



Person and Family Engagement in Quality Measurement

1	Introduction	2
2	Options for Engagement and Selected Best Practices.....	2
2.1	Member of Standard Technical Expert Panel (TEP)...	4
2.2	The Person- or Family-Representative-Only TEP.....	4
2.3	Focus Groups	5
2.4	Working Groups.....	5
2.5	Testing.....	5
2.6	One-On-One Interviews.....	5
2.7	Surveys.....	6
2.8	Virtual Community.....	6
2.9	Engagement Activities: Virtual vs. In-Person.....	6
3	Recruitment	7
4	Options for Engagement by Measure Lifecycle Stage and Selected Best Practices	8
4.1	Engagement Activities: Virtual vs. In-Person.....	9
4.2	Measure Specification	9
4.3	Measure Specification	10
4.4	Measure Implementation.....	11
4.5	Measure Implementation.....	12
5	Other Considerations.....	12
5.1	Paperwork Reduction Act (PRA) Exemption for Measure Development Activities	12
5.2	Budgeting Considerations.....	12
5.3	Participant Compensation	13
6	Key Points.....	13
	References.....	14

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 measure testing) is among the many ways 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 content on the MMS Hub, [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. According to the CMS [Person & Family Engagement Strategy](#), “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 individuals by helping to identify issues that are important and meaningful from their perspective. It also supports identification of information individuals need to make informed healthcare decisions. Person and family engagement helps measure developers produce high-quality, easily understood, relevant [quality measures](#) useful to individuals.

2 OPTIONS FOR ENGAGEMENT AND SELECTED BEST PRACTICES

This document discusses, and [Table 1](#) summarizes, best practices for engaging persons and family representatives 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. The [Person and Family Engagement Toolkit](#) serves as a roadmap for measure developers as they engage persons and families throughout the Measure Lifecycle. The Toolkit provides resources, templates, and tools to facilitate successful engagement, orientation, and communication strategies. The CMS [Person and Family Engagement Network](#) (PFEN) is another source for participants. The PFEN is a diverse and growing community of patients, families, advocates, and clinicians ready to serve on working groups and TEPs. See the Blueprint content, [Measure Lifecycle](#), on the MMS Hub 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

Phase	Best Practices for Implementing Person and Family Engagement Activities
Preparing for Person and Family Engagement Activities	<ul style="list-style-type: none"> • Set clear expectations. Inform potential person and family representative 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 each phase of work, and the overall timeline for completing measure development. • Ensure that persons 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 measure 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	<ul style="list-style-type: none"> • Adhere to best practices for qualitative research. Use cognitive and plain language testing, which 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. • Practice transparency with persons and families, thus cultivating an environment that emphasizes respect and equity for persons and families. • 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 representative 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	<ul style="list-style-type: none"> • 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 the team values their input. • 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 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 and 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. An advantage of including persons and family representatives on the TEP is that it ensures there is a balance between clinical and research concerns and healthcare user perspectives. Involving individuals in the TEP requires few additional resources. However, the measure developer must recognize the views expressed by these one or two individuals may not be representative of the larger user population.

Best Practices

- Assign an advocate. Link participants 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 representative'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.
- Provide persons and families information about key aspects of the project, including any relevant background information. This training may occur outside a standard TEP meeting. This will help ensure the persons and families understand critical terminology and background information, feel comfortable with meeting materials, and feel empowered to speak up during the TEP meetings.

"I quickly realized as a patient advocate that [TEP participation] was one of the most meaningful ways for me to get engaged in improving patient care because a lot of the things we did at the time would help a group of patients, but this really helped thousands of patients have a better experience or better outcomes based on our experiences."

Derek -Patient and patient advocate

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 participants 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 and family representatives through a discussion by posing specific questions to the group about their own (or a family representative'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. The main objective is to get opinions and thoughts. Individual focus groups normally meet once. 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 representatives, and advocates. In the context of a working group, measure developers seek group input on a topic related to the measure(s) under development. The working group usually has several meetings and proposes recommendations to the question(s) posed. 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 representatives in the same group), as persons and family representatives may have very different perspectives on some topics. [The callout box](#) contains a list of best practices for TEPs and working groups.

Selected Best Practices: TEPs and Working Groups

- Schedule meetings at times that are convenient for participants.
- Ensure participants are well prepared for meetings.
- Provide read-ahead materials that are easy to understand.
- Communicate with participants between meetings.

TEP and Working Group Best Practices

2.5 TESTING


In the context of an interview, the measure developer converses with one individual at a time. Measure developers can use this technique as a one-time information gathering exercise. 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 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 ONE-ON-ONE INTERVIEWS

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

- Concept testing is the process of evaluating individual interest in and response to measurement-related topics.

- Cognitive testing involves presenting individuals 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 individuals' 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 content on the MMS Hub, [Measure Testing](#) .


2.7 SURVEYS

Surveys can be effective for obtaining input when the measure developer wants to ask specific questions about the measure(s) under construction with multiple choice questions or brief answers. For example, 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 short time frame. While surveys enable individuals 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. Measure developers may use virtual communities to promote discussion and commentary among persons and 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, participants 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 healthcare user population at large.

2.9 ENGAGEMENT ACTIVITIES: VIRTUAL VS. IN-PERSON

Except for the text-based virtual community, which is, by definition, conducted online, measure developers may implement all techniques described in Subsections [2.1-2.7](#) in-person or virtually using web meetings, web cameras, telephones, and other technology, or using a hybrid approach (i.e., some individuals participate in-person and others participate 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 the person and family representatives will play in measure development. Measure developers should only use virtual approaches when they can reasonably expect individuals to participate, given their potential

¹ Additional information about plain language testing can be found through resources such as <http://www.plainlanguage.gov/> and <http://centerforplainlanguage.org/>.

literacy, socioeconomic, or technology-related constraints. Some at-risk populations, for example, 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. Measure developers should ensure technical support is available to all participants prior to and during the meeting.

3 RECRUITMENT

There are diverse options for reaching persons and family representatives; 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 [Technical Expert Panel Call for TEP Web Posting Template](#) on applicable websites, but recognize there may be a requirement for other sources and methods. This list includes some possible recruitment approaches:

- Network with [measured entities](#) currently active on TEPs who may be willing to place recruitment materials where persons or their family representatives may see them.
- Reach out to healthcare advocacy organizations such as the [American Association of Retired Persons \(AARP\) Inc](#). In addition to facilitating connections to advocates, organizations 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 facilitate connections to persons and family representatives interested in being involved in quality measure development include

- [AARP](#)
- [AgingCare.com](#)
- [Caring.com](#)
- [Connecticut Center for Patient Safety](#)
- [dailystrength](#)
- [Empowered Patient Coalition](#)
- [HealthWise](#)
- [MedHelp](#)
- [PatientsLikeMe](#)
- [MMS Hub Public Comments](#)
- [People for Quality Care](#)
- [National Quality Forum](#)
- [WebMD](#)

These websites and similar sites often include contact information, including social media sources. Measure developers may 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 when the goal is to find participants who represent the typical target/initial 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. The callout box contains an example of a featured best practice for recruitment.

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 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.

Example of Recruitment Best Practice

4 OPTIONS FOR ENGAGEMENT BY MEASURE LIFECYCLE STAGE AND SELECTED BEST PRACTICES

As discussed in the Blueprint content on the MMS Hub, the [Measure Lifecycle](#) consists of five stages: measure conceptualization; measure specification; measure testing; measure implementation; and measure use, continuing evaluation, and maintenance. Find more information about stakeholder engagement in different Measure Lifecycle stages on the [MMS Hub](#). We present descriptions of the most useful engagement techniques for each stage of the Measure Lifecycle in the next sections.

4.1 ENGAGEMENT ACTIVITIES: VIRTUAL VS. IN-PERSON

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 representatives can be very helpful in framing the problems and prioritizing steps for quality measure evaluation. Refer to [the callout box](#) for an illustrative best practice.

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 we have done better?”

Sample techniques:

- 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 be useful because they allow persons or family representatives 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 be advantageous at this stage. Measure developers can test the extent to which persons or family representatives find the concepts interesting or relevant to their own situation to determine the measures that are the best candidates for further development.

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-based [performance measure](#) instruments
- defining the target population
- determining [risk adjustment](#) approaches

Featured Best Practice: Measure Conceptualization and Specification

The measure developer for the Hospital-Acquired Condition (HAC) Reduction Program wants to identify new, potentially suitable measures to fill HAC performance gaps and examine the current [scoring](#) methodology to determine the need for modifications. The measure developer utilizes a person or family advisory panel early on to obtain input on additional HACs that measured entities could track and measure as part of the HAC Reduction Program, and which of these items persons/family representatives consider to be of the greatest importance. The measure developer uses this feedback to identify new suitable measures, and begins to work with statisticians to examine the current scoring methodology. The advisory panel is not involved in the meetings focused on scoring methodology. Later, as the measure developer has focused on two viable scoring methods, it re-engages with the person or family advisory panel to seek feedback on the revised scoring method concepts under consideration.

Measure Conceptualization and Specification Best Practice

- 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 the [callout box](#) in Section 4.1, Measure Conceptualization, 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 representatives with the opportunity to ask questions.
- TEPs 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 participants 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 SPECIFICATION

During the measure testing stage, 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 sense 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 person and family representatives 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 the measure measuring)?
- What does the performance [score](#) mean (i.e., what influences whether a measured entity 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 individuals 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. Participants 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 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 IMPLEMENTATION

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 are still meaningful to them. Measure developers should refine measures to ensure more precise measurement. Any time there is an update to a measure, retest the language used to explain the measure to the public with person and family representatives and adjust as needed.

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

6 KEY POINTS

Person and family engagement helps measure developers produce high-quality, easily understood, relevant measures that are useful to healthcare users. Prior to measure conceptualization, measure developers should compile a comprehensive plan outlining the incorporation of person and 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 has the flexibility for virtual implementation, 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 by Measure Lifecycle stage. As part of planning patient and family engagement activities, measure developers working with the federal government also need to take need to consider the PRA exemption for measure development activities, budget, and participant compensation into consideration.

REFERENCES

- AgingCare.com. (n.d.). *AgingCare.com*. Retrieved April 13, 2022, from <https://www.agingcare.com/>
- American Association of Retired Persons. (n.d.). *AARP*. Retrieved April 13, 2022, from <https://www.aarp.org/>
- American Diabetes Association. (n.d.). *Home*. Retrieved April 13, 2022, from <https://www.diabetes.org/>
- Caring.com. (n.d.). *Home*. Retrieved April 13, 2022, from <https://www.caring.com/>
- Centers for Medicare & Medicaid Services. (n.d.-a). *Person & family engagement strategy. Sharing with our partners*. Retrieved April 13, 2022, from <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/Downloads/Person-and-Family-Engagement-Strategy-Summary.pdf>
- Centers for Medicare & Medicaid Services. (n.d.-b). *Welcome to the CMS person and family engagement network*. Retrieved April 13, 2022, from <https://pfenetwork.org/>
- Connecticut Center for Patient Safety. (n.d.). *Connecticut center for patient safety*. Quality healthcare is a right. Retrieved April 13, 2022, from <https://www.ctcps.org/about-us.cfm>
- Empowered Patient Coalition. (n.d.). *The empowered patient coalition. Promoting patient safety*. Retrieved April 13, 2022, from <https://empoweredpatientcoalition.org/>
- HealthWise. (n.d.). *Healthwise for every health decision*. Retrieved April 13, 2022, from <https://www.healthwise.org/solutions/care-transformation.aspx>
- [Medicare Access and CHIP Reauthorization Act of 2015](#), Pub. L. No. 114-10, 87 Stat. 129 (2015).
- National Quality Forum. (n.d.). *Home*. Retrieved April 13, 2022, from <https://www.qualityforum.org/Home.aspx>
- PatientsLikeMe. (n.d.). *Home*. Retrieved April 13, 2022, from <https://www.patientslikeme.com/?format=html>
- [Paperwork Reduction Act of 1995](#), Pub. L. No. 104-13, 109 Stat. 163 (1995).
- Patient-Centered Outcomes Research Institute. (n.d.). *Advisory panel on patient engagement*. Retrieved April 13, 2022, from <https://www.pcori.org/engagement/engage-us/join-advisory-panel/advisory-panel-patient-engagement>
- Patient-Centered Outcomes Research Institute. (2016). *Engagement rubric for applicants*. Retrieved April 13, 2022, from <https://www.pcori.org/sites/default/files/Engagement-Rubric.pdf> (Original work published 2014)
- People for Quality Care. (n.d.). *Home*. Retrieved April 13, 2022, from <http://www.peopleforqualitycare.org/>
- Pharmacy Quality Alliance. (2019, September). *The patient engagement in quality measurement rubric: A guide to patient partnership in the quality measure lifecycle*. Retrieved April 13, 2022, from <https://www.pqaalliance.org/assets/PQA-Patient-Engagement-Rubric.pdf>
- Sharecare, Inc. (n.d.). *Dailystrength*. Retrieved April 13, 2022, from <https://www.dailystrength.org/>

The Michael J. Fox Foundation for Parkinson's Research. (n.d.). *Home*. Retrieved April 13, 2022, from <https://www.michaeljfox.org/>

Vitals Consumer Services. (n.d.). *MedHelp*. Retrieved April 13, 2022, from <https://www.medhelp.org/>

WebMD. (n.d.). *Be a part of the WebMD community*. Retrieved April 13, 2022, from <https://exchanges.webmd.com/default.htm>