

MEASURES MANAGEMENT SYSTEM

Person and Family Engagement

According to [CMS's Person & Family Engagement Strategy](#), *patients and families are partners in defining, designing, participating in and assessing the care practices and systems that serve them to assure they are respectful of and responsive to individual patient preferences, needs and values.* One way that CMS supports person and family engagement is by including persons and families in measure development activities. As used here, the term *person* reflects an individual's identity as more than a patient by recognizing his or her participation in prevention and wellness. *Family* is used broadly to include participants in a person's healthcare including informal and primary caregivers who assist with healthcare decision making.¹

Person and family engagement supports

- Identification of issues that are important and meaningful to consumers.
- Identification of information that consumers need to make informed healthcare decisions.
- Production of useful, high quality measures.
- Development of messaging that resonates with the public.

Techniques for Involving Persons and Family Representatives in Measure Development

Prior to measure conceptualization, measure developers should create a plan outlining how they will incorporate person and/or family representative input at each stage of the measure lifecycle. Developers should involve persons/family representatives as early as possible to ensure their perspectives are captured adequately.

A commonly used technique for involving persons and family representatives in measure development is including one or more such individuals on a technical expert panel (TEPs). As members of the TEP, persons and family members serve alongside professionals and may be asked to share aspects of their experience as healthcare consumers. An advantage of including persons/family members on the TEP is that it ensures that clinical and research concerns are balanced against consumer perspectives. Other useful methods for seeking input from persons and family members include focus groups, working groups, one-on-one interviews, testing, and surveys.

- During *measure conceptualization*, person and family members can help developers generate and prioritize a list of concepts to be measured. Useful techniques at this stage are ones that allow persons and families to share their care stories (e.g., TEPs, focus groups or individual interviews).
- During *measure specification*, developers can use comments from persons and family representatives to draft measure specifications and conduct an initial feasibility assessment. TEPs, working groups, and interviews may be useful for gathering input at this stage.
- In the *measure testing phase*, developers can use person and family input to develop and/or implement the measure testing plan and ensure that individuals understand the measure. One-

¹Centers for Medicare & Medicaid Services (2016). Person & Family Engagement Strategy. Sharing with our Partners. <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/Downloads/Person-and-Family-Engagement-Strategy-Summary.pdf>.

MEASURES MANAGEMENT SYSTEM

on-one data collection methods such as cognitive testing and plain language testing are excellent options for gathering feedback during this phase.

- During *measure implementation*, persons and family representatives can review language and displays to ensure that measures are presented in an understandable way. Useful engagement techniques include those that allow for “knee jerk” reactions such as focus groups and surveys.
- During *measure use, continuing evaluation, and maintenance*, feedback from person/family representatives can help developers determine whether a measure is still relevant and easily understood. Cognitive testing and plain language testing can be helpful for this purpose.

Techniques for Involving Persons and Family Representatives in Measure Development

- Standard technical expert panels (TEPs)
- Person or family member only TEPs
- Focus groups
- Working groups
- One-on-one interviews
- Testing (concept, cognitive, plain language)
- Surveys

Each of the techniques mentioned in this article and corresponding best practices for their use are described more fully in the [Measures Management System \(MMS\) Blueprint](#). Regardless of the methods developers use, it is critical that they provide person and family representatives with clear expectations about what their participation in measure development activities will entail. Developers may also want to consider the principles in the [Patient-Centered Outcomes Research Institute \(PCORI\) Engagement Rubric](#) when collaborating with persons and family members.

Recruitment of Person and Family Representatives for Measure Development Activities

There are a variety of options for recruiting persons and family members for measure development activities. Examples include

- Posting the call for TEP ([MMS Blueprint](#)).
- Networking 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.
- Reaching out to consumer advocacy organizations.
- Contacting condition-specific advocacy organizations 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).

For more information on the topic of person and family engagement, please refer to [the MMS Blueprint](#).