



The Patient Engagement in Quality Measurement Rubric

A Guide to Patient Partnership in the
Quality Measure Lifecycle



Acknowledgements

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Overview of the Patient Engagement in Quality Measurement Rubric

Introduction

Measurement is increasingly integrated throughout the United States healthcare system as a powerful tool to guide quality improvement efforts, inform healthcare choices, and assess quality in value-based purchasing and reimbursement models. Quality measures that are currently used may have incorporated the best available evidence, but at the time they were developed and implemented, meaningful involvement from the patient community (defined as patients, family caregivers, advocates, and patient groups) was not included. For example, representatives from the patient community may not be included in certain segments of the quality measure lifecycle or may be brought into the process after much of the work is complete.¹ Additionally, individuals may be asked to represent the views or experiences of all patients. This signifies a missed opportunity to align system efforts and incentives around what matters most to patients – and what could most effectively improve outcomes.

To have optimal utility, a quality measure must be co-created in partnership with the patient community. As noted by the Centers for Medicare & Medicaid Services (CMS), strengthening individual, family representative, and caregiver engagement in the measure development process helps to identify meaningful issues from their perspective and to create high-quality measures that are easily understood, relevant, and useful.² To achieve this, quality measure developers and stewards must have a robust process in place to engage with the patient community as well as a method to evaluate the level of engagement. A similar necessity has been expressed in other facets of healthcare, including research, drug development, and value assessment. Within each of these areas, there are tools available to the patient community and other stakeholders to guide meaningful partnership with the patient community throughout their respective processes.³⁻⁶

The Patient-Centered Outcomes Research Institute (PCORI) provides guidance for patient engagement in research.^{3,7-9} For drug development, the Center of Excellence in Regulatory Science and Innovation at the University of Maryland established a framework and a rubric for assessing meaningful patient engagement.⁵ Lastly, the National Health Council (NHC) has developed both a Patient-Centered Value Model Rubric for value framework developers and a Patient Engagement Rubric that can be broadly applied across the health ecosystem.^{4,6} However, with respect to healthcare quality, a patient engagement rubric for the quality measure lifecycle does not exist.

To address the gap present in healthcare quality measurement, the Pharmacy Quality Alliance (PQA), in partnership with the NHC and the National Quality Forum (NQF), convened a national roundtable through a series of meetings with representatives from the patient, measure development, and other relevant stakeholder communities (Appendix A), to develop a Patient Engagement Rubric for Quality Measurement. This work built upon existing rubrics and is focused on describing the hallmarks of patient centeredness in the context of quality measurement and providing concrete guidance for engagement in the measure lifecycle.

The development of a quality-focused, patient-centered rubric will enhance the measurement community's ability to integrate meaningful patient partnership and engagement. It will also increase the patient community's capacity to systematically engage within the quality measure lifecycle. This tool will improve the ability to discern meaningful versus low engagement and provide recommended engagement activities that both the measurement and patient communities can utilize. Furthermore, implementation and use of this rubric will enable identification of patient engagement good practices within the quality measure lifecycle and opportunities for further rubric refinement and use.

Assessment of Patient Engagement in Quality Measurement

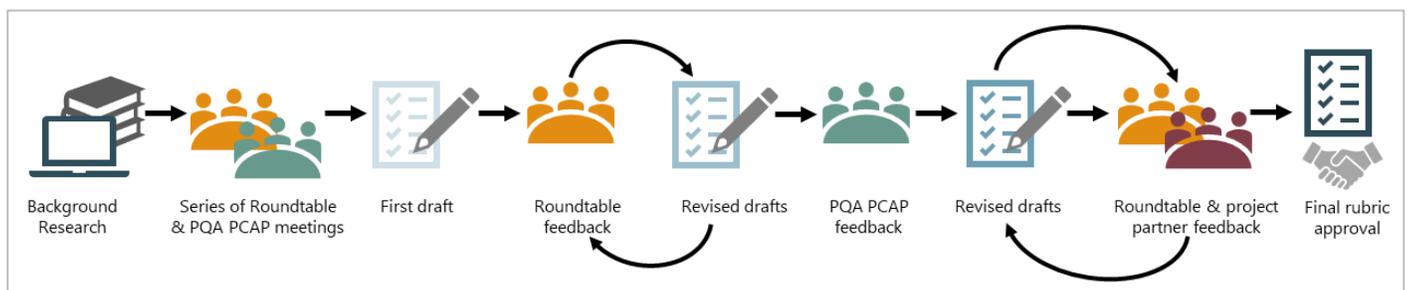
Rubric Development Process

In 2019, the PQA, NHC, and NQF convened a series of multi-stakeholder roundtable meetings with the objective of creating a patient engagement rubric to describe the characteristics of patient-centered quality measurement with the goal of supporting both meaningful engagement and evaluation of engagement in quality measurement. The roundtable was comprised of 17 individuals, with representation from measure and rubric development, patient-centered research, and the patient community (see Appendix A).

During the first roundtable meeting, participants discussed recent experiences with measure development, reviewed existing patient engagement rubrics and research in patient-centered principles, and identified hallmark characteristics of patient centeredness in quality measurement.^{4-6,10,11} Concurrent to the roundtable meeting, PQA engaged its Patient and Caregiver Advisory Panel (PCAP; Appendix B), a group that provides patient community voice to PQA measure development. The PQA PCAP agreed with recommendations provided by the roundtable and added further substantive suggestions, which were needed to create the first draft of the rubric.¹²

The draft rubric was then circulated through an iterative process to the roundtable participants, the PQA PCAP and the project partners for suggestions, edits, and refinement. Members of the roundtable, PQA PCAP, and project partner teams provided substantive edits during each round, making this rubric a co-written, patient-centered effort (See Figure 1).

Figure 1. Rubric Development Process¹



PQA PCAP: Pharmacy Quality Alliance Patient and Caregiver Advisory Panel

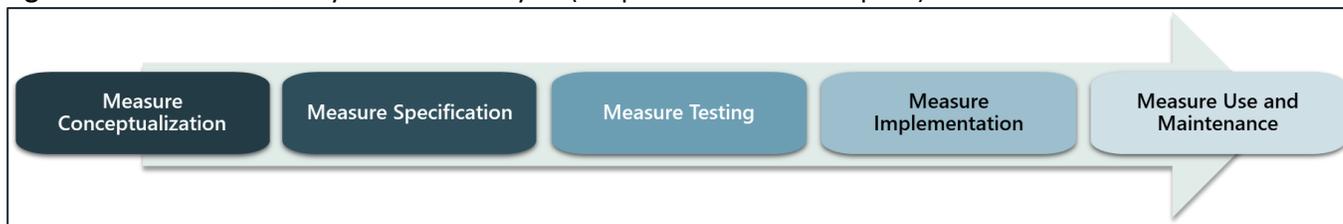
¹ Background research was conducted to identify existing patient engagement rubrics, patient-centered principles, and hallmark characteristics of patient-centeredness in quality measurement. Roundtable participants and the PQA PCAP discussed these items to inform the first draft of the rubric, which was revised through an iterative process with input from roundtable participants and project partners. The rubric was then shared with the PQA PCAP to obtain additional perspectives. Revisions were incorporated, and the draft rubric went through a second round of iterative edits among the roundtable participants and project partners. The final rubric was approved by all individuals listed and referred to in the acknowledgements section.

The Quality Measure Lifecycle: Domains and Descriptions

It is important to engage patients, family caregivers, and patient advocacy organizations within each domain of the quality measure lifecycle (see Figure 2), and there are many opportunities to do so. The quality measure lifecycle consists of five distinct domains as listed below and described in more detail in Appendix C.²

1. **Measure Conceptualization** – gathering information (e.g., identifying measurement and care gaps) to generate and prioritize a list of concepts to be developed.
2. **Measure Specification** – drafting the measure specifications (e.g., numerator, denominator, exclusions) and conducting an initial feasibility assessment.
3. **Measure Testing** – testing the measure to make sure it is working as intended.
4. **Measure Implementation** – taking the measure from development to an active, in-use state, which includes but is not limited to, consensus endorsement processes, measure selection processes, and measure rollout.
5. **Measure Use, Continuing Evaluation, and Maintenance** – evaluating and maintaining a measure based on their use and impact. To ensure ongoing viability for use, measures are evaluated on a regular basis for its importance and are updated or retired as needed to reflect current evidence, guidelines, and standards.

Figure 2. Domains of Quality Measure Lifecycle (adapted from CMS Blueprint)



Patient Centeredness Principles within the Quality Measure Lifecycle

Patients have important and unique perspectives and insights that enhance quality measurement. As the recipients of healthcare services, their perspectives, insights, and feedback represent key elements of developing optimal and meaningful quality measures. As such, the measure development community should aim to partner with the patient community throughout the quality measure lifecycle. After consideration, consensus was reached that a rubric to guide and assess patient engagement in the measure lifecycle should include the patient centeredness principles described in Table 1.

Table 1. Definitions of Patient-centeredness Principles

Principle	Definition
Patient Partnership	The patient community should be meaningfully engaged and supported throughout the quality measure lifecycle. This includes building and maintaining a co-learning, co-development environment where there is trust, honesty, and reciprocity. It also includes consideration of the tools and resources patient partners need, as well as adequate training for measure developers so they can achieve meaningful engagement.
Transparency	The patient community has timely access to understandable information needed to engage in the measure lifecycle. This includes the roles and expectations of the patient community, information needed to make decisions, and feedback on how their contributions have impacted the measure(s) being developed and/or implemented.

Principle	Definition
Representativeness	Representativeness refers to “who” and “how many” individuals to include in an interaction in order to, as closely as possible, engage with individuals that represent the broader population of people whose experience or outcomes are captured by the measure. ¹³ This also includes diversity of the representatives (e.g., stage of life, trajectory of disease, socioeconomic status, health literacy).
Meaningfulness	Patient-provided information about their goals, preferences, and priorities is incorporated into the measure lifecycle and drives what is measured and how performance is assessed. Patient-provided information can be generated from methods such as one-on-one interviews, focus groups, assessments, surveys, Delphi method.

Using the Patient Engagement in Quality Measurement Rubric

Involving the patient community in the quality measure lifecycle enhances the development of measures that are easily understood, meaningful, and useful for addressing quality issues important to the public. Thus, the Patient Engagement Rubric for Quality Measurement was developed as a standardized tool to guide and assess patient-community engagement in the measure lifecycle.

Definitions

Throughout the rubric, various terms are referenced. The following definitions should be considered while using the rubric:

- **Patient community:** The patient community includes individual persons, family representatives, caregivers, patient advocates, healthcare consumers*, and organizations that represent patients. Patient communities are diverse and include different populations and subpopulations.
- **Patient partners:** Patient partners refer to the individual persons from the patient community that are directly involved in the measure lifecycle processes. The intent is that individuals are representative of the population of interest for a measure. Patient partners are members of the measure development team and as such, are involved in measure development decision-making.
- **Patient-friendly and relevant materials:** Information and resources that describe the processes, outcomes, and expectations of the patient community in each domain of the measure lifecycle. These materials (e.g., read-ahead documents, preparatory calls) should be assessed for health-literacy appropriateness and be provided in plain language so as to be easily understood by patient partners and include information needed to make decisions during the measure lifecycle.
- **Patient-provided information:** Data generated from one-on-one interviews, focus groups, assessments (e.g., cognitive testing, plain language testing), surveys, Delphi method, and other methods to capture information from the patient community relevant for measurement (e.g., needs, goals, experiences). Suggestions of various qualitative and quantitative methods appropriate for use in the measure development process are available in the CMS Blueprint.² In the context of this rubric, “patient-provided information” is used to capture the extent to which the measure development processes and outcomes are meaningful to the patient community.

**It is important to note that individuals may view themselves as healthcare consumers, patients, or both. A person with a chronic disease relies on the healthcare system in a different way than a healthy person, who moves in and out of the healthcare system as needs change.⁶ This rubric uses the term “patient community” to more broadly capture these diverse perspectives.*

Intended Audiences and Uses

This rubric is intended for use by a variety of stakeholders and can be used for many purposes, including continuous quality improvement, guidance and assessment of meaningful patient engagement in the quality measure lifecycle, decision-making in measure implementation, and communication of the rationale for and process of engaging meaningfully. Although the rubric was primarily designed to be used by measure developers, it is suitable for use by measure implementers and the patient community, including individuals who are new to quality measurement. Table 2 below describes examples of stakeholders and potential uses of the rubric. Presented after the rubric are fictional vignettes to provide illustrations of potential real-world use by various stakeholders.

Table 2. Intended Audiences and Uses

Audience	Uses
Measure Developers	The rubric can be used by measure developers as a quality improvement tool to identify areas of opportunity for enhanced patient engagement and partnership.
Measure Implementers	The rubric may be suitable to assess the level of patient engagement across quality measures. This tool may be used in decisions where measures are being selected for implementation.
Patient Community	The rubric can be used by current patient partners to assess how their partnerships can be enhanced as well as allow those new to this area the ability to identify engagement opportunities in the quality measure lifecycle.

The rubric is comprised of two sections:

- Section I: Overall Measure Lifecycle Assessment
- Section II: Recommended Patient Engagement Activities for the Quality Measure Lifecycle

The first section assesses applicable patient-centeredness principles within the overall quality measure lifecycle. Measure developers have the flexibility to adjust the sequence of steps or to complete them concurrently and iteratively.²

The second section provides a list of recommendations for specific engagement activities across the measure lifecycle. This section is not meant to be prescriptive; it simply reflects recommended engagement activities identified in the CMS Blueprint, by the multi-stakeholder roundtable, and by the PQA PCAP. It should be noted that not all measure developers utilize the same processes, so not all activities will apply in all situations. The rubric does, however, offer a way to raise awareness of the importance of, and methods for, engagement.

This rubric is a living document to be refined over time based on feedback from the patient community, measure developers, and other stakeholder-user experiences. Rubric feedback may be sent to PQA at research@pqaalliance.org.

The Patient Engagement in Quality Measurement Rubric

Section I. Measure Lifecycle Assessment

The purpose of this section is to provide users with a mechanism to guide and assess patient engagement in the measure lifecycle. The rubric components are presented in a grid describing patient-centeredness principles and three levels of engagement (meaningful, progressing and low). Rubric items are applied to all domains of the measure lifecycle, which can be assessed at any time. Users should select the description that best reflects activities that occurred across the quality measure lifecycle.

If the patient community was not engaged, please refer to Section II for recommended patient engagement opportunities. Lack of engagement should provide an opportunity for the rubric user to identify and address barriers to engagement.

Patient-Centeredness Principle	Meaningful	Progressing	Low
Patient Partnership			
The patient community is included in all domains of the measure lifecycle.	Patients are included as partners in all domains of the measure lifecycle for which the entity is responsible.	The patient community: <ul style="list-style-type: none"> Provides occasional input, but no partnership, OR Is included as partners in some, but not all domains of the measure lifecycle. 	The patient community is not included in the measure lifecycle.
The measure developer has established a process to recruit patient partners.	Patient partners are recruited to participate in the quality measure lifecycle.	Some patient partners participate in the measure lifecycle, but no process is in place to recruit new partners.	Few or no recruitment processes are in place with patient communities to recruit patient partners.
Measure developer staff are properly trained to support patient-centered measure development.	Measure developer staff receive initial training with clearly specified learning objectives; written materials, such as formal models, rubrics, or checklists and ongoing support through mentorship, technical assistance, or an extended training program.	Measure developer staff receive initial training, which may include some tools to guide patient-centered measure development, but do not receive ongoing training, mentorship, or support.	Measure developer staff are given a recommendation to be patient-centered but are not provided with training or tools to accomplish patient-centered measure development.

Patient-Centeredness Principle	Meaningful	Progressing	Low
Patient Partnership (continued)			
Measure developers are capturing patient-community perspectives during relevant times in the measure lifecycle. (See Section II to identify relevant times in the measure lifecycle)	As part of the development team, patient partners help shape measure development decisions throughout the process.	Patient partners are included in measure development processes and are supported to share perspectives and opinions with other stakeholders but are not included in the decision making.	Patient communities are not included, or their involvement only includes review and comment (e.g., public comment). They are not active partners on the development team.
Patient partners are supported with patient-friendly and relevant materials, to meaningfully engage in the measure lifecycle.	Patient partners are supported with patient-friendly and relevant materials to meaningfully contribute in the measure lifecycle during all domains of the measure lifecycle.	Patient partners are provided with some patient-friendly and relevant materials during some but not all domains of the measure lifecycle. Or patients were provided materials that weren't tailored for their needs.	Patient partners are included in measure lifecycle domains. However, no patient-friendly and relevant materials were provided for patient partners.
The time and contributions of patient partners are equitably valued and compensated or recognized appropriately.	Patient partners participate in planning and determining adequate compensation and/or recognition for contributions to measure development OR patient partners evaluate the adequacy of compensation and/or recognition and deemed it appropriate.	Patient partners are compensated and/or recognized for contributions to measure development. However, patient partners did not inform or evaluate the adequacy of compensation and/or recognition.	Patient partners are not compensated and/or recognized for their contributions to measure development.
The patient community has equal decision-making authority as compared to other stakeholders during relevant times in the measure lifecycle. (See Section II to identify relevant times in the measure lifecycle)	Decisions at relevant points in the measure lifecycle are at least equally weighted among patient community and other stakeholders.	Decisions at relevant points in the measure lifecycle are equally weighted among patient community and other stakeholders. However, decisions are only sought for a subset of decisions.	Patient partners did not have decision-making authority OR decisions are not equally weighted among patient community and other stakeholders.

Patient-Centeredness Principle	Meaningful	Progressing	Low
Transparency			
The process for selection of patient partners is transparent (publicly available).	Measure developers specify criteria to identify, select, and invite patient partners, along with a rationale. This information is public.	Measure developers have a process to identify patient partners, although the specific criteria used to identify, select, and invite patient partners is not disclosed.	No systematic process and/or criteria for selecting patient partners is described.
Patient partners are provided with the resources and tools needed to understand the nature of engagement and the roles and expectations for participation in measure development.	Measure developers provide patient-friendly information and resources readily available to the patient community that describes the roles, expectations, and patient engagement opportunities in each domain in the measure lifecycle.	Measure developers have patient-friendly information to patient partners that describe the roles and/or expectations of participation in the measure development process.	Patient partners have access to materials describing each domain of the measure lifecycle, but a description of patient engagement opportunities or expectations is not provided, OR information is not provided in a patient-friendly format or timely manner.
Patient partners report they are satisfied with how their contributions have impacted the measure(s) being developed and/or implemented.	Patient-provided information (e.g., findings from focus group, survey) indicates partners are satisfied with their experience in all domains of the quality measure lifecycle for which they partnered, and/or feedback is incorporated by the measure developer to improve patient experience in the measure lifecycle.	Patient-provided information (e.g., focus group, survey) evaluating patient experience in the quality measure lifecycle is obtained for some but not all domains in which patient partners are involved.	No process for obtaining patient-provided information (e.g., focus group, survey) from patient partners and/or the patient community is in place.
The rationale for decisions made are provided to patient partners.	Patient partners are provided (e.g., verbal, plain language materials) with the outcomes and rationale for all decisions that were made during the entire measure lifecycle.	Patient partners are provided (e.g., verbal, plain language materials) with the outcomes and rationale for some, but not all , decisions that were made during the measure lifecycle.	Patient partners are not briefed on decisions and rationale that were made during the measure lifecycle.

Patient-Centeredness Principle	Meaningful	Progressing	Low
Representativeness			
Representative patient-community members are included in all domains of the measure lifecycle.	Multiple patient partners with relevant lived experiences and from diverse communities are included in all domains of the measure lifecycle. Or rationale for exclusion is described.	Multiple patient partners with relevant lived experiences are included in some, but not all , domains of the measure lifecycle. Or patient partners do not reflect diverse communities with the relevant lived experiences.	Patient partners with relevant lived experiences are not included the domains of the measure lifecycle OR there is an inadequate number of patient partners with lived experiences relevant to the measure.
Rationale to substantiate the adequacy of the ratio of patient to non-patient stakeholders is provided.	At least two patient partners are included in all activities involving patient partners and rationale was provided for stakeholder composition.	At least two patient partners are included in some activities, or rationale is provided for stakeholder composition.	No rationale is provided for stakeholder composition or no explicit consideration for the appropriate ratio was made.

Patient-Centeredness Principle	Meaningful	Progressing	Low
Meaningfulness			
Patient goals, preferences, and priorities inform quality measurement.	Patient-provided information is incorporated in all domains of the measure lifecycle.	Patient-provided information is incorporated in some, but not all , domains of the measure lifecycle.	No process for obtaining patient-provided information from patient partners and/or the patient community is in place, but patient feedback or anecdotal information is used in some domains of the measure lifecycle.
Measure is aligned with the patient-community goals, preferences, and/or priorities.	Representative patient-provided information clearly indicates the measure is aligned with patient goals, preferences and/or priorities.	Some patient-provided information indicates that the measure is aligned with patient goals, preferences and/or priorities.	Patient-provided information indicates that the measure is not aligned with patient goals, preferences OR there is no process for obtaining this information.
Measure can be used by the patient community to make decisions (when applicable).	Representative patient-provided information clearly indicates that the measure can be used by the patient community to make decisions.	Some patient-provided information indicates that the measure can be used by the patient community to make decisions.	Patient-provided information indicates the measure cannot be used by the patient community to make decisions OR there is no process for obtaining this information.

Section II. Recommended Patient Engagement Activities in the Quality Measure Lifecycle

The purpose of this section is to provide measure developers, the patient community, and other stakeholders with a tool to identify opportunities for enhanced patient engagement in the measure lifecycle. The following checklist includes recommended engagement opportunities aligned with the patient-centeredness principles in Section I. It should be noted that not all measure developers utilize the same processes, so not all activities will apply in all situations. Additionally, this is not an exhaustive list of potential activities.

Patient-Partnership Characteristics	Recommended Patient Engagement Activities
Establish a process to recruit patient partners for all relevant domains in the measure lifecycle. ^{7,8}	<ul style="list-style-type: none"> <input type="checkbox"/> Work with patient groups, community groups, and advocacy groups to share partnership opportunities.
Train measure development staff to support patient-centered measure development.	<ul style="list-style-type: none"> <input type="checkbox"/> Provide training in formal patient engagement models, rubrics, and/or checklists. <input type="checkbox"/> Provide ongoing training and support to further develop skills.
Support the patient community with patient-friendly and relevant materials to meaningfully and actively engage in discussions and make decisions.	<ul style="list-style-type: none"> <input type="checkbox"/> Use plain language and avoid jargon. Define key terms and technical concepts essential to understanding the work. <input type="checkbox"/> Provide relevant background information without unnecessary technical detail. <input type="checkbox"/> Organize information in ways that make it easy to read and understand <input type="checkbox"/> Provide information in patient partners’ preferred formats (e.g., written, audio/video, large font or high contrast if needed) <input type="checkbox"/> Clearly explain key needed decisions, trade-offs, and ramifications of measure lifecycle decisions in patient-friendly language. <input type="checkbox"/> Assess the ease of understanding of patient-friendly materials (e.g., health literacy) <input type="checkbox"/> Explicitly describe pros, cons, and tradeoffs of measure lifecycle decisions and provide adequate time for partners to review. <input type="checkbox"/> Collaborate with the patient community to evaluate the adequacy of and revise patient-friendly, relevant, and health-literacy appropriate materials.
Include the patient community in all relevant domains of the measure lifecycle.	<ul style="list-style-type: none"> <input type="checkbox"/> Engage multiple patients as partners on measure development teams and/or technical expert panels. <input type="checkbox"/> Provide an opportunity to for patient partners to participate in planning and determining adequate and equitable compensation and/or recognition. <input type="checkbox"/> Weight consensus decisions and/or voting at least equally among patient partners and other stakeholders.

Patient-Partnership Characteristics (continued)	Recommended Patient Engagement Activities
<p>Partner with the patient community to discuss and make consensus decisions at relevant points during each of the following domains:</p> <p>D1: conceptualization D2: specification D3: testing D4: implementation D5: use & maintenance</p>	<p>Patient partners may be meaningfully engaged to:</p> <p>D1 <input type="checkbox"/> Propose new measure concept ideas and/or information about measure gaps. <input type="checkbox"/> Rank/prioritize new measure concept ideas.</p>
	<p>D2 <input type="checkbox"/> Define measure specification components (e.g., target population, inclusion criteria, methodology). <input type="checkbox"/> Harmonize measures (e.g., identify and consider related and competing measures). <input type="checkbox"/> Discuss and determine the accountable entity, unit of analysis, and potential for unintended consequences of measures. <input type="checkbox"/> Discuss measure feasibility. <input type="checkbox"/> Select a tool/instrument (e.g., survey) if developing a patient-reported outcome measure.</p>
	<p>D3 <input type="checkbox"/> Discuss measure testing. <input type="checkbox"/> Identify and/or refine risk-adjustment approaches. <input type="checkbox"/> Interpret measure scores and testing results. <input type="checkbox"/> Determine best data collection techniques (e.g., when to collect, how to collect) for patient-reported measures.</p>
	<p>D4 <input type="checkbox"/> Vote on organization-specific measure endorsement (e.g., PQA-endorsement). <input type="checkbox"/> Create patient-friendly materials to describe measure specifications, results, and importance.</p>
	<p>D5 <input type="checkbox"/> Discuss measure maintenance, including potential retirement, at critical points (e.g., new clinical guideline release). <input type="checkbox"/> For measures that lacked meaningful patient engagement, enhance patient-centeredness by incorporating patient-community input relevant to each measure lifecycle domain.</p>

Transparency Characteristics	Recommended Patient Engagement Activities
<p>Ensure the patient community has timely access to understandable information needed to engage in the measure lifecycle and continuity of engagement is obtained.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> During recruitment, provide the patient community with specific criteria used to identify, select, and invite patient partners, along with rationale. <input type="checkbox"/> Provide patient-friendly resources and tools needed to understand the nature of their engagement, including description of roles, expectations, and opportunities in each domain. <input type="checkbox"/> Evaluate patient-partner satisfaction by obtaining feedback regarding their perspectives with how their contributions have impacted the measure lifecycle. This may be conducted at several points in the lifecycle and overall. <input type="checkbox"/> Incorporate patient-partner suggestions to improve the patient experience with engaging in the measure lifecycle. <input type="checkbox"/> Provide access to patient-friendly and relevant materials detailing the outcomes and rationale for all measure lifecycle decisions. <input type="checkbox"/> When moving from domain to domain, share the patient-partner engagement that has occurred to date with all stakeholders engaged in development.

Representativeness Characteristics	Recommended Patient Engagement Activities
<p>Ensure the patient partners represent the broader, population of people whose experience or outcomes are captured by the measure.</p>	<ul style="list-style-type: none"> □ Include multiple patient partners with relevant conditions and from diverse communities (e.g., stage of life, trajectory of disease, socioeconomic status, health literacy) in all relevant domains of the measure lifecycle. □ Provide a rationale to substantiate the adequacy of the ratio of patient to non-patient stakeholders.

Meaningfulness Characteristics	Recommended Patient Engagement Activities
<p>Ensure patient goals, preferences, and priorities inform quality measurement.</p>	<ul style="list-style-type: none"> □ Engage patient partners in all domains of the measure lifecycle. □ Collect representative patient-provided information (e.g., one-on-one interviews, focus groups, assessments, surveys, Delphi method, and other mechanisms) to determine: <ul style="list-style-type: none"> ▪ Whether the measure resonates with patient goals, preferences, and/or priorities ▪ Whether the patient community can use the measure to make decisions ▪ What value the measure has for the patient community

Fictional Vignettes:

Application of the Patient Engagement Rubric for Quality Measurement

Use of the rubric from a measure developer perspective

The *Quality Measure Association (QMA)* develops healthcare quality metrics for use in many settings, including hospitals, primary care clinics, and health insurance plans. All these settings have one thing in common – interaction with the patient community. As such, and in keeping with measure development industry best practices, the QMA believes it is important to meaningfully engage the patient community throughout the quality measure lifecycle (from conception to use to retirement).

Recently a rubric to evaluate patient engagement in quality measurement was released, and the QMA decided to evaluate their own practices. “Using Section I: Measure Lifecycle Assessment”, they found varying levels of patient engagement. Their assessment across each of the patient-centeredness principles included a count of how many items were meaningful, progressing, or low, as follows:

Patient Centeredness Principle	Meaningful	Progressing	Low
Patient Partnership	1	4	2
Transparency	1	2	1
Representativeness	--	1	1
Meaningfulness	1	1	1

The QMA rated themselves as “low” in two areas of patient partnership, because they found that while they were inviting patient partners to participate, it was only in one quality measure domain. They also learned from the patient partners that the materials provided to prepare for group discussion were challenging to understand.

In response to this assessment, the QMA has developed an action plan to enhance patient engagement and partnership across their measure lifecycle. To do that, the QMA utilized “Section II: Recommended Patient Engagement Activities for the Quality Measure Lifecycle” to identify additional opportunities for engagement. In that checklist, they found several key activities that would allow them to engage with patient partners throughout the measure lifecycle. For example, QMA historically struggled to include patient partners during the testing domain. Using Section II, they discovered several testing engagement activities, such as including patient partners in identifying or refining risk-adjustment approaches. They also learned that patient partners could be helpful in translating measure scores to patient-community language.

Other key activities that helped them to achieve “progressing” and “meaningful” in all sections of the rubric included creating and providing training and ongoing support for both measure developer staff and patient partners. They also sought feedback from their patient partners to ensure that materials provided to the patient community were patient friendly, relevant, and included health-literacy appropriate material to clearly explain key needed decisions, roles, and engagement activities during each domain of the measure lifecycle.

Use of the rubric from a patient-partner perspective

Three years ago, Camille was diagnosed with Primary-Progressive Multiple Sclerosis (PPMS). Camille is an active member of the Washington, DC local chapter of an MS patient organization. She and another patient, Steve, from Colorado were approached about an opportunity to partner with a quality measure developer (QMD) and agreed to participate. Staff from the QMD worked with Camille and Steve to discuss logistics and compensation. Camille is local and was able to attend meetings in-person and can drive herself. Steve prefers not to fly due to mobility constraints and joined meetings by video conference. Along with Camille and Steve, the QMD advisory group also included two clinicians. Camille and Steve were supplied with plain language documents in advance of meetings, so they could actively participate and make informed decisions. Camille and Steve believed their input was considered equal to that of the other advisory board members. While not everything Camille and Steve contributed was incorporated into the final measure, they believed it measured something important to them and their voices were heard in the development process.

Following the review, the QMD asked Camille and Steve to evaluate their experience using "Section II: Recommended Patient Engagement Activities for the Quality Measure Lifecycle". Based on their assessment of the activities in which they engaged, Camille and Steve rated the QMD process as follows:

Patient-Centeredness Principle	Camille	Steve
Patient Partnership	Very Good	Very Good
Transparency	Very Good	Very Good
Representativeness	Moderate	Moderate
Meaningfulness	Very Good	Good

While Camille and Steve are from different geographical areas, they were only comfortable representing their own experiences. They suggested that next time their lived experiences could be supplemented by data from a survey of MS patients with broader demographic representation.

Overall Camille and Steve provided a positive evaluation of the QMD. They believed the process for developing the quality measure was transparent, informative, collaborative and ultimately had the patients' end goals in mind. As a next step, the QMD decided that for the next measure they develop, they will reach out not only to individual patients but will also work with a national patient organization to field a simple survey.

Use of the rubric from a measure-implementer perspective

The *Dedicated to Great Patient Care Hospital* (Hospital) uses healthcare quality metrics for its contracts with health plans to help ensure it is delivering high-value, patient-centered care. As patients are at the heart of the hospital's mission, it believes it is essential to adopt metrics that are meaningful to patients and to make those performance data available to help patients make decisions about their care.

Recently, a rubric to evaluate patient engagement in quality measurement was released and the Hospital decided to evaluate their selected measures and public reporting. "Using Section I: Measure Lifecycle Assessment", the Hospital found varying levels of patient engagement. Their assessment across each of the patient-centeredness principles included a count of how many items were meaningful, progressing, or low, as follows:

Patient Centeredness Principle	Meaningful	Progressing	Low
Patient Partnership	1	3	3
Transparency	2	1	1
Representativeness	--	--	2
Meaningfulness	2	1	--

In response to this assessment, the Hospital has developed an action plan to enhance patient engagement across their measure lifecycle. To do that, they used the descriptions under "Meaningful" within Section I of the rubric as well as "Section II: Recommended Patient Engagement Activities for the Quality Measure Lifecycle" to create an action plan.

In that checklist, the Hospital identified several key activities that were applicable to their implementation and reporting processes. Several activities helped them to achieve "progressing" and "meaningful" in all sections of the rubric. For example, the Hospital realized its Patient & Family Advisory Committee (PFAC), which informs measure selection and reporting (among other activities) was relatively small and did not represent a very broad or diverse population. To address this, the Hospital expanded its PFAC to include more individuals with the conditions and diversity represented in their population. When they surveyed their PFAC, they learned that the information regarding hospital quality that they provided to the community was difficult to understand. In response, they worked with the PFAC to conduct community focus groups and to develop patient-friendly quality reports and web-based information. Finally, the Hospital researched the measures in its contracts and selected alternative measures with a higher level of patient centricity, where possible.

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Appendix A: National Roundtable Participants

Marie Abraham, MA

Vice President, Programming & Publications
Institute for Patient- and Family-Centered Care

Rebekah Angove, PhD

Vice President
Patient Experience & Program Evaluation
Patient Advocate Foundation

Cynthia Chauhan

Patient & Advocate

Elizabeth Cinqueonce

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Morgan Daven

Senior Director, Health Systems
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Hala H. Durrah, MTA

Patient Family Engagement Consultant &
Advocate

Lori Frank, PhD

Senior Behavioral Scientist
RAND Corporation

Lindsey Galli

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Emma Kopleff, MPH

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Deirdre Mylod, PhD

Senior Vice President, Research & Analytics
Executive Director, Institute for Innovation
Press Ganey

N. Lee Rucker, MSPH

Principal and Founder
Enhance Value

Tonya Saffer, MPH

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American Institutes for Research

Adam Thompson

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AIDS Education & Training Center
Jefferson Health New Jersey – Infectious
Diseases

Samantha Tierney, MPH

Senior Director, Measurement Science
PCPI Foundation

Appendix B: PQA Patient & Caregiver Advisory Panel

The PQA Patient and Caregiver Advisory Panel (PCAP) is a small group of individuals, selected by PQA staff through a nomination process, to provide patient and caregiver input into the measure development process to reflect the patient's voice in PQA measures. The Patient & Caregiver Advisory Panel meets five times per year via webinar.

Jennifer Dingman

Founder, PULSE

Richard Erickson

Patient Partner

Health Partners / Park Nicollet

Eagan, MN

Lisa Freeman, BA

Executive Director

Connecticut Center for Patient Safety

Pastor Bruce Hanson. MDiv. PA/C

Patient Advocate Consultant

Volunteer, PCORI Ambassador

Michelle Juhanson, CHC, CPHC

VP, Chief of Staff II, Medicare Part D

Magellan Rx Management

Becky Martins

Patient, Family Caregiver, Advocate

Arlene Salamendra

Patient Advocate

Ken Witkowski

Patient Partner

Appendix C: Quality Measure Lifecycle Domains

<p>Domain 1: Measure Conceptualization</p> <p>Generate and prioritize a list of measure concepts to be developed and compile the evidence base to develop the rationale for developing the measure and the basic elements of measures.</p>
<p>This is typically completed in two phases:</p> <ul style="list-style-type: none"> • Measure identification: In the identification phase of conceptualization, measure developers determine whether an existing measure may be adopted or revised to fulfill an identified need. If no measures match, the measure developer engages a multi-stakeholder panel to gather information by conducting environmental scans and soliciting measure concepts. • Measure prioritization: In the prioritization phase of measure conceptualization, a multi-stakeholder group evaluates, and ranks collected measure concepts according to importance, feasibility of measurement, and usability & use (e.g., need in the market).
<p>Domain 2: Measure Specification</p> <p>Draft measure specifications, harmonize, and assess initial feasibility.</p>
<p>Key components of the technical measure specifications are developed through an iterative process that includes multi-stakeholder input. Key components include, but are not limited to, measure name and description, numerator, denominator, inclusion and exclusion criteria, and target populations.</p>
<p>Domain 3: Measure Testing</p> <p>Develop a testing plan and test a measure to ensure it works as intended.</p>
<p>Measure testing allows a measure developer to assess scientific acceptability, usability, and feasibility. Results from testing also provide key information needed to refine the measure specifications further.</p>
<p>Domain 4: Measure Implementation</p> <p>Convert a measure from a development state to an active, in-use state, which includes, but is not limited to, consensus endorsement process, measure selection process, and measure rollout.</p>
<p>Endorsement can be internal or external. Internal endorsement occurs when the measure developer itself conducts a multi-stakeholder vote for approval of a measure. Not all measure developers conduct such a vote. External endorsement is the process of vetting a measure through an external body (e.g., The National Quality Forum) via the consensus development process, which is necessary for measures that will be used in Federal payment programs.</p>
<p>Domain 5: Measure Use, Continuing Evaluation, and Maintenance</p> <p>Evaluate and maintain measures based on their use and impact. To ensure ongoing viability for use, measures are evaluated on a regular basis for their importance and are updated as needed to reflect current evidence, guidelines, and standards.</p>
<p>Measure developers continuously reassess their measures to ensure they continue to remain relevant and useful. This is completed by several methods including environmental scans and literature review. Results of assessment may require a measure to be re-specified and tested to ensure they align with the most up-to-date evidence.</p>

Appendix D: About Project Partners

PHARMACY QUALITY ALLIANCE

Established in 2006, the Pharmacy Quality Alliance is a 501(c)3 designated non-profit alliance with over 240-member organizations. PQA is a multi-stakeholder, consensus-based membership organization committed to promoting appropriate medication use and developing strategies for measuring and reporting performance related to medications. PQA's commitment to improving patient outcomes includes extensive involvement in education, research and demonstration projects. PQA's metrics add definition and meaning to interventions, further demonstrating their impact in the marketplace. PQA's performance metrics for safe and appropriate medication use have been implemented broadly including, but not limited to:

- Centers for Medicare & Medicaid Services' Medicare Part C and Part D Star Ratings Program;
- Medicaid Adult Core Set of Healthcare Quality Measures;
- Health Insurance Marketplace Quality Reporting System;
- Accreditation programs; and
- Commercial health plans.

Additionally, several of PQA's metrics have received endorsement by the National Quality Forum. For more information, visit www.pqaalliance.org and follow PQA on Twitter @pqaalliance.

NATIONAL HEALTH COUNCIL

Founded in 1920, the National Health Council (NHC) brings diverse organizations together to forge consensus and drive patient-centered health policy. The NHC provides a united voice for the more than 160 million people with chronic diseases and disabilities and their family caregivers. Made up of more than 125 national health-related organizations and businesses, the NHC's core membership includes the nation's leading patient advocacy organizations, which control its governance and policy-making process. Other members include health-related associations and nonprofit organizations including the provider, research, and family caregiver communities; and businesses representing biopharmaceutical, device, diagnostic, generic, and payer organizations. We envision a society in which all people have access to quality, affordable health care that respects personal goals and aspirations to promote their best possible health outcomes.) In collaboration with the National Quality Forum, the NHC developed an [educational program](#) to expand patient-community capacity to engage on quality.

NATIONAL QUALITY FORUM

The National Quality Forum is a nationally-recognized, consensus-based healthcare organization for quality performance measurement. As such, NQF engages with various quality measure agencies and implements standards for quality measure development. As a membership organization, NQF brings together diverse organizations with a stake in improving health and healthcare through quality measurement. Members represent everyone with an interest in healthcare—hospitals, healthcare systems, patients, families, insurers, employers, and many more. NQF has experience in convening multi-stakeholder roundtables and meetings to identify and resolve key issues within the healthcare quality landscape. These activities produce tools and reports that provide information, recommendations, and standards to its members and others. Examples include, "Patient-Reported Outcomes in Performance Measurement" and most recently, "Measuring What Matters to Patients: Innovations in Integrating the Patient Experience into Development of Meaningful Performance Measures".