be measured using decision quality instruments (DQIs).
- Decision Regret is a patient’s remorse or distress over a decision. Decision regret can be measured using the Decision Regret Scale, a five-item scale designed to be administered to patients after making a key healthcare decision to assess their level of regret regarding that decision.
- SDM Experience is the patient’s experience of participating in the process of making treatment-related decisions based on clinical evidence that balances risks and expected outcomes with patient preferences and values, with or informed by clinicians. Two measures of SDM Experience were identified: the Shared Decision-Making Process Scale and CollaboRATE, both of which assess a patient’s actual level of engagement in and perspectives on the SDM process for a specific health decision.
- Decisional Conflict, or uncertainty about course of action to be taken when choice among competing actions involves risk, loss, or challenges to values and beliefs, can be measured using the SURE scale and the Decisional Conflict Scale.

Engagement refers to a continuum on which patients, families, their representatives, and health professionals work in partnership to improve health and healthcare. Measure topics within engagement include patient knowledge, patient activation, adherence, self-management, discharge preparedness, and trust in clinician. Measures within the engagement subdomain were most likely to be tailored to specific health conditions.

- **Knowledge** includes a patient's misconceptions, as well as their knowledge about illness, lifestyle, treatment management or monitoring, skill and technique acquisition, health services navigation, allowed and recommended activities, entitlements, and social healthcare support. Patient knowledge measures identified in the literature were often condition-specific, such as the Child Knowledge of Asthma Management and Cancer Risk Perception measures.
- Adherence is the degree to which an individual’s healthcare actions and behavior align with the care plan established by their clinician. Medication adherence measures were identified in CDS studies, including patient-reported measures such as the Statin Adherence measure, as well as measures assessed using pharmacy and prescribing records such as the Medication Possession Ratio.
- Self-Management most commonly describes activities or behaviors that patients undertake to maintain control over their disease. The Child Self-Efficacy for Asthma Treatment measure is an example of a self-management measure identified in the literature.
- Discharge Preparedness describes a patient’s perception of their own readiness to leave inpatient care and can be measured with the Brief PREPARED questionnaire.
- Trust in Clinician is another important outcome of patient engagement in PC CDS and can be measured using the Trust in Physician Scale.

Care Experience encompasses patients’ ranging interactions with the healthcare system, including aspects of care delivery that patients value and that have a bearing on improved patient outcomes. Patient experience is comprised of five measure topics: timeliness, access to information, communication, patient satisfaction, and coordination. Across subdomains, patient satisfaction was the measure topic best represented in CDS studies.

- **Patient Satisfaction with Care** refers to the extent patients feel the care they receive meets their expectations or aligns with their preferences for care. Patient-reported satisfaction with care measures identified in CDS studies include the Patient Experience Survey, the Patient Experience of Primary Care survey (and included subscales), and the Satisfaction with Information About Medicines Scale (and included subscales).

Patient-Reported Health Outcomes

These outcomes encompass subdomains and measure topics related to patients’ physical functioning and other symptomatology, including general, physical, mental, and social health. Forty-two patient-reported health outcomes were compiled and described at the measurement topic level for this review.

- **General Health** comprises measurement topics related to a patient’s general perceived health and health-related quality of life. Health-related quality of life, both condition-specific and condition-agnostic, was the most common patient-reported health outcome referenced in the reviewed CDS literature.
- **Physical Health** includes general perceived physical health, physical functioning, mobility, fatigue, and pain outcome measure topics, with specific measures identified in the literature related to physical functioning and pain.
- Mental Health encompasses measurement topics related to general perceived mental health, vitality, depression symptoms, anxiety symptoms, and sleeping. This review identified studies assessing general perceived mental health, depression, and anxiety.
- Social Health includes general perceived social health, interpersonal functioning, and work outcomes, with a specific measure related to general perceived social health identified in the reviewed CDS literature.

Considerations

The literature review and discussions with Workgroup members and key informants indicate that selection of outcome measures should be based on consideration of several key questions, including:

- **What patient health journey and/or patient-reported health outcomes are likely to be impacted by the PC CDS?** It is critical to identify patient-reported measures meaningful for patients and caregivers, as well as those with robust measurement properties, that are actionable and feasible.

- **What type of outcomes assessment is being done: evaluation, quality improvement, or accountability (includes reporting)?** The context for outcomes assessment will also influence measure selection, including tolerance for measurement bias, and requirements for precision, reliability, and validity.

- **Does the measure meet relevant measure selection criteria?** Several key resources, including those by the Consensus-based Standards for the Selection of Health Measurement Instruments (COSMIN), National Quality Forum (NQF), and the International Society for Quality of Life Research (ISOQOL) can provide guidance about assessing the appropriateness of measures based on validity, reliability, responsiveness, feasibility, and usability.

Recommendations for Future Work

While not exhaustive, our literature scan surfaced several patient-focused measurement areas that have received little to no attention to date with respect to use in evaluating PC CDS.

- **Patient Health Journey Outcomes.** Several measurement topics commonly associated with Engagement and Care Experience subdomains in the broader literature were not found in our literature review. These were patient activation, adherence to non-medication-related treatment regimens, condition-agnostic measures for self-management, timeliness, information access, communication quality, and care coordination.
- **Patient-Reported Health Outcomes.** Our scan did not identify measures of general perceived physical health, fatigue, or mobility within the Physical Health subdomain. Within the Mental Health subdomain, no outcome measures were found for vitality or sleeping. Finally, within the Social Health subdomain, no measures were identified to assess interpersonal functioning or work outcomes.

These evidence gaps and discussions with key informants highlighted three areas for future work:

- **Patient Health Journey Outcomes Measurement:** Develop and identify patient health journey measures in areas with limited attention in the PC CDS literature. This includes measures of non-medication treatment adherence and patient experience.
- **Patient-Reported Health Outcomes Measurement:** Develop and identify patient-reported health outcome measures in areas with limited attention in the PC CDS literature. This includes measures of general perceived physical health, fatigue, mobility, interpersonal functioning, work, vitality, and sleeping.
- **Implementation:** Research into how patient health journey measures can be routinely captured within clinical workflows, opportunities, and challenges of using patient-reported health outcomes to measure the effectiveness of PC CDS, how evaluations of PC CDS can assure there are not disparities in who benefits from the use of technology, approaches for PC CDS measurement that enable continuous quality improvement, and approaches to prioritize and select measures important to patients within system settings.

Conclusion

Evaluating CDS with an eye toward patient-centeredness requires accounting for the effects of PC CDS on 1) patients' lived experiences of their health journeys and 2) health outcomes important to patients, such as symptoms and functioning. While not exhaustive, the measures gathered as part of this report, and the use cases presented, may provide a starting point for studying how PC CDS influences patient-focused outcomes in both research and real-world settings. This work may help researchers, developers, and implementers select measures that are fit-for-purpose in evaluating PC CDS relative to outcomes of import for patients. As the field of PC CDS continues to evolve, it will be imperative to undertake future work that addresses existing gaps in measurement and advances evidence on this topic. This can help ensure that assessments of PC CDS effectiveness reflect patients' needs and priorities, so that future development and deployment can be responsive.

1. Introduction

Clinical decision support (CDS) encompasses tools and processes designed to enable timely decision making and subsequent delivery of evidence-based care.[3] Historically, CDS has primarily been clinician facing and used to deliver diagnostic and treatment guidance based on clinical guidelines at the point of care.[3] Specifically, patient-centered CDS (PC CDS) supports decision making informed by patient-centered factors related to:

- Knowledge, such as findings from patient-centered outcomes research (PCOR) and comparative effectiveness research (CER).
- Data, including patient-generated, patient-reported, and patient-specific information.
- Delivery, incorporating patient-facing tools (e.g., apps, patient portals, text messages).
- Use, particularly in the context of shared decision making (SDM).[1,4,5,6]

PC CDS advances patient-centered care through its utilization of data and tools to identify care plan options tailored to individual patient needs, to engage patients and caregivers in decision making, and to ensure that care decisions are informed by individual patient goals and preferences.

1.1 Outcomes Measurement of PC CDS

Outcomes measurement is a key component of determining whether or not PC CDS is achieving its intended purpose. Results can be used to report PC CDS effectiveness to key stakeholders, identify ways to improve implementation, and inform strategic decisions about if PC CDS tools need to change or adapt. Measurement provides the means to assess effectiveness by generating the information needed to determine whether a PC CDS intervention warrants modification.

PC CDS is intended to support patient-centered care; thus, it is essential that the field identify measures to assess whether (and how) PC CDS influences the outcomes *important to patients.* Exposure to PC CDS may modify a patient's relationship with the experience of receiving care, as well as their perceived role in their care. For this reason, accurately evaluating PC CDS effectiveness requires not only assessing clinical and other health outcomes, but also an intervention's impact on patients' experiential journeys. This report conceptualizes the "patient health journey" as the range of experiences a patient has throughout the course of accessing and receiving healthcare, including interactions and engagement with providers and systems, as well as the patient's experience of living with their health condition(s).[7,8]

The literature reveals gaps in evidence related to the identification of outcomes and respective indicators most relevant for assessing PC CDS.[1] To date, CDS outcomes assessment has primarily focused on topics such as uptake, workflow, acceptance, and system factors (i.e., cost).[1,9] As a result, little is known about the types of measures that could be used to examine the impact of PC CDS on patient-focused outcomes (i.e., patient experience and other patient-reported outcomes). To help address this gap, this report focuses specifically on the availability of measures relevant to these types of outcomes.

This report is intended to identify potential measures for use in assessing PC CDS effectiveness with respect to patient-focused outcomes. Key contributions of this product include 1) an inventory of measures related to patient health journey outcomes and 2) an overview of patient-reported health outcomes documented in the literature as having been used for assessing PC CDS effectiveness.

Additional Measurement Resources from the CDSiC

- The PC CDS Implementation, Planning, and Reporting Checklist and User Guide are tools for comprehensively describing how PC CDS is designed, developed, deployed, used, maintained, and evaluated along four key implementation domains: 1) planning and needs assessment, 2) design and development, 3) implementation and adoption, and 4) evaluation and impact. An accompanying user guide describes how to use the checklist.
- The PC CDS Performance Measurement Inventory and User Guide are tools that can be used to identify 1) what measures are available to assess PC CDS performance and 2) tools and measurement approaches to collect and analyze PC CDS performance data.

1.2 Roadmap of this Report

This report contains the following sections:

- Section 2, *Methods*, describes our primary research aims and approaches used for the measures scan, literature review, and semistructured interviews.
- Section 3, *Findings: PC CDS Effectiveness Measurement*, summarizes key findings by outcome measurement area: patient health journey and patient-reported health.
- Section 4, *PC CDS Outcomes Measurement Considerations & Resources,* provides a brief discussion of key considerations related to outcome measure selection. It also summarizes key resources to aid evaluators in these activities.
- Section 5, *Use Cases*, presents three scenarios demonstrating how to identify outcome measures relevant to PC CDS.
- Section 6, *Recommendations for Future Work,* highlights existing knowledge gaps that can inform future research efforts and stimulate further discovery of best practices.
- Section 7, *Conclusion,* summarizes this work's contribution to the field and outlines potential ways the report can be used by different PC CDS stakeholders.

This product is primarily intended as a resource for stakeholders involved in assessing PC CDS effectiveness, including clinicians and health systems at the forefront of developing and deploying PC CDS, as well as quality improvement (QI) or research evaluators. Additional audiences (e.g., patients) may also find this report useful.

2. Methods

Our work, guided by four main research questions (**Table 1**), involved scanning peer-reviewed literature that included systematic reviews related to outcome measures for evaluating CDS. Preliminary findings were validated through four key informant interviews (KIIs) representing clinical information experts (n=3) and healthcare practitioners (n=1). Clinical Decision Support Innovation Collaborative (CDSiC) Outcomes and Objectives Workgroup members were engaged throughout the process and provided input on domain categorization, measure inclusion, and use case quality of content. Our methods, summarized below, are fully detailed in **Appendix A.**

Table 1. Research Questions.

Research Questions
1. To what extent have patient health journey and patient clinical/health outcomes been reported in CDS studies to date? Specifically: a. What patient health journey outcome measures have been reported in the literature? b. What types of patient-reported health outcomes have been reported in the literature?
2. What, if any, gaps exist in the assessment of patient health journey or patient-reported health outcomes relevant to PC CDS?
3. For measure topics related to Questions 1 and 2: a. What established definitions exist? b. What measure banks (or other resources) exist?
4. What measurement-related factors should be considered when planning for PC CDS outcomes assessment?

2.1 Measure Domains

We organized patient-focused outcome measure concepts potentially relevant to PC CDS into the following two domains:

- **Patient Health Journey Outcomes.** This domain encompasses subdomains and measure topics related to patients' lived experience of (and satisfaction with) decision support-assisted care: decision making, engagement, and overall care experience.
- **Patient-Reported Health Outcomes.** This domain encompasses subdomains (i.e., general, physical, mental, and social health) and measure topics related to patients' physical functioning and other symptomatology.

For the patient health journey domain, the CDSiC Outcomes and Objectives Workgroup identified three subdomains: decision making, engagement, and care experience. Initial measure topics under each subdomain were identified by the Workgroup based on their knowledge of PC CDS, SDM, and patient-centered care; these topics were expanded and refined by the literature search findings (**Table 2**).

Table 2. Patient-Reported Health Journey Outcomes Subdomains and Measure Topics.

Subdomain	Measure Topic
Decision Making	Decision Quality
	Decision Regret
	Shared Decision Making (SDM) Experience
	Decisional Conflict
Engagement	Knowledge
	Activation
	Adherence
	Self-Management
	Discharge Preparedness
	Trust in Clinician
Care Experience	Timeliness
	Information Access
	Communication
	Coordination
	Satisfaction (Care)

For the patient-reported health outcomes domain, subdomains and measure topics were determined via review of existing patient-centered outcomes frameworks. The CDSiC Outcomes and Objectives Workgroup reviewed different frameworks and generally agreed that the International Consortium for Health Outcomes Measurement (ICHOM) Patient-Centered Outcomes Measures Framework for Overall Adult Health[10] would be suitable for identifying and categorizing patient-reported health outcomes for this product. To develop the framework, ICHOM convened an international panel of patients, clinicians, and topic experts who reviewed literature, developed a conceptual framework, and conducted a modified Delphi process.[11] While not exhaustive, the resultant subdomains include measure topics outcomes that matter most to adults who have good health (or "no" disease), well-controlled disease, and poorly controlled disease (**Table 3**).[11]

Table 3. Patient-Reported Health Outcomes Subdomains and Measure Topics.

Subdomain	Measure Topic
General Health	General Perceived Health
Physical Health	General Perceived Physical Health
	Physical Functioning
	Mobility
	Fatigue
	Pain

Subdomain	Measure Topic
Mental Health	General Perceived Mental Health
	Vitality
	Depression Symptoms
	Anxiety Symptoms
	Sleeping
Social Health	General Perceived Social Health
	Interpersonal Functioning
	Work

2.2 Literature Search for Measures and Resources

To assess the current landscape and potential gaps in patient health journey outcome measures and patient-reported health outcome measures for PC CDS, we conducted a scan of systematic reviews on outcome assessment for CDS implementation and evaluation (**Appendix A**). We began with seminal articles shared by CDSiC Outcomes and Objectives Workgroup members and then searched PubMed to identify other peer-reviewed literature.

Identification of Measures. Our initial searches yielded 69 peer-reviewed systematic reviews, sourced from PubMed. We then conducted a title/abstract review to assess which of these reviews met our eligibility criteria; we accordingly marked each review as *eligible, ineligible,* or *uncertain.* Reviews were deemed eligible if they: 1) compiled studies of CDS, 2) were in English, and 3) included a discussion of outcomes assessment. For articles deemed *uncertain* at the title/abstract level, full texts were then reviewed to confirm eligibility; then, all *eligible* articles (n=31) meeting inclusion criteria were reviewed at the full-text level. All 31 systematic reviews included patient journey outcomes; however, only 18 of these reviews were reviewed for patient-reported health outcomes. Measures for both domains were identified as follows:

- ***Patient Health Journey Outcome Measures.*** The 31 systematic reviews that included patient journey outcomes compiled information from 1,929 studies. We reviewed the titles and abstracts for these studies to determine if they assessed patient journey outcomes. After reviewing full-text articles for studies appearing to include relevant outcomes, we extracted 54 patient journey measures from 20 studies for inclusion in the **Patient Health Journey Outcomes Inventory** (**Appendix B**).
- ***Patient-Reported Health Outcome Measures.*** A subset of 18 of the initial 31 systematic reviews were reviewed to identify patient-reported health outcomes; in total, these 18 systematic reviews compiled information from 800 studies. Reviewers examined patient-reported health outcomes assessed in these studies, extracting data from the 18 systematic reviews and reviewing full-text articles of studies as needed to supplement information provided in the reviews. Patient-reported health outcomes were counted, and exemplar measures and instruments to assess these outcomes were extracted and compiled. In addition, we chose to focus on capturing patient-reported outcomes to reflect outcomes that are most important and relevant to patients. We extracted a total of 42 patient-reported health outcome measures.

Supplemental Searches. We supplemented our search with targeted searches of the CDS literature, to fill gaps in two areas: patient-centered outcome measure frameworks and outcome measure selection criteria (**Appendix A**) to inform our understanding of considerations and resources.

2.3 Key Informant Interviews

To supplement our literature review, we conducted four qualitative interviews. Interviews were conducted between June and July 2023, following preliminary development of the organizing constructs and measure review. The interviews were intended to prompt review of example measures included as preliminary findings, assess the validity of our organizing constructs, and solicit feedback to inform refinement. Informants were prompted to focus specifically on patient health journey and patient-reported health outcomes relevant to PC CDS. Informants also identified gaps in measurement topics for PC CDS assessment, along with considerations for selecting and using outcome measures relevant to PC CDS.

The project team identified four key informants comprising clinical information experts and patient-centered care practitioners. Specific recommendations were solicited from CDSiC Outcomes and Objectives Workgroup members. A total of four individuals participated in KIIs. A semistructured discussion guide was developed to solicit general feedback, and to probe in domains where subdomain or organization was uncertain. Video and audio were recorded for these interviews, conducted via Zoom, which lasted approximately 60 minutes each. Transcript-style notes were taken during each interview, supplemented by these recordings. These data were then analyzed using thematic approaches to validate and refine the organizing construct and included measures, and to identify themes within and across interviews to inform PC CDS outcomes measurement considerations.

2.4 Use Cases

Three use case scenarios were developed iteratively with input from CDSiC Outcomes and Objectives Workgroup members, as well as key informants. Each use case presents a hypothetical study in which a PC CDS application or tool is tested for a given health condition; the purpose is to demonstrate how patient outcomes relevant to PC CDS can be identified in a variety of evaluation scenarios.

Each use case first presents the clinical context for a specific condition, followed by a description of the hypothetical PC CDS application or tool. This includes details about the application's capabilities, required inputs, and methods of end-user interaction with the PC CDS. Finally, each use case proposes potential patient outcome measures that could be used to assess PC CDS effectiveness—outlining the measurement concept, specific measure proposed, data source, measure-specific considerations, and any additional comments. The components of each use case are detailed in **Table 4** below**.**

Table 4. Components of PC CDS Outcomes Measurement Illustrative Use Cases.

Use Case Component	Component Description
Clinical Context	The target clinical population and specific setting or decisional context in which PC CDS will be applied.

Use Case Component	Component Description
PC CDS Functionality	A description of what the PC CDS tool is designed to do based on real-world examples of CDS tools, including whether it is clinician- or patient-facing and how it facilitates the clinical context-decision interaction.
Outcomes Measurement	A list of outcome measures that may be appropriate for evaluating the PC CDS, as well as details related to each outcome: measurement concept, specific measure, measure data source, and measure-specific considerations.

3. Findings: PC CDS Effectiveness Measurement

In the following sections, findings regarding patient outcomes for assessing PC CDS effectiveness are summarized in two areas:

1) Patient health journey measures compiled and described at the measure level.
2) Patient-reported health outcome measures compiled and described at the measurement topic level.

3.1 Patient Health Journey Outcomes

We identified 54 patient health journey outcome measures used to assess CDS within the three subdomains, reflecting 10 measure topics (**Table 5**). Notably, half of the measures identified specifically focused on measuring patient satisfaction with care and thus were included in the care experience subdomain. The following sections present specific findings by subdomain, providing context for each measurement topic and illustrative examples of validated measures and instruments. The full patient health journey outcomes inventory with detailed descriptions of measures can be found in **Appendix B**.

Table 5. Identified Patient Health Journey Outcome Measure Topics.

Patient Health Journey Subdomain	**Decision Making**	**Engagement**	**Care Experience**
Measure Topics	• Decision Quality • Decision Regret • SDM Experience • Decisional Conflict	• Knowledge • Adherence • Self-Management • Discharge Preparedness • Trust in Clinician	• Patient Satisfaction with Care
Number of Measures Identified	10	19	25

3.1.1 Decision Making

Patient involvement in decision making is a key component of quality healthcare; studies have shown that engaging patients in the decision-making process may lead to higher levels of patient satisfaction, patient knowledge of and adherence to treatment, and possibly better health outcomes.[12] Despite its importance, we identified the fewest patient journey measures in the PC CDS literature for this subdomain.

We identified measure topics in four areas: decision quality, decision regret, SDM Experience, and decisional conflict. We identified at least one instrument or scale that can be used to measure PC CDS effectiveness for each of these four measure topics. Below, we describe each measure topic and the measures we identified.

Decision Quality. Decision Quality is "the extent to which treatments reflect the considered preferences of well-informed patients and are implemented."[13] Two key factors in decision quality are 1) the extent that patients are informed about the evidence on clinically appropriate options and outcomes and 2) how well the treatment aligns with a patient's goals or preferences.[14] As such, decision quality is an important measure topic in the assessment of PC CDS; it can provide insight into whether patients receive and understand PC CDS recommended treatment options, and how well these treatment options align with their goals and preferences.

- *Measuring Decision Quality.* Decision quality instruments (DQIs) can be used to create a concordance score, which reflects the percentage of patients who receive treatment matching their goals.[15] While useful for measuring decision quality, DQIs offer limited general usability, as they only currently exist in condition-specific formats for 14 common health conditions, such as breast cancer and osteoarthritis.[16] For example, the study identified in this review that assessed decision quality as a patient outcome utilized a DQI specific to hip and knee osteoarthritis.[17]

Decision Regret. Decision Regret is defined as a patient's remorse or distress over a decision.[18] High decision regret can highlight the need for the patient and the clinician administering PC CDS to engage in shared decision making. Evidence suggests that PC CDS that provides clear and transparent information to support decision making might decrease the occurrence of decision regret.[19]

- *Measuring Decision Regret.* The Decision Regret Scale is designed to be administered to patients after making a key healthcare decision to assess their level of decisional regret for a specific healthcare decision.[17] This unidimensional, five-item scale provides a numeric decision regret score; higher scores correlate with higher levels of remorse or distress related to a decision.[20]

SDM Experience. SDM Experience is the patient's experience of participating in the process of making treatment-related decisions (e.g., selecting tests, treatment options, and care plans) based on clinical evidence that balances risks and expected outcomes with patient preferences and values,[21] and with or informed by clinicians and other members of the care team. The SDM Experience measure topic accounts for patients' desired and actual levels of engagement throughout the decision-making process.

- *Measuring SDM Experience.* Two measures of SDM experience were identified during this review: the Shared Decision-Making Process Scale and CollaboRATE. These measures assess a patient's actual level of engagement in and perspectives on the SDM process for a specific healthcare decision.[17]

Decisional Conflict. Decisional Conflict is defined as "uncertainty about course of action to be taken when choice among competing actions involves risk, loss, or challenge to values and beliefs" in the context of a healthcare decision.[22] Evidence indicates that patients actively engaged in the decision-making process may have lower levels of decisional conflict.[23]

- *Measuring Decisional Conflict.* The literature review identified two instruments that have been utilized to assess outcomes of decisional conflict: the SURE Scale and the Decisional Conflict Scale (DCS). The DCS comprises five measure subscales assessing whether the patient was informed, if they had clarity regarding their decisional values, level of support received, level of uncertainty regarding decision making, and whether the patient was satisfied with their decision.[24] The subscales can be used separately or combined into an overall measure. The SURE scale is a condensed, four-item version of the DCS.[25]

3.1.2 Engagement

Patient engagement refers to a continuum on which patients, families, their representatives, and health professionals work "in active partnership at various levels across the healthcare system…to improve health and healthcare."[26] We identified measures within this subdomain related to the measure topics of knowledge, adherence, self-management, discharge preparedness, and trust in clinician.

Knowledge. A patient's *knowledge* includes their misconceptions as well as knowledge about illness, lifestyle, treatment management or monitoring, skill and technique acquisition, health services navigation, allowed and recommended activities, entitlements, social, and healthcare support.[27] Patients with higher levels of knowledge and deeper understanding of the rationale for recommended actions are more likely to adhere to those recommendations and to choose the appropriate treatments.[28,29] Informants noted that knowledge may be the Engagement subdomain measure topic most important to patients.

- *Measuring Patient Knowledge.* Patient knowledge measures were commonly tailored to specific conditions or interventions. For example, Cancer Risk Perception measures the patient's risk perception around the likelihood of developing breast/bowel cancer relative to the general population through a study-specific questionnaire related to knowledge on condition.[30] Additionally, the Child Knowledge of Asthma Management measures children's knowledge of asthma self-management based on a 30-item study-specific survey related to patient knowledge on treatment.[31] Other knowledge measures were tailored to specific interventions, such as the Patient Knowledge of Statins measure[32] or a Knowledge and Appraisal Questionnaire, which featured questions specific to an "Asthma Files" educational program.[33]

Adherence. Adherence is the degree to which an individual's healthcare actions and behavior align with the care plan established with their clinician (e.g., medication use, followup care, lifestyle, or behavioral changes).[34] Adherence can be measured in two ways: directly via clinical measurement or indirectly using patient self-report or medication monitoring.[35] Measures that assess adherence indirectly were extracted for this review.

- *Measuring Adherence.* The seven adherence measures identified were all related to medication adherence. Most of the adherence measures identified have general usability for various types of medication interventions; however, the Statin Adherence and Patient-Reported Medication Adherence measures have more limited usability, as they were tailored to specific medication regimens.[32,36] Additionally, five of the seven adherence measures identified for the inventory are patient-reported measures, while the Medication Possession Ratio[37] and Medication Refill Adherence[36] measures are assessed using pharmacy and prescribing records.

Self-Management. Self-management can mean different things to different people in different contexts, which makes it difficult to characterize. Most commonly, this term is used to describe activities or behaviors that patients undertake to maintain control over their disease (e.g., getting exercise, monitoring symptoms, asking followup questions in healthcare appointments).[38] Self-management can sometimes speak to interventions designed to train patients in these activities.

- *Measuring Self-Management.* One self-management measure, the Child Self-Efficacy for Asthma Treatment, was identified in the literature. The measure was developed specifically for an intervention and aims to evaluate patients' change in confidence in performing self-regulatory and asthma-specific behaviors.[39]

Discharge Preparedness. Input from Workgroup members and key informants suggested that patients' engagement in PC CDS can influence perceptions of their preparedness for discharge, described as a patient's perception of their own readiness to leave inpatient care. Thus, preparedness for discharge was identified as one engagement-related outcome. One measure for this was identified through the literature review.

- *Measuring Discharge Preparedness.* The Brief PREPARED (B-PREPARED) patient questionnaire assesses patient perceptions of their preparedness for discharge.[40] This measure topic is interrelated with those of self-management and knowledge—the questionnaire assesses knowledge and receipt of instructions regarding key discharge information (such as information regarding community services or home medication regimens), as well as the patient's confidence in managing their own care post-discharge.[41]

Trust in Clinician. Input from Workgroup members and key informants also suggested that a patient's level of trust in their clinician can be an important outcome of their engagement in PC CDS. A clinician, in this case, can be conceptualized as a patient's individual physician, care team, or the health system more broadly. In the CDS literature, only one measure was identified related to trust in clinician as an outcome related to patient engagement, which focused on an individual physician.

- *Measuring Trust in Clinician.* The Trust in Physician Scale was identified in the literature as a measure to assess a patient's level of interpersonal trust in their physician. This scale comprises 11 items asking patients' level of agreement or disagreement with items related to their perception of trust in their physician based on their experience interacting with and receiving care from a particular clinician. [42,43]

3.1.3 Care Experience

Patient care experience encompasses patients' interactions with clinicians; other aspects of healthcare delivery, such as timeliness of care and accessibility of needed information; and satisfaction with the care received.[44] Measures of patient experience can provide insight on the extent to which PC CDS is respectful of and responsive to patients' preferences and needs. Within the Care Experience subdomain, we identified measures related to only the satisfaction with care measure topic**.** Aside from patient satisfaction with care, outcome measures related to other Experience subdomain measure topics were noticeably missing from the literature.

Patient Satisfaction with Care. Patient satisfaction with care refers to the extent patients feel the care they receive meets their expectations or aligns with their preferences for care.[45]

- *Measuring Patient Satisfaction with Care*. While some patient satisfaction measures probed satisfaction with care generally, many patient satisfaction measures used in CDS studies were tailored by setting (e.g., primary care or outpatient care). Importantly, all of the patient satisfaction measures identified in CDS studies were assessed using patient report via questionnaire. Additionally, five patient satisfaction measures include subscales that can be assessed as standalone measures for more specific constructs related to patient satisfaction. Collectively, these primary scales and subscales represent 22 of the 25 satisfaction measures identified:
    - Patient Experience Survey captures patient satisfaction with emotional support: asking patients to rate the amount of the emotional support they receive and the amount they desire from each member of their care team.[46]
    - Patient Experience of Primary Care assesses patients' experiences and satisfaction with their primary care provider using five subscales that specifically probe satisfaction with access to care, experience waiting prior to their visit, experience with their provider, experience with personalized aspects of care, and overall care experience.[47]
    - The Satisfaction with Information About Medicines Scale assesses patient satisfaction with information about medications using two subscales that probe specifically on patient satisfaction with the action and usage of their medication and the potential problems with their medication.[40]
    - The Press Ganey® Outpatient Medical Practice Survey assesses overall satisfaction with care, but also has measure subscales that specifically probe satisfaction with personal issues, the care provider, nursing assistants, moving through visit, and access to outpatient care.[48]
    - The Patient Satisfaction Questionnaire (PSQ) measures patient satisfaction overall, but also comprises measure subscales related to patient satisfaction with access to care, financial aspects of care, availability of resources, continuity of care, technical quality, and interpersonal manner.[49]

3.2 Patient-Reported Health Outcomes

The CDS studies reviewed most frequently used measures that fall outside of the patient-reported health outcomes domain. These included measures to assess healthcare utilization (including readmission rates and length of stay),[50 - 56] intermediate clinical surrogates (i.e., blood glucose, blood pressure),[57 - 64] morbidity and mortality,[50,52-56,65-70] and adverse events.[54,55,61,62,65-69,71] While these outcomes are important, they do not necessarily represent the outcomes most important to patients. We focused our findings on patient-reported health outcomes, which reflect patients' direct perceptions of their health and well-being.[72]

The measure scan uncovered 42 of these patient-reported health measures, which have been used in CDS studies (**Table 6**). These outcome measures assessed general health, physical health, mental health, and social health. Notably, 33 out of 42 outcome measures were focused on general health.

Table 6. Patient-Reported Health Outcomes Identified in CDS Studies.

Patient-Reported Health Outcome Subdomain	Number of Outcome Measures Identified
General Health	33
Physical Health	3
Mental Health	5
Social Health	1

3.2.1 General Health

The General Health subdomain encompasses outcome measures related to the patient's general perceived health and health-related quality of life. Health-related quality of life, whether condition-specific or -agnostic, was the most common patient-reported health outcome referenced in the reviewed CDS literature. Twenty-four out of 33 general health outcomes focused on health-related quality of life.

- *Measuring General Health.* Example condition-agnostic instruments used to assess general health in CDS studies include the EuroQol-5d (health-related quality of life; EQ-5D) and the Short-Form Health Survey (general perceived health; SF-36, SF-12). Many health-related quality-of-life measures were condition-specific. In particular, condition-specific questionnaires were identified for individuals with respiratory conditions (e.g., chronic respiratory disease, asthma) or conditions related to cardiovascular disease (e.g., cardiomyopathy, angina). Condition-specific instruments used to assess general perceived health in the CDS studies include the St. George Respiratory Questionnaire (condition-specific general health status), the Kansas City Cardiomyopathy Questionnaire (health-related quality of life), the McMaster Asthma Quality-of-Life Questionnaire (health-related quality of life), the European Organization for Research and Treatment of Cancer Questionnaire (health-related quality of life), and the Seattle Angina Questionnaire (condition-specific general health status).

3.2.2 Physical Health

Few (three) of the 42 patient-reported health outcomes were identified in the Physical Health subdomain, which includes measurement topics related to physical functioning, fatigue, mobility, and pain.

- *Measuring Physical Health*. Two studies assessed physical functioning via the patient's functional status and ability to physically complete activities of daily living.[73,74] One study assessed pain via a patient-reported pain assessment.[75] Notably, measures identified in the CDS literature for assessing physical health-related outcomes did not utilize (or did not document the use of) validated instruments for this measurement.

3.2.3 Mental Health

Five out of 42 patient-reported health outcomes were identified in the mental health subdomain. The mental health subdomain encompasses general perceived mental health, vitality, depression symptoms, and anxiety.

- *Measuring Mental Health.* Two of the identified patient-reported mental health outcomes were related to general perceived mental health. Both studies utilizing this outcome assessed general perceived mental health with the General Health Questionnaire.[76,77] Only two studies assessed depression symptoms, and one assessed anxiety. Depression symptoms were assessed using the Geriatric Depression Scale, as well as a study-specific patient-reported assessment.[78] The State-Trait Anxiety Inventory was used for the study employing anxiety as a patient outcome.[79]

3.2.4 Social Health

Social health can be defined as personal well-being related to an individual's ability to create and maintain personal relationships, and to actively participate in their community.[80] The Social Health subdomain comprises measurement topics related to general perceived social health, interpersonal functioning, and work (i.e., the individual's ability to obtain and successfully maintain employment). Only one of the identified 42 patient-reported health outcomes was related to social health, assessing self-reported psychosocial impairment as a patient outcome of shared vascular decision support in the primary care setting.[81]

- *Measuring Social Health.* One study assessed general perceived social health with the Psychosocial Index, which assesses psychosocial impairment using a self-rating scale that includes items related to stress, well-being, distress, and behavior.[82]

4. PC CDS Outcomes Measurement Considerations

The literature review and discussions with Workgroup members and key informants indicate that selection of outcome measures should be based on consideration of several key questions, including:

1) What patient health journey and/or patient-reported health outcomes are likely to be impacted by the PC CDS?
2) What type of outcomes assessment is being done: evaluation, quality improvement, or accountability (includes reporting)?
3) Does the measure meet relevant criteria for validity/reliability, usability, feasibility, and responsiveness?[83]

Considerations of cost, access, and equity are also important to assessing the patient-centered implementation of an intervention. Resources related to guidance and considerations for measure selection, as well as notable measure and item banks, are included in **Appendix C.**

To balance these often-competing considerations, measure selection should be done iteratively and collaboratively with key research partners. This helps to ensure selected measures both reflect the priorities of patients and families and support rigorous evaluation of the intervention.[84]

4.1 Measure Topic Identification/Prioritization

Collaborating with diverse stakeholders and patient partners helps researchers ensure transparency, accessibility, and reciprocity in the measure selection process; it also yields the selection of measures that are actionable, the results of measurement provide information that can be interpreted and acted upon, and feasible to implement for data collection and analysis.[85] Further, given the imperative to measure patient-reported health outcomes as part of patient-centered implementation, participatory evaluation processes that prioritize patient voices (or at least account for patients' priorities) are especially valuable.[86]

These collaborative processes, informed by the depth and breadth of input from diverse partners, can help surface outcome measures for assessing effectiveness in ways that are meaningful for key stakeholders.[87] Thus, to account for diverse perspectives, measure selection processes should:

- Initially identify the measure topics prioritized by patients, families, and caregivers from diverse backgrounds and communities.[86]
- Intentionally include both subject matter experts (SMEs) and those with lived experience in the intervention context.[88]

By developing robust partnerships, rather than soliciting ad hoc input, researchers can facilitate the solicitation and integration of invaluable input about the patient-reported health outcome measures most salient from patient, family, and caregiver perspectives.[89]

As it is critical to identify patient-reported health outcome measures meaningful for patients and caregivers, it is also critical to select those with robust measurement properties (i.e., content validity, construct validity, reliability).[90,91] In these processes, input from SMEs (e.g., clinicians, payers, industry representatives, measure developers) can supplement patient perspectives and inform selection of feasible, actionable measures: those meeting minimum standards set by the field to ensure production of rigorous, evidence-based findings that can contribute to generalizable knowledge.[90]

4.2 Measure Use

Outcome measurement of PC CDS typically falls into one of three categories:

- **Research and Evaluation Measurement** generates new evidence and knowledge for the field. Since these measures should be specific and tailored to a given intervention being used, the broad applicability of a measure is not a concern in this application.[92]
- **Quality Improvement Measurement** is used to glean information that assists clinicians, organizations, or systems in reforming or shaping care delivery.[93] Measurement for quality improvement typically focuses on assessing current, cross-sectional "snapshots" of information that are easy to collect, interpret, or use.[92] For quality improvement applications, measurement results can help demonstrate or inform progress toward achieving goals related to delivering high-quality, efficient, effective, patient-centered care.
- **Accountability Measurement** can be used to inform actionable judgments or decisions, based on observed performance. For example, performance measurement results can be used to dictate reward, reimbursement, or punitive action. Measures selected for accountability reporting are typically preselected as measures of importance by an external body or party.[92] It is essential that the accountable body (e.g., clinician, organization, system) have control or influence over the aspects of care assessed by measures used for accountability measurement.

Notably, the tolerance thresholds for corresponding measure selection criteria are influenced by these different contexts in which measures are used: research and evaluation, quality improvement, or reporting and accountability. For example, measurement bias is less a concern when measuring for quality improvement purposes as opposed to research or reporting purposes. When implementing measurement for quality improvement, if the same measure is utilized at baseline and for all subsequent measurement, changes and trends for a given measure can be assessed relative to baseline—despite the presence of bias.[92] In contrast, measures used for research and reporting purposes require a high level of precision, reliability, and validity.

4.3 Measure Selection Criteria

Selection of appropriate and accurate measures for use in both research and clinical practice is critical for advancing high-quality care. A measure needs to be selected and tailored (by condition, setting, population, or service-specific considerations) to correspond with its relevance as a patient outcome of a given intervention. When selecting and adapting a measure, it is important to account for the 1) priorities of the patient or other communities served, 2) measure's purpose and intended use, 3) clinical context or care environment in which it will be used, and 4) features of the PC CDS and of the broader intervention and/or implementation plan.

Several key resources, including those by the Agency for Healthcare Research Quality (AHRQ),[94] Centers for Medicare & Medicaid Services (CMS),[95] Consensus-based Standards for the Selection of Health Measurement Instruments (COSMIN),[96] International Society for Quality of Life Research (ISOQOL),[83] National Academy of Medicine (NAM),[97,98] National Committee for Quality Assurance (NCQA),[99] and National Quality Forum (NQF),[100] guided identification of the following considerations for assessing the appropriateness of a given measure for use in evaluating CDS: validity, reliability, responsiveness, feasibility, and usability.

The validity and reliability of a measure refers to the precision and accuracy of data collection. These concepts were commonly cited as important considerations for measure selection in the tools listed above. **Reliability** is commonly described as the consistency of scores collected under similar conditions,[101] whereas **validity** characterizes the extent an instrument measures what it is intended to measure—as well as the precision of data elements or scores reflecting the quality of care.[1,2,102]

Responsiveness is particularly significant when patients' outcomes are continuously monitored, as it assesses the speed and accuracy with which a measure can detect and reflect observed changes in scores consistent with actual changes resulting from the impact of the intervention in the target population. Ultimately, when considering outcome measure selection, as one KI stated, it's important to be thoughtful and intentional to choose measures most likely to responsively demonstrate an intervention's impact. Responsiveness can be considered a component of validity, as well.[3]

Feasibility considers the extent that concepts and findings related to a given measure are designed to be applicable and sustainable in future studies; NQF measures feasibility based on the ease of using collected data to assign qualitative meaning to an instrument's quantitative score or change in scores. **Usability** on the other hand, is the degree that potential audiences are using or might use performance data for accountability and performance enhancement in order to provide those in need with high-quality, efficient healthcare.[1,2] That is, a usable measure is one for which there are clear actions that can be taken in response to measure results.

Overall, selecting appropriate outcome measures by considering the reliability, validity, responsiveness, feasibility, and usability of a measure can help ensure generation of unbiased, actionable results that meaningfully contribute to care and/or practice improvement decisions. As noted by key informants, the selection of a few reliable, valid, feasible measures that are responsive to an intervention's impact will often result in more actionable evaluation results than a larger selection of less well-suited measures.

5. Use Cases

Three use cases were developed to demonstrate how outcome measurement may be applied in an evaluation of PC CDS. Selection of outcome measures is only one component of a comprehensive evaluation. The below use cases illustrate factors that need to be taken into account when planning a measurement approach for a PC CDS evaluation, including clinical context and tool functionality, as well as outcome measure selection. The use cases below were selected to present discrete outcome measurement, as illustrated using common clinical scenarios and framed in a way to be accessible to audiences both deeply familiar with CDS, as well as those less familiar.

The first use case (Use Case 1: Breast Cancer Screening) was selected to represent patient health journey outcomes, including improved knowledge and the ability to participate in shared decision making as outcomes of PC CDS. The second (Use Case 2: Chemotherapy CDS) and third (Use Case 3: Heart Failure Treatment) use cases were chosen to demonstrate the identification and selection of relevant patient-reported health outcomes. Use Case 2 includes general, condition-agnostic, perceived health, as measured through the Short Form Health Survey (SF-36), whereas Use Case 3 demonstrates perceived health status outcome measurement via a cardiomyopathy-specific questionnaire. These use cases were specifically selected to show the contrast between a general health outcome and a disease-specific outcome.

Outcome measures can be implemented in clinical workflows in various ways, such as integrating survey questionnaires into a pre-visit assessment via a patient portal, or pulling data directly from an EHR, FHIR, or SMART application. Key informants emphasized the importance of considering feasibility of data collection and measure integration with existing functional systems and workflows when selecting measures.

5.1 Use Case 1: Breast Cancer Screening

Clinical Context: Personalized education for patients for breast cancer screening

The U.S. Preventive Services Taskforce (USPTF) recommends that women who are 40-74 years old and are at average risk of breast cancer receive a mammogram every 2 years.[103] Mammograms lower the risk of dying of breast cancer, and it is important for individuals to understand their risk.[104] There is a wide variation in expected benefits vs. harms (e.g., false positives, false negatives, etc.).[105]

PC CDS Functionality: Many decision support applications exist related to cancer screening and other preventive treatment. In one scenario, a decision support application could provide alerts to the patient to suggest screening at regular intervals, along with providing information on the net benefit of screening, the strength of the evidence, the USPSTF recommendation, and the rationale for the recommendation. The app could connect to the EHR to leverage information about a family or personal history of breast cancer, the patient's age, and the patient's genetic results to personalize the recommendations and assessment of benefits. Patients could use the tool to learn about their risk of breast cancer and understand the risks associated with screening mammography. Patients would have the option to read through the information to prepare for a discussion with their clinician.

Outcomes Measurement:

Measure Topic	Specific Measure	Data Source	Measure-Specific Considerations
Knowledge	Study-specific questionnaire querying patient knowledge of breast cancer risk factors	Survey questionnaire	This questionnaire would be tailored to align with the information about breast cancer risk factors conveyed via the application
Shared Decision Making Experience	CollaboRATE	Survey questionnaire	

5.2 Use Case 2: Chemotherapy Clinical Decision Support

Clinical Context: Detecting worsening symptoms in patients receiving chemotherapy

Patients with cancer who are receiving chemotherapy may experience symptoms due to disease progression or undesirable side effects of their treatment.[106,107] These symptoms can sometimes progress to the point where acute care services (e.g., admission or emergency department use) are necessary.[108] An application that captures patient symptoms and informs the patient or clinician when the patient's condition is worsening could lead to interventions that would mitigate the need for acute services.[51] Such a hypothetical application would take patient-generated data as input and use clinical decision support to generate status flags (e.g., red, yellow, green) based on symptom severity.

PC CDS Functionality: The patient could use a mobile app to enter their symptoms and signs (e.g., temperature) on a daily or twice-daily basis. The application could interface with the EHR both to receive data about the patient and to communicate the results of CDS assessment to the clinician. The patient status would be "green" if there are no or very mild symptoms; "yellow" if the symptoms are moderate, thus triggering an alert to chemotherapy team; or "red" if the symptoms are worrisome, generating an alert to an on-call clinician. Data elements captured by the app would include patients' general well-being, sensation of fever and/or actual temperature, list of symptoms appropriate to cancer/chemotherapy (e.g., shortness of breath, nausea, vomiting, abdominal pain, diarrhea), appetite, and others.

Outcomes Measurement:

Measure Topic	Specific Measure	Data Source	Measure-Specific Considerations
General Perceived Health	Short Form Health Survey (SF-36)	Survey Questionnaire	Instrument also available in 12-item length
Satisfaction (Care)	Patient Satisfaction Questionnaire (PSQ)	Survey Questionnaire	
General Perceived Physical Health	MD Anderson Symptom Inventory	Survey Questionnaire	Condition-specific inventory

5.3 Use Case 3: Heart Failure Treatment

Clinical Context: Monitoring heart failure

Heart failure patients are at risk for frequent admissions, which is a circumstance that patients are eager to avoid.[109] Patients with heart failure may gain weight due to increased fluid retention, become weaker, and become increasingly short of breath between encounters with their clinicians.[110] Automated methods to capture the patient's weight (e.g., Bluetooth-enabled scales) and symptom monitoring methods can be used to inform clinicians when the patient's condition is worsening.[111-113]

PC CDS Functionality: A decision support application could be used to track a patient's current treatment regimen and weight. When the app detects an increase in the patient's weight, it can interact with the patient to ask about symptoms related to heart failure (e.g., weakness, shortness of breath). The application then can generate recommended next steps for the patient or the clinician. For example, a patient may be advised to restrict salt intake, while a clinician may receive a recommendation for medication changes.

Outcomes Measurement:

Measure Topic	Specific Measure	Data Source	Measure-Specific Considerations
General Perceived Health	Kansas City Cardiomyopathy Questionnaire	Survey Questionnaire	Need method of implementation to assure capture of data in proximity to a scheduled visit
Satisfaction (Care)	The Press Ganey® Outpatient Medical Practice Survey	Survey Questionnaire	

6. Discussion: Gaps, Limitations, and Recommendations for Future Work

As PC CDS is intended to support patient-centered care, it is essential that the field identify measures to assess whether (and how) PC CDS influences the outcomes important to patients. While this report offers an early effort to do this based on available literature, it also highlighted the need and opportunity for future work to develop this evidence base. The following sections present 1) measurement gaps in the existing literature, as identified through the scan; 2) limitations of this review; and 3) recommendations for future research. These recommendations are organized into the following three focus areas: patient health journey outcomes measurement, patient-reported health outcomes measurement, and implementation.

6.1 Measures with Limited Attention in the CDS Literature

PC CDS is intended to support patient-centered care; thus, it is essential that the field identify measures to assess the impact PC CDS has on outcomes important to patients. While not exhaustive, our literature scan surfaced the following patient-focused measurement areas that have received little to no attention to date, with respect to use in evaluating PC CDS.

Patient Health Journey Outcomes Measurement. Several measurement topics commonly associated with Engagement and Care Experience subdomains in the broader literature were not found in our literature review.

Specifically, in the Care Experience subdomain, we documented measures of only patient satisfaction with care in the CDS literature. Topics not identified included:

- Timeliness: the ability of a patient to access needed appointments, medication, care, and other services in an appropriate timeframe.[114]
- Information access: the timeliness, transparency, accessibility, and content of information transmitted between a patient and their clinician.
- Communication quality: whether the correct information is communicated at the correct time, in the correct ways, and in ways that are aligned with best practice (e.g., reflecting respect for patients and sensitivity to what they can understand).[115]
- Care coordination: the extent to which delivery of patient care and health information is synchronized and managed across multiple clinicians, systems, or other service providers.[116]
- Satisfaction: a number of measures related to patient satisfaction were identified in the CDS literature. However, there is opportunity to explore use of additional instruments, such as the Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys. The CAHPS surveys are widely used to assess patient satisfaction with care in the U.S. healthcare system, and their adoption in this context could afford new opportunities to link with policy programs that support scale and spread of PC CDS, as well.

In the Engagement subdomain, we did not identify measures related to:

- Patient activation: indicators of if, how, and/or how often patients collaborate with their clinicians in decision making or otherwise participate in managing their condition (given appropriate skills, knowledge, health functioning, and access to appropriate care).[117] Key informants noted this lack of patient activation measures as a significant gap in existing literature.
- Non-medication-related adherence: measures of adherence tended to focus solely on medication adherence rather than accounting for adherence to other elements of a care plan (e.g., lifestyle changes). This may be because these are measured by the indicator of adherence (e.g., smoking status) rather than as a patient-reported care plan adherence measure. Alternatively, this “measurement gap” may reflect the types of CDS that have been developed and reported on to date, rather than a true gap in measurement.
- Condition-agnostic measures for self-management: these measures were always tailored to clinical context. It is unclear if this reflects a true gap or a reality that these measures must be tailored in order to produce the level of validity/responsiveness needed for outcome evaluation in the PC CDS context.
- Trust: trust in individual physician was the only measure identified in the CDS evaluation literature. Contributing experts agreed that the multidimensional nature of trust and the complexity of patient interactions merits assessment of trust in care teams and the broader system, as well as individual physicians, so these may represent opportunities for future outcome assessment in PC CDS evaluation.

Patient-Reported Health Outcomes Measurement. Our scan also surfaced several measurement areas included in the ICHOM Framework that were not represented in the CDS outcome evaluation literature, such as general physical health, fatigue, mobility, vitality, sleeping, interpersonal functioning, and work-related outcomes. As above, we did not independently assess whether these reflect missed measurement opportunities versus the variation in target clinical decision contexts targeted by CDS described in the literature to date. While measures for these outcomes were not identified in the literature review, a number of validated measures and instruments do exist and could be considered by PC CDS evaluators in the future, if these topics are relevant to their assessments. A non-exhaustive list of examples is provided below by subdomain:

- Physical Health
  - Patient Reported Outcomes Measurement Information System (PROMIS) Scale v1.2 – Global Health[118] – *general physical health, fatigue*
  - World Health Organization (WHO) Disability Assessment Schedule 2.0[119] – *mobility*
  - PROMIS Mobility[120] – *mobility*
- Mental Health
  - WHO-5 Well-Being Index[121] – *vitality, sleeping*
  - PROMIS Sleep-Disturbance[122] – *sleeping*
- Social Health
  - Protocol for Responding to and Assessing Patient Assets, Risks, and Experiences (PRAPARE)[123] – *interpersonal functioning*
  - WHO Disability Assessment Schedule 2.0[119] – interpersonal functioning, work-related outcomes

6.2 Limitations

This review is subject to several limitations. First, while a large number of CDS studies were reviewed to identify and catalogue relevant outcomes, this report does not reflect a comprehensive, systematic review or compilation of all patient outcome measures documented in the literature. Since we leveraged systematic reviews as the main data source, data were solely extracted from these articles and studies they encompassed. This may have limited the scope of literature we reviewed and, thus, our ability to report the full breadth of patient outcome measures researchers have utilized. Additionally, as work to categorize and standardize these patient outcome measures is nascent, some suggested groupings may require further refinement. Finally, measurement domains and subdomains were identified as relevant *a priori* in consultation with SMEs, rather than via conceptual or empirical causal analysis of PC CDS.

6.3 Recommendations for Future Work

The literature review and KIIs presented in this report revealed several noteworthy gaps in the current landscape of research on patient outcome measures for PC CDS. In general, there are opportunities for assuring that both patient health journey outcomes and patient-reported health outcomes are captured as part of assessing PC CDS effectiveness. Additionally, further research to explore and understand implementation considerations can improve the use of these outcomes in practice—to support meaningful evaluations and generate new knowledge about PC CDS effectiveness. **Table 7** outlines potential priorities for addressing knowledge gaps and operationalizing the measurement of patient outcomes in PC CDS assessment.

Table 7. Areas for Future Work.

Focus Area	Topics
Patient Health Journey Outcomes Measurement	• Develop and identify measures for adherence to non-medication treatment or clinical guidelines that may be used to evaluate PC CDS effectiveness. • Develop and identify measures of patient experience that may be used to evaluate PC CDS effectiveness. • How can existing resources such as the Consumer Assessment of Healthcare Providers and Systems (CAHPS) capture patient experiences with PC CDS?
Patient-Reported Health Outcomes Measurement	• Develop and identify measures of general perceived physical health, fatigue, and mobility that may be used to evaluate PC CDS effectiveness. • Develop and identify measures of interpersonal functioning and work that may be used to evaluate PC CDS effectiveness. • Develop and identify measures of vitality and sleeping that may be used to evaluate PC CDS effectiveness.
Implementation	• How can patient health journey outcome measures be routinely captured within clinical workflows? • What opportunities and challenges exist for using patient-reported health outcomes to measure PC CDS effectiveness? • How can evaluations of PC CDS assure there are not disparities in who benefits from the use of technology? • What approaches for PC CDS measurement implementation enable continuous quality improvement? • What are the best approaches to prioritize and select measures important to patients within system settings?

7. Conclusion

Evaluating CDS with an eye toward patient-centeredness requires accounting for the effects of PC CDS on 1) patients' perceptions of, engagement with, and experiences of their health journeys and 2) health outcomes important to patients, such as symptoms and functioning. While not exhaustive, the measures gathered as part of this report, and the use cases presented, may provide a starting point for studying how PC CDS influences patient-focused outcomes in both research and real-world settings. This work may help researchers, developers, and implementers select measures that are fit-for-purpose in evaluating PC CDS relative to outcomes of import for patients. As the field of PC CDS continues to evolve, it will be imperative to undertake future work that addresses existing gaps in measurement and advances evidence on this topic. This can help ensure that assessments of PC CDS effectiveness reflect patients' needs and priorities, so that future development and deployment can be responsive.

Appendix A. Methods

Table A1. Level of Analysis and Inclusion Criteria for Literature Search Findings.

Level of Analysis	Inclusion Criteria	Results
Systematic Review	• Compiled studies of CDS • English language • Included a discussion of outcomes assessment	Summary of all patient outcomes used to evaluate CDS
Study	• Included in one of 31 identified systematic reviews • Full-text study available • Evaluation that included assessment of patient outcomes	Types of patient-reported health outcomes aligned with the ICHOM Framework used to evaluate CDS
Measure	• Included in one of 31 identified systematic reviews • Full-text study available • Evaluation that included assessment of patient journey outcome	Inventory of patient health journey outcome measures used in CDS effectiveness assessment to-date

Table A2. Search Strategy.

Search Strategy	Results	Relevant Results
(("cochrane database syst rev"[Journal] AND "review"[Publication Type]) OR "systematic review"[Publication Type] OR ("systematic review"[Title] OR "systematic literature review"[Title] OR "systematic scoping review"[Title] OR "meta-analysis"[Title])) AND ("clinical decision support"[Title/Abstract] OR "decision support systems, clinical"[MeSH Terms]) AND "outcome assessment, health care"[MeSH Terms]	26	12
(("cochrane database syst rev"[Journal] AND "review"[Publication Type]) OR "systematic review"[Publication Type] OR ("systematic review"[Title] OR "systematic literature review"[Title] OR "systematic scoping review"[Title] OR "meta-analysis"[Title])) AND ("clinical decision support"[Title/Abstract] OR "decision support systems, clinical"[MeSH Terms]) AND "patient outcomes"	43	14 (6 duplicates from previous searches removed)
Searches pulled from the CDSiC Scaling, Measurement, and Dissemination Workgroup		5
Total	**69**	**31**

Appendix B. Patient Health Journey Outcome Measure Inventory

Table B1. Measures of Decision Making.

Measure Topic	Measures from CDS Studies	Measure Description	Validated?	Instrument Name *(if validated)*
Decision Quality	Decision Quality Instrument (DQI)	Decision-specific questionnaires that assess decisional quality in three different areas:[16,17] 1) Decision-specific knowledge questions that assess patient understanding of the options and outcomes. 2) Decision-specific goals and concerns that are used to examine the extent to which patients receive treatment that is concordant with their goals. 3) Involvement questions that assess the extent to which patients are meaningfully involved in the decision-making process with their clinician.	Yes	Decision Quality Instrument (DQI)
Decision Regret	Decision Regret Scale	Five-item survey with each question using a five-level Likert scale that measures regret or remorse after a decision. Patients respond to the items after reading the prompt: "Please think about the decision you made about [chosen healthcare decision] after talking to your [doctor, surgeon, nurse, health professional, etc.]." A total score (0-100) is calculated with higher scores indicating more regret.[17,124]	Yes	Decision Regret Scale
SDM Experience	Shared Decision-Making Process Scale	Brief survey that measures the level of patient engagement in SDM. Survey items focus on four main aspects of SDM: discussion of options, pros, cons, and preferences. A total score is generated (from 0-4) with higher scores indicating more SDM.[17,125]	Yes	Shared Decision-Making Process Scale
	CollaboRATE	Three-item measure assessing the patient's perspective of the level of shared decision making at a clinical encounter. Items prompt patients to reflect on how much effort was made to 1) help them understand their health issues, 2) listen to the things that matter most to them about their health issues, and 3) include what matters most to them in choosing what to do next.[17,126]	Yes	CollaboRATE
Decisional Conflict	SURE Scale	Brief, four-item version of the widely used Decisional Conflict Scale that measures patients' uncertainty about which treatment to choose and factors contributing to uncertainty. The four items address key concepts related		SURE Scale

Measure Topic	Measures from CDS Studies	Measure Description	Validated?	Instrument Name *(if validated)*
		to decisional conflict: 1) Sure of myself ("Do you feel sure about the best choice for you?); 2) Understand information ("Do you know the benefits and risks of each option?"); 3) Risk-benefit ratio ("Are you clear about which benefits and risks matter most to you?"); and 4) Encouragement ("Do you have enough support and advice to make a choice?").[17,25]		
	Decisional Conflict Scale: Informed Subscale	This subscale has three items and measures how informed a respondent feels regarding their care options. It is part of an instrument with 16 questions and five subscales. The overall score ranges from 1–5, with 5 representing greater decisional conflict.[17,127]		Decisional Conflict Scale
	Decisional Conflict Scale: Values Clarity Subscale	This subscale has three items and measures how clearly the respondent feels about their personal values for benefits and risks/side effects. It is part of an instrument with 16 questions and five subscales. The overall score ranges from 1–5, with 5 representing greater decisional conflict.		Decisional Conflict Scale
	Decisional Conflict Scale: Support Subscale	This subscale has three items and measures how supported the respondent feels in making their decision. It is part of an instrument with 16 questions and five subscales. The overall score ranges from 1–5, with 5 representing greater decisional conflict.[17,127]		Decisional Conflict Scale
	Decisional Conflict Scale: Uncertainty Subscale	This subscale has three items and measures how certain the respondent feels about their choice. It is part of an instrument with 16 questions and five subscales. The overall score ranges from 1–5, with 5 representing greater decisional conflict.[17,127]	Yes	Decisional Conflict Scale
	Decisional Conflict Scale: Effective Decision Subscale	This subscale has four items and measures whether the respondent feels they have made a good or bad decision. This last subscale is usually used after the decision only. It is part of an instrument with 16 questions and five subscales. The overall score ranges from 1–5, with 5 representing greater decisional conflict.[17,127]	Yes	Decisional Conflict Scale

Table B2. Measures of Patient Engagement.

Measure Topic	Measures from CDS Studies	Measure Description	Validated?	Instrument Name *(if validated)*
Knowledge	Child Knowledge of Asthma Management	Study-specific 30-item survey assessing children's knowledge of asthma self-management. Each item presents a statement about asthma self-management and includes possible responses of “yes,” “no,” and “don't know.”[39]	No	N/A
	Patient Knowledge of Statins	Study-specific, self-administered written questionnaire that included 7-point Likert-type scales to explore patient perceptions of the amount, clarity, and helpfulness of the information, willingness to recommend the way statins were discussed with others, and desirability of using the process of sharing information in future decisions. The questionnaire included 14 knowledge questions to assess patient understanding of the relative merits of using or not using statins.[32]	No	N/A
	Knowledge and Appraisal Questionnaire	Study-specific instrument developed by study authors to assess information retained after using the "Asthma Files" educational program.[33]	No	N/A
	Pediatric Asthma Care Knowledge Survey	50 questions on basic asthma concepts and 10 questions on dilemmas dealing with real-life asthma scenarios.[31]	No	N/A
	Patient Beliefs of Breast Cancer Risk Factors	Study-specific measure corresponding to the patient responses to a postal questionnaire about perceived breast cancer risk.[128]	No	N/A
	Cancer Risk Perception	Study-specific questionnaire mailed to patients to measure cancer risk perception. Risk perception was measured on a scale of 1-7, relative to the general population, considering 1 as 'much less likely…' and 7 as 'much more likely to develop breast/bowel cancer than other people of your age.' For one analysis, responses of 1-4 were classified as 'population risk' and 5-7 as 'increased risk'. This was compared to a risk assessment conducted by the Regional Genetics Clinic to classify patients as under-estimators, accurate-estimators, and over-estimators.[28]	No	N/A
	Knowledge of Self-Management Questionnaire	Study-specific instrument developed by study authors to assess self-management and knowledge of Heart Failure (HF) care. For example, to determine the extent to which patients recognized their HF medications, the interviewer collected the prescription bottles for all current medications, read the name and presented each medication to the patient, and asked the patient to indicate whether it was taken for his/her heart condition or related side effects.[78]	No	N/A
Adherence	Morisky Medication	Eight-item structured, self-report measure that assesses medication adherence. If a patient	Yes	Morisky Medication

Measure Topic	Measures from CDS Studies	Measure Description	Validated?	Instrument Name *(if validated)*
	Adherence Scale-8 (MMAS-8)	scores higher on the scale, they are considered more adherent.[37]		Adherence Scale-8 (MMAS-8)
	Medication Possession Ratio	Formula used to determine adherence from the first to last prescription. It is a ratio of the days of medication supplied for a period over the duration of the period.[37]	No	N/A
	Statin Adherence	Study-specific survey to determine whether patients were taking statins and, using a single question, whether they had missed any statin doses in the last week.[32]	No	N/A
	Patient-Reported Medication Adherence	Study-specific adherence telephonic questionnaire, with three items were adapted from the Brief Medication Questionnaire, which asked about number of days in past week a pill was forgotten, not taken on purpose, or added. Two additional items were developed specifically for this study to assess average adherence without reference to a specific time frame and inquired whether less medication was taken because the patient felt less need for it, and how often the patient forgot to take their medicine.[36]	No	N/A
	Medication Refill Adherence: Automated Pharmacy Records on Refill Adherence and Lapsed Refilling	Prescription refill adherence was assessed by reviewing pharmacy records. Records included the drug name, quantity, dose strength, and dose frequency of hypertension medication. Refill adherence was based on the time-weighted average of the proportion of days for which there was (referred to as refill adherence) or was not (referred to as lapsed refilling) adequate supply of antihypertensive medication as determined from automated pharmacy dispensing records during the 12 months before electronic monitoring.	No	N/A
	Medication Refill Adherence: Pill Counts During Electronic Monitoring	Prescription refill adherence was assessed by reviewing pharmacy records. Records included the drug name, quantity, dose strength, and dose frequency of hypertension medication. Pharmacists counted and recorded the number of tablets remaining in returned medication vials whenever participants refilled their prescriptions during the study.[36]	No	N/A
	Medication Refill Adherence: Electronic Adherence Monitors (Dose Count and Timing)	Prescription refill adherence was assessed by reviewing pharmacy records. Records included the drug name, quantity, dose strength, and dose frequency of hypertension medication. Electronic dose count adherence was calculated based on the proportion of prescribed doses consumed. Electronic dose timing adherence was calculated based on the proportion of recorded doses taken close to the recommended time.	No	N/A

Measure Topic	Measures from CDS Studies	Measure Description	Validated?	Instrument Name *(if validated)*
Self-Management	Child Self-Efficacy for Asthma Self-Management	Study-specific 23-item questionnaire developed to determine change in confidence in performing self-regulatory and asthma specific behaviors. Items included in the questionnaire are related to: confidence in monitoring symptoms, environment, medicine taking, and healthcare use; confidence in deciding whether there is an asthma problem; and confidence in determining appropriate solutions and acting on them.[39]	No	N/A
Preparedness	B-PREPARED: Self-Care Information for Medications and Activity	Measures patient perception of preparedness for hospital discharge. This component assesses self-care information for medication and activities with five items, while the tool overall assesses three components: self-care information for medications and activities, equipment and services, and confidence with eleven items.[40,41]	Yes	The Brief-PREPARED Patient Questionnaire
	B-PREPARED: Equipment and Services	Measures patient perception of preparedness for hospital discharge. This component assesses equipment and services with four items, while the tool overall assesses three components: self-care information for medications and activities, equipment and services, and confidence with eleven items.[40,41]	Yes	The Brief-PREPARED Patient Questionnaire
	B-PREPARED: Confidence	Measures patient perception of preparedness for hospital discharge. This component assesses patient confidence with two items, while the tool overall assesses three components: self-care information for medications and activities, equipment and services, and confidence with eleven items.[40,41]	Yes	The Brief-PREPARED Patient Questionnaire
Trust in Clinician	Trust in Physician Scale	An eleven-item self-report instrument developed to assess an individual's level of interpersonal trust in their physician. The measure uses a 5-point scale (1=strongly disagree, to 5=strongly agree).[42,129]	Yes	Trust in Physician Scale

Table B3. Measures of Patient Experience.

Measure Topic	Measures from CDS Studies	Measure Description	Validated?	Instrument Name *(if validated)*
Satisfaction	American Board of Internal Medicine Patient Satisfaction Questionnaire (ABIM-PSQ)	10-item questionnaire developed to measure patient satisfaction with physicians' communication abilities.[37]	Yes	American Board of Internal Medicine Patient Satisfaction Questionnaire (ABIM-PSQ)

Measure Topic	**Measures from CDS Studies**	**Measure Description**	**Validated?**	**Instrument Name *(if validated)***
	Patient Experience Survey (Emotional Support Satisfaction)	The PES captures patient demographic variables and patient satisfaction on emotional support through ten questions (measured on a Likert scale ranging from zero to ten). The PES also asks patients to rate the amount of emotional support they receive (get) and the amount desired (need) from each member of the multidisciplinary team, expressed as a Relative Emotional Support Index score (get − need). A positive score indicates receipt of more than desired, and a negative score reflects receipt of less than desired.	No	N/A
	Patient Experience Survey (Treatment Support Satisfaction)	The PES captures patient demographic variables and patient satisfaction with treatment support through ten questions (measured on a Likert scale ranging from zero to ten). A positive score indicates receipt of more than desired, and a negative score reflects receipt of less than desired.	No	N/A
	Satisfaction with Provider	Study-specific measure utilizing a single item to assess patient satisfaction with treatment: "if a friend were in need of similar help from a GP would you recommend your GP to him/her."[76]	No	N/A
	Patient Experience of Primary Care: Access to Care Scale	Survey instrument that assesses patients' experiences with their primary care providers (including satisfaction) and to aid users' quality improvement efforts.[47] This subscale measures patients' access to care through four items (e.g., ease of scheduling appointment).	Yes	Name of instrument not confirmed
	Patient Experience of Primary Care: Office Visit Scale	Survey instrument that assesses patients' experiences with their primary care providers (including satisfaction) and to aid users' quality improvement efforts.[47] This subscale measures patients' experience in the waiting area prior to the visit (e.g., courtesy of registration staff).	Yes	Name of instrument not confirmed
	Patient Experience of Primary Care: Care Provider Scale	Survey instrument that assesses patients' experiences with their primary care providers (including satisfaction) and to aid users' quality improvement efforts.[47] This subscale measures patients' experience with their provider (e.g., provider's clarity of communication with the patient).	Yes	Name of instrument not confirmed
	Patient Experience of Primary Care: Personal Issues Scale	Survey instrument that assesses patients' experiences with their primary care providers (including satisfaction) and to aid users' quality improvement efforts.[47] This subscale measures patients' experience with more personalized aspects of their care (e.g., sensitivity to patients' needs.	Yes	Name of instrument not confirmed

Measure Topic	Measures from CDS Studies	Measure Description	Validated?	Instrument Name *(if validated)*
	Patient Experience of Primary Care: Overall Assessment Measure	Survey instrument that assesses patients' experiences with their primary care providers (including satisfaction) and to aid users' quality improvement efforts.[47] This subscale measures patients' overall assessments of their care (e.g., likelihood to recommend practice).	Yes	Name of instrument not confirmed
	Satisfaction with Information About Medicines Scale: Action and Usage Subscale	Seventeen-item scale that assesses patient satisfaction with information about medications, specifically whether patients feel that they have received enough information about their prescribed medications, with high scores meaning high satisfaction. The scale comprises two subscales, identifying patients' satisfaction with 1) the action and usage of their medication, and 2) the potential problems of their medication.[40,130]	Yes	Satisfaction with Information About Medicines Scale
	Satisfaction with Information About Medicines Scale: Potential Problems of Medication Subscale	Seventeen-item scale that assesses patient satisfaction with information about medications, specifically whether patients feel that they have received enough information about their prescribed medications, with high scores meaning high satisfaction. The scale comprises two subscales, identifying patients' satisfaction with 1) the action and usage of their medication, and 2) the potential problems of their medication.[40,130]	Yes	Satisfaction with Information About Medicines Scale
	Press Ganey® Outpatient Medical Practice Survey – Overall Satisfaction with Care	A 2-item scale focused on overall satisfaction with *care received during* an outpatient visit. One of six scales in the 24-item Press Ganey® Outpatient Medical Practice Survey instrument which measures patient satisfaction with outpatient healthcare in the United States.	Yes	Press Ganey® Outpatient Medical Practice Survey
	Press Ganey® Outpatient Medical Practice Survey – Satisfaction with Personal Issues	A 4-item scale focused on patient satisfaction with *personal issues* during an outpatient visit. One of six scales in the 24-item Press Ganey® Outpatient Medical Practice Survey instrument which measures patient satisfaction with outpatient healthcare in the United States.	Yes	Press Ganey® Outpatient Medical Practice Survey
	Press Ganey® Outpatient Medical Practice Survey – Satisfaction with Care Provider	A 10-item scale focused on patient satisfaction with *care provider* during an outpatient visit. One of six scales in the 24-item Press Ganey® Outpatient Medical Practice Survey instrument which measures patient satisfaction with outpatient healthcare in the United States.	Yes	Press Ganey® Outpatient Medical Practice Survey
	Press Ganey® Outpatient Medical Practice Survey – Satisfaction with Nurse Assistant	A 2-item scale focused on patient satisfaction with *nursing assistant care* during an outpatient visit. One of six scales in the 24-item Press Ganey® Outpatient Medical Practice Survey instrument which measures patient satisfaction with outpatient healthcare in the United States.	Yes	Press Ganey® Outpatient Medical Practice Survey

Measure Topic	Measures from CDS Studies	Measure Description	Validated?	Instrument Name *(if validated)*
	Press Ganey® Outpatient Medical Practice Survey - Satisfaction with Moving Through Visit	A 2-item scale focused on patient satisfaction with their experience *moving through an outpatient visit.* One of six scales in the 24-item Press Ganey® Outpatient Medical Practice Survey instrument which measures patient satisfaction with outpatient healthcare in the United States.	Yes	Press Ganey® Outpatient Medical Practice Survey
	Press Ganey® Outpatient Medical Practice Survey - Satisfaction with Access to Outpatient Care	A 4-item scale focused on patient satisfaction with *access* to outpatient care. One of six scales in the 24-item Press Ganey® Outpatient Medical Practice Survey instrument which measures patient satisfaction with outpatient healthcare in the United States.	Yes	Press Ganey® Outpatient Medical Practice Survey
	Patient Satisfaction with Doctor's Explanation of Problem	Study-specific measure corresponding with the proportion of patients who answered, "very satisfied" to the question "Rate your satisfaction of the doctor's explanation of your problem" (response options ranged from "dissatisfied" to "very satisfied".)[131]	No	N/A
	Patient Satisfaction Questionnaire (PSQ): Access to Care Subscale	This subscale of the PSQ focuses on access to care, and contains seven items (e.g., convenience of services). The PSQ contains over 50 Likert-type items that measure patient perceptions of aspects of their care. The items address satisfaction with care generally, but also have scales specific to six aspects of care: technical quality, interpersonal manner, communication, financial aspects of care, time spent with doctor, and accessibility of care.[49,132]	Yes	Patient Satisfaction Questionnaire (PSQ)
	Patient Satisfaction Questionnaire (PSQ): Financial Aspects Subscale	This subscale of the PSQ focuses on financial aspects of care, and contains eleven items (e.g., cost of care, insurance coverage). The PSQ contains over 50 Likert-type items that measure patient perceptions of aspects of their care. The items address satisfaction with care generally, but also have scales specific to six aspects of care: technical quality, interpersonal manner, communication, financial aspects of care, time spent with doctor, and accessibility of care.[49,132]	Yes	Patient Satisfaction Questionnaire (PSQ)
	Patient Satisfaction Questionnaire (PSQ): Availability of Resources Subscale	This subscale of the PSQ focuses on availability of care resources, and contains six items (e.g., availability of family doctors). The PSQ contains over 50 Likert-type items that measure patient perceptions of aspects of their care. The items address satisfaction with care generally, but also have scales specific to six aspects of care: technical quality, interpersonal manner, communication, financial aspects of care, time spent with doctor, and accessibility of care.[49,132]	Yes	Patient Satisfaction Questionnaire (PSQ)

Measure Topic	Measures from CDS Studies	Measure Description	Validated?	Instrument Name *(if validated)*
	Patient Satisfaction Questionnaire (PSQ): Continuity of Care Subscale	This subscale of the PSQ focuses on continuity of care, and contains four items (e.g., continuity of same provider across family members). The PSQ contains over 50 Likert-type items that measure patient perceptions of aspects of their care. The items address satisfaction with care generally, but also have scales specific to six aspects of care: technical quality, interpersonal manner, communication, financial aspects of care, time spent with doctor, and accessibility of care.[49,132]	Yes	Patient Satisfaction Questionnaire (PSQ)
	Patient Satisfaction Questionnaire (PSQ): Technical Quality Subscale	This subscale of the PSQ focuses on technical quality of care, and contains thirteen items (e.g., the quality and competence of a provider's care). The PSQ contains over 50 Likert-type items that measure patient perceptions of aspects of their care. The items address satisfaction with care generally, but also have scales specific to six aspects of care: technical quality, interpersonal manner, communication, financial aspects of care, time spent with doctor, and accessibility of care.[49,132]	Yes	Patient Satisfaction Questionnaire (PSQ)
	Patient Satisfaction Questionnaire (PSQ): Interpersonal Manner Subscale	This subscale of the PSQ focuses on the provider's interpersonal manner during care, and contains ten items (e.g., the quality of provider's communication with patients). The PSQ contains over 50 Likert-type items that measure patient perceptions of aspects of their care. The items address satisfaction with care generally, but also have scales specific to six aspects of care: technical quality, interpersonal manner, communication, financial aspects of care, time spent with doctor, and accessibility of care.[49,132]	Yes	Patient Satisfaction Questionnaire (PSQ)
	Patient Satisfaction Questionnaire (PSQ): Overall Satisfaction Subscale	This subscale of the PSQ focuses on patients' overall satisfaction with care, and contains four items (e.g., general satisfaction with medical care). The PSQ contains over 50 Likert-type items that measure patient perceptions of aspects of their care. The items address satisfaction with care generally, but also have scales specific to six aspects of care: technical quality, interpersonal manner, communication, financial aspects of care, time spent with doctor, and accessibility of care.[49,132]	Yes	Patient Satisfaction Questionnaire (PSQ)

Appendix C. Resources

The following tables present compiled patient outcomes measurement frameworks and repositories (i.e., measure and item banks) that can support identification, selection, and utilization of patient outcome measures relevant for PC CDS.

C.1 Measurement Frameworks and Sets

There exist many validated, widely used frameworks to identify and classify patient outcomes and to guide the selection of measures for research and evaluation. Some prominent patient outcome measure frameworks are presented in **Table C1**, below.

Table C1. Measurement Frameworks.

Title & Links	Source	Description
Framework of Overall Adult Health Domains Diagram	International Consortium for Health Outcomes Measurement (ICHOM)	A conceptual outcomes framework that features the present health state (i.e., quality of life, pain, cognitive function) and future health state (i.e., mortality risk at 5 years, life expectancy) as the two major domains of outcomes. An additional third domain, modifiable predictors of future health status (i.e., patient activation, lifestyle, health literacy) is also included as representing key factors that can impact a patient's present health state and future health state.
COMET COS Outcome Classification Taxonomy & Supplementary Table	Core Outcome Measures in Effectiveness Trials (COMET) Core Outcome Sets (COS)	This taxonomy was developed to help categorize key outcomes included in all COS, systematic reviews, trials and trial registries. It is based on other existing taxonomies but is unique in that it particularly focuses on outcomes relevant to clinical trials. The core outcome areas covered by the taxonomy include death, physiological/clinical, life impact, resource use, and adverse events. These core areas contain specific outcome domains ranging from mortality/survival to cardiac outcomes to global quality of life.
PROMIS Adult Domain Framework	Patient-Reported Outcomes Measurement Information System (PROMIS)	The PROMIS framework is both a classification system and a health outcomes model that depicts self-reported health as consisting of three specific aspects: • Physical Health (PH) (i.e., physical function, fatigue, sleep function). • Mental Health (MH): (i.e., cognitive function, depression, anger). • Social Health (SH): (i.e., quality of social support, social role performance, and social role satisfaction).
OMERACT Filter 2.0 Core Areas Framework	Outcome Measures in Rheumatology (OMERACT) Consensus Initiative	This framework was based off COS developed specifically for rheumatological conditions. The framework serves as a conceptual underpinning for the development of COS for specific health conditions, and thereby contains key patient-centered outcomes for clinical trial contexts. The framework includes three core Areas (i.e., Death, Life Impact, and Pathophysiological Manifestations) and one strongly recommended Area (i.e., Resource Use). Examples of domains include disease, quality of life, psychosocial impact, societal resource use for care, biomarkers, and reversible pathophysiological manifestations.

Title & Links	Source	Description
National Quality Forum (NQF) Measure Evaluation Criteria	National Quality Forum (NQF)	These measure evaluation criteria from the National Quality Forum contain key considerations for the development and evaluation of measure sets and measurement systems. Key criteria to consider include importance to measure and report, scientific acceptability of measure properties, feasibility, usability and use, and requirements for related and completing measures.
International Society for Quality of Life Research: User's Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice	International Society for Quality-of-Life Research	The International Society for Quality of Life Research User's Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice provides guidance to clinicians in selecting patient-reported outcomes measures in a clinical context. The guide provides considerations to a number of key questions useful for selecting measures (i.e., "What are your goals for collecting PROs in your clinical practice and what resources are available?", "Which key barriers require attention?", "Which groups of patients will you assess?", "How do you select which questionnaire to use?"). The guidance given under each of these questions offers potential approaches to measure selection, such as advantages and disadvantages to choosing a particular group of patients to evaluate with the patient-reported outcomes for example.

C.2 Measure and Item Banks

Organizations have also developed and maintained measure and item banks that enable researchers and evaluators to easily identify applicable measures for key patient outcomes. A selection of eminent measure and item banks are compiled in **Table C2**, below.

Table C2. Measure and Item Banks.

Title & Link(s)	Source	Description
COSMIN Database of Systematic Reviews of Outcome Measure Instruments	Consensus-based Standards for the selection of health Measurement Instruments (COSMIN)	This database curates and maintains systematic reviews of outcome measurement instruments. These reviews serve as resources to support researchers and research partners in choosing fit for purpose outcome measure instruments by providing key information regarding the quality measurement properties of these instruments. The database features different query fields including health domains (i.e., biological and physiological factors, health-related quality of life, symptom status), type of outcome measure instrument, and characteristics of the study population.
COMET Initiative Database of Studies Relevant to Core Outcome Set Development	COMET	The COMET Initiative Database curates studies that involve the development of core outcome sets for a variety of different health conditions, target populations, and intervention types. These core outcome sets are utilized within clinical trials. The database includes different query fields to qualify searches including disease category, disease name, and whether the study is published or unpublished. .

Title & Link(s)	Source	Description
PROMIS HealthMeasures Database	PROMIS	The HealthMeasures Database contains over 400 PROMIS measures from domains ranging from anxiety or fear to relationships or social support. The database provides the option to view the measure, scoring options, the measure administration platform(s), translations of the measure into other languages if available, and other background information. provides resources on, and is the distribution center for, PROMIS. The HealthMeasures Dataverse is a data repository housing nearly 40 de-identified datasets from studies that include PROMIS measures. Each dataset is accompanied by a brief description, codebook, and list of related publications.
Clinical Outcome Assessment (COA) Compendium	Food and Drug Administration (FDA)	The COA Compendium is a resource that contains a non-comprehensive list of clinical outcome assessments that have been utilized in clinical trials. The Compendium describes the particular disease or condition that the COA is relevant to, the population it may be used for, the concept that the COA measures, as well as the type of COA. that describes how certain COAs have been used in clinical trials to measure patients' experiences (e.g., disease-related symptoms) and to support labeling of claims.
Centers for Medicare and Medicaid Services Measures Inventory Tool	Centers for Medicare and Medicaid Services (CMS)	The Centers for Medicare and Medicaid Services Measures Inventory Tool (CMIT) contains over 500 quality measures that have been used by CMS. It includes key metadata regarding individual measures such as the measure's title, numerator, denominator, target population, data sources, type, meaningful measure areas, similar measures, and analysis from an environmental scan of the literature on the measure.
The University of Miami's Center of Excellence for Health Disparities Research: El Centro Measures Library	The University of Miami's Center of Excellence for Health Disparities Research: El Centro	The University of Miami's Center of Excellence for Health Disparities Research: El Centro Measures Library contains individual measures related to health disparities and organized by a number of qualifying categories including culture measures, stress and coping measures, general health measures, and healthcare service experience measures. The Measures Library summarizes key information about measures, allows users to view measures, and provides relevant information about relevant literature and translated versions of the measures as available.

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