This document provides information about Person and Family Engagement (PFE). Involving persons and family representatives in the measure development process (e.g., on Technical Expert Panels [TEPs], in focus groups, during testing) is among the many ways that measure developers can accomplish the goal of strengthening person and family engagement as partners in their care. This information supplements information found in the *Blueprint*, Chapter 4, Measure Conceptualization.

1 INTRODUCTION

Person and family engagement in measure development is the process of involving persons and/or family representatives in a meaningful way throughout the Measure Lifecycle. The CMS *Person & Family Engagement Strategy* states that, “the term ‘person’ is used to reflect an individual’s identity as more than a patient, to recognize his or her participation in prevention and wellness.” In this context, family “is used broadly to include participants in a person’s healthcare, including informal caregivers, along with the primary caregivers of persons who are in need of the support of their caregivers to make informed healthcare decisions.” Advocates and advocacy groups can also be involved to provide the person and family perspective.

Engaging persons and family representatives benefits consumers by helping to identify issues that are important and meaningful from their perspective. It also supports identification of information that consumers need to make informed healthcare decisions. Person and family engagement helps measure developers produce high-quality, easily understood, relevant measures that are useful to consumers.

2 OPTIONS FOR ENGAGEMENT AND SELECTED BEST PRACTICES

There is discussion throughout this document, and summarized in Table 1, about best practices for engaging persons and family members in measure development activities. Regardless of the engagement methods used, it is critical to provide individuals involved with measure development efforts with clear expectations about what their participation will entail. Measure developers may also consider the principles in the *Patient-Centered Outcomes Research Institute (PCORI) Engagement Rubric*. Another valuable rubric is the *Patient Engagement in Quality Measurement Rubric* developed by a coalition including the Pharmacy Quality Alliance, National Health Council, and the National Quality Forum. See the *Blueprint*, Chapters 4 and 6, for more information on best practices for conducting qualitative research, constructing surveys and interviews, and testing.
Table 1. Best Practices for Implementing Person and Family Engagement Activities, by Phase of Engagement

<table>
<thead>
<tr>
<th>Phase</th>
<th>Best Practices for Implementing Person and Family Engagement Activities</th>
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| Preparing for Person and Family Engagement Activities | - Set clear expectations. Inform potential person and family member participants during recruitment about the time commitment requirements and the nature of the input requested from them. Be transparent about what stage of development the measure is in, the timeline for this phase of work, and the overall timeline for completing measure development.  
- Ensure that individuals understand the nature of their participation, particularly around issues of confidentiality, and explain that their participation in measure development activities is voluntary. Find confidentiality language in the TEP Nomination Form Template and in the TEP Charter Template.  
- Prior to the session, provide participants with person-centered, read-ahead materials that are easy to understand. Provide individuals with ample time to review materials and ask questions. For individuals without email or Internet access, mail the printed materials to them.  
- Conduct preparatory calls with participants.  
- Remind participants of the date and time of the meeting 1 to 2 days before the meeting.  
- For in-person meetings, when applicable, consider using a facility that allows the development team to observe the discussion and enables the moderator to check in with the team during the session. |
| During Person and Family Engagement Activities    | - Adhere to best practices for qualitative research. Cognitive and plain language testing are essentially semi-structured, in-depth qualitative interviews. Be sure to have a trained facilitator who knows how to develop and follow a protocol and work with a respondent in a neutral, engaged setting. If possible, use a facilitator who has experience working with the relevant patient population.  
- Ensure that introductions clarify the purpose of the meeting and the role that each participant will play. Ensure persons and families have a clear understanding of what parts of the measure they can impact and which things are out of scope.  
- Take time to clearly explain technical measure concepts and answer questions to ensure persons and families can participate effectively. Minimize the use of technical jargon.  
- Ensure participants feel comfortable participating in the discussion and emphasize that everyone’s input is important. For TEPs, remind persons and families of the expertise they bring to measure development.  
- Convey the expectation that the group should hear and respect each participant’s perspective.  
- Foster freedom of thought. Encourage participants to be free with their ideas even if they feel it may not be pertinent to the discussion at hand. Communicate the plan for tracking suggested ideas that do not directly fit into the current discussion but may be relevant for future work.  
- Assist person or family member participants who become stuck in a personal story or situation, acknowledging the power of their experience and linking it to the objectives of the meeting.  
- Continue assisting with technology needs for virtual or teleconference meetings, as needed. |
| Following Person and Family Engagement Activities  | - Hold one-on-one calls to encourage ongoing participation and answer questions.  
- Keep persons and families updated on future decisions and the next stages of measure development after the working group, TEP, or other engagement activity has ended so they can understand the impact of their participation.  
- Debrief participants and emphasize that their input was valued.  
- Listen to participants’ suggestions to improve their experience and the experience of others. |

Prior to measure conceptualization, measure developers should compile a comprehensive plan outlining the incorporation of person and/or family representative input at each stage of the Measure Lifecycle. Many techniques are available to measure developers for engaging persons and family representatives in the development process. To capture the person and family perspective adequately, measure developers should involve persons/family representatives as early as possible in the Measure Lifecycle and should consider incorporating two or more techniques in their development work. Discussion of several options for person and family engagement in the Measure Lifecycle is in subsections 2.1–2.9.

2.1 Member of Standard Technical Expert Panel (TEP)

A TEP is a group of stakeholders and experts that contributes direction and thoughtful input to measure developers during the measure development and maintenance processes. The TEP may work with the
measure developer to develop the technical specifications and business case for measure development, review testing results, and identify potential measures for further development or refinement. Descriptions of the steps for convening a TEP are in the supplemental material, Technical Expert Panels.

Measure developers should include one or more persons or family representative(s) on a TEP. As members of the TEP, consumers serve alongside professionals and may share aspects of their experience as healthcare consumers. An advantage of including persons/family members on the TEP is that it ensures that there is a balance between clinical and research concerns and consumer perspectives. Involving consumers in the TEP requires few additional resources. However, the measure developer must recognize that the views expressed by these one or two individuals may not be representative of the larger consumer population.

Best Practices

- Assign an advocate. Link representatives with a peer or professional who is familiar with the measure development process and relevant terminology and can support them before, during, and after serving on the TEP by providing background information and answering questions.
- Include at least two individuals representing the person and family perspective on the TEP so they do not feel isolated being on a TEP by themselves. In some instances, measure developers have found appointing a patient as the leader of the TEP an effective strategy:
  - Ask persons or caregivers to share their journey or story at the outset of the TEP (e.g., their own or a family member’s experience with cancer treatment or a hospitalization for heart failure). This process often engages and energizes the TEP.
  - Any time information gathering occurs outside of the formal TEP (e.g., during one-on-one interviews), be sure to relay information back to the full TEP.

2.2 THE PERSON- OR FAMILY-REPRESENTATIVE-ONLY TEP

A variant of the standard TEP is a TEP composed solely of persons or family representatives. An advantage of this approach over the standard TEP is that representatives may feel more comfortable sharing their own experiences with others like them. The person- or family-representative-only TEP runs alongside a standard TEP and may have a representative on the standard TEP.

2.3 FOCUS GROUPS

In a focus group, a skilled facilitator guides a group of persons or family representatives through a discussion by posing specific questions to the group about their own (or a family member’s) experiences with health and healthcare-related issues. Condition-based groups involve guided discussions among persons who have the health condition relevant to the measure under development. Seasoned measure developers have found that a group of five or six persons and family representatives is the ideal size for discussion, as the group is small enough to promote informal conversation yet large enough that the measure developer hears multiple views. Recruiting widely is a good strategy for recruiting a diverse group representing a variety of perspectives.

2.4 WORKING GROUPS

Working groups are composed of a leader and five or six individuals such as patients, family members, consumers, and advocates. In the context of a working group, measure developers seek group input on
a topic related to the measure(s) under development. Seasoned measure developers have found that working groups often promote close partnerships among measure developers and person and family representatives. When forming a working group or a focus group, measure developers should consider issues related to group composition (e.g., whether it is acceptable to have both persons and family members in the same group), as persons and family members may have very different perspectives on some topics. Figure 1 contains a list of best practices for TEPs and working groups.

2.5 ONE-ON-ONE INTERVIEWS

In the context of an interview, the measure developer converses with one individual at a time. Use this technique as a one-time information gathering exercise. However, one-on-one interviews can also be useful for touching base with individuals and keeping them engaged between TEP meetings or multiple working group meetings. An advantage of this technique is that it enables the measure developer to obtain in-depth information, encourages ongoing participation in the measure development effort, and provides measure developers with the opportunity to answer participants’ questions.

2.6 TESTING

Three types of testing relevant to measure development are concept testing, cognitive testing, and plain language testing.

- Concept testing is the process of evaluating consumer interest in and response to measurement-related topics.
- Cognitive testing involves presenting consumers with measure-related definitions and concepts and asking them to interpret the terms in their own words. This technique is particularly useful for appraising newly designed patient-reported measures because it enables the measure developer to evaluate whether consumers’ interpretations are accurate.
- Plain language testing investigates whether individuals are accurately translating the technical measure specifications into a description of the measured concept and why. This technique is particularly useful for evaluating measures planned for public reporting.¹

Find additional information about measure testing in the Blueprint Chapter 6, Measure Testing.

2.7 SURVEYS

Surveys can be effective for obtaining input when the measure developer has specific questions about the measure(s) under construction that can be asked with multiple choice questions or brief answers (e.g., Would this measure help you decide whether to have cardiac surgery at Hospital X?). Depending on the project, the measure developer may conduct surveys using paper instruments, via telephone, or online. Surveys can be an efficient way to gather information from a broad group of individuals in a

¹ Additional information about plain language testing can be found through resources such as http://www.plainlanguage.gov/ and http://centerforplainlanguage.org/.
short time frame. While surveys enable consumers to provide responses at their convenience, a
drawback is that they do not allow respondents to ask questions or exchange ideas with and solicit feedback from the measure developer.

2.8 Virtual Community

A virtual community is a network of individuals who interact through social media such as message boards, chat rooms, and social networking sites. Use virtual communities to promote discussion and commentary among persons/family representatives about measure development through use of focused questions and topic threads (e.g., “describe your experience selecting a nursing home for your family member”). This technique may provide valuable insight into a person’s or family representative’s viewpoints. At all points in the Measure Lifecycle, representatives can be engaged in the online panel to review and comment on information related to the measure and its development. A caveat is that text-based, virtual community discussions may not yield responses that are representative of the consumer population at large.

2.9 Engagement Activities: Virtual vs. In-Person

Except for the text-based virtual community, which is, by definition, conducted online, all techniques described in subsections 2.1-2.7 have the flexibility in how to conduct in-person or virtually using web meetings, web cameras, telephones, and other technology; or using a hybrid (e.g., some participants in-person and others online). A primary advantage of using a virtual approach is that it presents low burden to participants and measure developers and typically costs less to convene than in-person meetings. When deciding whether virtual or in-person interaction is preferable, measure developers should consider the population of interest and the role that the person and family members will play in measure development. Only use virtual approaches when the reasonable expectation is that individuals will participate, given their potential literacy, socioeconomic, or technology-related constraints (e.g., some at-risk populations may not have reliable access to the internet).

Best Practice. When using virtual technology, measure developers should work with all participants in advance of each meeting to ensure they know how to use the technology and that technical support is available to all participants prior to and during the meeting.

3 Recruitment

There are diverse options for reaching persons and family members; however, it can still be a challenge to find individuals who are willing and able to participate in measure development. Use recruitment strategies such as posting the TEP (Call for TEP) Web Page Posting form, but there may be a requirement for other sources and methods. This list includes some possible recruitment approaches:

- Network with providers or clinicians currently active on TEPs who may be willing to place recruitment materials where persons or their family members may see them.
- Reach out to consumer advocacy organizations such as the American Association of Retired Persons (AARP) Inc. In addition to the advocates, they may have information on persons who are capable and willing to contribute.
• Contact condition-specific advocacy organizations such as the American Diabetes Association or the Michael J. Fox Foundation for Parkinson’s Research that may know of individuals who are active in support groups and knowledgeable about quality for those specific conditions.
• Some organizations such as the PCORI Patient Engagement Advisory Panel have person engagement representatives, who are experienced mentors and know of persons who are able to participate.
• For panel participation that will involve reviewing detailed information, it may be useful to contact people who have served on local community advisory groups such as Patient Family Advisory Councils (PFACs).

Examples of websites of advocacy organizations and support groups that may provide ways to reach out to persons and/or family members who would be interested in being involved in quality measure development include:

- AARP
- Empowered Patient Coalition
- WebMD
- AgingCare.com
- Caring.com
- Connecticut Center for Patient Safety
dailystrength
- HealthWise
- MedHelp
- PatientsLikeMe
- CMS Quality Measures Public Comments webpage
- People for Quality Care
- National Quality Forum

These websites and similar sites often include contact information, including social media sources. Consider using social media for recruitment. Social networking pages such as Twitter, Facebook, and other social media hosts are potential options. These forms of recruitment are low-cost and can be extremely effective.

Best Practices. For focus groups and interviews where the goal is to find participants who represent the typical target population, it works well to recruit people from a variety of sources. In order to represent multiple perspectives, it can also be beneficial to seek persons from diverse geographical and sociodemographic backgrounds. Figure 2 contains an example of a featured best practice for recruitment.

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Featured Best Practice: Recruitment

A measure developer was planning a TEP meeting in Washington, D.C. to discuss new measures for consideration for the Readmissions Reduction Program (RRP). To facilitate person participation, the measure developer made several options available:

- Option for home pick-up by a ride service and driven to the meeting for those living within 50 miles of the meeting venue.
- Option to dial-in via a toll-free conference line, and/or participate virtually via web-based meeting software.

Figure 2. Recruitment Practices
4 OPTIONS FOR ENGAGEMENT BY MEASURE LIFECYCLE STAGE AND SELECTED BEST PRACTICES

As discussed in the Blueprint Chapter 3, the Measure Lifecycle consists of five stages: measure conceptualization; measure specification; measure testing; measure implementation; and measure use, continuing evaluation, and maintenance. We present descriptions of the most useful engagement techniques for each stage of the Measure Lifecycle in the next sections.

4.1 MEASURE CONCEPTUALIZATION

During the measure conceptualization stage, the measure developer’s primary task is to generate and prioritize a list of concepts for development. Often, the measure developer starts by developing a framework or logic model that captures important domains or topics. While it is critical to ground the framework in the scientific literature, perspectives of patients and family members can be very helpful in framing the problems and prioritizing steps for quality measure evaluation. Refer to Figure 3 for a best practice on measure conceptualization.

Techniques. Qualitative methods that enable measure developers to learn from patients and families about their care stories are particularly useful during measure conceptualization. From these stories, the team can map out typical encounters or episodes of care. Prompts that may be useful for eliciting this information include “Tell us your story,” “What went well?” and “What could have been done better?”

Examples of methods include

- One-on-one interviews with a skilled interviewer using a planned interview guide may be convenient and particularly useful when the care event under study is complex or highly personalized.
- Focus groups may also be useful because they allow persons or family members to compare notes and help the team identify common responses and priorities.
- Concept testing (performed in the context of either an interview or focus group) can also be advantageous at this stage. Measure developers can test the extent to which persons or family members find the concepts interesting or relevant to their own situation to determine the measures that are the best candidates for further development.

Featured Best Practice: Measure Conceptualization

In support of measure development efforts for the Inpatient Psychiatric Facility Quality Reporting Program, an interviewer asked patients and family members to describe their experience during each step in the care experience: admission, care during the inpatient stay, discharge, and after care in the community. Next, the interviewer asked patients to share what went well and what could have been better. In addition, the interviewer also prompted patients to prioritize a list of topics identified through evidence review and expert input. This process made it possible to identify areas of agreement about priority topics from patients, family members, and other experts.

Figure 3. Measure Conceptualization Best Practice
4.2 **Measure Specification**

During the measure specification stage, the measure developer drafts the measure specifications and conducts an initial feasibility assessment. Person and family representatives can provide input on a variety of measure specification decisions such as:

- Helping to determine the clinical outcome of the measure.
- Selecting patient-reported outcome performance measure instruments.
- Defining the target population.
- Determining risk adjustment approaches.
- Refining measure methodology.

By including person and family perspectives during the measure specification stage, measure developers can optimize measure usability and interpretability to patients, and maximize how meaningful the measure can be. Persons can help measure developers prioritize areas for future analyses or research while there is still time to modify the measure development approach, if necessary. Refer to Figure 4 for a best practice on measure conceptualization and specification.

**Techniques.** Mechanisms that enable discussion and ongoing exchange of ideas work best during new measure development and specification:

- Working groups are an excellent way for measure developers and person and family collaborators to discuss technical concepts and provide persons and family members with the opportunity to ask questions.
- Use TEPs to enable persons and families to weigh in on measure specifications and respond to other stakeholders in a multi-stakeholder environment.
- One-on-one interviews enable the measure developer to gather targeted information to inform specific aspects of the measure under development.

**Best Practices.** When conducting discussions about measure specifications, it is critical to ensure representatives have a clear understanding of which parts of the measure they can impact and which things are out of scope. This understanding will help focus the recommendations they provide to the measure developer.

4.3 **Measure Testing**

During the measure testing phase, the measure developer tests the measure to ensure it is working as intended. Engaging person and family representatives during this stage ensures that the measure makes...
sence to the public and will be beneficial for public reporting. This is an opportunity for the measure developer to ensure adequate translation of the patient-centered measure they set out to develop. If there are gaps in understanding, the measure developer can determine whether there is a need for adjustments at the specification level or at the translation level.

During this stage, the measure developer should ensure that consumers understand and are able to answer each of these key questions:

- Why is this measure important for the public to know and understand?
- How is this measure derived (i.e., what specifically is being measured)?
- What does the performance score mean (i.e., what influences whether a provider has a higher versus a lower score)?

**Techniques**

Mechanisms that enable individuals to evaluate what the measure means and explain how they interpret the measures work best at this stage. These one-on-one data collection methods are often useful:

- Use cognitive testing to determine how person and family representatives are interpreting the measure and whether they can accurately answer each of the key questions.
- Use plain language testing to test whether consumers are accurately translating the measure specifications.

**Best Practices**

- Test in a “realistic” environment. Measure developers may consider testing using a webinar platform so the person or family representative can be in front of their computer and review the information as they would if they were using the Internet.
- Write for the web and a web-based attention span. Measure developers should consider that the average person will spend about 30 seconds evaluating the measure. Present material in short, easy-to-understand paragraphs.

### 4.4 MEASURE IMPLEMENTATION

At the measure implementation stage, measure specifications are complete and the focus of the work is the framing and presentation of the measure. Measure developers can partner with persons and families during measure implementation to obtain feedback on the presentation of the measure to various stakeholders, including persons and families. Representatives can review language and displays that describe measure specifications and result interpretations, and measure importance for appropriate word choice, reading level, inclusion of concepts that are important to persons and families, and exclusion of concepts that may not be important. Including person and family input can ensure the language and displays used to describe the measure are both relevant to, and easily understood by, individuals who may use the measure to inform their healthcare decision-making.

**Techniques**

Mechanisms that enable informal, interpretive, and reactive discussions or quick, spontaneous feedback are often effective at this stage of measure development:
• Use focus groups to observe individuals’ reactions to various language/display options and enable them to provide critical feedback and make suggestions for improvement. Also use focus groups to assess the interpretation of proposed language/displays and whether that interpretation is consistent with the measure developer’s intent.
• Surveys are an excellent tool to obtain reactions to descriptive text or display options, obtain quick preference ranking of several options, and assess interpretation of unguided wording/phrasing.

Best Practices

• Set clear expectations. Measure developers should explicitly state the goals of the implementation work (e.g., improving readability, testing the comprehension of various language or displays about the measure).
• Provide appropriate framing or context. Measure developers should explain why the descriptive language about the measure or measure display is in its current format and describe previously received feedback.

4.5 Measure Use, Continuing Evaluation, and Maintenance

During this stage, the measure developer tests the measure post-development and once the measure is in use (and potentially, actively publicly reported). At this point in the Measure Lifecycle, engaging person and family representatives ensures that the measure remains relevant. Clinical practices change over time, but so does the public’s understanding of concepts. It is important to ensure that over time, measures continue to resonate with person and family representatives and that the measures are still meaningful to them. Also, over the life of a measure, changes happen (e.g., when specifications change in response to new clinical guidelines). Refine measures to ensure more precise measurement. Any time there is an update to a measure, also update the language used to explain and describe that measure to the public, which requires retesting the measure with person and family representatives.

Techniques

As during the initial measure testing stage, mechanisms that enable individuals to evaluate what the measure means and explain how they interpret the measure work best at this stage. One-on-one data collection methods—in particular, cognitive testing and plain language testing—are beneficial at this stage. As during measure testing, ask the same types of questions to ensure accurate understanding and interpretation of the measure and to confirm that the measure can still help person and family representatives make informed healthcare decisions.

Best Practices

Test measures at least every 2 to 3 years and every time an edit occurs to ensure the concepts remain useful and relevant. If the adjustment is small, testing with one or two individuals may be sufficient. Measure developers should verify the accurate interpretation and understanding of the measure and never assume a small change will be intuitive or easy for the public to understand.
5 Other Considerations

5.1 Paperwork Reduction Act (PRA) Exemption for Measure Development Activities

The PRA mandates that all federal government agencies obtain approval from the Office of Management and Budget (OMB) before collection of information that will impose a burden on the public. However, with the passage of the Medicare and CHIP (Children’s Health Insurance Plan) Reauthorization Act of 2015 (MACRA), data collection for many quality measure development projects is now exempt from PRA requirements. Measure developers working on government-sponsored measure development projects for programs that are not PRA-exempt should factor time—6 to 8 months on average—into their project timeline for OMB to review their Information Collection Request.

5.2 Budgeting Considerations

During the budgeting/planning process, measure developers should include costs for activities related to engaging persons/family representatives at multiple time points during the measure development process in their project budgets. For work that is ongoing, measure developers should consider ways to gather person and family input within the constraints of their existing project plan and budget. For both new and existing projects, lower cost options such as virtual/web-based meetings (as opposed to in-person meetings that may require significant travel-related expenses) may be worth considering.

5.3 Participant Compensation

In the past, compensation for person and family members contributing to measure development efforts has been on a case-by-case basis. Such compensation may make recruitment easier. Additionally, measure developers should be prepared to reimburse person and family members for any travel-related expenses incurred as part of the project. However, financial remuneration may negatively affect the disability payments of persons receiving disability.

6 Key Points

Person and family engagement helps measure developers produce high-quality, easily understood, relevant measures that are useful to consumers. Prior to measure conceptualization, measure developers should compile a comprehensive plan outlining the incorporation of person and/or family representative input at each stage of the Measure Lifecycle. Many techniques are available to measure developers for engaging persons and family representatives in the development process, including TEPs, focus groups, working groups, one-on-one interviews, testing, surveys, and virtual communities. Each of these techniques have the flexibility to be virtual, however, measure developers should only use virtual approaches when there is a reasonable expectation that individuals will participate, given their potential literacy, socioeconomic, or technology-related constraints. Useful engagement techniques may vary for each stage of the Measure Lifecycle. In addition, as part of planning patient and family engagement activities, measure developers also need to take need to take the PRA exemption for measure development activities, budget, and participant compensation into consideration.
REFERENCES


