April 2024

PERSON AND FAMILY ENGAGEMENT

TOOLKIT

A Guide for Measure Developers

Prepared by
Rainmakers Strategic Solutions LLC

CMS
CENTERS FOR MEDICARE & MEDICAID SERVICES

WELCOME MEASURE DEVELOPERS AND THANK YOU FOR USING THE PERSON AND FAMILY ENGAGEMENT (PFE) TOOLKIT!

PFE is a critical tenet of the healthcare quality measurement process and ensures development of meaningful and appropriate quality measures. Engagement with PFE Partners consisting of patients, families, caregivers, consumers, and advocates brings invaluable insight and expertise to the measure development process. The Centers for Medicare & Medicaid Services (CMS) developed the PFE Toolkit as a roadmap for successful engagement with PFE Partners. It is an easy-to-follow, comprehensive guide intended to support implementing best and standard practices for PFE across all CMS contractors. The PFE Toolkit will provide essential information and resources for measure developers to improve or establish PFE processes across their organizations. We appreciate the time and effort measure developers put into this important work.

The PFE Toolkit includes the following components.

- **Instructive Content:** Sections 1–8 focus on different aspects or phases of the PFE process and provide related information, key considerations, helpful hints, and resources. These sections address:
  - Preparing Your Organization;
  - The PFE Process;
  - Strategic Planning;
  - How to Engage;
  - Recruitment;
  - Onboarding and Orientation;
  - Facilitating Engagement; and
  - Ongoing Communication.
- **Ready-to-use Tools:** *Section 9: Resources* contains printable, online-friendly versions of tools, templates, and handouts that can be used to start engaging PFE Partners.
- **Scenario-based Examples:** Beginning with Toolkit *Section 3: Strategic Planning*, each section includes an example based on a measure developer experience, which incorporates key concepts covered throughout the Toolkit.

CMS

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SECTION 1:
Preparing Your Organization

PFE Partners (patients, family, caregivers, consumers, and advocates) bring unique perspectives to measure development and implementation, which are essential for ensuring delivery of measures that are high-priority and useful to the public. PFE Partners' inputs are valuable and purposeful and may impact how a measure is developed or cause a brand new course of action. Engaging PFE Partners allows them to relay issues that are important and meaningful from their perspective and supports identifying information consumers need to make informed healthcare decisions.

This section describes key considerations to help prepare your organization to engage with PFE Partners.

Topics discussed in this section include the following:

- Organizational Culture;
- Budget;
- CMS Requirements;
- The Paperwork Reduction Act (PRA);
- Confidentiality, Conflict of Interest, and Privacy;
- CMS PFE Strategy; and
- CMS Framework for Health Equity.

Resources:

The end of this section has a preview of relevant tools and templates on this topic. You can also click the links below to access printable versions that are included in Section 9: Resources of this Toolkit.

- Paperwork Reduction Act Decision Tree Tool
- Facilitator Guide for Activities in PFE Training Tool
- Personal Health Information and Privacy Agreement Template

Preparing Your Organization: Section Highlights

- Meaningful engagement with PFE Partners requires a culture where PFE Partners are viewed as equal team members and experts.
- The budget required to fully integrate PFE Partners into your measure development processes varies by organization and includes factors, such as staffing, training, recruitment, expanded timelines, and honoraria.
- The Measures Management System Blueprint (MMS Blueprint) serves as a measure developer's roadmap, describing best practices, key steps, and deliverables for each phase of measure development, inclusive of templates and other resources.
- CMS' Framework for Health Equity is a helpful resource for measure developers to consider priorities for reducing disparities in healthcare.
- The PRA is considered whenever you contact the public to collect data or information in which data/information collection is federally sponsored, includes standardized questions, and ten or more respondents will participate.
- It is important to establish expectations regarding confidentiality, conflict of interest (COI), protected health information (PHI), and privacy to protect both your organization's interests and the interests of the PFE Partners with whom you collaborate.

SECTION 1:
Preparing Your Organization

> Person and family engagement is an essential part of developing national health care policy, quality measurement, reporting and improvement initiatives, and new payment models. In many cases, when the health, safety, values, and goals of the individual are considered, health care delivery improves. – **CMS PFE Strategy, pg. 4**

ORGANIZATIONAL CULTURE

Organizational culture varies widely, but typically represents the values and principles of its members. It drives organizational policy and processes and impacts staff behavior. Organizational culture naturally evolves over time and is influenced by factors, such as changes in leadership, industry trends, social movements, the type of work your organization commits to, and integrating new stakeholders into your workflow.

Meaningful engagement with PFE Partners requires an organizational culture in which:

- The diverse breadth of expertise, experiences, values, and perspectives of PFE Partners are central components in the measure development process;
- Leadership and staff are open to changing direction or outcomes of projects;
- PFE Partners are included and viewed as team members;
- PFE Partner input is weighed equally to that of other experts;
- An organization's leadership demonstrates strong and consistent support, facilitating the possibility of a successful PFE;
- Leadership articulates a unified vision for PFE and links that vision to the organization's goals;
- Leadership reinforces the broad, positive impact PFE has on healthcare nationally; and
- Staff acknowledge the challenges and support organizational change.
- Incorporates plain language and flexible to PFE partners needs.

BUDGET

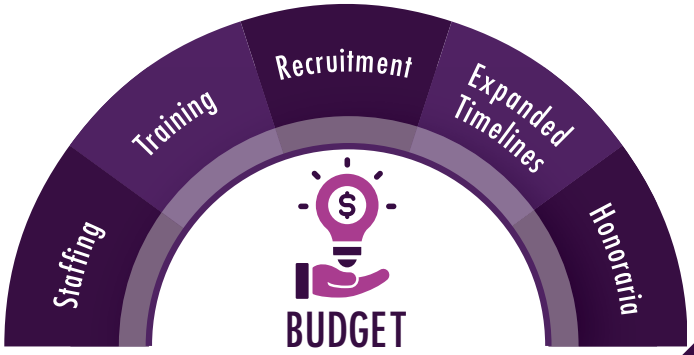
The budget required to fully integrate PFE Partners into your measure development processes will vary by organization, with a number of factors to consider and plan for as described below.

Factors that influence your budget include staffing, honoraria, training, recruitment, expanded timelines, and a budget ceiling.

Staffing

Meaningful PFE is relational work and can be time intensive, particularly at the outset during the learning curve. For example, you will need to develop an organizational PFE strategy that includes:

- When and with whom you plan to engage;
- How you will oversee PFE activities to ensure best practices are adhered to consistently across your organization;
- How you plan to measure success of PFE involvement;
- Modification of existing structures and processes to fully integrate PFE in measure development;
- Time spent developing relationships with PFE



Partners; and

- Considerations for engaging with PFE Partners with specific characteristics related to diversity (e.g., ethnicity, age, socioeconomic, education level).

This strategy requires effort, planning, developing new skills and expertise, and dedicated staff time. Determining the staffing plan, including roles and responsibilities, early on is critical to success. Some organizations may hire new staff to support their PFE work, while others may assign existing staff. Some will add PFE staff to existing measure development teams to focus solely on PFE activities, while others may choose to create a new PFE Team to centralize and support all PFE work across their organization. Regardless of how your organization decides to staff this work, it will be important to account for the additional hours all staff will need to perform the PFE-related work effectively.

Training

Your organization may need to invest in training for staff and teams to build the skills necessary to ensure effective PFE.

To successfully navigate integrating PFE Partners into your organization's established measure development processes, your organization should be prepared to offer staff training on:

- The unique, multidimensional benefits of incorporating PFE Partners into the process;
- The inherent challenges associated with bringing new stakeholders to the table and strategies for addressing those challenges;
- Effective meeting facilitation;
- Navigating modifications to longstanding internal processes;
- Developing project timelines that allow for meaningful engagement with PFE Partners; and
- How to identify priority patient characteristics and effectively engage with a diverse group of PFE Partners before, during, and after an engagement.
- Training on health equity, social determinants of health, health related social needs, cultural humility, implicit bias, and health disparities.

It is important to give your staff a strong foundation to build their PFE knowledge and skillsets. An effective way to accomplish this is to develop training activities and materials for your staff. Please see the **Facilitator Guide to PFE Training Tool** to guide your organization's PFE training.

While some training can be performed in-house, some may require external knowledge and expertise and should be considered in budget planning.

Recruitment

Identifying, recruiting, orienting, and onboarding PFE Partners to work collaboratively with your teams takes time, patience, and resources. These tasks also require specialized knowledge and experience. Additionally, most organizations do not have established relationships with a network of advocacy groups to support expedited recruitment. As a result, organizations may choose to recruit stakeholders using the following approaches:

- MIDS contractors can utilize the services of **Rainmakers Strategic Solutions** to engage with PFE partners;
- Use existing patient networks, such as the American Cancer Society;
- Subcontract with external organizations; and/or
- Attempt to recruit PFE Partners on their own.

The PFEN Network consists primarily of persons, families, caregivers, and advocates who have volunteered their time and expertise to help CMS and measure developers. These perspectives provide unique insights into developing and implementing quality measures to ensure the measures are relevant to the individuals directly impacted by them.

Rainmakers Strategic Solutions provides MIDS contractors with patient recruitment and onboarding throughout the full scope of a given engagement effort. Please refer to **Section 5: Recruitment** for more

information.

Regardless of the approach your organization selects, it is important to account for these costs in your budget.

Expanded Timelines

Incorporating new processes or stakeholders into an existing workflow inevitably increases the amount of time and resources needed to complete those processes, particularly at the outset. This may result in financial expenditures that should be considered. Effective PFE requires planning to identify meaningful engagement opportunities, coordinating and scheduling with external parties, and preparing tailored materials accessible for PFE Partners. It is important to level set expectations across all levels of the organization as measure development timelines will require some modification to accommodate the new PFE work.

Honoraria

PFE Partners are working with you as volunteers, holding full-time jobs, caring for family members, or managing illnesses and chronic conditions themselves, so it is important to acknowledge their time and contributions. Providing PFE Partners financial remuneration, no matter how large or small, is symbolic of your appreciation of their time and energy. The amount provided to PFE Partners depends on several factors, including the number of projects, meetings attended, or the length of commitment. It is most appropriate for your organization to establish a uniform honorarium for each PFE Partner for a similar set of engagement expectations.

The two main approaches to honoraria are pay-per-period and pay-per-activity. Pay-per-period is when PFE Partners join your project for a specific duration (i.e., 12 months) and receive their compensation at the end of that term. Pay-per-period is useful if you expect to work with the same PFE partners over a longer period of time, such as with a Technical Expert Panel (TEP); however, this method can be more challenging to implement as PFE Partners are being asked to contribute without compensation up front. Pay-per-activity is when PFE Partners receive payment immediately after each engagement (i.e., after a meeting or interview) and is good for short-term engagements like focus groups or workshops that only require one or two meetings; however, pay-per-activity can require additional processing for each payment after each activity.

Either pay-per-activity or pay-per-period can be applied to short or long-term engagements depending on the length of commitment, budget, and capacity of the project staff.

CMS REQUIREMENTS

Measures Management System (MMS) Blueprint

CMS developed the MMS as a standardized system for measure development and reevaluation. The **MMS Blueprint** serves as a measure developer's roadmap and describes best practices, key steps, and deliverables for each phase of measure development; templates to use as guides; and other resources to help throughout the process. The **MMS Supplemental Material: Person and Family Engagement in Quality Measure Document** provides additional information on the PFE strategy. All measure developers contracted with CMS are expected to adhere to MMS processes and guidance. The MMS Blueprint is updated regularly to meet the evolving needs of measure developers. The latest MMS Blueprint includes a section on **Stakeholder Engagement**, which highlights the importance of PFE engagement throughout the measure lifecycle. Reviewing the above-mentioned sections of the MMS Blueprint carefully will ensure your PFE plans align with necessary processes and requirements. Prioritizing collaboration with PFE Partners may require integrating existing processes with new ones, adapting existing processes, or eliminating processes that do not work. Once your organization determines how PFE may impact your timeline and deliverables, share your findings and seek approval from your CMS Contracting Officer Representative (COR).

THE PAPERWORK REDUCTION ACT

The Paperwork Reduction Act (PRA) is a United States law that requires federal agencies to obtain approval before collecting information from the American public. Its main purpose is to minimize the amount

of paperwork the public must fill out on behalf of the federal government. Engaging with PFE Partners will require your organization to recruit, interact with, and solicit input from the public.

When Does the PRA Apply to PFE?

The PRA is considered whenever you contact the public to collect data or information in which:

- Data/information collection is federally sponsored;
- Data/information collection includes standardized questions; and
- Ten or more respondents will participate.

Any work paid for with federal dollars is considered "federally sponsored," which includes work performed under contract with federal agencies, such as CMS, the Agency for Healthcare Research and Quality (AHRQ), or the Food and Drug Administration (FDA). This is true whether your organization is a prime contractor, subcontractor, consultant, or vendor. Engaging with the public with funding the federal government provides through another group or organization still counts as being federally sponsored.

Any time your organization asks ten or more people the same set of standardized questions, the PRA applies. Common examples that may be subject to the PRA requirements include:

- Basic surveys or similar quantitative methods;
- Qualitative research or program evaluations; and
- Recruitment.

PRA Exemption

The Medicare Access and CHIP Reauthorization Act (MACRA) of 2015 provides a PRA exemption for measure development and reevaluation. To determine if the PRA applies and whether your organization is eligible for exemption, review your PFE plans and the **PRA Decision Tree** with your COR and the Office of Strategic Operations and Regulatory Affairs (OSORA) as necessary to categorize the work (development and implementation) and assess how the PRA and the exemption may apply. Once exemption eligibility is established, you or your COR may also need to consult with the Office of Management and Budget to confirm exemption. Once approval is received to collect information from the public, recruitment can start. This process takes time—up to a year or longer—so plan ahead.

Additional information on the PRA can be found **here**.

CONFIDENTIALITY, CONFLICT OF INTEREST, AND PRIVACY

It is important to establish expectations regarding confidentiality, Conflict of Interest (COI), Protected Health Information (PHI), and privacy prior to launching PFE work. Doing so protects both your organization's interests and the interests of the PFE Partners with whom you collaborate. For example, during collaboration, PFE Partners may share personal experiences and intimate health information. Most will only do so in a safe environment, one in which their privacy and confidentiality is explicitly protected. Their personal experiences are typically what has brought PFE Partners to participate in this work, and they will likely want to share their stories. It is your responsibility to protect their privacy and make sure they feel comfortable. One strategy is to create and walk through a **Protected Health Information and Privacy Agreement** both you and the PFE Partner signs.

Additionally, your organization may have contractual and legal requirements stipulating you must maintain confidentiality of proprietary measure development information and the development of measures without the influence of any personal or financial COIs. Your organization may have confidentiality, COI, and privacy templates on file, or you may need to work with in-house or outside counsel to develop them for this work.

Some PFE Partners will be unaccustomed to completing these types of documents due to various factors, such as age or literacy level. Plan to build in adequate time to ensure these documents have plain language, explain the documents, share why they are important, and respond to any questions from PFE Partners.

CMS PFE STRATEGY

CMS Person and Family Engagement Strategy

In December 2016, CMS released its **PFE Strategy**. CMS developed this Strategy for a wide variety of stakeholders to share the Agency's PFE vision and encourage the healthcare community to consider and/or take action to incorporate the principles into their work practices. The PFE Strategy describes CMS' PFE values, foundational principles, and goals. CMS' intra-agency Person and Family Engagement Affinity Group developed the Strategy with input from key stakeholders, including patient advocacy groups, associations, providers, and caregivers.

"CMS recognizes that PFE is essential to the health and well-being of our communities and is committed to supporting, implementing and integrating PFE principles into all of our actions and programs." – **CMS PFE Strategy, 2023**

The PFE Strategy directly aligns with one of the priority focus areas of the CMS Quality Strategy—to strengthen person and family engagement as partners in their care. Specifically, it focuses on ensuring high quality care is delivered to patients in ways that reflect person and family values and preferences, improve their experiences, and enable them to actively engage in directing and self-managing their care. The information below lists the strategic goals and objectives for the **CMS National Quality Strategy** 2023.

National Quality Strategy

- Ensure individuals and caregivers have the information needed to make the best choices for quality and safety, their health, as well as a direct, significant, and equitable contribution to how CMS evaluates.
- Expand individual and community outreach efforts to obtain meaningful, bi-directional engagement and include diverse perspectives in CMS strategy and policy.
- Promote interperability of health care data to ensure all individuals have access to their personal health information through patient portals.
- Increase access to and utilization of public reporting websites (e.g., Care Compare) to promote informed and collaborative decision-making.
- Integrate feedback from individuals and communities through person-reported quality metrics.

CMS Framework for Health Equity

In 2022, CMS released an updated **framework** to "further advance health equity, expand coverage, and improve health outcomes for more than 170 million individuals supported by CMS programs." All priorities discussed in this framework directly affect the Measure Development process, and it is vital for all Measure Developers to read the framework in its entirety and strategize on how their engagement with PFE Partners will contribute to the priorities listed below.

Health Equity Priorities for Reducing Disparities in Health

- Priority 1: Expand the Collection, Reporting, and Analysis of Standardized Data
- Priority 2: Assess Causes of Disparities Within CMS Programs and Address Inequities in Policies and Operations to Close Gaps
- Priority 3: Build Capacity of Health Care Organizations and the Workforce to Reduce Health and Health Care Disparities
- Priority 4: Advance Language Access, Health Literacy, and the Provision of Culturally Tailored Services
- Priority 5: Increase All Forms of Accessibility to Health Care Services and Coverage

How does each priority area directly relate to the measure development process?

Priority 1: Expand the Collection, Reporting, and Analysis of Standardized Data

- Measure Developers can strive to better understand the communities impacted by healthcare and consider social determinants of health data (e.g., race/ethnicity, language, sex, disability status, geographic location) and diverse sets of patients when engaging Patient Partners for measure development efforts.

Priority 2: Assess Causes of Disparities Within CMS Programs and Address Inequities in Policies and Operations to Close Gaps

- Measure Developers can aim to measure equity through development of measures that take health equity/disparities into account; by developing measures around health equity, Measure Developers can close healthcare gaps in access, quality, and outcomes.

Priority 3: Build Capacity of Healthcare Organizations and the Workforce to Reduce Health and Health Care Disparities

- Measure Developers can also support development of measures that build up the capacity of healthcare organizations; they can help CMS develop approaches to health care delivery that address barriers to access and health care services, such as workforce shortages and network coverage, and create quality improvement tools to identify and reduce disparities and resources tailored to communities.

Priority 4: Advance Language Access, Health Literacy, and Provision of Culturally Tailored Services

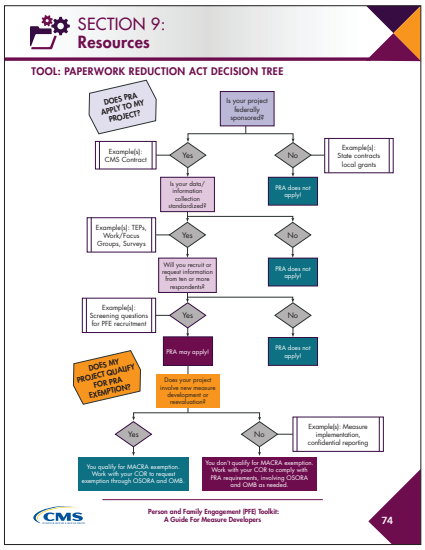
- Measure Developers can consider tailoring documents to be in line with varying health literacy levels and languages to connect with a more diverse set of PFE Partners.

Priority 5: Increase All Forms of Accessibility to Healthcare Services and Coverage

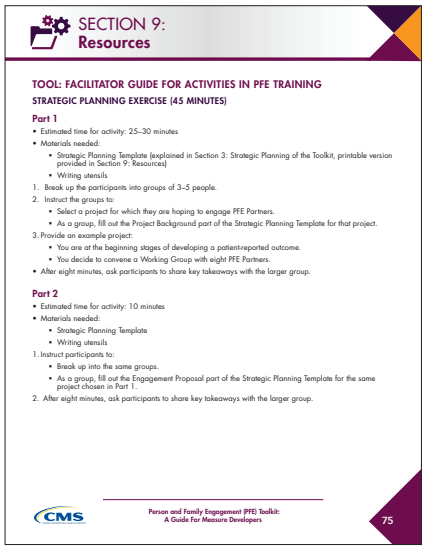
- Measure Developers can systematically help CMS assess the accessibility of the healthcare system's services for individuals with disabilities. This includes making infrastructure improvements, strengthening training for providers and staff, and ensuring services are designed to meet the needs of the patients they serve.

TOOL: Preparing Your Organization

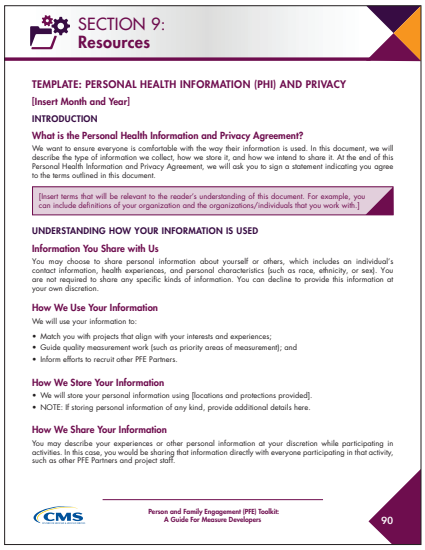
SECTION 1 TOOLS AND TEMPLATES



[TOOL: Paperwork Reduction Act Decision Tree]



[TOOL: Facilitator Guide to Activities for PFE]



[TEMPLATE: Personal Health Information and Privacy]

SECTION 2: The PFE Process

The process of measure development is complex and may vary across organizations. Depending on an organization's current measure development process, incorporating PFE Partners may change how things are done and may ultimately impact work processes, work outcomes, and the measures developed. Meaningful PFE commands its own process that incorporates well-defined, logical steps that systematically guide an organization through the phases of engagement and yield quality measures designed with authentic person and family input. The PFE process will be incorporated into and will become an integral part of the measure development processes. PFE Partners bring a unique type of expertise rooted in personal experience and often tied to emotion.

This section describes a systematic process for and benefits of engaging with PFE Partners.

Topics discussed in this section include the following:

- How PFE Will Help Your Organization; and
- Phases of the Process.

The end of this section contains a preview of a relevant handout on this topic. You can also click the link below to access a printable version that is included in Section 9: Resources of this Toolkit.

- PFE Process Summary Handout

The PFE Process: Section Highlights

- Proactively establishing a systematic PFE process within your organization will help orient staff to PFE and provide an easy-to-follow road map.
- Broad organizational support is critical to ensuring successful PFE work.
- A systematic PFE process includes discrete phases with specific goals.
- Assigning team members to specific phases of the process (e.g., recruitment, prep calls) will foster a sense of accountability.
- The six critical phases of the PFE process include the following:
  - Strategic Planning: Work with your teams to determine the why, what, how, who, and when of engagement;
  - Recruitment: Recommend recruitment timelines to include adequate time in advance of the first activity to allow time for identification, selection, onboarding, orientation, or potential candidate drop-out;
  - Preparing PFE Partners and Staff: Follow basic procedures related to onboarding and orientation;
  - Facilitation: Include planning, facilitating, and following up on the engagement activity itself (e.g., TEP, Working Group, and Focus Group);
  - Follow-up: Conduct individual debrief calls with PFE Partners, ideally within one to two days of the engagement; and
  - Refining the Approach: Consistently monitor your approach to PFE and making improvements in real-time.

SECTION 2: The PFE Process

> Person and Family engagement goes beyond informed consent. It is about proactive communication and partnered decision making between healthcare providers, patients, families, and caregivers. It is about building a care relationship that is based on trust and inclusion of individuals values and beliefs. – **CMS PFE Strategy, pg. 6**

The PFE Process is a logical step-by-step guide for measure developers to progress through planning, recruitment, and engagement with PFE Partners to produce quality measures designed with authentic person and family input.

HOW PFE WILL HELP YOUR ORGANIZATION

PFE will inevitably introduce changes to the measure development processes to which your staff are accustomed. Proactively establishing a systematic PFE Process within your organization provides numerous benefits, including the following.

Prepared Staff

Establishing a systematic process will help orient staff to PFE in an organized way and provide a roadmap to follow. This is particularly important for team members who may be new to PFE. Reviewing the PFE Process with your staff will also help prepare them for the changes to come while providing the opportunity to reset expectations related to measure development, workflow, and timeliness and will help you proactively identify and address new challenges.

Shared Vision

Broad organizational support is critical to ensuring successful PFE work. This begins with a shared understanding of what PFE is among an organization's leadership and staff and their commitment to the PFE Process. When challenges arise or setbacks occur, revisiting the process will assist in assessing goals and determining the appropriate path forward.

Approachable Framework

A systematic process breaks PFE down into discrete phases, each with specific goals. The PFE Process also serves as a framework for staff as they develop or modify their timelines to accommodate PFE components. This approach may make the undertaking feel more manageable.

Shared Responsibility

A systematic process ensures shared accountability across team members. Assigning certain team members responsibility for specific phases of the process (recruitment, prep calls with PFE Partners, etc.) will build each team member's sense of ownership and accountability for the outcome of PFE work.

Future Organizational Planning

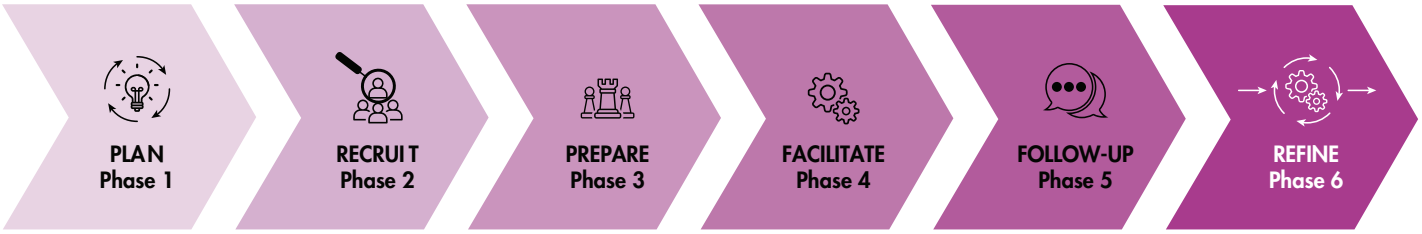
Using a systematic process inherently organizes all PFE work into distinct components that can be tracked for staffing, evaluation, and budgeting purposes.

Diversity of Feedback

Establishing a comprehensive PFE process will incorporate a diversity of PFE Partners who come from different backgrounds and will offer a diversity of lived experiences. PFE Partners' input to measure development will augment the perspectives of other TEP or Workgroup members who may have clinical or research expertise but not the direct patient or caregiver perspective.

THE PHASES

There are six critical phases in the PFE Process: plan, recruit, prepare, facilitate, follow-up, and refine (see the figure below). Each phase is equally important and plays a critical role in the success of the phases that follow. Though the phases are sequential and described as stepwise, the overall process must remain adaptable to allow for modifications or improvements based on your team's experiences moving through each phase. A description of each phase is provided on the following pages. Specific information and guidance for each phase is provided in the sections that follow. For more information, please refer to the PFE Process Summary Handout.



The PFE Process

Phase	Timing	Key Areas
Phase 1: Strategic Planning	As soon as possible once PFE is identified for an activity	Timeline, Patient Characteristics, Expectations of PFE Partners
Phase 2: Recruitment	At least 45 days prior to engagement activity	Appropriate Engagement Mechanism, Refine Patient Characteristics (as needed)
Phase 3: Prepare PFE Partners	At least ten days prior to engagement activity	Timely Onboarding and Orientation
Phase 4: Facilitate	Date is determined by measure developer in coordination with PFE Partners	Conduct Engagement, Use of Best Practices
Phase 5: Follow-Up	Ideally within 1–2 days of engagement (but may depend on availability of PFE Partner)	Debrief Calls or Online Surveys
Phase 6: Refine Approach	In real time—as soon as you receive feedback from PFE Partners after engagement activity	Use Feedback for Process Improvement, Share Lessons Learned

Phase 1: Strategic Planning (see Section 3: Strategic Planning and Section 4: How to Engage)

The most critical phase of the PFE Process is strategic planning, which addresses working with your teams to determine the why, what, how, who, and when of engagement.

Project goals and specific objectives for engaging PFE Partners in the work need to be defined at the outset (the "why"). The project goals and objectives can then be leveraged to determine where PFE input will be beneficial (the "what"). These pieces will all help in selecting the appropriate mechanism for engaging with PFE Partners (the "how"). Where input is needed will naturally dictate the specific characteristics of PFE

Partners that will support the goals of the project and who is targeted during recruitment (the "who").

Teams are set up to succeed when adequate time and consideration are allocated to this phase. Before moving on to the next phase, take time to allocate resources and conduct staff training on PFE Fundamentals and Process, Strategic Planning, and Recruitment (Facilitator Guide for Activities in PFE Training Tool).

Lastly, contractual obligations and the overall project timeline will dictate when PFE can be integrated into your projects. For example, are patients needed to join a TEP, Focus Group, or Working Group for a specific measure?

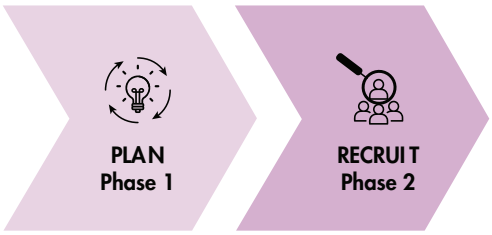
Questions to Consider When Strategic Planning:

1. How long is the engagement?
2. What is the timeline for recruitment?
3. What are the patient characteristics and specific types of diversity (e.g., ethnicity, geographic, socioeconomic, age) being sought?
4. What does the onboarding process look like?
5. What are the expectations for the PFE Partners?
6. What is the best method for communicating consistently with PFE Partners (before, during, and after the engagement)?

Phase 2: Recruitment (see Section 5: Recruitment)

Strategic planning will allow you to have a good sense of who you are looking to engage with and how. You will have identified key characteristics of PFE Partners that will be most helpful to your project. For example, you may have decided to target PFE Partners who are family members or caregivers for chronically ill patients, patients with Type 2 Diabetes, familiar with kidney disease, and/or impacted by opioid medication management.

Recruiting PFE Partners that are a good match for both the content area (e.g., end of life care) and engagement mechanisms (i.e., surveys, patient only meetings, TEPs) poses unique challenges and can take time. Be sure to allot adequate time to this phase. It is recommended to begin the recruitment process before the first activity to ensure ample time for identification, selection, onboarding, orientation, or a candidate drop-out. Additionally, to reduce the likelihood of candidate dropouts, decisions on the inclusion of candidates should be communicated to potential candidates within ten days of their interview.



The PFE Process Phases 1 and 2

Phase 3: Prepare PFE Partners and Staff (see Section 6: Onboarding and Orientation)

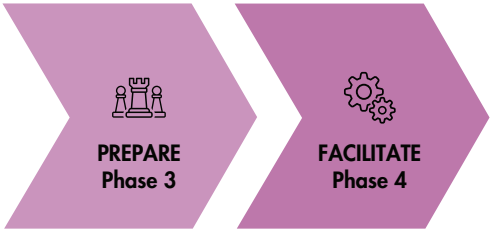
Preparation begins with the basic procedures of onboarding and orientation. The onboarding and orientation processes should be executed in a timely fashion following recruitment efforts. For example, after interviewing potential candidates, decisions about selecting candidates and invitations to join project teams should be communicated to participants and finalized no less than ten days prior to your team's first scheduled engagement activity.

PFE Partners will be asked to complete contractual, COI, and privacy documentation. Your teams will also meet with PFE Partners to share the organization's vision for PFE and orient them to how they will contribute and the work that is being done. Once onboarding and orientation are complete, your organization will prepare PFE Partners to engage on the specific project (see **Section 6: Onboarding and Orientation**).

To adequately prepare PFE Partners, meet with them individually prior to the engagement activity. During these prep calls, review the specific objectives of the engagement, discuss the types of questions they may be asked, set clear expectations (such as time commitments), and answer any content-related questions. It is important to also explain how the engagement will go and how feedback will be solicited. Most importantly, reiterate that PFE Partners are experts and bring a critical expertise to measure development. Prepare staff by providing training in effective meeting facilitation using the **Facilitator Guide for Activities in PFE Training Tool**.

Phase 4: Facilitate (see Section 7: Facilitating Engagement)

This phase includes planning, facilitating, and following up on the engagement activity itself (e.g., TEP, Focus Group, Working Group, interviews). It can also include conducting meetings, designing website displays, collecting feedback on key decisions, generating conceptual frameworks through surveys, and more. While engaging with PFE Partners, be sure to use best practices and be cognizant of opportunities for process improvement.



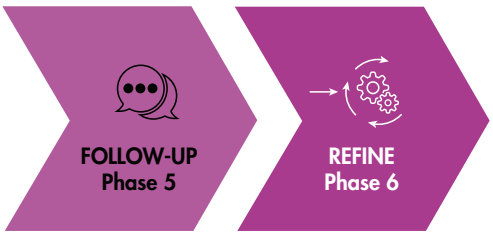
The PFE Process Phases 3 and 4

Phase 5: Follow Up with PFE Partners (see Section 8: Ongoing Communication)

After each engagement activity, it is important to follow up with PFE Partners by conducting individual debrief calls, ideally within one to two days of the engagement. During these calls, assess their overall experience during the engagement, discuss what went well and what they found difficult, answer any questions, and provide guidance. Depending on the engagement activity and number of participants, some PFE Partners may prefer to not share specific thoughts in real-time or may have developed additional perspectives since the engagement occurred. Debrief calls provide the opportunity for PFE Partners to share additional feedback or perspective in a more private setting. Online surveys may also be useful tools in gathering feedback from participants.

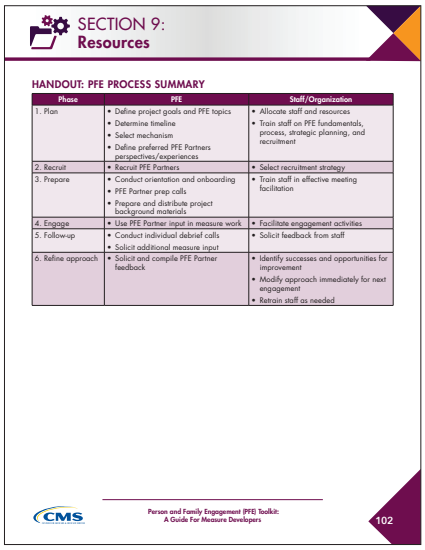
Phase 6: Refine Approach

Consistently monitoring your approach to PFE and making improvements in real-time helps ensure the PFE Partners have positive and meaningful experiences, which leads to authentic input received from PFE Partners and rich, productive, and impactful engagements. Some organizations may choose to solicit anonymous feedback from PFE Partners to measure success, help clarify where things are going well, and identify opportunities for improvement. Other organizations may simply compile feedback they hear during PFE Partner debrief calls. Regardless of the mechanism, it is important for your organization to plan for and actively manage rapid, real-time, PFE process improvements and to share lessons learned across all teams engaging with PFE Partners. This will ensure high quality standards of practice at an organizational level.



The PFE Process Phases 5 and 6

SECTION 2: HANDOUT



SECTION 9:
Resources

HANDOUT: PFE PROCESS SUMMARY

Phase	PFE	Staff/Organization
1. Plan	• Define project goals and PFE topics • Determine timeline • Select mechanism • Define preferred PFE Partners perspectives/experiences	• Allocate staff and resources • Train staff on PFE fundamentals, process, strategic planning, and recruitment
2. Recruit	• Recruit PFE Partners	• Select recruitment strategy
3. Prepare	• Conduct orientation and onboarding • PFE Partner prep calls • Prepare and distribute project background materials	• Train staff in effective meeting facilitation
4. Engage	• Use PFE Partner input in measure work	• Facilitate engagement activities
5. Follow-up	• Conduct individual debrief calls • Solicit additional measure input	• Solicit feedback from staff
6. Refine approach	• Solicit and compile PFE Partner feedback	• Identify successes and opportunities for improvement • Modify approach immediately for next engagement • Retrain staff as needed

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HANDOUT: PFE Process Summary

SECTION 3: Strategic Planning

Strategic Planning provides guidance on each step of the strategic planning process that is crucial to the success of the engagement. Adequate planning and familiarity with the key technical considerations are important. This section outlines key considerations for incorporating PFE into strategic planning processes and provides targeted guidance to help plan strategically. Before launching a project with PFE Partners, it is important to know the goals, timeline for reaching each goal, and the stakeholders needed to reach each goal.

Topics discussed in this section include the following;

- Importance of Creating a Strategic Plan;
- How to Develop a Strategic Plan;
- Completing the Strategic Planning Template; and
- Scenario-Based Example.

Resources:

The end of this section has a preview of a template and a handout relevant to this topic. You can also click on the links below to access the printable versions that are included in Section 9: Resources of this Toolkit.

- Strategic Planning Template
- Elements of Strategic Planning Handout

Strategic Planning: Section Highlights

- Developing the strategic plan prior to starting the measure development process ensures you are making informed decisions regarding the product you can deliver, project timelines, staffing, and other resource needs.
- Reviewing and updating the strategic plan regularly keeps you accountable in reaching your PFE goals.
- Consider using a standard template to generate a strategic plan, such as the Strategic Planning Template.
- Creating an individual strategic plan for each new measure, concept, or project you are launching is a good practice. A useful strategic plan will address each of the five critical planning elements—why, what, how, who, and when.
    - Why: Think about why engaging with PFE Partners is critical to the project's success. The goal might be to develop a new measure, refine existing measures, adapt measures to new programs, or develop implementation strategies.
    - What: Identify the big picture topics, concepts, or decisions you are planning to collaborate on with your PFE Partners.
    - How: Select an engagement mechanism (e.g., TEP, survey) that best suits your project and the goals for your engagement as well as your timeline.
    - Who: Ensure the people you are working with are a good fit for your specific project and that you have a diverse set of perspectives. Define what type of diversity you are looking for and want to prioritize, such as age, socioeconomic status, geography, sex, race/ethnicity, insurance status, language spoken at home, health literacy level, etc.
    - When: As a measure developer, you likely have contractual obligations to complete measures on a certain timeline or meet key milestones for rule making or endorsement by the CMS National Consensus Based Entity (CBE) The Partnership for Quality Measurement (PQM)™.

SECTION 3: Strategic Planning

> Prior to measure or quality topic conceptualization, the measure developer and others desiring stakeholder engagement should compile a comprehensive plan outlining how they will incorporate person and/or family representative input at each stage of the Measure Lifecycle or quality project. – **CMS MMS, Blueprint Measure Lifecycle: Stakeholder Engagement: Types of Stakeholder Engagement**

IMPORTANCE OF CREATING A STRATEGIC PLAN

A detailed, comprehensive strategic plan is critical to successful engagement with PFE Partners. First, developing the plan prior to starting the work ensures you are making informed decisions regarding what product you can deliver, project timelines, staffing, and other resource needs. Secondly, a strategic plan serves as an important record of what your team and the organization committed to and, when referenced regularly, will help keep you on track toward your PFE goals. Finally, as the project evolves over time, you can use the strategic plan to document changes you decide to make to your PFE approach and determine potential timeline or budgetary implications.

HOW TO DEVELOP A STRATEGIC PLAN

Creating an individual strategic plan for each new measure, concept, or project you are launching is good practice. However, each project invariably has unique challenges and nuanced considerations and will require tailoring. For example, if your organization is developing two new measures and you want to engage with PFE Partners in both projects, you should develop two individual strategic plans. On the other hand, if you are planning to work with one group of PFE Partners to select the outcome, cohort, and risk-adjustment approach of a single measure, you can likely include all those steps within the same strategic plan.

We recommend using a standard template to generate a strategic plan, such as the template we will review here, within ten business days of initial discussions with your COR to guide your project timeline. We also recommend reviewing the completed template within ten days to ensure your team is mapping out processes to guide PFE far enough in advance to avoid potential delays to all subsequent steps in the PFE Process (i.e., outreach, recruitment, onboarding, engagement).

A useful strategic plan will address each of the five critical planning elements—why, what, how, who, and when. We recommend continuously updating the plan when project scope or timelines change and making revisions to strategic plans within three to five business days of an identified deviation from the original plan to quickly adjust recruitment and engagement strategies accordingly.

Use the **Elements of Strategic Planning Handout** to ensure you identify and incorporate these concepts into your strategic plan within ten business days of initial discussions with your COR to guide your project timeline. You will likely need to consult with others in your organization as you complete your strategic plan. For instance, if you hope to recruit ten PFE Partners, you will need to confirm your organization has the time, staff, and other needed resources to recruit and prepare these individuals (see **Section 5: Recruitment** for recruitment strategies and guidance).

Begin the planning process early and allow time for consultation and review within your organization.

COMPLETING THE STRATEGIC PLANNING TEMPLATE

In this section, we will walk through each step of completing the **Strategic Planning Template**. We will use a mock case study to provide an example of how you might answer each question.

Step 1: Why – Your Project and PFE Goals

Think about why engaging with PFE Partners is critical to the success of this project. Briefly state the overall goal(s) of the project. The goal might be to develop a new measure, refine existing measures, adapt measures to new programs, or develop implementation strategies. Your PFE goals might be to develop a patient-centered measure or ensure patients can understand the language you use to describe the measure outcome. Perhaps you are creating a measure that has sensitivities and challenges relevant to PFE Partners, such as a measure that evaluates hospice care and decision-making. You may also be considering measures that address health equity. For example, the National Committee for Quality Assurance (NCQA) has added race and ethnicity stratification to eight additional Healthcare Effectiveness Data and Information Set (HEDIS) measures in measurement year 2023. More than 200 million people are enrolled in plans that report HEDIS results, and HEDIS is one of healthcare's most widely used performance improvement tools. HEDIS measures may inspire your own measures related to health equity and these goals drive everything else. Write your goals down in your strategic plan and reference them regularly throughout the project.

CASE STUDY EXAMPLE:

Our overall project goal is to develop a new patient reported outcome measure related to diabetes care. We want to make sure the specific outcome we are measuring is something that truly matters to patients and can be used when making care decisions. Our PFE goal is to select a measure concept that focuses on outcome information a patient can provide during care. Therefore, our PFE goal for this project will be to gather input from a group of PFE Partners to ensure the measure information can be used by patients and families.

Step 2: What – The Main Questions or Topic Areas for PFE Collaboration

Topics for PFE are usually selected based on where you are in the development cycle. Are you ready to select a cohort or develop a risk-adjustment methodology? Are you earlier in the process where you are prioritizing what measure to create or selecting an outcome? It is a good idea to start with a few clear topic areas where you think PFE Partner input is most critical. Then, be flexible and open to shifting courses based on PFE Partner input. A list of initial measurement topics for your consideration is included in the **Engagement Topics and Decisions Summary Tool**. At this stage of the planning process, you do not need to identify the exact questions you will ask PFE Partners or the specific options you will present to them. Instead, you are simply identifying the big picture topics, concepts, or decisions you are planning to collaborate on with your PFE Partners. PFE Partners will often surprise you and show you ways they can shape your measurement project that you never imagined.

CASE STUDY EXAMPLE:

Our team is developing a new measure focused on functional assessments and outcomes for patients who have had hip replacements. I want PFE Partners who have had similar surgeries to provide input on what functional outcome goals they had following their surgery. Their input will help us prioritize and select an outcome for functional outcome measure. My team has several ideas in mind, so we'll present the options to the PFE Partners and use their feedback to make a final decision.

Step 3: How – The Engagement Mechanism

The PFE Toolkit refers to the way you engage with PFE Partners as the "engagement mechanism," which could be a Measure Working Group, a TEP, a survey, or something else you create. You should select an engagement mechanism that best suits your project and the goals for your engagement as well as your timeline (see **Section 4: How to Engage, Part 2: Selecting an Engagement Mechanism**).

CASE STUDY EXAMPLE:

We are early in the development process, and we want to be sure we have the opportunity for in-depth discussions about selecting the outcome for our diabetes measure. I think a PFE Partner-only Focus Group would be the best engagement mechanism.

Step 4: Who – What Perspectives, Experiences, or Expertise Do I Want Represented by the PFE Partners?

PFE Partners have their own unique experiences. You will want to ensure the people you are working with are a good fit for your project and that you have a diverse set of perspectives. Diverse PFE Partners can mean looking at a variety of characteristics, including, but not limited to, age, socioeconomic status, geography, sex, race/ethnicity, insurance status, and preferred language to accommodate varying health literacy levels. Measure developers should also keep in mind that some patient populations may be challenging to recruit due to historical distrust of the healthcare system and should allow additional time for building trust with those populations. However, you should prioritize which characteristics are most important to your specific engagement effort, perhaps selecting your top three characteristics. Also, some individuals may be able to meet multiple characteristics you are looking for. For example, you may want to find PFE Partners who are similar

CASE STUDY EXAMPLE:

We are developing a measure that evaluates the flow of communication between a referring provider, a specialist, and the patient. We want to hear from people with one or multiple health conditions or family members who are caregivers for patients with complicated health needs. We also want to ensure we have various backgrounds and demographic characteristics represented, including varying socioeconomic status, race/ethnicity, health literacy levels, and geographic location. This will ensure we gain a diverse array of perspectives in our engagement.

Step 5: When – Your Anticipated Timeline

As a measure developer, you likely have contractual obligations to complete measures on a certain timeline or meet key milestones for rulemaking or endorsement. Make sure to incorporate meaningful engagement with PFE Partners into your timeline from the beginning and allow enough time before you begin engaging PFE Partners and between your engagement activities.

CASE STUDY EXAMPLE:

We are building our project plan and want to identify when we should start recruiting our PFE Partners. It could take us two to three months to recruit the patients and family members who meet our desired characteristics. Initially, we want to have three two-hour Focus Group meetings with our PFE Partners to help refine our measure concept. We will need several months to meet with our PFE Partners to select the outcome. We anticipate it will take the team about a year to finish the measure specifications and complete testing activities. We want to bring our PFE Partners in again later in the development process to discuss the testing results and ensure the measure concept represents patient priorities.

SCENARIO-BASED EXAMPLE

Your Objective: Performing Development and Reevaluation Work for Measures

Engagement Strategy: Evaluating Preliminary Results or Displays

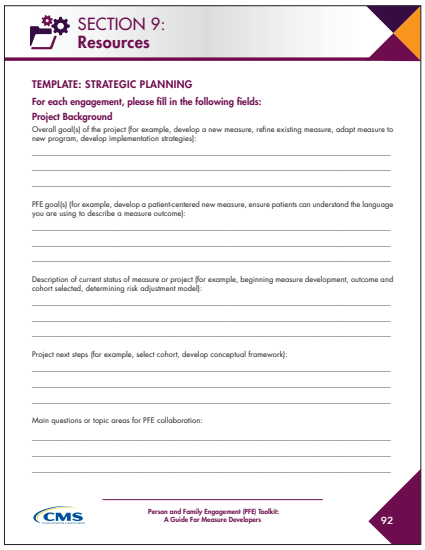
Mechanism: Technical Expert Panel

Your team would like feedback from a TEP of five PFE Partners on the development and reevaluation of several outcome measures, including a clinician-level Patient Reported Outcomes Performance Measure (PRO-PM), following procedures in ambulatory surgical centers. You bring the preliminary measure results to your TEP so they can see how the surgical centers would perform on the measure nationally. You show a chart that depicts the numbers of facilities performing worse than average, average, and better than average, and you point out that most of the facilities fall into the "average" category. You ask PFE Partners if the current version of the measure is useful given these specifications and results. PFE Partners express concern the measure is not particularly useful to patients attempting to select a facility for their surgery. Because so many facilities are lumped together as average, they would not know how to select among them. Your team discusses the suggestions and takes another look at the statistical models. Unfortunately, you determine data limitations prevent you from further refining the performance categories.

While your engagement with PFE Partners has not substantially improved the usability of the measure because you were unable to immediately address the TEP's concerns, you now have patient-selected priorities for measure reevaluation. You can also proactively strive to provide clear, patient-friendly language to publicly describe the measure results knowing that other patients may also have the same concerns as the TEP. Overall, PFE Partner feedback and their unique lived experiences help shape the measure.

Consider discussing what was gleaned from those examples with respect to diversity and what Measure Developers should consider when developing their measure and strategically planning the measure.

SECTION 3 TOOLS AND TEMPLATES


SECTION 9:
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TEMPLATE: STRATEGIC PLANNING

For each engagement, please fill in the following fields:

Project Background

Overall goal(s) of the project (for example, develop a new measure, refine existing measure, adapt measure to new program, develop implementation strategies):

PFE goal(s) (for example, develop a patient-centered new measure, ensure patients can understand the language you are using to describe a measure outcome):

Description of current status of measure or project (for example, beginning measure development, outcome and cohort selected, determining risk adjustment model):

Project next steps (for example, select cohort, develop conceptual framework):

Main questions or topic areas for PFE collaboration:

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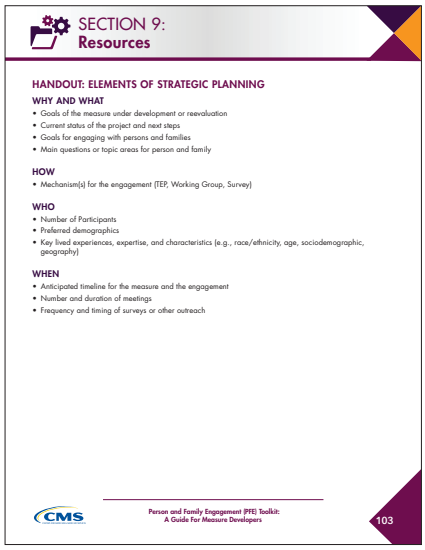
[TEMPLATE: Strategic Planning Template]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HANDOUT: ELEMENTS OF STRATEGIC PLANNING

WHY AND WHAT
- Goals of the measure under development or reevaluation
- Current status of the project and next steps
- Goals for engaging with persons and families
- Main questions or topic areas for person and family

HOW
- Mechanism(s) for the engagement (TEP, Working Group, Survey)

WHO
- Number of Participants
- Preferred demographics
- Key lived experiences, expertise, and characteristics (e.g., race/ethnicity, age, sociodemographic, geography)

WHEN
- Anticipated timeline for the measure and the engagement
- Number and duration of meetings
- Frequency and timing of surveys or other outreach

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[HANDOUT: Elements of Strategic Planning Handout]

SECTION 4: How to Engage

How to Engage provides recommendations for selecting topics suitable for engagement, mechanisms for engaging with PFE Partners on these topics, and strategies for handling highly technical topics. Measure development is complex and needs substantial and varied input from experts. Like many other stakeholders engaged with measure development, PFE Partners bring unique perspectives and use their requisite expertise and lived experiences to inform goals, prioritize measure development topics, and provide input in the decision-making process. Engaging a diverse group of PFE Partners will support building high-quality, patient-centered measures.

Topics discussed in this section include the following:

- Selecting Topics;
- Selecting an Engagement Mechanism;
- Matching PFE Partners to Engagement Mechanisms and Projects;
- Strategies for Discussing Quality Measures with PFE Partners; and
- Scenario-Based Example.

Resources:

The end of this section has a preview of tools relevant to this topic. You can also click the links below to access printable versions that are included in **Section 9: Resources** of this Toolkit.

- **Engagement Topics and Decisions Summary Tool**
- **Choosing Your Engagement Mechanism Tool**

How to Engage: Section Highlights

- Selecting topics to engage PFE Partners is easier when approached systematically. For more details, see the **Engagement Topics and Decisions Summary Tool**.
- Depending on the project, its phase of development, and other factors, different engagement mechanisms will satisfy your project and PFE goals. For example, it is common to engage PFE Partners through more than one mechanism for a single project.
- Goals for matching PFE Partners to engagement mechanisms and projects should reflect the following:
  - PFE Partners have a positive experience with your organization and are able to make an impactful contribution to your work;
  - Your organization receives the support it needs to make high-quality, patient-centered measures; and
  - Individual project topic or content and mechanism align with a PFE Partner's characteristics.
- We recommend three broad strategies you can use to plan for highly technical quality measurement discussions: 1) generating ideas, 2) weighing options, and 3) evaluating preliminary results or displays.

SECTION 4: How to Engage

> 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. – **CMS MMS Hub, Supplemental Material (Person and Family Engagement in Quality Measurement)**

SELECTING TOPICS

Deciding which topics or questions to bring to your PFE Partners for each engagement can be challenging. Your time with PFE Partners may be limited, or you may be concerned about discussing highly technical topics. Selecting topics is easier when approached in a systematic manner, as described below. For more details see the **Engagement Topics and Decisions Summary Tool**.

Step 1: Go Back to Basics

Meaningful engagement means collaborating in ways that impact the measure you are developing. You are engaging with PFE Partners because they bring an expertise you do not have and will make your measure better; you should remind your PFE Partners of this regularly.

Step 2: Revisit Your Goals

Revisit your Strategic Plan often (see **Section 3: Strategic Planning**) to review your project goals and specific engagement objectives. Focus on topics that will help you achieve these targets and deprioritize others. You can always come back to them later.

Step 3: Use Selection Criteria

After successfully narrowing down the potential topics that help achieve project and PFE goals and capitalize on the expertise of your PFE Partners, use the three criteria described on the next page to select the topics.

Patient-Centered Outcomes Research Institute (PCORI) Principles to Keep in Mind (From MMS Hub: Types of Stakeholder Engagement)

- **Reciprocal Relationships:** Define roles and decision-making authority of all involved collaboratively and clearly.
- **Co-Learning:** It is important to ensure PFE Partners understand the measure development process.
- **Partnership:** Value the time and contributions of PFE Partners. Time commitment and attendance requests for persons need to be thoughtful and reasonable. The measure developer research team should remain committed to diversity and demonstrate cultural competency, including disability accommodations, as appropriate.
- **Trust, Transparency, Honesty:** Encourage measure developers to express commitment to open and honest communication with PFE Partners in a meaningful and usable way and ensure to make major decisions inclusively.

Engagement Topic Selection Criteria

Discussion Is Feasible
Do you have the information, data, or evidence required for an informed discussion and decision-making? Are you open to feedback despite the status of your project? Are you willing to reverse decisions or change course?

Feedback Is Actionable
Are the potential decisions to be made within your control? Can PFE Partners influence the process?

Topic Is Within Scope
Does the work fall within your scope of work and CMS' expectations?

SELECTING AN ENGAGEMENT MECHANISM

Selecting an engagement mechanism is as much an art as it is a science. Depending on the project, its phase of development, and other factors, different engagement mechanisms will satisfy your project and PFE goals. Consider your range of options to understand the strength of each mechanism. It is common to engage PFE Partners through more than one mechanism for a single project. Below is a list of different engagement mechanisms commonly used by measure developers.

For more details, see the **Choosing Your Engagement Mechanism Tool**.

Technical Expert Panel

A TEP is a group of multi-stakeholder experts (i.e., clinicians, scientists in specialized areas, measure implementers) who participate in a set of meetings (typically conference calls) to weigh in on key measure decisions, often required by the **MMS Blueprint**. A variation of the standard TEP is a TEP comprised only of persons or family representatives, which often runs alongside a standard TEP. An advantage of this approach over the standard TEP is that representatives may feel more comfortable sharing their own experiences.

Characteristics/Guidelines for a TEP:

- Recommended number of PFE Partners: three, which can vary and depends on the nature of the TEP and the specific goals of the measure developers;
- Used for integrating PFE Partners into existing measure development activities;
- Multiple meetings;
- Discussion-focused; and
- Consists of PFE Partners and Multi-Stakeholder Experts (i.e., clinicians, scientists, or vendors).

Helpful Resources: MMS Blueprint TEP Templates

You may find the **MMS Blueprint** TEP templates helpful in informing your own TEP planning and implementation. Several TEP template examples are included below for easy reference:

- **TEP Charter Template**
- **TEP Call for TEP Web Posting Template**
- **TEP Membership List Template**
- **TEP Summary Web Posting Template**

Testing

The 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 measure-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.

Characteristics/Guidelines for Testing:

- Recommended number of PFE Partners: five to eight and can vary depending on the project;
- Used to gain user insights to refine measures before finalization;
- Multiple meetings; and
- Discussion-focused.

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.

Characteristics/Guidelines for a Virtual Community:

- Recommended number of PFE Partners: unlimited;
- Used to promote discussion and commentary among persons/family representatives about measure development through use of focused questions and topic threads; and
- This technique may provide valuable insight into a person's or family representative's viewpoints.

Measure Working Group

A Measure Working Group is a group of PFE Partners who meet regularly with measure developers to make recommendations for key measure decisions, identify issues relevant to persons and families, plan for TEPs, and prioritize development activities.

Characteristics/Guidelines for a Measure Working Group:

- Recommended number of PFE Partners: four to eight and can vary depending on the project;
- Used for providing input early in the measure development process;
- PFE Partner participation only;
- Multiple meetings; and
- Discussion-focused.

Communication Workshop

A Communication Workshop is a PFE Partner-only meeting focused on acquiring immediate reactions and specific edits to language, displays, or measure framing.

Characteristics/Guidelines for a Communication Workshop:

- Recommended number of PFE Partners: four to six;
- Used for rapid input; and
- PFE Partner participation limited to one or two meetings.

Interview

An Interview is a focused discussion with an individual PFE Partner or small group of PFE Partners.

Characteristics/Guidelines for an Interview:

- Recommended number of PFE Partners: one to three per interview; and
- Used for specific input on a PFE subject area.

Survey

A Survey can be online or via email, paper, or phone and is used to elicit real-time input or feedback from PFE Partners. Surveys can collect information on broad concepts, prioritize or rank options, or conduct a rapid vote on a key measure decision. Since these tools collect information from the American public, adhering to the PRA guidelines should be considered.

Characteristics/Guidelines for a Survey:

- Recommended number of PFE Partners: unlimited;
- Used for providing input early in the measure development process;
- Engaging a large number of PFE Partners;
- Rapid input generation; and
- Structured/quantitative feedback.

Public Comment Opportunity

A Public Comment Opportunity offers PFE Partners the opportunity to provide their feedback during public comment periods for new measure development or rulemaking. They can provide their feedback on aspects of measure development or on using a measure in CMS programs. This type of activity can supplement direct PFE on a measure project. PFE Partners may not know when or how to learn about public comment opportunities, so you may need to inform them, or you can partner with advocacy groups known to the PFE Partners for awareness. It may also be helpful to provide PFE Partners a summary of the rule, issue, or policy for which they are being encouraged to review.

Characteristics/Guidelines for Public Comment Opportunities:

- Recommended number of PFE Partners: unlimited;
- Engaging with a large number of PFE Partners;
- Integrating PFE Partners into existing measure development activities; and
- PFE engagement through all phases of measure development.

Helpful Resources: MMS Blueprint Public Comment Templates

You may find the MMS Hub public comment templates helpful. Several public comment template examples are included below for easy reference:

- Public Comment Call Web Posting Template
- Public Comment Summary Report Template
- Public Comment Summary Web Posting Template

Focus Groups

Focus Groups are facilitated discussions among a group of selected individuals to identify perceptions about a particular topic. These groups may be held in person, online via webinar, or via conference call. Webinars tend to be the most successful for engagement as patients may also submit input via chat box functions to avoid concerns of speaking out in large groups.

Characteristics/Guidelines for Focus Groups:

- Recommended number of PFE Partners: approximately 10–15;
- Integrating PFE Partners into a targeted topic with specific input requests (e.g., priority rankings, experiences with a particular procedure);
- Flexible around time commitments (i.e., ranges from one hour to a full day); and
- PFE engagement throughout all phases of measure development.

Virtual vs. In-Person Engagement

You are encouraged to be creative and to work with PFE Partners in ways to determine how to adapt these mechanisms or create new ones to achieve your engagement goals and ensure a meaningful experience for your PFE Partners.

These mechanisms are just a starting point. Be creative and work with PFE Partners to determine how to adapt these mechanisms or create new ones to achieve your engagement goals and ensure a meaningful experience for PFE Partners. For example, you should only use virtual approaches if individuals are able to participate given any potential literacy, socioeconomic, or technology-related constraints. Some vulnerable populations may not have reliable access to the internet.

Using a virtual platform may be the best option for reaching participants living in rural areas who either may have limited transportation options or have limited time to travel to an in-person engagement. The virtual option allows flexibility for participants in rural areas to join an engagement remotely.

Consider implementing engagement strategies 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). Free virtual platforms are available based on number of participants or time (i.e., Zoom). Using a virtual approach is less burdensome to participants and measure developers and is more cost-effective than in-person meetings. When deciding whether to conduct virtual or in-person engagements, you should consider possible barriers to in-person engagement and the role the person and family representatives will play in measure development.

MATCHING PFE PARTNERS TO ENGAGEMENT MECHANISMS AND PROJECTS

Now that you have selected an engagement mechanism, you need to decide on an appropriate mix of PFE Partners with whom to collaborate. Your goals should ensure:

1. PFE Partners have a positive experience with your organization and are able to make an impactful contribution to your work;
2. Your organization receives the support it needs to make high-quality, patient-centered measures; and
3. The individual project topic or content, and mechanism, align with a PFE Partner's characteristics.

PFE Partner Diverse Characteristics

Specific Medical Conditions. You may want to engage with individuals who have experience with a specific medical condition or procedure that matches the focus of your measure. Note that individuals with related conditions or experiences may also have important perspectives to share and may help you think more broadly about the measure cohort or outcome. For instance, a PFE Partner with experience with multiple chronic conditions or frequent hospital stays may be able to contribute to any number of measures even if that partner has not experienced the specific outcome being measured. Additionally, some PFE Partners have special causes on which they want to focus their engagement, and others may want to use their skills in Plain Language, graphic design, or public speaking.

Significant H ealth E xperiences. M any P FE P artners have had significant, p ossibly n egative, h ealthcare experiences or may have cared for someone who did, and your team will want to acknowledge their experiences. Your team should also be aware some topics are sensitive and should consider establishing boundaries that make sure PFE Partners are comfortable. You may need to consider how much time has lapsed since these individuals experienced their hospitalization, other medical event, or loss of a loved one prior to engaging and ensure they are comfortable partic

and socioeconomic status) may be sensitive topics for PFE Partners and should think of ways to handle them in a culturally and socially appropriate manner.

PFE Partner Roles

PFE Partners may not be suitable for every mechanism. For example, mechanisms that involve multi-stakeholder dynamics, such as TEPs, can sometimes be intimidating for patients or family caregivers unfamiliar with these activities, making representatives from an advocacy organization a better fit. Alternatively, representatives from advocacy organizations may not feel comfortable speaking on behalf of patients or family caregivers in some situations where first-hand experience with a medical event is critical. Overall, you will likely want to engage with a group of PFE Partners who represent a variety of roles to ensure you obtain diverse perspectives. PFE Partner roles and recruiting are discussed further in **Section 5: Recruitment**.

The Table below describes the PFE Partner roles, mechanism fit, and additional considerations when matching roles and mechanisms.

PFE Partner Engagement Mechanisms

PFE Partner Roles	Mechanism Fit	Additional Considerations
Patient Individuals who interact with the healthcare system on a regular basis and who are living with, or managing, one or more health conditions	**Best Fit:** Working Group, Communication Workshop, Survey, Interview **Conditional Fit:** TEP Based on specific PFE Partner characteristics: • Multi-stakeholder experience • Outgoing • Being comfortable speaking up in group settings	End-of-life conditions, adequate time since medical events, healthcare-related employment
Caregiver Individuals who interact with the healthcare system on a regular basis (currently or in the past) to provide support and assist a family member, friend, or loved one in managing their health and health care		End-of-life conditions, adequate time since medical events, age and relationship of person cared for, healthcare-related employment
Consumer Individuals who have experience with the healthcare system but may not be currently living with or managing a health condition		Healthcare-related employment
Advocate Individuals who work at or volunteer on behalf of a nonprofit, mission-oriented organizations that represent a specific constituency of consumers or patients	**Best Fit:** TEP, Measure Working Group, Communication Workshop **Conditional Fit:** Survey, Interview	Perspectives of constituent group versus personal experience

STRATEGIES FOR DISCUSSING QUALITY MEASURES WITH PFE PARTNERS

Each project, technical measurement topic, and group of PFE Partners is unique. You will need to employ creative and tailored strategies to engage persons and families in the technical aspects of quality measurement.

The approach used will depend on many factors, such as the PFE Partners themselves and your engagement mechanism, as well as the topic, question, or decision discussed. For more sample topics, see the **Engagement Topics and Decisions Summary Tool**.

We recommend three broad strategies you can use to plan for highly technical discussions: 1) generating ideas, 2) weighing options, and 3) evaluating preliminary results or displays. These strategies are meant to generate a starting point from which you can craft an approach to your engagement to obtain the PFE Partner input you are seeking. Several scenario-based examples that show how you can implement and tailor these techniques for various technical measurement topics are presented after the strategy overviews.

Enhance all strategies with these facilitation best practices:

- Define new vocabulary prior to technical discussions
- Illustrate contrasting options or new concepts using concrete examples
- Use visual aids to accommodate PFE Partners' diverse learning styles and preferences
- Regularly ask PFE Partners if they have questions throughout the technical discussions

Strategy 1: Generating Ideas

Definition: Use open-ended questions or prompts to solicit a wide range of PFE Partner ideas and feedback to your measure development team.

When to use: Use this strategy when you have a general measurement topic or approach in mind but are open to feedback and anticipate debate, further investigation or analysis, and synthesis of information before making decisions.

Example:

Your team is developing one or more measures looking at several elective surgical procedures. You originally planned to use complication rates as the measure outcome. However, an initial survey of PFE Partners has informed you that a broader outcome, as opposed to only complications, is more meaningful to patients. A finding like this should generate further PFE Partner input to define the outcome. This situation calls for using "Generating Ideas" strategy with a TEP of six patients and family caregivers to determine the specific outcome you should measure. In the first meeting of the TEP, after you conduct introductions and orient your PFE Partners to the goals of your project, you give a basic description of the elective surgical procedures you are considering measuring, typical patients, and what their care looks like.

A Typical Surgical Patient and Their Care

- 70+ years of age
- Managing multiple chronic conditions
- Stayed in the hospital two to three days following the procedure
- Required follow-up care at a rehabilitation facility or skilled nursing facility

Existing Outcome Measures for Surgical Procedures

- Readmission rates
- Mortality rates
- Complication rates (e.g., sepsis, pneumonia)
- Consider other outcomes that could be measured

Next, lead a discussion about selecting the outcome. To give the PFE Partners some context, you explain what outcomes are and what has been measured in the past. You should think of ways to discuss the measure that make it understandable and relatable to PFE Partners and ask your PFE Partners how the measure applies to their own personal experiences and values. For example, a PFE Partner may have experienced a complication requiring follow-up care, such as sepsis, after a hospital stay.

During this discussion, PFE Partners may suggest measuring the length of time spent in the hospital, the length of time in rehabilitation, the amount of time using medical devices for continuing treatment, and the effectiveness of the transition from the surgeon and hospital staff to a primary care doctor and rehabilitation medical staff.

Based on this feedback, you decide to conduct further research on the options recommended by PFE Partners to assess the feasibility of effectively measuring those outcomes.

Strategy 2: Weighing Options

Definition: Use when PFE Partners need to select from, rank or prioritize two or more options you present.

When to use: This strategy works well when you have a series of very specific measure decisions to make, such as determining inclusion and exclusion criteria. It can be effective early in measure development when you are still defining the scope of the measure and later, such as when you are developing and testing measure specifications. Before meeting with PFE Partners or conducting a survey, conduct background research or analyses and make some preliminary decisions to narrow down the choices.

Example:

Your team has been tasked with developing a new outcome measure for pressure injuries. Identifying which patients should be included in your cohort is a key measure decision. Specifically, your team is trying to determine whether or not to include hospice patients. You have conducted several analyses to evaluate the impact of including or excluding hospice patients in the measure, and both approaches have pros and cons. Concurrently, you established a Measure Working Group of seven PFE Partners that have been collaborating on this measure. You bring the results of these preliminary analyses to your Measure Working Group and obtain PFE Partner input on this decision using the Weighing Options Strategy.

To help PFE Partners understand the decisions that need to be made, provide concrete examples whenever appropriate. Real world examples are a great way to illuminate the different scenarios or options PFE Partners are being asked to consider. With the examples, share other information on pros and cons of including or excluding hospice patients for their consideration.

A measure that includes hospice patients:

- More inclusive measure; can measure quality of care for hospice patients
- Cohort is 10% larger
- More hospitals included in the measure
- Risk-adjustment model performs slightly worse
- May be measuring an outcome that does not align with the treatment plan and goals of the patient for this population

A measure that excludes hospice patients:

- Less inclusive measure; cannot measure quality of care for hospice patients
- Cohort 10% smaller
- 40 small volume hospitals do not have enough cases to be included in the measure
- Risk-adjustment model performs slightly better

- What would tell us something negative happened to the patient or they received poor quality care?
- What would tell us something positive happened to the patient or they received high quality care?
- When should we be looking for these signs of quality? How soon before or after the procedure?
- What are some key recovery milestones for a patient having this procedure?
- What types of follow-up care have a big impact on patients' overall experience and perception of their care? How might a patient feel about needing to unexpectedly receive various types of follow-up care? How might they feel about the frequency of needing to obtain follow-up care?

Strategy 3: Evaluating Preliminary Results or Displays

Definition: Use PFE Partners reactions to open-ended or closed-ended questions about preliminary results, outputs, or displays. Results may include testing results, provider performance, or measure scores.

Descriptions of measure language and displays may include samples of the measure specifications, results, or visual displays of measure scores.

When to use: This strategy can often be used later in measure development when you seek PFE Partner feedback or reactions to measure performance results or measure framing, language, or displays. It can be used to ask questions about how PFE Partners may use the results and if they can understand them, or if language and displays highlight the information most important to them.

Example:

Your team recently completed specifications on a surgical readmission outcome measure that gives an overall surgical readmission score for a given hospital but also gives scores for three stratification approaches based on the type of surgical procedure. You are excited this novel approach provides more detailed quality information to hospitals and to patients and try to determine the best way to display the results. You convene a TEP of six PFE Partners to co-create the displays using the Evaluating Preliminary Results/Displays approach.

You explain why you created a stratified measure, the purpose of each result you provide, and what each result tells you about the quality of care of each hospital. You then share an example and several mockup display options to convey the overall score and each of the stratified scores with your PFE Partners.

Example: Hospital A has an overall surgical readmission rate of 10%. The three divisions have individual readmission rates of 1%, 9%, and 17%.

Questions for PFE Partners:

1. If you were selecting a hospital to have a surgical procedure, which readmission rate would you use to judge the quality of each hospital: the overall readmission rate for the hospital or one of the individual readmission rates? Why?
2. Are the differences in the readmission rates among the three divisions meaningful to you? How would you interpret them if you only read the numbers?
3. Does the display affect your interpretation of the various readmission rates? Does it increase your understanding of the differences between the various rates?
4. Are any parts of the display confusing?
5. What improvements would you make to the display to better understand or find the information you are looking for?

Several PFE Partners tell you some of the displays are too complex and provide too much detail, making it difficult for them to interpret the hospital scores. They think many patients would prefer to just see the overall score for the hospital as opposed to the overall score plus the stratified scores, even though the stratified scores provide more detailed information. Other PFE Partners argue the stratified scores help them better understand the quality of the care they are likely to receive. They value the added information so much that they are willing to do the extra work it may take to dig into the details and interpret the complex displays. You work together with your PFE Partners to repeatedly revise and test a series of mockups.

Regardless of which of the three strategies you choose to use, the following open-ended questions can help guide discussion to gain PFE Partner input.

Sample Questions:

- Should we include or exclude this population in the cohort?
- We are considering two options for risk-adjusting the measure. Do you think Option A or Option B is the better choice? Why?
- Which of these five measure concepts is the highest priority for development?
- Is the measure in its current form useful for patient decision-making about where or how to receive care? Why or why not?
- Does this description of the measure make sense to you? Does it use terms you are familiar with? Does it discuss concepts that are important to you?
- Does this display present the most important information about the measure? Is it easy to understand?

SCENARIO-BASED EXAMPLE

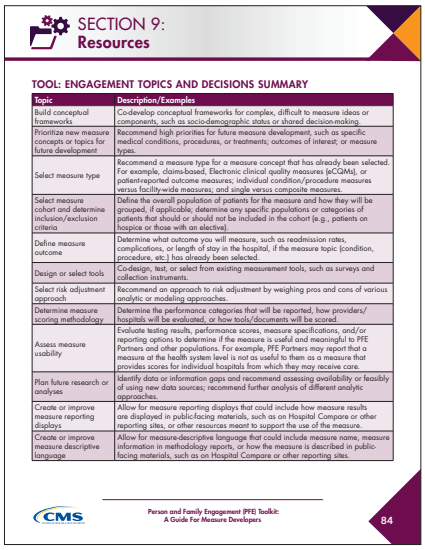
Your Objective: Build conceptual frameworks

Engagement Strategy: Generating Ideas

Mechanism: Measure Working Group

Your team is interested in developing behavioral healthcare quality of care measures. Your first measure concept focuses on appropriately assessing and treating alcohol dependency. You are attempting to develop a conceptual framework that measures the quality of treatment for alcohol dependency and also accounts for social determinants of health variables, such as poverty status, level of education, race, and geographic region. You want to ensure the measure is meaningful to patients and will help measure disparities in care among diverse populations. You have recruited PFE Partners who have experienced a diagnosis of alcohol or substance dependency or caregivers for patients that have similar lived experiences. In this early stage of development, you decide to convene several Working Groups of five PFE Partners and decide the "Generating Ideas" strategy is the ideal way to begin mapping out a broad, inclusive framework for all the factors that could affect their decision to seek care, including their perceptions and experience with behavioral healthcare, burden of cost, culturally sensitive viewpoints, and ability to access care. The result is a comprehensive conceptual framework co-designed with PFE Partners that represents the thoughts of diverse PFE Partners' factors when seeking behavioral healthcare.

SECTION 4: TOOLS AND TEMPLATES



SECTION 9:
Resources

TOOL: ENGAGEMENT TOPICS AND DECISIONS SUMMARY

Topic	Description/Examples
Build conceptual frameworks	Co-develop conceptual frameworks for complex, difficult to measure ideas or components, such as socio-demographic status or shared decision-making.
Prioritize new measure concepts or topics for future development	Recommend high priorities for future measure development, such as specific medical conditions, procedures, or treatments; outcomes of interest; or measure types.
Select measure type	Recommend a measure type for a measure concept that has already been selected. For example, claims-based, Electronic clinical quality measures (eCQMs), or patient-reported outcome measures; individual condition/procedure measures versus facility-wide measures; and single versus composite measures.
Select measure cohort and determine inclusion/exclusion criteria	Define the overall population of patients for the measure and how they will be grouped, if applicable; determine any specific populations or categories of patients that should or should not be included in the cohort (e.g., patients on hospice or those with an elective).
Define measure outcome	Determine what outcome you will measure, such as readmission rates, complications, or length of stay in the hospital, if the measure topic (condition, procedure, etc.) has already been selected.
Design or select tools	Co-design, test, or select from existing measurement tools, such as surveys and collection instruments.
Select risk adjustment approach	Recommend an approach to risk adjustment by weighing pros and cons of various analytic or modeling approaches.
Determine measure scoring methodology	Determine the performance categories that will be reported, how providers/hospitals will be evaluated, or how tools/documents will be scored.
Assess measure usability	Evaluate testing results, performance scores, measure specifications, and/or reporting options to determine if the measure is useful and meaningful to PFE Partners and other populations. For example, PFE Partners may report that a measure at the health system level is not as useful to them as a measure that provides scores for individual hospitals from which they may receive care.
Plan future research or analyses	Identify data or information gaps and recommend assessing availability or feasibly of using new data sources; recommend further analysis of different analytic approaches.
Create or improve measure reporting displays	Allow for measure reporting displays that could include how measure results are displayed in public-facing materials, such as on Hospital Compare or other reporting sites, or other resources meant to support the use of the measure.
Create or improve measure descriptive language	Allow for measure-descriptive language that could include measure name, measure information in methodology reports, or how the measure is described in public-facing materials, such as on Hospital Compare or other reporting sites.

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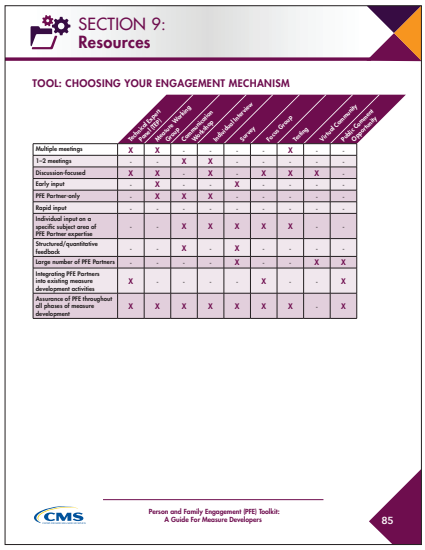
TOOL: Engagement Topics and Decisions Summary



SECTION 9:
Resources

TOOL: CHOOSING YOUR ENGAGEMENT MECHANISM

	Balanced Expert Panel (TEP)	Measure Working Group	Communication Workshop	Individual Interview	Survey	Focus Group	Testing	Virtual Community	Public Comment Opportunity
Multiple meetings	X	X	-	-	-	-	X	-	-
1–2 meetings	-	-	X	X	-	-	-	-	-
Discussion-focused	X	X	-	X	-	X	X	X	-
Early input	-	X	-	-	X	-	-	-	-
PFE Partner-only	-	X	X	X	-	-	-	-	-
Rapid input	-	-	-	-	-	-	-	-	-
Individual input on a specific subject area of PFE Partner expertise	-	-	X	X	X	X	X	-	-
Structured/quantitative feedback	-	-	X	-	X	-	-	-	-
Large number of PFE Partners	-	-	-	-	X	-	-	X	X
Integrating PFE Partners into existing measure development activities	X	-	-	-	-	X	-	-	X
Assurance of PFE throughout all phases of measure development	X	X	X	X	X	X	X	-	X

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TOOL: Choosing Your Engagement Mechanism

SECTION 5: Recruitment

This section offers guidance on how to recruit PFE Partners using three different recruitment options as well as how to plan for recruitment timelines.

The success of PFE efforts is impacted by an organization's ability to recruit a diverse selection of PFE Partners for collaboration whose unique experiences align to the project. Recruiting diverse voices should be of the utmost importance to ensure inclusive, balanced, and equitable feedback for your project. Many measure developers describe recruitment as one of the most challenging aspects of PFE. Selecting the appropriate recruitment approach is the first step to finding the right PFE Partners. Working with organizations that have broad advocacy networks or established relationships with persons and families can be a great way to find PFE Partners. Regardless of the approach, many individuals are passionate about improving the quality of health care.

Topics discussed in this section include the following:

- PFE Partner Roles;
- Options for Identifying and Recruiting PFE Partners;
- PFE Recruitment Process and Contacts;
- Recruitment Timelines; and
- Scenario-Based Example.

Resources:

The end of this section has a preview of a relevant tool on this topic. You can also click the link below to access a printable version that is included in **Section 9: Resources** of this Toolkit.

- **Sample PFE Partner Recruitment Questions Tool**

Recruitment: Section Highlights

- PFE Partners typically represent four distinct categories of perspectives: persons/patients, caregivers, consumers, and advocates. Additionally, PFE Partners often possess a combination of perspectives and may fit into more than one role.
- This PFE Toolkit describes three different recruitment approaches for organizations to consider: 1) build organizational capacity to identify and recruit persons and families; 2) select an organization to identify and recruit persons and families; and 3) draw from an existing network of persons and families.
- The PFE recruitment process includes three main steps: 1) define an ideal candidate; 2) reach out to relevant organizations or individuals; and 3) hold conversations with potential PFE Partners.
- The nine types of individuals/organizations for recruitment include: 1) person and family engagement network; 2) civic and community-based organizations; 3) population-specific organizations; 4) organizations focusing on diverse populations/health equity; 5) condition-specific organizations; 6) patient and family advisory council (PFAC) experience; 7) patients with experience in research; 8) organizations that work with patient advocates; and 9) community health centers.
- Due to the time-sensitive nature to recruit PFE Partners, several tips to keep in mind include: identify potential PFE Partners with the required skills, interests, and experiences for specific projects; conduct outreach to potential PFE Partners and hold initial conversations; and notify PFE Partners that are selected in a timely manner.

SECTION 5: Recruitment

> Patients and families are extremely important stakeholders in the quality measurement enterprise, and CMS is committed to gathering their input during priorities planning. Engaging persons and family representatives benefits consumers by helping to identify issues that are important and meaningful from their perspective. – **CMS MMS Hub**

PFE PARTNER ROLES

PFE Partners typically represent four categories of perspectives (see **Section 4: How to Engage** for more information about selecting PFE Partners who represent roles that best fit the appropriate engagement mechanism).

The following four groups offer valuable perspectives.

- **Persons/Patients:** Individuals who interact with the healthcare system on a regular basis and are living with, or managing, one or more health conditions.
- **Caregivers:** Individuals who interact with the healthcare system on a regular basis (currently or in the past) to provide support and assist a family member, friend, or loved one in managing their health and healthcare.
- **Consumers:** Individuals who have experience with the healthcare system but may not be currently living with or managing a health condition.
- **Advocates:** Individuals who work or volunteer at nonprofit, mission-oriented organizations that represent a specific constituency of consumers or patients. Examples of consumer advocacy organizations include the American Association of Retired Persons (AARP), the Young Women's Christian Association (YWCA), Patient Advocate Foundation, Kidney Care Partners, National Association for the Advancement of Colored People, and faith-based organizations.

OPTIONS FOR IDENTIFYING AND RECRUITING PFE PARTNERS

Recruitment is often one of the most challenging aspects of PFE for measure developers. This **PFE Toolkit** describes three different recruitment approaches for organizations to consider:

PFE Partners often possess a combination of perspectives and, therefore, may fit into more than one role. For example, depending on their experiences, a caregiver can possess attributes similar to those of an advocate. When engaging with PFE Partners, you should discuss their intended primary role.

- **Approach A:** Build organizational capacity to identify and recruit persons and families;
- **Approach B:** Partner with an organization to identify and recruit persons and families; and
- **Approach C:** Draw from an existing network of persons and families.

Approach A: Build Organizational Capacity

The first recruitment approach is to build your organizational capacity to conduct recruitment yourself. To pursue this route, your organization needs to have existing relationships with groups, organizations, and other entities that have established relationships with persons, family caregivers, consumers, and advocates. Alternatively, you will need staff and resources to build those relationships.

This approach also necessitates staff who can recruit persons and caregivers with the characteristics and experiences that will have the most value to your upcoming projects and then be able to onboard and orient those persons and families to ensure their effective engagement. This could entail preparing general background documents, conducting an orientation webinar, or making telephone calls outlining roles

and responsibilities. For more information about this initial preparation of PFE Partners, see Section 6: Onboarding and Orientation.

Recruiting PFE Partners is a significant undertaking and requires an organized and well-structured recruitment process to ensure you identify and collaborate with PFE Partners who are best suited for providing input to the measure development work based on the priority characteristics (e.g., race/ethnicity, age, lived experience with specific clinical condition) and role the measure developer is seeking.

See the PFE Recruitment Process and Contents later in this section for details on how to conduct your own recruitment and potential contacts to get you started.

Approach B: Partner with an External Organization

Partnering with an external organization that has existing relationships with persons and families and/or with organizations and entities that work closely with persons, caregivers, consumers, and advocates is an effective way to conduct recruitment. For example, CMS' Person and Family Engagement Quality Measure Development contractor, Rainmakers Strategic Solutions, recruits for measure developers. We advise partnering with an organization that possesses extensive experience and expertise with recruiting, onboarding, and development.

Note that subcontracting with an external organization may require financial resources, and you may need to consider building in the costs associated with recruiting, onboarding, and orienting.

Approach C: Draw from an Existing Network

A third recruitment approach involves partnering with an organization that curates an existing network of patients, caregivers, consumers, and advocates and then recruits PFE Partners from that network. These PFE Partners are interested and capable collaborators and may have received training and support to prepare them to engage with you. While seasoned PFE Partners provide useful insights, be open to PFE Partners who are newer to advocacy and may not have formal experience serving on an engagement effort (e.g., TEP). Similar to partnering with an external organization, it will be important to include funds in your budget to cover any costs associated with accessing an existing network. While this approach may be less resource-intensive from a staffing perspective than the other options, your organization will still need to train and prepare staff to work effectively with PFE Partners. To get started, see the Facilitator Guide for Activities in PFE Training Tool.

PFE RECRUITMENT PROCESS AND CONTACTS

This section will be most helpful to organizations electing to do their own recruiting for PFE Partners. If you decide to partner with an external organization or draw from an existing network, those organizations may follow a similar approach to the one described below. This section will give you an idea what goes into recruiting PFE Partners, including these three main steps;

1. Defining an ideal candidate;
2. Reaching out (see the following pages for potential organizations to get started); and
3. Holding conversations with potential PFE Partners.

Recruitment Step 1: Defining an Ideal Candidate

When seeking potential PFE Partners, you will want to find people who will be a good fit for collaborative and healthcare-focused work. We recommend considering the following characteristics when determining whether to recruit a potential PFE Partner. Be mindful and intentional as to why you are targeting a specific PFE Partner for their perspective, and ensure you are selecting PFE partners whose experiences align with the objectives of your measure.

Highly Recommended

- Familiarity and experience with the healthcare system as a patient or a caregiver;
- Varying healthcare experiences—both positive and negative;
- Experience with target conditions or procedures;
- Representative of diverse patient populations (i.e., age, sex, race, education, geography, socioeconomic status, health literacy, and language);
- Inquisitive and able to provide constructive feedback;
- Open-minded with a collaborative approach;
- Willing to speak up, ask questions, and share ideas;
- Able and interested in volunteering time and energy; and
- Openness to changing timelines and project goals throughout their participation.

Be open to working with PFE Partners who are new to quality measures as their experiences and insights are incredibly valuable and bring new ideas to the table that may not be heard otherwise. They may need additional support, but it is worth the effort.

Recommended Depending on Project Goals and Engagement Mechanism

- Experience participating in multi-stakeholder processes and/or Patient and Family Advisory Councils;
- Understanding of quality measures or experience with measure development;
- Having technical skills necessary for virtual activities (i.e., access to a computer, regularly checks email, reliable access to a telephone), with accommodations for a potential PFE Partner without access to technology or lacking technological skills; and
- Willingness to learn, to reflect a diverse group of persons and caregivers.

Diversity and Representation: PFE Partners can represent all ages, sexes, races, ethnicities, economic statuses, and geographies. It is important to ensure as many voices are included when possible. African American, indigenous, and other people of color, as well as members of the LGBTQIA+ communities, are underrepresented in person and family engagement opportunities. We encourage you to find PFE Partners from diverse backgrounds to represent patient experiences in quality measure development.

Unheard Voices: Historically, vulnerable and at-risk populations have been left out of the decision-making process in healthcare, so it is especially important to be inclusive of PFE Partners of different backgrounds during the measure development process and gain their trust through honest and open conversations during the recruitment process.

PFE Partner characteristics may shift during the project, and we recommend you identify the most important characteristics to guide your initial recruitment efforts. Characteristics, such as demographics, diagnoses, and specific healthcare experiences, may become clearer and more focused closer to the engagement activity. More general personality characteristics, such as comfort speaking in larger groups, openness to shifting timelines, and a collaborative attitude, should be sought out in the initial stages of recruitment.

Recruitment Step 2: Reaching Out

The second step in the recruitment process is reaching out to individuals or organizations. This section is divided into nine strategies based on different categories of organizations or PFE Partners you are looking for and general tips. You will likely need to consider a variety of strategies to find the diverse PFE Partners desired for your project. For example, you will likely recruit younger patients from different sources than older patients. If you are seeking patients who have specific conditions, you will need to be more targeted in your outreach. Be mindful and

find ways to build trust with PFE partners throughout the recruitment process. PFE partners have varied healthcare experiences, which may have created mistrust of the healthcare system. See the **Sample PFE Partner Recruitment Questions Tool**.

CASE STUDY EXAMPLE:

Let's take a deeper dive into the "Who" part of recruitment to think about the perspectives, experiences, or expertise represented by the PFE Partners. Our PFE goal is to select a measure concept that focuses on outcome information a patient with diabetes can provide during care.

My team has selected a Measure Working Group; therefore, patients, caregivers, consumers, and advocates can all be a good fit.

- We want to have a mix of Type 1 and Type 2 diabetes participants, and we will want to have several of them be patients managing the disease.
- Since caregivers can play a key role in managing a chronic condition like diabetes, we will recruit several caregivers.
- Since we are having a PFE Partner-only group, we do not need to address multi-stakeholder experience.
- We will also think about representation by women and men, people of different ages, and a variety of social and cultural backgrounds (e.g., race/ethnicity, sociodemographic, varying health literacy levels).

Strategies for Recruitment Through Organizations

1. Person and Family Engagement Network

CMS' Person and Family Engagement Member Network (PFEN), which the Rainmakers Strategic Solutions recruits for and manages, is a growing community of patients, caregivers, advocates, and clinicians who are experienced and prepared to collaborate on TEPs, Working Groups, and Focus Groups alongside measure developers. The table below highlights the diversity of PFEN memberships.

PFEN Membership/ Affiliated Organization	Organization	Organization Description and Website
PFE Partners	N/A	Persons, caregivers, advocates, clinicians, and other stakeholders
Disease-Specific Organizations	WomenHeart	The first and only national patient-centered organization dedicated to serving women with heart disease whose mission is to improve the lives of women with or at risk for heart disease while fighting for equity in heart health. https://www.womenheart.org
	Preeclampsia Foundation	National organization dedicated solely to improving the outcomes of hypertensive disorders of pregnancy like preeclampsia, HELLP syndrome, and eclampsia by educating, supporting, and engaging the affected community, improving healthcare practices, and finding a cure. https://www.preeclampsia.org

PFEN Membership/ Affiliated Organization	Organization	Organization Description and Website
Disease-Specific Organizations, continued	Muscular Dystrophy Association	Committed to transforming the lives of people affected by muscular dystrophy, ALS, and related neuromuscular diseases through innovations in science and innovations in care. https://www.mda.org
	Ryan White Planning Council	The mission is to improve the quality of life and advocate for those living with and/or affected by HIV by taking a leadership role in planning and assessing HIV resources. http://www.rwpchouston.org
Community-Based Organizations	USA Patient Network	Consists of patients, caregivers, and their friends and family members with a common goal to ensure medical treatments are as safe, effective, and affordable as possible. https://www.usapatientnetwork.org
	Well Spouse Organization	Advocates for and addresses the needs of individuals caring for a chronically ill and/or disabled spouse or partner, offers peer support, and educates health care professionals and the general public. https://wellspouse.org
	Families Together Inc.	Encourages, educates, and empowers Kansas families to be effective advocates for their children with disabilities and/or special healthcare needs ages 0 to 26 years by providing individualized assistance and parent-to-parent support. https://familiestogetherinc.org
	Family Voices	Grassroots network of families and friends of children and youth with special healthcare needs and disabilities; promotes partnership with diverse families to improve healthcare services and policies for children. https://familyvoices.org
Advocacy Organizations	Jace's Journey	Based on their own healthcare experiences, Tomeka and Brandon Isaac developed this nonprofit to raise awareness and contribute to improving maternal/fetal disparities through education, advocacy, and community engagement in honor of their son Jace. https://www.jacesjourney.org/about

PFEN Membership/ Affiliated Organization	Organization	Organization Description and Website
Advocacy Organizations, continued	Society to Improve Diagnostic Medicine (SIDM)	As the only organization focused solely on the problem of diagnostic error and improving the accuracy and timeliness of diagnosis, SIDM leads change to improve diagnosis and eliminate harm from diagnostic error by working with patients, their families, the healthcare community, and other stakeholders. https://www.improvediagnosis.org
	Patient Safety Action Network	A coalition of individuals and organizations consisting of patients who have been medically harmed, their loved ones, and concerned patient safety advocates with the aim of eliminating preventable medical errors, to save lives, and to advocate and support policies that promote patient safety. https://www.patientsafetyaction.org
	Society for Participatory Medicine	Not-for-profit organization devoted to promoting the practice of participatory medicine, which enables collaborative communication and information sharing among patients, caregivers, and healthcare professionals. https://participatorymedicine.org

Rainmakers Strategic Solutions is comprised of subject matter experts, coordinators, and recruiters who have specialized experience in person and family engagement in quality measure development. They provide recruitment assistance, consultation on person and family engagement, and assistance with the onboarding and orientation process for TEP, Working Groups, or Focus Groups.

To learn more about PFEN and how it can help meet your PFE needs, please visit https://pfenetwork.org.

2. Civic and Community-Based Organizations

These organizations may have staff interested in collaborating with you in the advocate role. Staff may also refer members from the organization to serve as PFE Partners. These organizations vary as to whether they focus on healthcare issues. However, many of the individuals associated with these organizations have experience serving as volunteers and likely have had experiences within the healthcare system. Examples of these organizations include the following.

Organization	Organization Description and Website
Citizens Action Coalition	CAC is Indiana's oldest and largest consumer and environmental advocacy organization. In 1987, CAC helped pass the legislation that created the CHOICE program to provide in-home care to the elderly and people with disabilities in Indiana. http://www.citact.org
Kiwanis Club	Kiwanis is a global organization of volunteers dedicated to improving the world one child and one community at a time. http://www.kiwanis.org

League of Women Voters	A women-led political grassroots network and membership organization that believes the freedom to vote is a nonpartisan issue and works to empower voters and defend democracy. https://www.lwv.org
Lion's Club	1.4 million caring men and women serving together so they can make a lasting impact and change more lives through 48,000 Lion's Clubs across the world. Their global causes include diabetes, vision, hunger, environment, and childhood cancer. http://www.lionsclubs.org/en
National Consumers League	Provides government, businesses, and other organizations with the consumer's perspective on concerns, including child labor, privacy, food safety, and medication information. http://www.nclnet.org
YWCA	The YWCA's mission is to eliminate racism and empower women through programming at local YWCA associations, special events, and advocacy/lobbying. http://www.ywca.org

3. Population-Specific Organizations

These organizations focus on the well-being of older adults and may be able to identify PFE Partners and/or staff who can serve in the advocate role. Also consider local senior centers and retirement communities. Examples of these organizations include the following.

Organization	Organization Description and Website
American Association of Retired Persons (AARP)	AARP is the nation's largest nonprofit, nonpartisan organization dedicated to empowering people to choose how they live as they age. https://www.aarp.org
USAging	USAging represents and supports the national network of Area Agencies on Aging and advocates for the Title VI Native American Aging Programs that help older adults and people with disabilities live with optimal health, well-being, independence, and dignity in their homes and communities. https://www.n4a.org
National Council on Aging	Its mission is to improve the lives of millions of older adults, especially those who are struggling with the goal of impacting the health and economic security of 40 million older adults by 2030, especially women, people of color, LGBTQ+, low-income, and rural individuals. https://www.ncoa.org

4. Organizations That Focus on the Well-Being of Diverse Populations and/or Health Equity

These organizations may be able to identify PFE Partners from diverse backgrounds and underrepresented racial or ethnic groups, and/or staff who can serve in an advocate role. Examples of these organizations include the following.

Organization	Organization Description and Website
Asian & Pacific Islander American Health Forum (APIAHF)	APIAHF influences policy, mobilizes communities, and strengthens programs and organizations to improve the health of Asian Americans & Native Hawaiians/ Pacific Islanders. http://www.apiahf.org
Black Men's Health Project	The mission of the Black Men's Health Project is to gain a deeper understanding of the unique health challenges of Black men and develop culturally competent strategies and solutions to improve the health outcomes for Black men. http://blackmenshealthproject.org
Black Women's Health Imperative (BWHI)	BWHI is the first and only national non-profit solely dedicated to achieving health equity for Black women in America. https://www.bwhi.org
Colorado Latino Leadership Organization (CLLARO)	CLLARO's mission is to empower Latinos through leadership development, advocacy, and policy research to strengthen Colorado. www.cllaro.org
National Association for the Advancement of Colored People (NAACP)	NAACP works to ensure the political, social, and economic equality of all persons and to eliminate racial hatred and discrimination. http://www.naacp.org
National Alliance for Hispanic Health	Science-based and community-driven organization that focuses on the best health for all, including 15 million Hispanics throughout the U.S. every year. https://www.healthyamericas.org

5. Condition-Specific Organizations

These organizations may be helpful if you are developing a condition-specific measure as they may be able to identify PFE Partners with specific chronic conditions and/or staff who can serve in an advocate role. Examples of these organizations include the following.

Organization	Organization Description and Website
American Heart Association	Largest not-for-profit funding source for cardiovascular and cerebrovascular disease research next to the federal government. http://www.heart.org
American Cancer Society	Leading cancer-fighting organization with a vision of ending cancer; the only organization working to improve the lives of people with cancer and their families through advocacy, research, and patient support, to ensure everyone has an opportunity to prevent, detect, treat, and survive cancer. http://www.cancer.org

Organization	Organization Description and Website
American Diabetes Association (ADA)	The ADA's mission is to prevent and cure diabetes and to improve the lives of all people affected by diabetes. The ADA leads the fight through research, service delivery, objective information, and giving voice to those denied rights due to diabetes. http://www.diabetes.org
National Health Council	The mission of the National Health Council is to provide a united voice for the 160 million people living with chronic diseases and disabilities and their caregivers. http://www.nationalhealthcouncil.org
National Breast Cancer Coalition	The National Breast Cancer Coalition's mission is to end breast cancer through the power of action and advocacy. https://www.stopbreastcancer.org
Sepsis Alliance	Sepsis Alliance is the leading sepsis organization in the U.S. working in all 50 states to save lives and reduce suffering from sepsis. https://www.sepsis.org
Sick Cells	Sick Cells is a national advocacy nonprofit for sickle cell disease (SCD) with a mission to elevate the voices of the SCD community and their stories of resilience. https://sickcells.org

6. Persons and Families with Experience Serving on a Patient and Family Advisory Council or Committee (PFAC) or Patient Affinity Group

In recent years, hospitals and ambulatory practices around the country have launched PFACs. The persons and families who participate in PFACs have experience with organized health care initiatives and may be a good fit for measure development.

The Health Care Payment Learning & Action Network (HCPLAN or LAN) is also an active group of public and private health care leaders dedicated to providing thought leadership, strategic direction, and ongoing support to accelerate adopting alternative payment models (APMs).

Additionally, CMS announced in its **2021 Innovation Center Strategy Refresh** whitepaper that one of the Center for Medicare & Medicaid Innovation (Innovation Center) strategic objectives was partnering to achieve system transformation, especially through beneficiary collaborations. This whitepaper notes how patient and caregiver perspectives are not often brought to the process early enough to influence the development of care management tools and programs, payment incentives for providers, and payment waivers and other flexibilities. CMS also highlights beneficiary and patient engagement and collaboration as a key mechanism for driving broad system transformation.

Initiative/CMS Priority Area	Organization Description and Website
Health Care Payment Learning & Action Network	An active group of public and private health care leaders dedicated to providing thought leadership, strategic direction, and ongoing support to accelerate adoption of alternative payment models. https://hcp-lan.org
CMS Person and Family Engagement	This CMS site highlights the importance of putting patients first and includes links to strategic plan and PFE strategy summary. https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/Person-and-Family-Engagement
Innovation Center Strategic Objective: Partner to Achieve System Transformation	In 2021, the Innovation Center launched a bold new strategy with the goal of achieving equitable outcomes through high-quality, affordable, person-centered care. To achieve this vision, the Innovation Center introduced a strategic refresh organized around five objectives. https://innovation.cms.gov/strategic-direction-whitepaper

7. Patients with Experience in Research

These organizations either maintain a network of patients who are engaged in research or are committed to engaging patients in research and may be able to identify potential PFE Partners. Examples of these organizations include the following.

Organization	Organization Description and Website
National Patient Advocate Foundation (NPAF)	NPAF is dedicated to amplifying the voices of patients and advocating for better access to affordable, equitable, quality care. As the advocacy affiliate of the Patient Advocate Foundation, NPAF provides educational resources to help patients advocate for themselves and make informed, personalized health care decisions. https://www.npaf.org
Patients Like Me	Patients Like Me believes in the power of community to improve the lived experience of patients managing complex health conditions. Their purpose is to create a trusted digital platform that empowers patients to navigate their health journeys together through peer support, personalized health insights, tailored digital health services, and patient-friendly clinical education. https://www.patientslikeme.com
Patient-Centered Outcomes Research Institute (PCORI)	PCORI is the leading funder of patient-centered comparative clinical effectiveness research in the U.S.. https://www.pcori.org/engagement/engage-us
Social Health Network	The Social Health Network is a community for patients, caregivers, and healthcare professionals with the goal of bringing empathy, support, and humanity to the healthcare industry. https://www.wegohealth.com

8. Organizations that Work with Patient Advisors

These organizations work to promote partnerships between persons and families and other healthcare stakeholders. They developed a network of patient advisors with experience collaborating to improve healthcare. Examples of these organizations include the following.

Organization	Organization Description and Website
Institute for Healthcare Improvement (IHI)	For more than 30 years, IHI has used improvement science to advance and sustain better outcomes in health and health care across the world. https://www.ihi.org
Institute for Patient-and Family-Centered Care (IPFCC)	The IPFCC provides essential leadership to advance the understanding and practice of patient- and family-centered care. By promoting collaborative, empowering relationships among patients, families, and health care professionals, IPFCC facilitates patient- and family-centered change in all settings where individuals and families receive care and support. http://www.ipfcc.org/about
National Partnership for Women & Families	The National Partnership for Women & Families is a national, non-profit, non-partisan organization that works to change policy and culture. Their mission is to improve the lives of women and families by achieving equality for all women. http://www.nationalpartnership.org
Patient Family Centered Care (PFCC) Partners	PFCC Partners has implemented hundreds of patient/family engagement programs across health system settings. Their mission is to support the learning and transformation of our complex system through community engagement. https://pfccpartners.com
Patient Partner Innovation Community	A group of people with experience in healthcare who are working through many different venues to improve the quality, safety, and experience of all patients. Many are volunteers in their own communities working directly with local and national healthcare organizations. https://www.ppiconline.com

9. Community Health Centers

By law, a majority (at least 51 percent) of members of Community Health Center boards must be individuals who are served by the health center. Current and past board members have multi-stakeholder and healthcare experience and may be good candidates to serve as PFE Partners. An example of these centers includes the following.

Program	Organization Description and Website
HRSA Health Center Program - Bureau of Primary Health Care	Health centers are community-based and patient-directed organizations that deliver comprehensive, culturally competent, high-quality primary health care services to the nation's most vulnerable individuals and families, including people experiencing homelessness, agricultural workers, residents of public housing, and veterans. https://bphc.hrsa.gov

General Outreach Tips

In addition to the outreach strategies above, it is recommended to:

- Contact churches, synagogues, community-based organizations, and other faith-based organizations to engage lay and professional health ministers on staff who may also be able to connect you with congregants who could serve as PFE Partners;
- Place recruitment notices in a variety of print and online publications, including newspapers or community newsletters;
- Leverage social networking pages, such as Twitter, Facebook, and other social media platforms, as these forms of recruitment are low-cost and can be extremely effective;
- Outreach to individual consumers or advocates who can recommend peers;
- Send direct notices through email, patient portals, or regular mail to persons and families;
- Outreach to individual healthcare providers, clinicians, and staff at facilities where your organization has relationships;
- Access online patient forums, especially for individuals and caregivers of individuals with chronic conditions or specific relevant conditions;
    - Identify and develop relationships with Administrator(s) of these forums;
    - Explain purpose and importance of your organization's measure development work to Administrators; and
    - Seek Administrator's advice on how best to post on forums.

Successful recruitment of persons and families relies on a relationship-based approach. Acknowledge that organizations you contact often have long-standing and established relationships with their members, constituents, or the people they serve.

Recruitment Step 3: Holding Conversations with Potential PFE Partners

Once a measure developer identifies a potential PFE Partner, the third step is to conduct a conversation with them to:

- Share an overview of your organization and your measure development work;
- Describe how you would like the potential PFE Partner to engage and the anticipated time commitment required;
- Ask questions to better understand the potential PFE Partner's interests, healthcare experiences, and any conditions or experience they may have that could assist your organization with its measure development work;
- Ask the PFE Partner what their initial impressions or thoughts are on the project;
- Answer any questions the potential PFE Partner may have;
- Ask for the PFE Partner's preferred method of communication (email, phone call, text); and
- Prioritize and tailor Onboarding and Orientation materials to accommodate PFE Partners' varying experience levels (e.g., new patient advocate or experienced patient advocate; those who may be new to quality measurement or those who have participated in many quality measurement engagements).

The goal of conducting conversations with potential PFE Partners is to determine whether your organization's measure development needs and the individual's interests and experience align.

We recommend you discuss this with the individual to determine if the potential PFE Partner is an ideal candidate for your project based on your priority patient characteristics (e.g., specific ethnicity, age, health condition, sociodemographic background) and if that person aligns to those characteristics. If so, you can invite the individual to participate and initiate onboarding. To be respectful, please also remember to notify patient partners if you choose not to engage them in the project. If you determine the potential

PFE Partner is not an ideal candidate, follow up and explain why. You also want to ask if they are willing to be contacted for future engagement opportunities with your organization when their experiences, interests, or time constraints may better match an upcoming project. Ensure that contact with PFE Partners is held within a reasonable amount of time, preferably no more than ten business days from initial contact to avoid gaps in communication and potential disinterest from Partners. The longer the gap in communication after the discussions, the more likely the Partner is to drop out due to disinterest or conflict.

See the suggested questions to ask PFE Partners in the **Sample PFE Partner Recruitment Questions Tool**.

Highlight your organization's mission and goal of improving healthcare quality. Be sure to articulate the ways in which collaborating with your organization aligns with the goals of the organizations from which you are recruiting or the interests or concerns of the persons and caregivers you are trying to recruit.

RECRUITMENT TIMELINES

Whichever recruitment option your organization decides to pursue, recruiting PFE Partners is a significant and time-consuming undertaking. When planning your PFE recruitment you need to build in time to:

- Identify potential PFE Partners with the required skills, interests, and experiences for specific projects;
- Conduct outreach to potential PFE Partners and hold initial conversations;
- Notify PFE Partners that are selected in a timely manner, such as communications regarding partner selection or delays in proceeding with onboarding be provided within seven to ten business days to avoid long periods of noncommunication and potential partner drop-out;
- Orient the PFE Partners to your organization, measure development, and your project (see **Section 6: Onboarding and Orientation** for detailed information on this topic); and
- Support the PFE Partners as they complete necessary documents and paperwork as part of Onboarding (see **Section 6: Onboarding and Orientation** for detailed information on this topic).

The most successful recruitment processes are those that are ongoing. You may identify PFE Partners that are not the best fit for your current project but would be well-suited to another project. Find ways to recruit in advance of future engagements, and maintain lists of potential contacts you identify along the way.

With the first two recruitment options, it can take six weeks or more from the time you begin the recruitment process (initial outreach) to the time in which a PFE Partner has completed onboarding and orientation and is ready to engage. The third recruitment option may take less time (three to four weeks), but the timeline will depend on your recruitment requirements and the composition of the existing network from which you are drawing PFE Partners. Be sure to incorporate these timelines into your Strategic Plan (see **Section 3: Strategic Planning**).

SCENARIO-BASED EXAMPLE

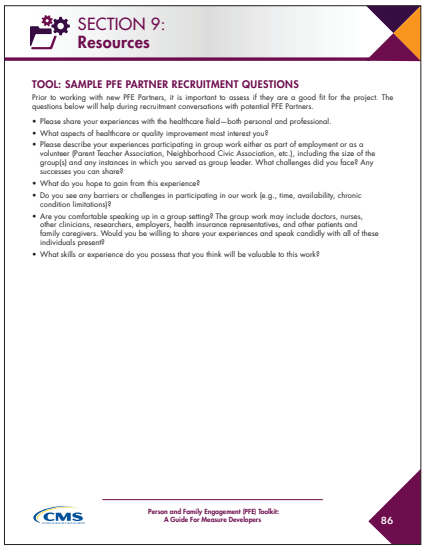
Your Objective: Developing new measure concepts

Engagement Strategy: Weighing Options

Mechanism: Focus Group

Your team is developing new measure concepts for an outpatient quality measurement program based on the Hospital Outpatient Department (HOPD) and/or the Ambulatory Surgery Center (ASC) setting. You decide to use the Weighing Options strategy with a Focus Group of 12 PFE Partners to generate new measure ideas to ensure stakeholder perspectives are incorporated as the measure goes through the development phase. Your team convenes the Focus Group and describes the outpatient quality measurement program. PFE Partners suggest several measure concepts that would serve to uphold both the HOPD and ASC settings. Your team decides to move forward with the PFE Partners' recommendations and include the measure concept suggestions for review.

SECTION 5 TOOLS AND TEMPLATES



SECTION 9:
Resources

TOOL: SAMPLE PFE PARTNER RECRUITMENT QUESTIONS

Prior to working with new PFE Partners, it is important to assess if they are a good fit for the project. The questions below will help during recruitment conversations with potential PFE Partners.

- Please share your experiences with the healthcare field—both personal and professional.
- What aspects of healthcare or quality improvement most interest you?
- Please describe your experiences participating in group work either as part of employment or as a volunteer (Parent Teacher Association, Neighborhood Civic Association, etc.), including the size of the group(s) and any instances in which you served as group leader. What challenges did you face? Any successes you can share?
- What do you hope to gain from this experience?
- Do you see any barriers or challenges in participating in our work (e.g., time, availability, chronic condition limitations)?
- Are you comfortable speaking up in a group setting? The group work may include doctors, nurses, other clinicians, researchers, employers, health insurance representatives, and other patients and family caregivers. Would you be willing to share your experiences and speak candidly with all of these individuals present?
- What skills or experience do you possess that you think will be valuable to this work?

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[TOOL: Sample PFE Partner Recruitment Questions]

SECTION 6: Onboarding & Orientation

Conducting onboarding and orientation prior to any engagement ensures PFE Partners have the necessary foundational knowledge to partner with your organization and possess a working understanding of healthcare quality improvement, measure development, and multi-stakeholder engagement best practices.

Preparing PFE Partners for engagement requires more than just diving into a discussion on measure development during the first meeting. Building relationships requires mutual understanding and early preparation. Onboarding and orientation are two key steps that make up the welcome process for PFE Partners in a new collaboration. In these steps, providing background information, reviewing essential processes, completing necessary paperwork, and establishing the responsibilities of everyone involved are addressed. Once onboarding and orientation are complete, PFE Partners will be ready to engage with the measurement team.

Topics discussed in this section include the following.

- Onboarding;
- Orientation; and
- Scenario-Based Example.

Resources:

The end of this section has a preview of a relevant tool and templates on this topic. You can also click the links below to access printable versions that are included in Section 9: Resources of this Toolkit.

- Sample "Getting to Know You" Questions and Biographies Tool
- Sample Email Communication Template
- PFE Charter Template
- Orientation Checklist Template

Onboarding and Orientation: Section Highlights

- Onboarding often sets the tone for the remainder of your relationship with each PFE Partner, and taking the time to get to know PFE Partners will promote better engagement once your measure project begins.
- You should ensure you build in adequate time (i.e., recommended no less than four business days) for your PFE Partners to complete the necessary onboarding documentation.
- Several topics to keep in mind during onboarding include providing PFE Partners with an introduction to your organization's mission and vision and how they fit into it and summarizing the goals and scope.
- The onboarding process should also include a discussion of roles and responsibilities, with a focus on what PFE Partners will likely expect and what you will expect from them during their participation on the TEP, Working Group, or Focus Group.
- Offering PFE Partners an orientation is an important opportunity to "lay the groundwork" prior to your collaboration. At this point, your team has welcomed PFE Partners, and they will generally understand your project, organization, and roles and responsibilities.
- Holding an orientation meeting will help ensure any outstanding questions are addressed and will also give PFE Partners a chance to virtually meet one another in a relaxed setting.

SECTION 6: Onboarding & Orientation

> Value comes by empowering persons, or patients, to make the best healthcare choices through increased person-centered quality measures and public transparency, while reducing burden to measured entities. – **CMS MMS Hub**

ONBOARDING

Onboarding may be your first opportunity to interact with PFE Partners directly if you used other organizations to support your recruitment. It is your chance to make a lasting impression and foster a meaningful relationship. For sample communication strategies that will help foster this new relationship, review the **Sample Email Communication Template**.

Onboarding often sets the tone for the remainder of your relationship with each PFE Partner. Taking the time to get to know PFE Partners will promote better engagement once your measure project begins. Ensure you are building in adequate time (i.e., recommended one to two weeks) for your Partners to complete the necessary onboarding documentation.

Onboarding topics to consider include the following.

- Greet PFE Partners with a welcoming email. Use the time to describe your appreciation for their collaboration and the importance of their contributions.
- Provide PFE Partners with an introduction to your organization's mission and vision and how they fit into it.
- Share biographic information of your team and your organization's leadership. Think creatively about how you are introducing yourself and your team. Go beyond sharing your credentials and explain your passion for improving the quality of health care for patients.
- Describe the type of support you will provide PFE Partners as your collaboration progresses.
- Identify a point-of-contact within your organization who can be reached for a variety of issues and who will respond promptly.
- Summarize the goals and scope of the project in which PFE Partners will participate. Keep this high-level; the details will be shared after PFE Partners receive further orientation.
- Obtain signed agreements related to the **Protected Health Information and Privacy Agreement Tool**.
- Obtain biographical information from each PFE Partner using the **Sample "Getting to Know You" Questions and Biographies Tool**. Include any necessary COI information, if applicable to your specific activity. In gathering COI information, communicate the purpose of collecting this data to ensure participants understand why they may be asked to disclose certain details of their employment history.
- Determine the preferred communication channels for each PFE Partner, and develop a support plan for any assistance required with technology, materials, or participation. Set expectations of PFE Partner responsiveness to communication due to the time-sensitive nature of the projects. Ensure communication materials and email language are meeting the varying levels of health literacy level of the PFE Partners through using plain language.

Tailor your onboarding approach to each PFE Partner's unique questions, concerns, and needs.

Roles and Responsibilities

The onboarding process should also include a discussion of roles and responsibilities, focusing on what PFE Partners should expect and what you expect from them. One way to guide a conversation with PFE Partners regarding roles and responsibilities is to develop a PFE Charter that details the following:

- The goal of the collaboration;
- The type of project or engagement mechanism the PFE Partner will engage and the length of time the PFE Partner will commit to the collaboration;
- Any honorarium the PFE Partner will receive in recognition of their participation;
- The PFE Partner's role;
- Your role as the measure developer;
- Expectations of PFE Partners (i.e., review materials, attend meetings, share their opinions); and
- Expectations of the measure developer (i.e., create background materials, facilitate meetings, be open to including PFE Partner input in measure decisions).

Review the **Sample Email Communication Template** for examples of a welcome email and an email for communicating with PFE Partners. In addition, review the **PFE Charter Template**.

ORIENTATION

Offering PFE Partners an orientation is an important opportunity to "lay the groundwork" prior to your collaboration. At this point, your team has welcomed PFE Partners, and they generally understand your project, organization, and roles and responsibilities. They may still have many questions about measure development or what it is like to join an engagement activity. Holding an orientation will help ensure any outstanding questions are addressed and will also give PFE Partners a chance to virtually meet one another in a relaxed setting. Using a standard orientation approach will ensure all PFE Partners come to their engagement with the same basic knowledge and expectations.

Recommended Orientation Content

- Conduct introductions, including your team and the PFE Partners.
- Set the broader context, and review the "ins and outs" of measure development and healthcare quality (e.g., define measure development terminology that a lay person may not be familiar with).
- Provide background on your project, what to expect throughout the process, and next steps.
- Build PFE Partner skills in multi-stakeholder engagement by reviewing engagement best practices and defining various stakeholder groups.
- Review the **Orientation Checklist template** for more information.

Recommended Orientation Participants

- PFE Partners;
- PFE Staff;
- Project team members and team leadership; and
- Organizational leadership, when possible.

Prepare orientation materials using plain language. Following health literacy guidelines, use a variety of adult learning mechanisms, such as a webinar presentation, written documents, and videos. More information on this topic can be found in **Section 6: Onboarding and Orientation**.

SCENARIO-BASED EXAMPLE

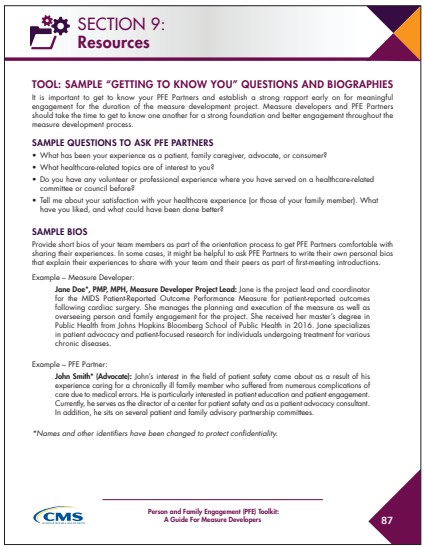
Your Objective: Seek input from a diverse group of patients and caregivers on a Patient-Reported Outcome Measure Under Development

Engagement Strategy: Weighing Options

Mechanism: Measure Working Group

Your team is very early in the process of developing a patient-reported outcome measure for a specific surgical procedure. You intend to use a mixed TEP of patients and caregivers of varied socioeconomic and educational backgrounds for their input. Because of their varied experiences, you put together an information packet (including overview of project and introduction to measure development), create a welcome video, and hold Office Hours for the new TEP members to get them up to speed. If TEP members become busy or are unable to attend meetings, you accommodate by recording the meetings so they can listen at a more convenient time. During the meetings, you make sure all members have a turn to voice their opinion without interruption on the development of the project. Because of this inclusive approach, you gather their valuable perspectives and opinions on the measure.

SECTION 6 TOOLS AND TEMPLATES


SECTION 9:
Resources

TOOL: SAMPLE "GETTING TO KNOW YOU" QUESTIONS AND BIOGRAPHIES

It is important to get to know your PFE Partners and establish a strong rapport early on for meaningful engagement for the duration of the measure development project. Measure developers and PFE Partners should take the time to get to know one another for a strong foundation and better engagement throughout the measure development process.

SAMPLE QUESTIONS TO ASK PFE PARTNERS

- What has been your experience as a patient, family caregiver, advocate, or consumer?
- What healthcare-related topics are of interest to you?
- Do you have any volunteer or professional experience where you have served on a healthcare-related committee or council before?
- Tell me about your satisfaction with your healthcare experience (or those of your family member). What have you liked, and what could have been done better?

SAMPLE BIOS

Provide short bios of your team members as part of the orientation process to get PFE Partners comfortable with sharing their experiences. In some cases, it might be helpful to ask PFE Partners to write their own personal bios that explain their experiences to share with your team and their peers as part of first-meeting introductions.

Example – Measure Developer:

Jane Doe*, PMP, MPH, Measure Developer Project Lead: Jane is the project lead and coordinator for the MDS Patient-Reported Outcome Performance Measure for patient-reported outcomes following cardiac surgery. She manages the planning and execution of the measure as well as overseeing person and family engagement for the project. She received her master's degree in Public Health from Johns Hopkins Bloomberg School of Public Health in 2016. Jane specializes in patient advocacy and patient-focused research for individuals undergoing treatment for various chronic diseases.

Example – PFE Partner:

John Smith* (Advocate): John's interest in the field of patient safety came about as a result of his experience caring for a chronically ill family member who suffered from numerous complications of care due to medical errors. He is particularly interested in patient education and patient engagement. Currently, he serves as the director of a center for patient safety and as a patient advocacy consultant. In addition, he sits on several patient and family advisory partnership committees.

**Names and other identifiers have been changed to protect confidentiality.*

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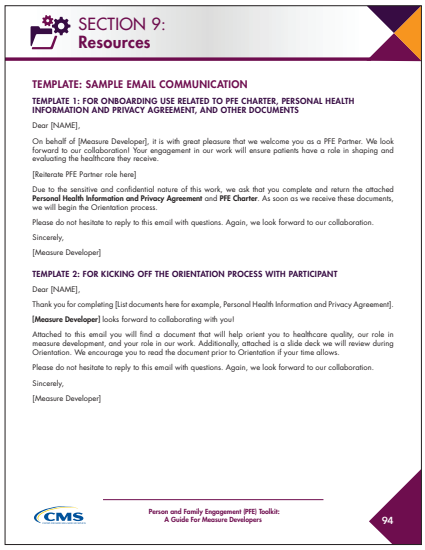
[TOOL: Sample "Getting to Know You" Questions and Biographies]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TEMPLATE: SAMPLE EMAIL COMMUNICATION

TEMPLATE 1: FOR ONBOARDING USE RELATED TO PFE CHARTER, PERSONAL HEALTH INFORMATION AND PRIVACY AGREEMENT, AND OTHER DOCUMENTS

Dear [NAME],

On behalf of [Measure Developer], it is with great pleasure that we welcome you as a PFE Partner. We look forward to our collaboration! Your engagement in our work will ensure patients have a role in shaping and evaluating the healthcare they receive.

[Reiterate PFE Partner role here]

Due to the sensitive and confidential nature of this work, we ask that you complete and return the attached **Personal Health Information and Privacy Agreement** and **PFE Charter**. As soon as we receive these documents, we will begin the Orientation process.

Please do not hesitate to reply to this email with questions. Again, we look forward to our collaboration.

Sincerely,

[Measure Developer]

TEMPLATE 2: FOR KICKING OFF THE ORIENTATION PROCESS WITH PARTICIPANT

Dear [NAME],

Thank you for completing [List documents here for example, Personal Health Information and Privacy Agreement].

[Measure Developer] looks forward to collaborating with you!

Attached to this email you will find a document that will help orient you to healthcare quality, our role in measure development, and your role in our work. Additionally, attached is a slide deck we will review during Orientation. We encourage you to read the document prior to Orientation if your time allows.

Please do not hesitate to reply to this email with questions. Again, we look forward to our collaboration.

Sincerely,

[Measure Developer]

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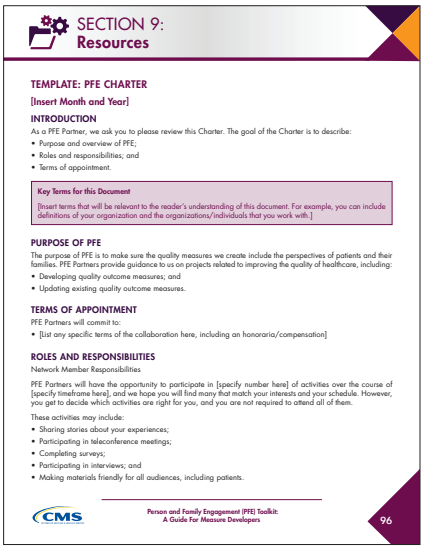
[TEMPLATE: Sample Email Communication]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TEMPLATE: PFE CHARTER

[Insert Month and Year]

INTRODUCTION

As a PFE Partner, we ask you to please review this Charter. The goal of the Charter is to describe:

- Purpose and overview of PFE;
- Roles and responsibilities; and
- Terms of appointment.

Key Terms for this Document

[Insert terms that will be relevant to the reader's understanding of this document. For example, you can include definitions of your organization and the organizations/individuals that you work with.]

PURPOSE OF PFE

The purpose of PFE is to make sure the quality measures we create include the perspectives of patients and their families. PFE Partners provide guidance to us on projects related to improving the quality of healthcare, including:

- Developing quality outcome measures; and
- Updating existing quality outcome measures.

TERMS OF APPOINTMENT

PFE Partners will commit to:

- [List any specific terms of the collaboration here, including an honoraria/compensation]

ROLES AND RESPONSIBILITIES

Network Member Responsibilities

PFE Partners will have the opportunity to participate in [specify number here] of activities over the course of [specify timeframe here], and we hope you will find many that match your interests and your schedule. However, you get to decide which activities are right for you, and you are not required to attend all of them.

These activities may include:

- Sharing stories about your experiences;
- Participating in teleconference meetings;
- Completing surveys;
- Participating in interviews; and
- Making materials friendly for all audiences, including patients.

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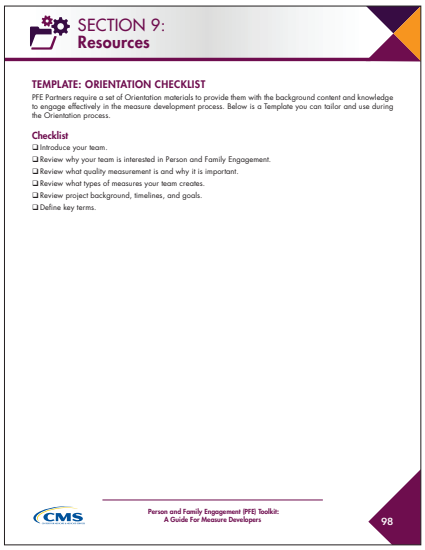
[TEMPLATE: PFE Charter]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TEMPLATE: ORIENTATION CHECKLIST

PFE Partners require a set of Orientation materials to provide them with the background content and knowledge to engage effectively in the measure development process. Below is a Template you can tailor and use during the Orientation process.

Checklist

- ❑ Introduce your team.
- ❑ Review why your team is interested in Person and Family Engagement.
- ❑ Review what quality measurement is and why it is important.
- ❑ Review what types of measures your team creates.
- ❑ Review project background, timelines, and goals.
- ❑ Define key terms.

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[TEMPLATE: Orientation Checklist]

SECTION 7: Facilitating Engagement

This section provides tips and strategies for successfully engaging with your PFE Partners, focusing on mechanisms that involve meetings, such as Measure Working Groups or TEPs. Many of the strategies described can be applied to other engagement mechanisms, such as surveys or interviews.

Meeting with PFE Partners is often the most exciting and fulfilling part of the engagement process. Forming personal connections, making key decisions, and building patient-centered measures together can be very rewarding. Sharing materials with PFE Partners before and during meetings can provide them with critical background information and effectively guide discussions and the decision-making process. To enhance understanding, focus on highlighting essential content, use an appropriate level of detail, and choose simple, straight-forward language with examples and visuals. Practice the four key elements of effective meeting facilitation: open communication, adequate preparation, customized meeting management, and real-time refinements to ensure meetings are productive and positive experiences for you and your PFE Partners.

Topics discussed in this section include the following:

- Scheduling Meetings with PFE Partners;
- Preparing PFE Partners;
- Meeting Facilitation;
- Meeting Facilitation Troubleshooting;
- Following-up with PFE Partners; and
- Scenario-Based Example.

Resources:

The end of this section has is a preview of a tool, templates, and handouts relevant to this topic. You can also click the links below to access printable versions that are included in Section 9: Resources of this Toolkit.

- Drafting Meeting Materials Tool
- Script for Meeting Introduction and Wrap Up Template
- Steps Leading Up to Your Engagement Template
- Meeting Facilitation Troubleshooting Handout
- Effective Meeting Facilitation Handout

Facilitating Engagement: Section Highlights

- Plan meeting days and time in advance. Identify times that accommodate PFE Partners' schedules but are also convenient for others as well. Online scheduling tools (e.g., Doodle) can be used to efficiently gather availability from participants.
- Thoroughly preparing PFE Partners is critical to ensuring effective engagement with your teams. Adequate project preparation includes background materials and prep calls.
  - Background Materials: It is a best practice to provide background information through a variety of media, such as written summary documents, webinar slides, videos, and journal articles, to educate PFE Partners on the technical, contractual, and any sensitive issues related to the project.
  - Prep Calls: One of the best ways to prepare PFE Partners for engagement is by conducting individual "prep calls" with each PFE Partner prior to each engagement.
- Four key elements of effective meeting facilitation include: open communication, adequate preparation, customized meeting management, and real-time refinements.
- It is equally important to check in with PFE Partners after meetings to evaluate and understand their experiences and improve the engagement process as needed. The best way to check in is to conduct individual debrief calls with each PFE Partner after each engagement.

SECTION 7:
Facilitating Engagement

> 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. This collaborative engagement allows patient values to guide all clinical decisions and drives genuine transformation in attitudes, behavior, and practice. – **CMS PFE Strategy, pg.8**

SCHEDULING MEETINGS WITH PFE PARTNERS

Most PFE Partners have important obligations, such as full-time or part-time work, caregiving responsibilities, and/or managing an illness. Busy schedules and competing priorities may make meeting and scheduling challenging, but you can employ strategies to identify times that are convenient. Below are suggestions for scheduling the meeting. For more details, see the Steps Leading Up to Your Engagement Template.

Tips and Tricks:

- **Meeting Duration:** Consider limiting meeting durations to ensure sustained engagement during a meeting. If you have a full agenda, consider hosting several meetings to ensure participants remain energized during the discussion.
- **Time Between Meetings:** If you are hosting numerous meetings, consider the length of time you will need between each one. This timeline will be impacted by contractual deadlines, deadlines for rulemaking, or Partnership for Quality Measurement (PQM) submission; the analyses, research, or deliberation that needs to occur between meetings; and the availability of data or other necessary information. To learn more about communicating with your PFE Partners between meetings, see Section 8: Ongoing Communication.
- **Meeting Formats:** When holding an in-person meeting, schedule it when all PFE Partners can participate to be most effective. Virtual meetings are also an option. Regardless of the selected format, keep it consistent for all participants to avoid any imbalance in perspective.

Planning

- Begin scheduling one month prior to your goal engagement (or earlier if you know who will be serving on the engagement)

Selecting Meeting Time Options

Offer PFE Partners

- At least five meeting times to choose from
- Varying times of day and days of the week
- Times that do not fit in the normal 9–5 workday (example, meeting start time of 5 pm)

Share Meeting Times with PFE Partners

- Use a poll for easy tracking
- Allow PFE Partners at least one week to respond
- Follow up if you do not hear back from PFE Partners

Determining the Best Meeting Time

- Select the time where most PFE Partners can join
- Create a plan to engage those who cannot make the meeting, such as sharing the meeting recording or meeting minutes
- If no meeting time is identified, repeat this process

- **Dates to Avoid:** Meetings around holidays, school breaks, and summer vacations can be particularly challenging to schedule with PFE Partners. Plan to offer more meeting times and have a plan in place if attendance is low.

- **Technology:** Some PFE Partners may be unfamiliar with online tools that will help you facilitate scheduling. Also, plan to offer customized support as needed, such as conducting a dry run for PFE Partners to test their connectivity before the actual meeting.
- **Expected and Unexpected Absences:** You may not be able to find a meeting time that is suitable for all PFE Partners, in which case you will need to choose the time that works best for the majority of PFE Partners. You may also have PFE Partners who unexpectedly need to miss a previously scheduled meeting. In these situations, identify alternative ways to engage with the PFE Partners who are unable to attend, such as through individual phone calls or over email. Be sure to share their input with the other members of the group via minutes or an email update.

PREPARING PFE PARTNERS

Thoroughly preparing PFE Partners is critical to ensuring effective engagement with your teams. PFE Partners first need to establish a foundational understanding of healthcare quality, performance measurement, and measure development, which they should receive during orientation and onboarding (see Section 6: Onboarding and Orientation). PFE Partners also require a thorough understanding of the specific project or measure they will be working on. Adequate project preparation includes background materials and preparatory calls.

Background Materials: Prior to engaging PFE Partners on a project that is new to them, you should prepare and distribute background materials that will help them understand the subject matter and the goals of the project. It is a best practice to provide background information through a variety of media, such as written documents, webinar slides, videos, and journal articles, to educate PFE Partners on the technical, contractual, and any sensitive issues related to the project. This approach is comprehensive and accommodates different learning styles. Additionally, keep in mind the diverse backgrounds of PFE Partners (e.g., ethnicity/race, sociodemographic background, age) to help guide the discussion from a culturally informed perspective.

Make sure your background materials are succinct and incorporate Plain Language standards.

Avoid jargon, acronyms, and technical terms when your PFE Partners are learning the project background. If you must use them in the background materials, be sure to define them. Once incorporated into the workflow, PFE Partners will become familiar with the language.

- It is helpful to vet materials before distributing them to PFE Partners to ensure they are accessible from a health literacy perspective (e.g., sixth-or seventh-grade reading level). The reading level and grammar functions in Word can be helpful for this.
- By distributing background documents at least two weeks prior to kicking off your collaboration, PFE Partners have time to review the documents before the first meeting. Distribute meeting-related documents at least one week prior to a meeting or other engagement activity. This enables PFE Partners to review the documents and flag questions or matters for discussion prior to preparatory calls.

Preparatory Calls: One of the best ways to prepare PFE Partners for engagement is by conducting individual "prep calls" with each PFE Partner. This is best applied to TEPs, Measure Working Groups, and other small group engagement activities.

Benefits of Preparatory Calls include the following:

- Helps PFE Partners feel prepared to fully engage before calling into a meeting or other engagement activity;
- Offers PFE Partners time for 1:1 discussion of any questions or concerns they have;
- Allows PFE Partners to follow up or ask questions about any background materials they may have received;
- Demonstrates their partnership matters to you and fosters relationship building; and
- Helps your team effectively run your upcoming engagement activity by explaining complex topics and prompting discussion on areas PFE Partners raised during their prep calls.

Ask PFE Partners if they have questions or concerns about any of the following:

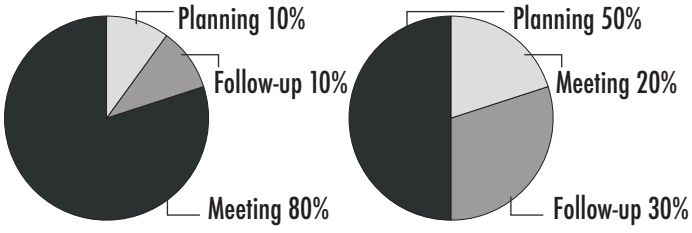
- Logistics of how and when to join the engagement;
- Technical content or measure terms they do not understand;
- How their lived experience or perspective ties into the content and how they can contribute (e.g., how a PFE Partners' experience with an inpatient patient safety event contributes to a new Patient Safety measure); and
- If there is anything they would like the project team to know or address prior to or during the engagement.

If you do not have the resources to conduct individual phone calls with each PFE Partner prior to each engagement, consider holding group prep calls with multiple PFE Partners. A joint prep call with multiple PFE Partners can work for established groups as they can exchange ideas and lessons learned. Some PFE Partners may decline to have prep calls before each engagement, especially if the group has met several times already. Continue to offer prep calls each time, but let PFE Partners know it is not mandatory to participate.

MEETING FACILITATION

Successfully facilitating meetings with PFE Partners is critical to achieving your PFE goals. Compared to other types of meeting facilitation, when engaging PFE Partners you will need to shift from a "typical meeting model" to a "PFE meeting model" (as depicted in the figure below). The PFE meeting model prioritizes planning, preparation, and follow-up. In contrast, the typical meeting model, such as those meetings within your measure development team or with traditional "technical" stakeholders, often prioritizes the meeting time itself.

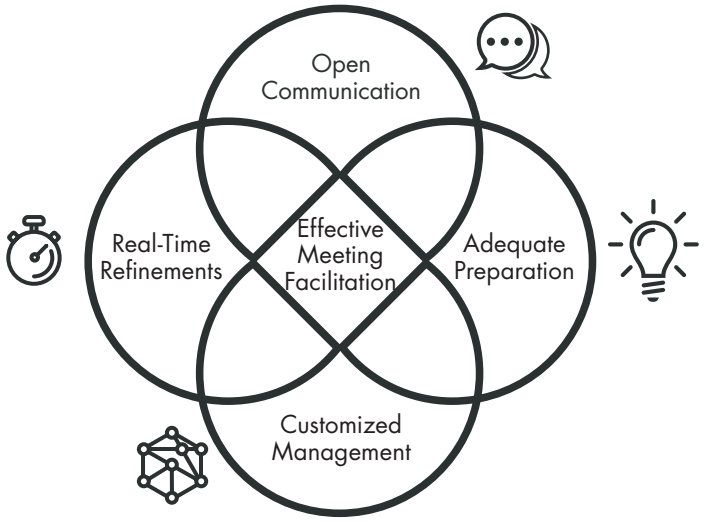
Typical Meeting Model ***PFE Meeting Model***



Effective facilitation is uniquely important for meetings because of PFE Partners:

- Have not engaged in quality measurement and may not be entirely comfortable with the content and terminology;
- Have important insights but may be unaccustomed to articulating them;
- May not have experience interacting in a multi-stakeholder environment; and
- May not have experience interacting with measure developers.

Person & Family Engagement Elements of Effective Meeting Facilitation



In this section, we describe four key elements of effective meeting facilitation: open communication, adequate preparation, customized meeting management, and real-time refinements.

Element 1. Open Communication

Open communication supports mutual understanding and respect and fosters partnership.

It is important to treat PFE Partners as team members when communicating with them. Open communication includes sharing and learning from each other, being open to new ideas, and being courteous and respectful. Communication should be ongoing (See

Section 8: Ongoing Communication). Honesty is a key component of open communication, which includes defining the boundaries of your project, sharing what you are uncertain about, and explaining why you are making certain decisions. To do so ensures that PFE Partners still feel comfortable openly sharing their ideas based on their diverse, unique experiences with the healthcare system.

To build a partnership and gain valuable input, it is vital to take the time to teach PFE Partners what you know.

- Avoid excessive technical jargon early on while PFE Partners are still learning about the project. Instead, teach them the technical terms that will be used so that they can understand the concepts.
- Start with the big picture, and once PFE Partners grasp those concepts, you can drill down into the details of the technical content that you would like to discuss.
- Continuously teaching and reinforcing their understanding of technical terms and concepts will be helpful.
- Be sure to routinely communicate with PFE Partners in between meetings to keep an open line of communication.
- We recommend you engage partners within 90 days following an engagement activity or meeting to avoid long gaps in communication.

Element 2. Adequate Preparation

Adequate preparation leads to the greatest participation and optimizes meeting productivity.

Thinking critically about all logistics is beneficial. In-person meetings can include:

- When and how to schedule meetings;
- Ensuring you have a meeting space with the necessary technology;
- Reserving your meeting space ahead of time to allow time for setup;
- Debriefing with your internal project team; and
- Strategizing an approach to obtain feedback from any PFE Partners who are unable to join the meeting.

For virtual meetings you should:

- Test virtual meeting platforms ahead of time to check speed capacity;
- Test access via computer and phone; and
- Test various functions of the platform, such as the camera and functions (mute, chat, hand raise, etc.).

Other meeting preparation items to keep in mind include:

- Define technical terms.
- Keep materials short and easy to follow.
- Avoid repeating content PFE Partners have already received.
- Distribute materials at least one week prior to the meeting to give PFE Partners time to review. This is one of PFE Partners' most commonly requested actions. For more details, see the Drafting Meeting Materials Tool.
- Build time for unique circumstances, such as working with a PFE Partner who requests a hard copy of materials sent by mail.
- Assign pre-work. You can ask PFE Partners to read the materials packet, think about a certain topic, consider a list of questions, and be ready to share their thoughts. Assign pre-work before the first scheduled activity to allow adequate time for candidates to review, ask questions, and complete tasks.

Finally, get to know your team, which will help you develop a working relationship. It makes them more comfortable discussing personal experiences, and it helps you, as a facilitator, better understand the context of their input. You can learn more about them by reading their biographies or resumes, asking them questions, and sending them your team's biographies with headshots. Refer to the Sample "Getting to Know You" Questions and Biographies Tool.

Whether you are communicating informally or technically, it helps to think about what your words mean to others. Your PFE Partners might live in or come from a different region of the country where the vernacular might be different than your own. Be aware of this potential communication barrier.

Element 3. Customized Meeting Management

Customized meeting management drives authentic person and family input.

This element is about what you do during meetings, starting with using a pre-determined meeting format. You can facilitate a meeting in many ways, and it is important to select a format before the meeting. Recommended formats include, but are not limited to:

Round Robin:	Modified Round Robin:	Question-Driven:
The facilitator calls on participants one at a time for a response.	This structure builds on a round robin that leads into an open group discussion or is an open group discussion that ends with a Round Robin.	Participants provide input on specific topics, respond, and discuss them with each other.

Your meeting goals and group dynamics will direct which format you choose. The Question-Driven format is one of the most open, free-flowing formats, while a Round Robin provides more structure. Presentation format is not recommended. At times, you may need to educate PFE Partners using a presentation format, but this is generally not the purpose of engagement groups. PFE Partners want to share their stories and their input, so you need to use a meeting format that allows for that input. One suggestion is that for each topic solicit patient and caregiver perspectives prior to those of the broader group.

No matter what format you choose, make sure to clearly explain it at the start of the meeting and assume the PFE Partners have done their pre-work.

- Set expectations up front; be clear about what you expect from PFE Partners, what PFE Partners can expect from you, and define your constraints. This theme applies to each of the four elements of meeting facilitation but is especially important to clarify at the start of each meeting.
- Be clear about what you will and will not discuss during the meeting and what you will discuss in future meetings.
- Review the decision-making process. If the goal of the meeting is decision-making, explain how and when you will make decisions and how and when you will communicate back to the PFE Partners.
- Prepare for troubleshooting common challenges and review the **Meeting Facilitation Troubleshooting Handout**.

Finally, it is important to start and end your meetings effectively. It sets the tone for current and future meetings.

- To start a meeting, allow for introductions, emphasize achievements to date, and summarize the impact of previous meetings. It is important for PFE Partners to have the opportunity to introduce themselves, share their story, and explain why they are interested in your work. It is helpful to let the PFE Partners know in advance what type of information they may want to share during the introduction and how much time they will have for the introduction. This helps establish them as experts to the rest of the group, allows them to be heard, and reinforces their meaningful contributions, which will help facilitate the discussion, particularly for those who tend to be more reserved.
- To end a meeting, summarize the feedback you heard during the call, and define how and when you will next communicate with the PFE Partners.

Element 4. Real-Time Refinements

Real-time refinements to your approach enrich partnerships and support ongoing successful engagement.

You want to ensure PFE Partners have a good experience and will continue working with you. To modify your approach to facilitating productive meetings, use feedback that is gathered through individual debrief calls with PFE Partners, participant experience surveys, and your observations during the previous engagement meeting. You might end up modifying your meeting format, the way you communicate between meetings, or your decision-making processes, all in real time. Review your approach after each meeting and assess how the meeting went, what could have gone better, and what can be changed to help ensure ongoing success and demonstrate to PFE Partners that their time is valued.

More information about effective meeting facilitation can be found in the **Effective Meeting Facilitation Handout** and the **Meeting Facilitation Troubleshooting Handout**. In addition, review the **Script for Meeting Introduction and Wrap Up Template**.

MEETING FACILITATION TROUBLESHOOTING

Challenges can still arise even with effective meeting facilitation. Below are four common challenges and helpful techniques to address them. Refer to the **Meeting Facilitation Troubleshooting Handout** for an overview of these techniques.

Scenario 1: A PFE Partner may raise a concern or recommend something that is out of scope or something you cannot address.

- Acknowledge the PFE Partner and the value of their contributions, and then explain why you cannot address the concern.
- Offer a separate one-on-one meeting at a later time to discuss the concern in more detail if the concern is significant or the PFE Partner seems dissatisfied with the response.
- Remind all participants of the scope and key technical aspects without singling out any one individual. If a PFE partner is struggling with technical content or purpose of the project, follow up with the individual PFE Partner after the meeting, if needed.
- Remind the entire group of the purpose of the discussion and any substantial limitations in scope.

Scenario 2: A PFE Partner does not speak up.

- Remind everyone at the start of each meeting that you are seeking input from all PFE Partners and that everyone brings valuable expertise and diverse perspectives.
- Consider using structured approach, such as a round robin, where PFE Partners have a specific time to speak during the meeting.
- Pause the discussion and ask if anyone who has not contributed on the topic has additional input.
- Keep the prompt general, and do not call out individuals by name.
- Provide PFE Partners with more targeted questions prior to subsequent meetings so they have time to prepare a response ahead of time.
- Reinforce PFE Partners' value to the project through email or a one-on-one call outside of group meetings to ensure they feel their perspectives are important and to instill confidence and more active participation.

Scenario 3: A PFE Partner dominates the discussion during a meeting.

- Remind everyone at the start of each meeting that you are seeking input from all PFE Partners.
- Thank the PFE Partner for his/her contributions to the discussion.
- Ask for contributions from those who have not had a chance to participate without calling on individuals by name, and specifically ask about similar or alternative perspectives to share.
- Consider using a round robin meeting format to ensure everyone has an opportunity to speak.
- Set time limits (e.g., two minutes) for responses at the start of the meeting or immediately before asking each question.

Scenario 4: A PFE Partner disagrees with another participant.

- Acknowledge the PFE Partner's points and the disagreement.
- Express appreciation for diverse opinions, remind everyone that you value all perspectives, and reiterate that diversity in opinions leads to a better measure.
- Explicitly state that you are hearing multiple opinions or a disagreement on an important topic, and consider asking follow-up questions and prompting discussion to fully understand the conflicting opinions.
- Explain why a certain decision was made when the team decides how to move forward with that choice.
- Share with PFE Partners if, how, and when you intend to further investigate alternative approaches.

Scenario 5: A PFE Partner is new to quality measures and serving on a TEP.

- Schedule a one-on-one time with that member before the TEP meeting to review the measure and answer questions.
- Provide the new PFE Partner with materials to review and follow up if they have questions or comments.
- Provide a short recap of previous discussions at the beginning of each meeting that includes key highlights, next steps, and action items.
- Ask the new member what their thoughts are about a topic or aspect of the measure to ensure they remain part of the discussion.

FOLLOWING UP WITH PFE PARTNERS

Just as it is a best practice to prepare PFE Partners for engagement, it is equally important to check in with them after meetings to evaluate and understand their experiences. The best way to check in is to conduct individual debrief calls with each PFE Partner after each engagement. It can be helpful for a neutral individual (i.e., someone other than the engagement facilitator or key project staff) to conduct the debrief calls. This neutral individual should attend all meetings related to the engagement and be familiar with the project. This approach helps PFE Partners feel more comfortable sharing negative feedback or concerns they may not feel comfortable sharing with the engagement facilitator directly.

Tips for Navigating Challenging Conversations

- Listen closely
- Thank the PFE Partner for their feedback
- Validate feelings
- Be mindful of tone and word choice
- Remember that each PFE Partner comes from a diverse, unique background and lived experience and brings those perspectives to the engagement

Why take the time to conduct debrief calls for PFE Partners?

- To use PFE Partner input to continue doing things that positively impacted PFE Partners' experiences;
- To use PFE Partner input to improve areas that negatively impacted their experiences;
- To answer lingering questions or address concerns in real time;
- To demonstrate that their partnership matters to you and to continue building relationships;
- To obtain additional measure or project input; and
- To troubleshoot meeting facilitation challenges together.

Ask about PFE Partners' impressions of the following:

- Were the background materials useful and understandable, and did they receive them far enough in advance?
- Were the prep calls helpful, and were their questions answered before the meetings?
- Did the meeting process and facilitation allow for everyone to weigh in and participate?

- Was the discussion among the group respectful, and did it result in decisions or feedback that was impactful?

Ask PFE Partners open-ended questions such as the following:

- Is there anything else you would like to share?
- Is there anything you would change or recommend we do differently next time?
- What was the most useful or effective part of the meeting?

If you do not have the resources to conduct individual phone calls with each PFE Partner after each meeting, consider debriefing via email, online surveys (i.e., Google Forms, SurveyMonkey), a brief survey, or phone calls. Consider providing members with written summaries or minutes, and allow members the opportunity to review, approve, and suggest any edits to statements they made. Further, consider combining your debrief call from meeting one with your prep call for meeting two, thereby reducing the burden of scheduling and conducting multiple calls. The most important thing is to sincerely and openly welcome feedback about PFE Partners' experiences and offer to support them in their engagement with you.

Debrief Call Logistics

- Thank the PFE partner for participating, and ask to schedule a debrief call
- Consider timing (within one week of engagement meeting)
- Plan for a 20–30-minute call
- Be flexible on scheduling
- Use standard templates for each call
- Take notes to share questions or concerns with your project team
- Be an active listener, pay close attention, and avoid interrupting
- Rephrase and ask questions

SCENARIO-BASED EXAMPLE

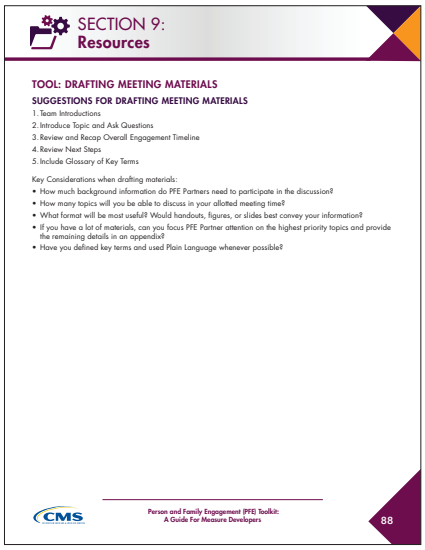
Your Objective: Review new measure concepts

Engagement Strategy: Weighing Options

Mechanism: Technical Expert Panel

Your team is planning to review a few new measure ideas. You are considering two new measure concepts: whether to develop a measure using Medicare claims data or one based on electronic health records. You decide to convene a TEP because this mechanism type is often best suited to review new measure ideas to help decide which ones should be further developed. In the TEP, you share a list of pros and cons for each measure concept, such as what burden will be placed on providers in collecting and reporting their data, how current the data would be, and the level of detail of clinical information obtainable from a claims-based measure compared to data from an electronic health record. You ask PFE Partners how they would prioritize these and other decision criteria for selecting the measure type. You take their recommendations back to CMS with your organization's proposal for the data source to collect for a measure. You feel confident you now have a PFE Partner perspective to inform this decision to balance or confirm any concerns or recommendations made by more typically included stakeholders, such as providers.

SECTION 7 TOOLS AND TEMPLATES


SECTION 9:
Resources

TOOL: DRAFTING MEETING MATERIALS

SUGGESTIONS FOR DRAFTING MEETING MATERIALS

1. Team Introductions
2. Introduce Topic and Ask Questions
3. Review and Recap Overall Engagement Timeline
4. Review Next Steps
5. Include Glossary of Key Terms

Key Considerations when drafting materials:

- How much background information do PFE Partners need to participate in the discussion?
- How many topics will you be able to discuss in your allotted meeting time?
- What format will be most useful? Would handouts, figures, or slides best convey your information?
- If you have a lot of materials, can you focus PFE Partner attention on the highest priority topics and provide the remaining details in an appendix?
- Have you defined key terms and used Plain Language whenever possible?

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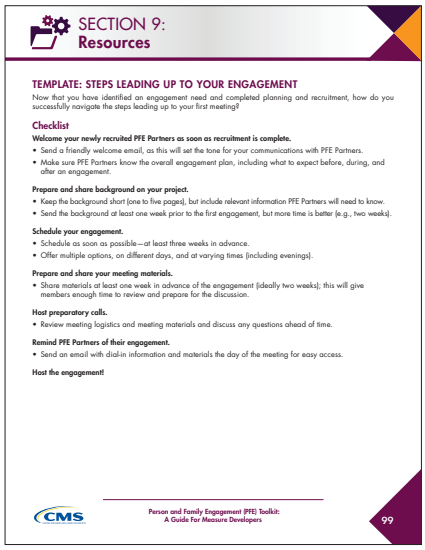
[TOOL: Drafting Meeting Materials]


SECTION 9:
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TEMPLATE: STEPS LEADING UP TO YOUR ENGAGEMENT

Now that you have identified an engagement need and completed planning and recruitment, how do you successfully navigate the steps leading up to your first meeting?

Checklist

Welcome your newly recruited PFE Partners as soon as recruitment is complete.

- Send a friendly welcome email, as this will set the tone for your communications with PFE Partners.
- Make sure PFE Partners know the overall engagement plan, including what to expect before, during, and after an engagement.

Prepare and share background on your project.

- Keep the background short (one to five pages), but include relevant information PFE Partners will need to know.
- Send the background at least one week prior to the first engagement, but more time is better (e.g., two weeks).

Schedule your engagement.

- Schedule as soon as possible—at least three weeks in advance.
- Offer multiple options, on different days, and at varying times (including evenings).

Prepare and share your meeting materials.

- Share materials at least one week in advance of the engagement (ideally two weeks); this will give members enough time to review and prepare for the discussion.

Host preparatory calls.

- Review meeting logistics and meeting materials and discuss any questions ahead of time.

Remind PFE Partners of their engagement.

- Send an email with dial-in information and materials the day of the meeting for easy access.

Host the engagement!

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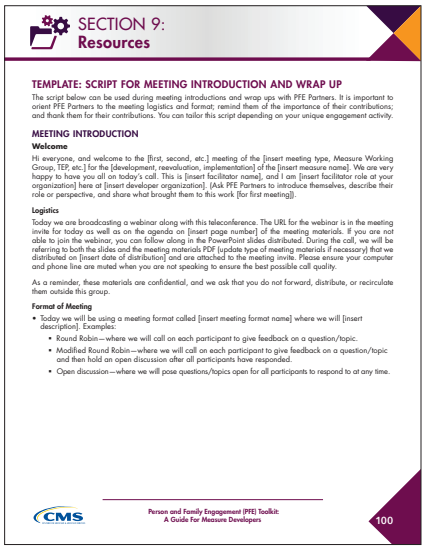
[TEMPLATE: Steps Leading Up to Your Engagement]


SECTION 9:
Resources

TEMPLATE: SCRIPT FOR MEETING INTRODUCTION AND WRAP UP

The script below can be used during meeting introductions and wrap ups with PFE Partners. It is important to orient PFE Partners to the meeting logistics and format; remind them of the importance of their contributions; and thank them for their contributions. You can tailor this script depending on your unique engagement activity.

MEETING INTRODUCTION

Welcome

Hi everyone, and welcome to the [first, second, etc.] meeting of the [insert meeting type, Measure Working Group, TEP, etc.] for the [development, reevaluation, implementation] of the [insert measure name]. We are very happy to have you all on today's call. This is [insert facilitator name], and I am [insert facilitator role at your organization] here at [insert developer organization]. [Ask PFE Partners to introduce themselves, describe their role or perspective, and share what brought them to this work (for first meeting)].

Logistics

Today we are broadcasting a webinar along with this teleconference. The URL for the webinar is in the meeting invite for today as well as on the agenda on [insert page number] of the meeting materials. If you are not able to join the webinar, you can follow along in the PowerPoint slides distributed. During the call, we will be referring to both the slides and the meeting materials PDF (update type of meeting materials if necessary) that we distributed on [insert date of distribution] and are attached to the meeting invite. Please ensure your computer and phone line are muted when you are not speaking to ensure the best possible call quality.

As a reminder, these materials are confidential, and we ask that you do not forward, distribute, or recirculate them outside this group.

Format of Meeting

- Today we will be using a meeting format called [insert meeting format name] where we will [insert description]. Examples:
  - Round Robin—where we will call on each participant to give feedback on a question/topic.
  - Modified Round Robin—where we will call on each participant to give feedback on a question/topic and then hold an open discussion after all participants have responded.
  - Open discussion—where we will pose questions/topics open for all participants to respond to at any time.

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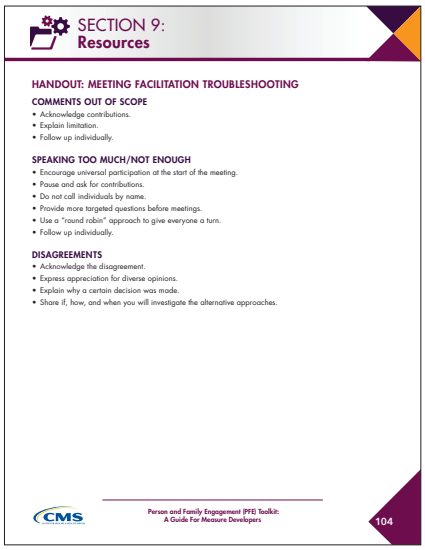
[TEMPLATE: Script for Meeting Introduction and Wrap Up]


SECTION 9:
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HANDOUT: MEETING FACILITATION TROUBLESHOOTING

COMMENTS OUT OF SCOPE

- Acknowledge contributions.
- Explain limitation.
- Follow up individually.

SPEAKING TOO MUCH/NOT ENOUGH

- Encourage universal participation at the start of the meeting.
- Pause and ask for contributions.
- Do not call individuals by name.
- Provide more targeted questions before meetings.
- Use a "round robin" approach to give everyone a turn.
- Follow up individually.

DISAGREEMENTS

- Acknowledge the disagreement.
- Express appreciation for diverse opinions.
- Explain why a certain decision was made.
- Share if, how, and when you will investigate the alternative approaches.

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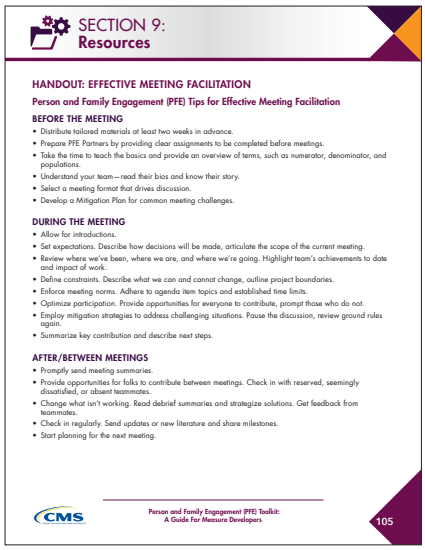
[HANDOUT: Meeting Facilitation Troubleshooting]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HANDOUT: EFFECTIVE MEETING FACILITATION

Person and Family Engagement (PFE) Tips for Effective Meeting Facilitation

BEFORE THE MEETING

- Distribute tailored materials at least two weeks in advance.
- Prepare PFE Partners by providing clear assignments to be completed before meetings.
- Take the time to teach the basics and provide an overview of terms, such as numerator, denominator, and populations.
- Understand your team—read their bios and know their story.
- Select a meeting format that drives discussion.
- Develop a Mitigation Plan for common meeting challenges.

DURING THE MEETING

- Allow for introductions.
- Set expectations. Describe how decisions will be made, articulate the scope of the current meeting.
- Review where we've been, where we are, and where we're going. Highlight team's achievements to date and impact of work.
- Define constraints. Describe what we can and cannot change, outline project boundaries.
- Enforce meeting norms. Adhere to agenda item topics and established time limits.
- Optimize participation. Provide opportunities for everyone to contribute, prompt those who do not.
- Employ mitigation strategies to address challenging situations. Pause the discussion, review ground rules again.
- Summarize key contribution and describe next steps.

AFTER/BETWEEN MEETINGS

- Promptly send meeting summaries.
- Provide opportunities for folks to contribute between meetings. Check in with reserved, seemingly dissatisfied, or absent teammates.
- Change what isn't working. Read debrief summaries and strategize solutions. Get feedback from teammates.
- Check in regularly. Send updates or new literature and share milestones.
- Start planning for the next meeting.

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[HANDOUT: Effective Meeting Facilitation]

SECTION 8: Ongoing Communication

This section provides guidance for communicating and managing relationships with PFE Partners. To engage with PFE Partners in a meaningful way, actively working to build relationships with them throughout the life cycle of the project is important. One way to achieve this is by using various communication tools throughout the life of the project. PFE Partners want to know they are part of the team and that their work adds value, so it is important to build in ways to communicate regularly about their work and its impact. Keeping PFE Partners informed and engaged demonstrates their input is valued and motivates them to continue working on an ongoing basis and on future projects.

Topics discussed in this section include the following:

- Project Communication;
- Supporting PFE Partners; and
- Scenario-Based Example.

Resources:

The end of this section has a preview of a tool relevant to this topic. You can also click on the link below to access the printable version that is included in Section 9: Resources of this Toolkit.

- Project Communication Tool

Ongoing Communication: Section Highlights

- Throughout your measurement project, you will need to communicate with your PFE Partners frequently about the status of the project to obtain their feedback and perspectives and to make key measure decisions.
  - Communicate clearly and concisely to make it easy for PFE Partners to follow and understand (e.g., use plain language).
  - Communicate with PFE Partners using their preferred mode of communication (i.e., email, phone, online survey).
  - Communicate with PFE Partners consistently—at the beginning of the project, before and after a meeting, during gaps in active engagement, and after the active engagement is complete.
- In addition to routine debrief calls after each meeting or engagement, communicate with your PFE Partners about their partnership.
  - These conversations help reinforce PFE Partners' understanding of your organization's commitment to meaningful partnership, ensure PFE Partners are having the best possible experience, and provide opportunities for continued organizational growth and improvement in PFE.

SECTION 8:
Ongoing Communication

> The measure developer must keep the person's/caregiver's point of view central throughout the Measure Lifecycle or quality project and provide opportunities for person input during the information gathering process. – **CMS MMS Hub**

PROJECT COMMUNICATION

Throughout the duration of your measurement project, you will need to communicate with your PFE Partners frequently about the status of the project to obtain their feedback and perspectives and to make key measure decisions. For more details, review the **Project Communication Tool**.

How to Communicate

Be clear and concise in your communications to make it easy for PFE Partners to follow and understand:

- Use **Plain Language**.
- Be consistent in how you refer to your project measure name and your PFE Partners.
- Lay out specific questions or materials and highlight key areas for PFE Partners to focus their attention.
- Provide a point-of-contact for your team who will be responsive to PFE Partners. Offer both an email address and a phone number.

Communication Methods

Whenever possible, communicate with PFE Partners using their preferred mode of communication. Follow best practices for whichever mode of communication you use.

Email (most common):

- Use a standard subject line for emails, such as<Task/project/team name>: <Activity>, <Date> to help PFE Partners readily sort and respond to communications from your team.
- When onboarding, request that PFE Partners add key team member email addresses to their address book, and confirm messages are not going to their spam folders.
- Combine information into fewer emails to avoid flooding PFE Partner inboxes with numerous messages.

Online survey tools:

- Confirm automated survey tool messages do not go to PFE Partner spam folders.
- Provide clear instructions for completing surveys.

Phone:

- Acknowledge that between meetings, some PFE Partners may prefer to discuss their concerns or measure feedback one-on-one by phone as opposed to email or in the larger group meetings.
- Call PFE Partners directly to help you connect with individuals who are not responsive to emails.

Mail:

- Understand some PFE Partners may require paper copies of meeting materials, surveys, and other paperwork, so allow extra time for mailing these materials.

Important Note: Once you schedule your meeting, try not to send too many updated meeting invites. Multiple invites for a single meeting can become confusing to PFE Partners who see numerous emails and invites, especially if they do not use an email or calendar program, such as Outlook.

SECTION 8: Ongoing Communication

When and What to Communicate

You should communicate with your PFE Partners frequently throughout the following times during the project.

At the Beginning of the Project

- Help prepare PFE Partners to engage in technical content by providing any background materials or information.
- Begin to build your relationship with PFE Partners.
- Share estimated project and meeting timelines with PFE Partners.

Prior to Meetings

- Send a meeting invitation several weeks in advance.
- Send materials at least one week in advance and offer to answer questions.
- Send a reminder email with the meeting materials and dial-in information the day of the meeting so it is easy for PFE Partners to locate the information.

After Meetings

- Share meeting minutes and explain next steps in the project generally and for PFE Partners specifically.
- Distribute surveys asking PFE Partners about their experience or for content or technical input on the project (if applicable), and request additional project input via email.
- Keep PFE Partners abreast of progress on the project, such as analyses your team is conducting.
- Notify PFE Partners of roadblocks or delays you encounter, such as a delay in receiving necessary data or obtaining unexpected testing results.
- Announce project milestones as soon as they occur (such as if the measure is submitted to the PQM for endorsement).

During Gaps in Active Engagement

- Alert PFE Partners if they should expect a long gap before the next meeting is scheduled and what that timeframe may be.

After the "Active" Engagement/Project Is Complete

- Acknowledge measures can take several years to go from development to implementation. You may decide to close out a Measure Working Group, TEP, or other engagement mechanism.
- Inform your PFE Partners why the engagement is ending (e.g., if measure specifications are complete), key measurement milestones, and how they can stay involved in the future of the measure. For example, notify PFE Partners when the measure enters rulemaking, and offer information on how they can participate in the public comment process.

Important Note: While it is very important to communicate information with your PFE Partners many times throughout your project, you can potentially overwhelm your PFE Partners with too many emails. Whenever possible, consolidate your communications by combining topics in a single email. For example, if you send a follow-up survey after a meeting, send it in the same email as the meeting minutes.

SUPPORTING PFE PARTNERS

Ongoing communication with PFE Partners about their PFE experience is critical to the success of your work and goes beyond discussing the technical aspects of measurement. In addition to routine debrief calls after each meeting or engagement, be sure to communicate with your PFE Partners about their partnership with your organization (see Section 2: The PFE Process). Below are valuable insights to learn about.

- Are they finding the work meaningful?
- Do they feel valued?
- Do they feel they are impacting the project and improving the quality of health care?
- Are they being invited to work on projects that interest them or have personal meaning for them?
- Are they comfortable with the frequency and duration of their engagement, and is it manageable with their other responsibilities and obligations?
- What can your organization do to further support them?

These conversations help reinforce PFE Partners' understanding of your organization's commitment to meaningful partnership, ensure PFE Partners are having the best possible experience, and provide opportunities for continued organizational growth and improvement in PFE.

SCENARIO-BASED EXAMPLE

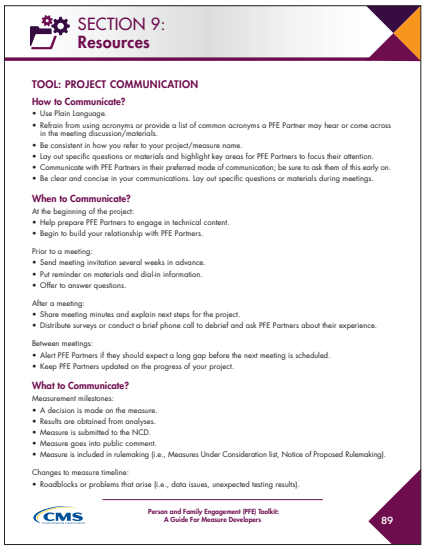
Your Objective: Plan future research or analyses

Engagement Strategy: Evaluating Preliminary Results or Displays

Mechanism: Measure Working Group

You are collaborating with a Measure Working Group to develop the specifications for a new clinical outcome measure. PFE Partners strongly feel that for this chronic health condition, several key patient factors are not currently accounted for in the risk adjustment model. They recommend some additional research into the feasibility of identifying these patient factors and including them in the model. You decide to develop an analytic plan for evaluating these complex factors and push back your upcoming TEP meeting to allow time for completing these analyses prior to moving forward with your current risk-adjustment model. When you later present the model to the TEP and to PQM, you will have a more robust risk-adjustment model that better incorporates patient perspectives and/or you will have greater evidence for the appropriateness of your existing risk-adjustment approach and lack of feasibility of incorporating any additional factors.

SECTION 8 TOOLS AND TEMPLATES



SECTION 9:
Resources

TOOL: PROJECT COMMUNICATION

How to Communicate?

- Use Plain Language.
- Refrain from using acronyms or provide a list of common acronyms a PFE Partner may hear or come across in the meeting discussion/materials.
- Be consistent in how you refer to your project/measure name.
- Lay out specific questions or materials and highlight key areas for PFE Partners to focus their attention.
- Communicate with PFE Partners in their preferred mode of communication; be sure to ask them of this early on.
- Be clear and concise in your communications. Lay out specific questions or materials during meetings.

When to Communicate?

At the beginning of the project:

- Help prepare PFE Partners to engage in technical content.
- Begin to build your relationship with PFE Partners.

Prior to a meeting:

- Send meeting invitation several weeks in advance.
- Put reminder on materials and dial-in information.
- Offer to answer questions.

After a meeting:

- Share meeting minutes and explain next steps for the project.
- Distribute surveys or conduct a brief phone call to debrief and ask PFE Partners about their experience.

Between meetings:

- Alert PFE Partners if they should expect a long gap before the next meeting is scheduled.
- Keep PFE Partners updated on the progress of your project.

What to Communicate?

Measurement milestones:

- A decision is made on the measure.
- Results are obtained from analyses.
- Measure is submitted to the NCD.
- Measure goes into public comment.
- Measure is included in rulemaking (i.e., Measures Under Consideration list, Notice of Proposed Rulemaking).

Changes to measure timeline:

- Roadblocks or problems that arise (i.e., data issues, unexpected testing results).

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[TOOL: Project Communication]

SECTION 9: Resources

Tools, templates, and handouts have been referenced throughout the Toolkit. This section organizes these resources to aid you in engaging with PFE Partners and follows the best practices outlined in the Toolkit. All materials are in a printable format and ready for use.

A list of all tools (something that can help guide decision-making or a process), templates (ready-made forms to adapt to specific needs), and handouts (a document to provide staff or persons or caregivers to help guide developing materials, understand a process, or facilitate meetings) is included below.

TOOLS

Paperwork Reduction Act Decisions Tree Tool ..... Section 1 ..... Page 74

Facilitator Guide for Activities in PFE Training Tool ..... Section 1 ..... Page 75

Engagement Topics and Decisions Summary Tool ..... Section 4 ..... Page 84

Choosing Your Engagement Mechanism Tool ..... Section 4 ..... Page 85

Sample PFE Partner Recruitment Questions Tool ..... Section 5 ..... Page 86

Sample "Getting to Know You" Questions and Biographies Tool ..... Section 6 ..... Page 87

Drafting Meeting Materials Tool ..... Section 7 ..... Page 88

Project Communication Tool ..... Section 8 ..... Page 89

TEMPLATES

Protected Health Information and Privacy Agreement Template ..... Section 1 ..... Page 90

Strategic Planning Template ..... Section 3 ..... Page 92

Sample Email Communication Template ..... Section 6 ..... Page 94

PFE Charter Template ..... Section 6 ..... Page 96

Orientation Checklist Template ..... Section 6 ..... Page 98

Steps Leading Up to Your Engagement Template ..... Section 7 ..... Page 99

Script for Meeting Introduction and Wrap Up Template ..... Section 7 ..... Page 100

HANDOUTS

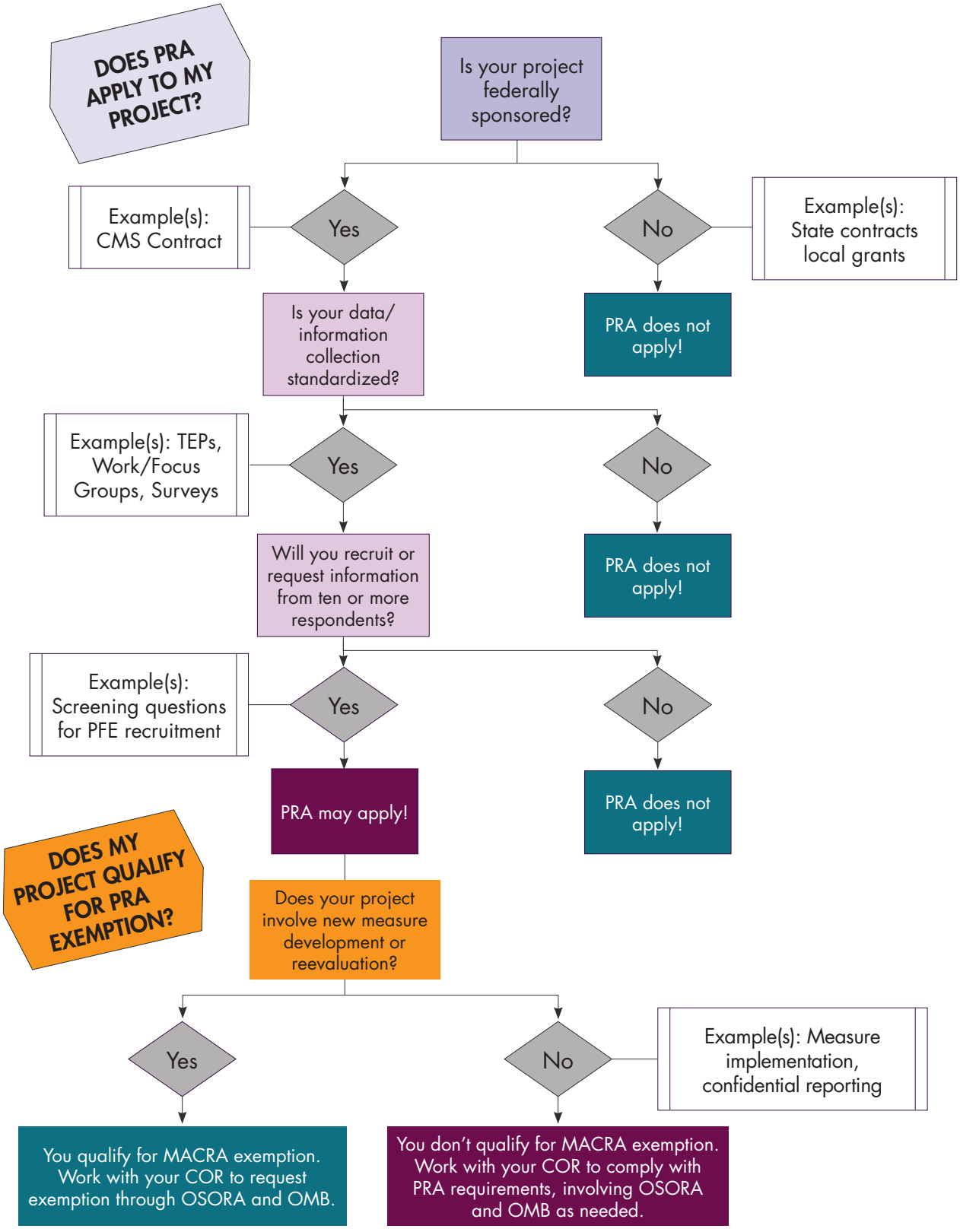
PFE Process Summary Handout ..... Section 2 ..... Page 102

Elements of Strategic Planning Handout ..... Section 3 ..... Page 103

Meeting Facilitation Troubleshooting Handout ..... Section 7 ..... Page 104

Effective Meeting Facilitation Handout ..... Section 7 ..... Page 105

TOOL: PAPERWORK REDUCTION ACT (PRA) DECISION TREE



TOOL: FACILITATOR GUIDE FOR ACTIVITIES IN PFE TRAINING

STRATEGIC PLANNING EXERCISE (45 MINUTES)

Part 1

- Estimated time for activity: 25–30 minutes
- Materials needed:
  - Strategic Planning Template (explained in Section 3: Strategic Planning of the Toolkit, printable version provided in Section 9: Resources)
  - Writing utensils

1. Break up the participants into groups of 3–5 people.
2. Instruct the groups to:
   - Select a project for which they are hoping to engage PFE Partners.
   - As a group, fill out the Project Background part of the Strategic Planning Template for that project.
3. Provide an example project:
   - You are at the beginning stages of developing a patient-reported outcome.
   - You decide to convene a Working Group with eight PFE Partners.

- After eight minutes, ask participants to share key takeaways with the larger group.

Part 2

- Estimated time for activity: 10 minutes
- Materials needed:
  - Strategic Planning Template
  - Writing utensils

1. Instruct participants to:
   - Break up into the same groups.
   - As a group, fill out the Engagement Proposal part of the Strategic Planning Template for the same project chosen in Part 1.
2. After eight minutes, ask participants to share key takeaways with the larger group.

COMMUNITY ACTIVITY

- Estimated time for activity: five minutes
- Materials needed:
  - Images, like the examples provided on the next page of this guide—one image for every two participants
  - Blank half-sheets of paper—one for every two participants
  - Envelopes
  - Writing utensils
- Purpose of activity: demonstrate the importance of communication. Be specific. Start with the big picture before getting into the details. Emphasize that language is important, and words mean different things to different people.

Before the Training

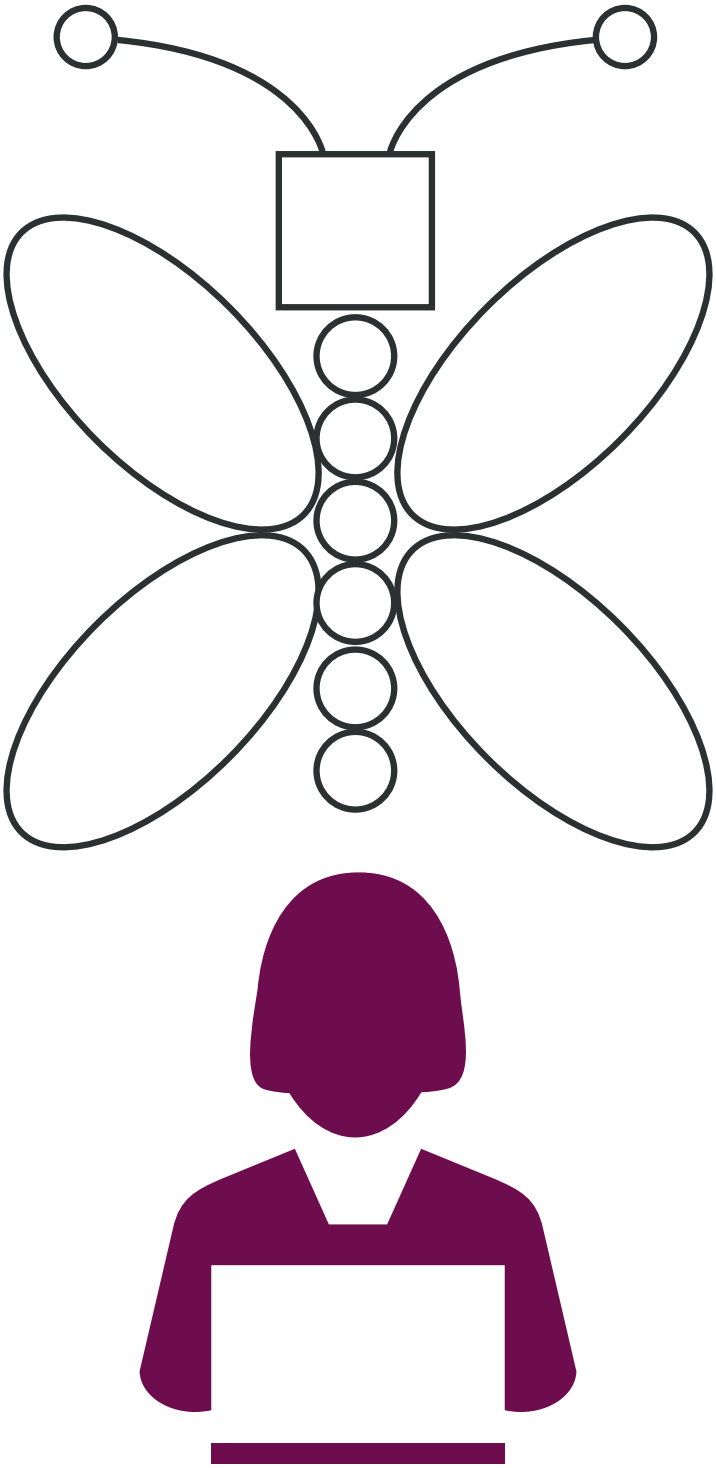
1. Print out images, like the examples provided on the next page. You need enough images so every two participants will have one image, but some pairs of participants can have the same image.
2. Place each image in an envelope.
3. Pair each envelope with a blank half-sheet of paper.

During the Training

1. Break up the participants into groups of two.
2. Each pair should be given an envelope and a blank half-sheet of paper with an instruction not to open the envelope until given the go-ahead.
3. Instruct the pairs that:
   - They will sit back-to-back so that they cannot see each other.
   - One person will open the envelope to find an image and will describe as best they can what the image is to their partner.
   - The other person will draw what they are hearing on the blank half-sheet of paper.
4. Inform participants this is a challenge to think critically about the way you are communicating and listening.
5. After two to three minutes, ask participants to show each other the images and drawings and share key takeaways with the larger group.
   - Participants will bring varying perspectives to the exercise, similar to how participants will bring different perspectives to a TEP, Working Group, or Focus Group based on their experiences and background.

TOOL: FACILITATOR GUIDE FOR ACTIVITIES IN PFE TRAINING

Example Images for Communication Activity:



TOOL: FACILITATOR GUIDE FOR ACTIVITIES IN PFE TRAINING

CHALLENGING SCENARIOS AND SCRIPT ACTIVITY

- Estimated time for activity: 15 minutes
- Materials needed:
  - Scenario A and Scenario B handouts provided on the next pages of this guide
  - Script Activity handout provided on the next pages of this guide
  - Writing utensils
- Purpose of activity: practice opening an engagement, responding to input from PFE Partners, and problem-solving common issues, which are all key components of meeting facilitation.
- Note: These could be conducted as two separate activities—one for Challenging Scenarios and one for Script—if time allows, which may be useful for staff who are brand new to PFE.

1. Break up the participants into groups of three to five people.
2. Each group should receive one of the three handouts: Scenario A, Scenario B, or Script Activity.
3. Instruct participants to follow the prompts on the handout:
   - For Scenarios A and B, groups should discuss how they would respond to the scenario and answer the question(s) provided.
   - For the Script Activity, groups should write out scripts according to the prompts. If time allows, they can practice reciting the scripts and/or role play.
4. After about 10 minutes, ask groups to share key takeaways with the larger group.
5. Sample responses for the facilitator to use are also provided on the next pages of this guide. Participants are encouraged to think about and write about their responses, then compare those with the sample responses.

SCENARIO A: REFOCUSING AN OUT OF SCOPE WORKING GROUP DISCUSSION

A new measure development team is creating a measure to assess harms from hypoglycemia (low blood sugar). The Working Group consists of six patients and caregivers with experience with diabetes, a condition in which treatment can lead to hypoglycemia. Though the focus of the measure is hypoglycemia, one Working Group member continues to remark on how their physician is trying to convince them to quit smoking given the serious health outcomes that can occur for diabetes patients who smoke. The Working Group member frequently talks about the challenges of quitting smoking during the Working Group calls, making it difficult to get through all the measure specification discussion questions. The measure development team is considering touching base with the Working Group member before their next call to speak one-on-one about the scope of the measure. How do you thank the member for their input without cutting them off when they continue to derail the conversation in the meetings? How do you approach the one-on-one call with them and allow them to share why they are having a hard time understanding the goals of the work?

SCENARIO B: LACK OF CONSENSUS BETWEEN STAKEHOLDERS IN TEPS AND WORKING GROUPS

When convening a multi-stakeholder meeting, your team likely has some specific goals in mind, whether it is getting sign-off on risk adjustment strategies, deciding on an outcome definition, or deciding on a direction for a key measure issue. Sometimes, things don't go quite as planned. In this scenario, you present some data and analyses, and you ask your stakeholders to select the best option for the measure.

Scenario B1: There is discord between TEP members. The PFE Partners support, including a particular patient group in the cohort, while the clinicians do not.

Scenario B2: There is discord among Working Group members. In one new measure Working Group of patient-reported outcomes, three members recommended adding an additional survey to capture general health status, while the other four members felt it would only create an undue burden for patients and providers.

How do you balance conflicting input on a TEP or Working Group?

TOOL: FACILITATOR GUIDE FOR ACTIVITIES IN PFE TRAINING

CHALLENGING SCENARIOS AND SAMPLE FACILITATOR RESPONSES

Scenario A: Refocusing an Out of Scope Working Group Discussion

Response during the meeting: Continue to thank the Working Group member for their feedback in the meeting. Bring the focus of the meeting back to the topic under discussion and remind all members of the focus/target of the measure.

After the meeting: Discuss with PFE team to raise the focus of the measure with the Working Group member during their follow-up call. Let PFE team know you would like to hold a one-on-one with the member prior to the next meeting to get the member on the same page so they can be more productive during the next call.

In the one-on-one call, thank the member for sharing their experiences and allow them to share why they are having difficulties with the current specifications/focus of the calls. Remind them of the goal of the measure and share that even though their experience could not be captured in the measure, the team is still interested in hearing their perspectives on other aspects of the measure.

Scenario B: Lack of Consensus Between Stakeholders in TEPs and Working Groups

Response: Task teams should remember to be nimble and open to change and feedback.

Often, a TEP will align perfectly with your expectations heading into the meeting. Other times, however, a TEP will have problems coming to a consensus or may oppose a task team's stance. Although not ideal, remember it is acceptable to emerge from a TEP meeting without TEP sign off on specific issues.

If you are having trouble gaining consensus, ask clarifying questions to make sure the team understands all viewpoints presented.

It is important to explain to group members why a certain decision was made if the approach lacked consensus. Address any concerns, giving specific rationale as to why the team decided one way or another. This will allow everyone to feel like part of the team and ensure the team is not dismissing ideas because it does not align with their preconceived ideas.

In addition, once a decision has been made, remind everyone that their input is valued and that a diversity of backgrounds, lived experiences, and opinions will lead to a better measure.

In the Working Group scenario, you can also follow up by asking if the incremental information gained by adding the generic health status instrument to the measure is worth the additional burden placed on patients to fill out and physicians to collect. Share existing guidance or literature on this decision point. Bring this to a TEP if they have not weighed in or test in a pilot study/dry run.

TOOL: FACILITATOR GUIDE FOR ACTIVITIES IN PFE TRAINING

PFE MEETING FACILITATION SCRIPT ACTIVITY

To practice meeting facilitation, write a brief script for opening a Working Group (welcome, introductions, etc.).

Now, write some possible responses to a Working Group member's input going beyond, "Thank you for your input, now let's hear from the next person." These can be one-line statements or questions.

TOOL: FACILITATOR GUIDE FOR ACTIVITIES IN PFE TRAINING

SAMPLE SCRIPT: FACILITATOR RESPONSES

Opening a Working Group (welcome, introductions, etc.)

Key points:

- Introduce yourself.
- Thank members for joining.
- Only introduce one or two key team members/presenters by name.
- Give an overview of the structure of the call.
- Make time for members to fully introduce themselves.

"Hello everyone, my name is [name], and I am a [role] at [organization]. First, I would like to thank you all so much for taking time out of your day to be on this call. Your input is so crucial to the work we do, and we really appreciate that you are willing to share your diverse perspectives and experiences with us. Here in the room with me are [names and roles of one or two other key team members/presenters], along with some other team members who work on this project. Before I ask you to introduce yourselves, I wanted to give you a sense of how we have structured this call. After introductions, [lead presenter name] will explain the project background using presentation slides, and then we will ask you to answer some broad questions. We'll stop along the way for questions and discussion. Please don't hesitate to stop us at any time, and no question is too small or silly. Now we would like each person on the call to introduce themselves—it would be great if you could say your name, where you are from, and a little bit about what led you to join us in this work."

Responding to input from working group members going beyond, "Thank you, now let's hear from the next person."

Key points:

- Synthesize and repeat back an idea, especially if you are not sure you understood it fully.
- Ask for members to respond to each other.
- Listen for common themes among what members are saying and point them out.
- Acknowledge disagreements among members.

"I think I am hearing you say [summarize in your own words what you heard], did I understand you correctly?" or "Thank you for that comment, [member name]; does anyone want to respond to that?"

"I am hearing several people mention [common theme]; we will definitely take note of that."

"It seems there is some disagreement about [issue]; it is helpful for us to hear these differing views and we will take it all into consideration."

TOOL: ENGAGEMENT TOPICS AND DECISIONS SUMMARY

Topic	Description/Examples
Build conceptual frameworks	Co-develop conceptual frameworks for complex, difficult to measure ideas or components, such as socio-demographic status or shared decision-making.
Prioritize new measure concepts or topics for future development	Recommend high priorities for future measure development, such as specific medical conditions, procedures, or treatments; outcomes of interest; or measure types.
Select measure type	Recommend a measure type for a measure concept that has already been selected. For example, claims-based, electronic Clinical Quality Measures (eCQMs), or patient-reported outcome measures; individual condition/procedure measures versus facility-wide measures; and single versus composite measures.
Select measure cohort and determine inclusion/exclusion criteria	Define the overall population of patients for the measure and how they will be grouped, if applicable; determine any specific populations or categories of patients that should or should not be included in the cohort (e.g., patients on hospice or those having an elective procedure).
Define measure outcome	Determine what outcome you will measure, such as readmission rates, complications, or length of stay in the hospital, if the measure topic (condition, procedure, etc.) has already been selected.
Design or select tools	Co-design, test, or select from existing measurement tools, such as surveys and collection instruments.
Select risk adjustment approach	Recommend an approach to risk adjustment by weighing pros and cons of various analytic or modeling approaches.
Determine measure scoring methodology	Determine the performance categories that will be reported, how providers/hospitals will be evaluated, or how tools/documents will be scored.
Assess measure usability	Evaluate testing results, performance scores, measure specifications, and/or reporting options to determine if the measure is useful and meaningful to PFE Partners and other populations. For example, PFE Partners may report that a measure at the health system level is not as useful to them as a measure that provides scores for individual hospitals from which they may receive care.
Plan future research or analyses	Identify data or information gaps and recommend assessing availability or feasibly of using new data sources; recommend further analysis of different analytic approaches.
Create or improve measure reporting displays	Allow for measure reporting displays that could include how measure results are displayed in public-facing materials, such as on Care Compare or other reporting sites, or other resources meant to support the use of the measure.
Create or improve measure descriptive language	Allow for measure-descriptive language that could include measure name, measure information in methodology reports, or how the measure is described in public-facing materials, such as on Care Compare or other reporting sites.

TOOL: CHOOSING YOUR ENGAGEMENT MECHANISM

	Technical Expert Panel (TEP)	Measure Working Group	Communication Workshop	Individual Interview	Survey	Focus Group	Testing	Virtual Community	Public Comment Opportunity
Multiple meetings	X	X	-	-	-	-	X	-	-
1–2 meetings	-	-	X	X	-	-	-	-	-
Discussion-focused	X	X	-	X	-	X	X	X	-
Early input	-	X	-	-	X	-	-	-	-
PFE Partner-only	-	X	X	X	-	-	-	-	-
Individual input on a specific subject area of PFE Partner expertise	-	-	X	X	X	X	X	-	-
Structured/quantitative feedback	-	-	X	-	X	-	-	-	-
Large number of PFE Partners	-	-	-	-	X	-	-	X	X
Integrating PFE Partners into existing measure development activities	X	-	-	-	-	X	-	-	X
Assurance of PFE throughout all phases of measure development	X	X	X	X	X	X	X	-	X

TOOL: SAMPLE PFE PARTNER RECRUITMENT QUESTIONS

Prior to working with new PFE Partners, it is important to assess if they are a good fit for the project. The questions below will help during recruitment conversations with potential PFE Partners.

- Please share your experiences with the healthcare field—both personal and professional.
- What aspects of healthcare or quality improvement most interest you?
- Please describe your experiences participating in group work either as part of employment or as a volunteer (Parent Teacher Association, Neighborhood Civic Association, etc.), including the size of the group(s) and any instances in which you served as group leader. What challenges did you face? Any successes you can share?
- What do you hope to gain from this experience?
- Do you see any barriers or challenges in participating in our work (e.g., time, availability, chronic condition limitations)?
- Are you comfortable speaking up in a group setting? The work group may include doctors, nurses, other clinicians, researchers, employers, health insurance representatives, and other patients and family. Would you be willing to share your experiences and speak candidly with all of these individuals present?
- What skills or experience do you possess that you think will be valuable to this work?

TOOL: SAMPLE "GETTING TO KNOW YOU" QUESTIONS AND BIOGRAPHIES

It is important to get to know your PFE Partners and establish a strong rapport early on for meaningful engagement for the duration of the measure development project. Measure developers and PFE Partners should take the time to get to know one another for a strong foundation and better engagement throughout the measure development process.

SAMPLE QUESTIONS TO ASK PFE PARTNERS

- What has been your experience as a patient, caregiver, advocate, or consumer?
- What healthcare-related topics are of interest to you?
- Do you have any volunteer or professional experience where you have served on a healthcare-related committee or council before?
- Tell me about your satisfaction with your healthcare experience (or those of your family member). What have you liked, and what could have been done better?

SAMPLE BIOS

Provide short bios of your team members as part of the orientation process to get PFE Partners comfortable with sharing their experiences. In some cases, it might be helpful to ask PFE Partners to write their own personal bios that explain their experiences to share with your team and their peers as part of first-meeting introductions.

Example – Measure Developer:

> **Jane Doe*, PMP, MPH, Measure Developer Project Lead:** Jane is the project lead and coordinator for the MIDS Patient-Reported Outcome Performance Measure for patient-reported outcomes following cardiac surgery. She manages the planning and execution of the measure as well as overseeing person and family engagement for the project. She received her master's degree in Public Health from Johns Hopkins Bloomberg School of Public Health in 2016. Jane specializes in patient advocacy and patient-focused research for individuals undergoing treatment for various chronic diseases.

Example – PFE Partner:

> **John Smith* (Advocate):** John's interest in the field of patient safety came about as a result of his experience caring for a chronically ill family member who suffered from numerous complications of care due to medical errors. He is particularly interested in patient education and patient engagement. Currently, he serves as the director of a center for patient safety and as a patient advocacy consultant. In addition, he sits on several patient and family advisory partnership committees.

**Names and other identifiers have been changed to protect confidentiality.*

TOOL: DRAFTING MEETING MATERIALS

SUGGESTIONS FOR DRAFTING MEETING MATERIALS

1. Team Introductions
2. Introduce Topic and Ask Questions
3. Review and Recap Overall Engagement Timeline
4. Review Next Steps
5. Include Glossary of Key Terms

Key Considerations when drafting materials:

- How much background information do PFE Partners need to participate in the discussion?
- How many topics will you be able to discuss in your allotted meeting time?
- What format will be most useful? Would handouts, figures, or slides best convey your information?
- If you have a lot of materials, can you focus PFE Partner's attention on the highest priority topics and provide the remaining details in an appendix?
- Have you defined key terms and used Plain Language whenever possible?

TOOL: PROJECT COMMUNICATION

How to Communicate?

- Use Plain Language.
- Refrain from using acronyms or provide a list of common acronyms a PFE Partner may hear or come across in the meeting discussion/materials.
- Be consistent in how you refer to your project/measure name.
- Lay out specific questions or materials and highlight key areas for PFE Partners to focus their attention.
- Communicate with PFE Partners in their preferred mode of communication; be sure to ask them of this early on.
- Be clear and concise in your communications. Lay out specific questions or materials during meetings.

When to Communicate?

At the beginning of the project:

- Help prepare PFE Partners to engage in technical content.
- Begin to build your relationship with PFE Partners.

Prior to a meeting:

- Send meeting invitation several weeks in advance.
- Put reminder on materials and dial-in information.
- Offer to answer questions.

After a meeting:

- Share meeting minutes and explain next steps for the project.
- Distribute surveys or conduct a brief phone call to debrief and ask PFE Partners about their experience.

Between meetings:

- Alert PFE Partners if they should expect a long gap before the next meeting is scheduled.
- Keep PFE Partners updated on the progress of your project.

What to Communicate?

Measurement milestones:

- A decision is made on the measure.
- Results are obtained from analyses.
- Measure is submitted to the PQM.
- Measure goes into public comment.
- Measure is included in rulemaking (i.e., Measures Under Consideration list, Notice of Proposed Rulemaking).

Changes to measure timeline:

- Roadblocks or problems that arise (i.e., data issues, unexpected testing results).

TEMPLATE: PROTECTED HEALTH INFORMATION (PHI) AND PRIVACY

[Insert Month and Year]

INTRODUCTION

What is the Protected Health Information and Privacy Agreement?

We want to ensure everyone is comfortable with the way their information is used. In this document, we will describe the type of information we collect, how we store it, and how we intend to share it. At the end of this Protected Health Information and Privacy Agreement, we will ask you to sign a statement indicating you agree to the terms outlined in this document.

[Insert terms that will be relevant to the reader's understanding of this document. For example, you can include definitions of your organization and the organizations/individuals that you work with.]

UNDERSTANDING HOW YOUR INFORMATION IS USED

Information You Share with Us

You may choose to share personal information about yourself or others, which includes an individual's contact information, health experiences, and personal characteristics (such as race, ethnicity, or sex). You are not required to share any specific kinds of information. You can decline to provide this information at your own discretion.

How We Use Your Information

We will use your information to:

- Match you with projects that align with your interests and experiences;
- Guide quality measurement work (such as priority areas of measurement); and
- Inform efforts to recruit other PFE Partners.

How We Store Your Information

- We will store your protected information using [locations and protections provided].
- NOTE: If storing protected information of any kind, provide additional details here.

How We Share Your Information

You may describe your experiences or other personal information at your discretion while participating in activities. In this case, you would be sharing that information directly with everyone participating in that activity, such as other PFE Partners and project staff.

TEMPLATE: PERSONAL HEALTH INFORMATION AND PRIVACY

In addition, we may share that information with CMS, if requested. We may share this information with other staff within our organization working on quality measurement projects. We may also publicly share the recommendations and guidance we receive from you, but we will not share any identifying information unless written consent is obtained.

Information Shared on a Technical Expert Panel, Working Groups, and Focus Groups

You may choose to participate in a Technical Expert Panel (TEP), Working Group, or Focus Group. Along with CMS, we make certain information about the engagement public, which includes, but is not limited to, your name, role, and recommendations made during meetings.

NOTE: If posting this information on a public forum of any kind, provide additional details here.

Publicly posted documents will not include personal health information. If you disclose personal health information by choice, that information and your communications are not subject to confidentiality laws.

How TEP, Working Group, and Focus Group Participants Can Remain Confidential

Your participation in this type of engagement can remain confidential in any publicly posted document. If you choose to remain confidential, your name will not be provided in public documents or posted online. Instead, you will be listed by role (for example, patient). All your contributions included in summary reports will be associated with their role and not their name.

PFE Partner Signs

Signed: Name: Address: Phone: Email: Date:

_____

_____

_____

_____

Measure Developer Signs

Signed: Name: Address: Phone: Email: Date:

_____

_____

_____

_____

TEMPLATE: STRATEGIC PLANNING

For each engagement, please fill in the following fields:

Project Background

Overall goal(s) of the project (for example, develop a new measure, refine existing measure, adapt measure to new program, develop implementation strategies):

_____

_____

_____

PFE goal(s) (for example, develop a patient-centered new measure, ensure patients can understand the language you are using to describe a measure outcome):

_____

_____

_____

Description of current status of measure or project (for example, beginning measure development, outcome and cohort selected, determining risk adjustment model):

_____

_____

_____

Project next steps (for example, select cohort, develop conceptual framework):

_____

_____

_____

Main questions or topic areas for PFE collaboration:

_____

_____

_____

For each engagement, please fill in the following fields:

Engagement mechanism(s):

Frequency of engagement (include estimated number of meetings, meeting length, time between meetings):

Estimated number of participants:

Preferred PFE Partner characteristics/expertise/experiences (e.g., race/ethnicity, education level, geographic location, sociodemographic, age, experience with specific clinical area):

Anticipated timeline (include start and end dates, as well as other project timeline dependencies):

TEMPLATE: SAMPLE EMAIL COMMUNICATION

TEMPLATE 1: FOR ONBOARDING USE RELATED TO PFE CHARTER, PERSONAL HEALTH INFORMATION AND PRIVACY AGREEMENT, AND OTHER DOCUMENTS

Dear [NAME],

On behalf of [Measure Developer], it is with great pleasure that we welcome you as a PFE Partner. We look forward to our collaboration! Your engagement in our work will ensure patients have a role in shaping and evaluating the healthcare they receive.

[Reiterate PFE Partner role here]

Due to the sensitive and confidential nature of this work, we ask that you complete and return the attached **Protected Health Information and Privacy Agreement** and **PFE Charter**. As soon as we receive these documents, we will begin the Orientation process.

Please do not hesitate to reply to this email with questions. Again, we look forward to our collaboration.

Sincerely,

[Measure Developer]

TEMPLATE 2: FOR KICKING OFF THE ORIENTATION PROCESS WITH PARTICIPANT

Dear [NAME],

Thank you for completing [List documents here for example, Personal Health Information and Privacy Agreement].

[Measure Developer] looks forward to collaborating with you!

Attached to this email you will find a document that will help orient you to healthcare quality, our role in measure development, and your role in our work. Additionally, attached is a slide deck we will review during Orientation. We encourage you to read the document prior to Orientation if your time allows.

Please do not hesitate to reply to this email with questions. Again, we look forward to our collaboration.

Sincerely,

[Measure Developer]

TEMPLATE 3: FOR INVITING PFE PARTNERS TO ENGAGE IN PFE COLLABORATION, SPECIFICALLY COMPLETING A SURVEY

Dear [NAME],

We are excited to present to you an engagement opportunity with our measure development team.

Below is a link to a survey called [Survey Name]. You can access the survey by clicking on the link below, and it will take approximately 10–15 minutes to complete. The survey will inform us of your specific areas of interest and specialty. [Include Link Here]. Please do not hesitate to reply to this email with questions.

Sincerely,

[Measure Developer]

[Insert Month and Year]

TEMPLATE: PFE CHARTER

[Insert Month and Year]

INTRODUCTION

As a PFE Partner, we ask you to please review this Charter. The goal of the Charter is to describe:

- Purpose and overview of PFE;
- Roles and responsibilities; and
- Terms of appointment.

Key Terms for this Document

[Insert terms that will be relevant to the reader's understanding of this document. For example, you can include definitions of your organization and the organizations/individuals that you work with.]

PURPOSE OF PFE

The purpose of PFE is to make sure the quality measures we create include the perspectives of patients and their caregivers. PFE Partners provide guidance to us on projects related to improving the quality of healthcare, including:

- Developing quality outcome measures; and
- Updating existing quality outcome measures.

TERMS OF APPOINTMENT

PFE Partners will commit to:

- [List any specific terms of the collaboration here, including an honoraria/compensation]

ROLES AND RESPONSIBILITIES

Network Member Responsibilities

PFE Partners will have the opportunity to participate in [specify number here] of activities over the course of [specify timeframe here], and we hope you will find many that match your interests and your schedule. However, you get to decide which activities are right for you, and you are not required to attend all of them.

These activities may include:

- Sharing stories about your experiences;
- Participating in teleconference meetings;
- Completing surveys;
- Participating in interviews; and

- Making materials friendly for all audiences, including patients.

Specific responsibilities of PFE Partners include:

- Signing a [List specific documents here. For example, Privacy Agreement and/or Conflict of Interest (COI) – Non-Disclosure Agreement (NDA)];
- Attending an orientation session;
- Reading background materials;
- Sharing your opinions;
- Participating in support calls; and
- Completing experience surveys.

Our responsibilities include:

- Partnering with PFE Partners in their quality measurement work;
- Respecting all PFE Partners and ensuring their voices are valued and appreciated;
- Delivering clear materials before activities;
- Reporting on your contributions to quality measurement projects; and
- Asking permission to contact you about additional opportunities.

PFE Partner Signs

Signed:

Name:

Address:

Phone:

Email:

Date:

Measure Developer Signs

Signed:

Name:

Address:

Phone:

Email:

Date:

TEMPLATE: ORIENTATION CHECKLIST

PFE Partners require a set of Orientation materials to provide them with the background content and knowledge to engage effectively in the measure development process. Below is a Template you can tailor and use during the Orientation process.

Checklist

- ❑ Introduce your team.
- ❑ Review why your team is interested in Person and Family Engagement.
- ❑ Review what quality measurement is and why it is important.
- ❑ Review what types of measures your team creates.
- ❑ Review project background, timelines, and goals.
- ❑ Define key terms.

TEMPLATE: STEPS LEADING UP TO YOUR ENGAGEMENT

Now that you have identified an engagement need and completed planning and recruitment, how do you successfully navigate the steps leading up to your first meeting?

Checklist

Welcome your newly recruited PFE Partners as soon as recruitment is complete.

- Send a friendly welcome email, as this will set the tone for your communications with PFE Partners.
- Make sure PFE Partners know the overall engagement plan, including what to expect before, during, and after an engagement.

Prepare and share background on your project.

- Keep the background short (one to five pages), but include relevant information PFE Partners will need to know.
- Send the background at least one week prior to the first engagement, but more time is better (e.g., two weeks).

Schedule your engagement.

- Schedule as soon as possible—at least three weeks in advance.
- Offer multiple options, on different days, and at varying times (including evenings).

Prepare and share your meeting materials.

- Share materials at least one week in advance of the engagement (ideally two weeks); this will give members enough time to review and prepare for the discussion.

Host preparatory calls.

- Review meeting logistics and meeting materials and discuss any questions ahead of time.

Remind PFE Partners of their engagement.

- Send an email with dial-in information and materials the day of the meeting for easy access.

Host the engagement!

TEMPLATE: SCRIPT FOR MEETING INTRODUCTION AND WRAP UP

The script below can be used during meeting introductions and wrap ups with PFE Partners. It is important to orient PFE Partners to the meeting logistics and format; remind them of the importance of their contributions; and thank them for their contributions. You can tailor this script depending on your unique engagement activity.

MEETING INTRODUCTION

Welcome

Hi everyone, and welcome to the [first, second, etc.] meeting of the [insert meeting type, Measure Working Group, TEP, etc.] for the [development, reevaluation, implementation] of the [insert measure name]. We are very happy to have you all on today's call. This is [insert facilitator name], and I am [insert facilitator role at your organization] here at [insert developer organization]. (Ask PFE Partners to introduce themselves, describe their role or perspective, and share what brought them to this work [for first meeting]).

Logistics

Today we are broadcasting a webinar along with this teleconference. The URL for the webinar is in the meeting invite for today as well as on the agenda on [insert page number] of the meeting materials. If you are not able to join the webinar, you can follow along in the PowerPoint slides distributed. During the call, we will be referring to both the slides and the meeting materials PDF (update type of meeting materials if necessary) that we distributed on [insert date of distribution] and are attached to the meeting invite. Please ensure your computer and phone line are muted when you are not speaking to ensure the best possible call quality.

As a reminder, these materials are confidential, and we ask that you do not forward, distribute, or recirculate them outside this group.

Format of Meeting

- Today we will be using a meeting format called [insert meeting format name] where we will [insert description]. Examples:
  - Round Robin—where we will call on each participant to give feedback on a question/topic.
  - Modified Round Robin—where we will call on each participant to give feedback on a question/topic and then hold an open discussion after all participants have responded.
  - Open discussion—where we will pose questions/topics open for all participants to respond to at any time.

Value of PFE Partner Voice

First Meeting

For a Technical Expert Panel

The TEP members on this call span various backgrounds and areas of expertise. We recognize that there are some (patients/patient advocates) on the TEP, and we are very excited to learn from their experiences and valuable input. Each TEP member's input and suggestions provided by this TEP will be considered during each decision-making process.

We will communicate your input to [insert list of who will hear about the contributions of the group, such as others at your organization, CMS, etc.]. We encourage you to give your honest input on the measure. We strongly believe your feedback will provide us with strong rationale and support to build the best measure possible together.

For a PFE Partner Only Meeting

The [insert team name] is excited to learn from your valuable input, expertise, and unique perspectives.

The input and suggestions provided by this [insert name of measure work group, TEP, etc.] will be considered during each decision-making process. We will communicate your input to [insert list of who will hear about the contributions of group, such as others at your organization, CMS, etc.]. We encourage you to give your honest input on the measure. We strongly believe your feedback will provide us with strong rationale and support to build the best measure possible together.

Future Meetings

This group made important contributions during our previous meeting(s). We look forward to hearing more of your unique perspectives today as we continue with developing this measure.

Meeting Content

After the introductory remarks above, introduce meeting content. When finished with meeting content, move into the Meeting Wrap Up script below.

Meeting Wrap Up

We want to thank everyone for joining us today. We received valuable feedback, which we will continue to discuss internally as we work on this measure. If you reflect on other ideas or questions after the meeting, we would love to hear those things by email. We will be following up with the minutes of today's call.

If anyone has any questions about anything we went over or didn't go over, please feel free to email [insert name of coordinator/lead]. Thank you again for your time.

HANDOUT: PFE PROCESS SUMMARY

Phase	PFE	Staff/Organization
1. Plan	• Define project goals and PFE topics • Determine timeline • Select mechanism • Define preferred PFE Partners perspectives/experiences	• Allocate staff and resources • Train staff on PFE fundamentals, process, strategic planning, and recruitment
2. Recruit	• Recruit PFE Partners	• Select recruitment strategy
3. Prepare	• Conduct orientation and onboarding • PFE Partner prep calls • Prepare and distribute project background materials	• Train staff in effective meeting facilitation
4. Engage	• Use PFE Partner input in measure work	• Facilitate engagement activities
5. Follow-up	• Conduct individual debrief calls • Solicit additional measure input	• Solicit feedback from staff
6. Refine approach	• Solicit and compile PFE Partner feedback	• Identify successes and opportunities for improvement • Modify approach immediately for next engagement • Retrain staff as needed

HANDOUT: ELEMENTS OF STRATEGIC PLANNING

WHY AND WHAT

- Goals of the measure under development or reevaluation
- Current status of the project and next steps
- Goals for engaging with persons and caregivers
- Main questions or topic areas for persons and caregivers

HOW

- Mechanism(s) for the engagement (TEP, Working Group, Survey)

WHO

- Number of Participants
- Preferred demographics
- Key lived experiences, expertise, and characteristics (e.g., race/ethnicity, age, sociodemographic, geography)

WHEN

- Anticipated timeline for the measure and the engagement
- Number and duration of meetings
- Frequency and timing of surveys or other outreach

HANDOUT: MEETING FACILITATION TROUBLESHOOTING

COMMENTS OUT OF SCOPE

- Acknowledge contributions.
- Explain limitation.
- Follow up individually.

SPEAKING TOO MUCH/NOT ENOUGH

- Encourage universal participation at the start of the meeting.
- Pause and ask for contributions.
- Do not call individuals by name.
- Provide more targeted questions before meetings.
- Use a "round robin" approach to give everyone a turn.
- Follow up individually.

DISAGREEMENTS

- Acknowledge the disagreement.
- Express appreciation for diverse opinions.
- Explain why a certain decision was made.
- Share if, how, and when you will investigate the alternative approaches.

HANDOUT: EFFECTIVE MEETING FACILITATION

Person and Family Engagement (PFE) Tips for Effective Meeting Facilitation

BEFORE THE MEETING

- Inform participants how often they will be engaged and what they can expect.
- Distribute tailored materials at least two weeks in advance.
- Prepare PFE Partners by providing clear assignments to be completed before meetings.
- Take the time to teach the basics and provide an overview of terms, such as numerator, denominator, and populations.
- Understand your team—read their bios and know their story.
- Select a meeting format that drives discussion.
- Develop a Mitigation Plan for common meeting challenges.

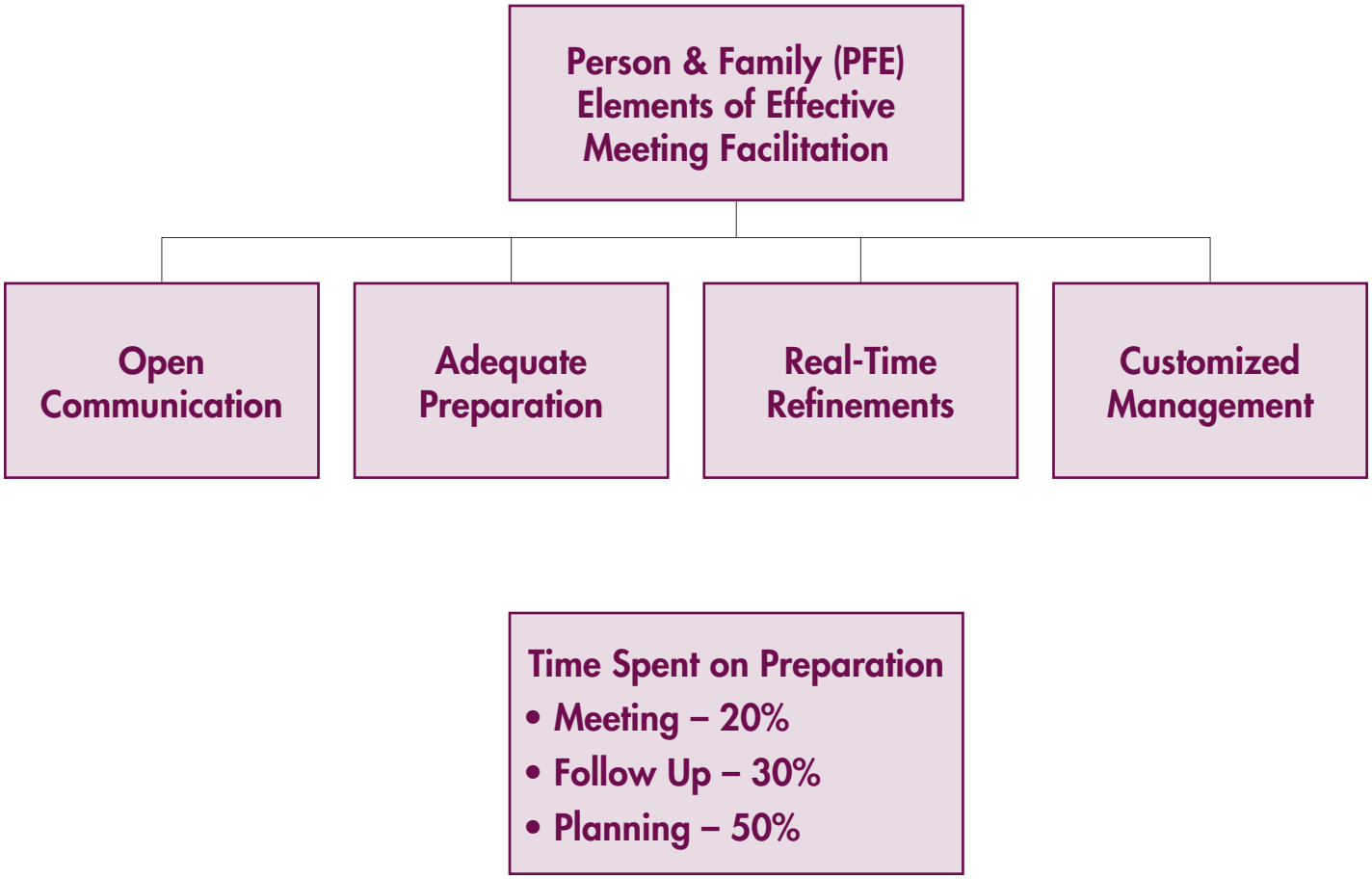
DURING THE MEETING

- Allow for introductions.
- Use an icebreaker.
- Set expectations. Describe how decisions will be made, articulate the scope of the current meeting.
- Review where we've been, where we are, and where we're going. Highlight team's achievements to date and impact of work.
- Define constraints. Describe what we can and cannot change, outline project boundaries.
- Enforce meeting norms. Adhere to agenda item topics and established time limits.
- Optimize participation. Provide opportunities for everyone to contribute, prompt those who do not.
- Employ mitigation strategies to address challenging situations. Pause the discussion, review ground rules again.
- Summarize key contribution and describe next steps.

AFTER/BETWEEN MEETINGS

- Promptly send meeting summaries.
- Provide opportunities for folks to contribute between meetings. Check in with reserved, seemingly dissatisfied, or absent teammates.
- Change what isn't working. Read debrief summaries and strategize solutions. Get feedback from teammates.
- Check in regularly. Send updates or new literature and share milestones.
- Inform participants when they can expect payment
- Start planning for the next meeting.

HANDOUT: EFFECTIVE MEETING FACILITATION



Fostering meaningful engagement with patients and their caregivers is crucial in providing patient-centered care and improving health outcomes.

For additional resources visit: https://www.pfenetwork.org