



# Person and Family Engagement (PFE) Toolkit

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**A Guide For Measure Developers**

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**April 2020**



# Toolkit

April 2020

Welcome measure developers and thank you for using the Person and Family Engagement (PFE) Toolkit!

The Centers for Medicare and Medicaid Services (CMS) developed the PFE Toolkit with measure developers for measure developers to serve as a roadmap to successful engagement with persons and families; a stakeholder group which brings invaluable expertise to quality measurement. It is an easy-to-follow, comprehensive guide intended to support implementation of best and standard practices for PFE across all CMS contractors, regardless of level of experience with PFE. From veteran contractors to those just starting out, the PFE Toolkit will help all measure developers improve or establish PFE processes for measure development and implementation across their organizations.

The PFE Toolkit provides essential information and resources measure developers need for effective engagement. It is comprised of five components:

- **Introductory video** (for access, please contact your CMS Contracting Officer Representative [COR]).
- **Instructive content** (eight sections): each section focuses on specific aspects or phases of PFE (for example, recruitment) and provides related information, key considerations, helpful tips, and resources.
- **Success stories**: each section (beginning with [Section 3: How to Engage](#)) ends with a success story based on real measure developer experiences, and which incorporates key concepts covered throughout the toolkit.
- **Staff Trainings**: Three ready-to-use trainings to adequately prepare your staff for PFE, including *PFE Fundamentals; Process, Strategic Planning, and Recruitment; and Effective Meeting Facilitation* (for access, please contact your CMS COR).
- **Ready-to-use tools**: Printable versions of tools, templates, and handouts your teams can use to start engaging right now ([Section 10: Resources](#)).

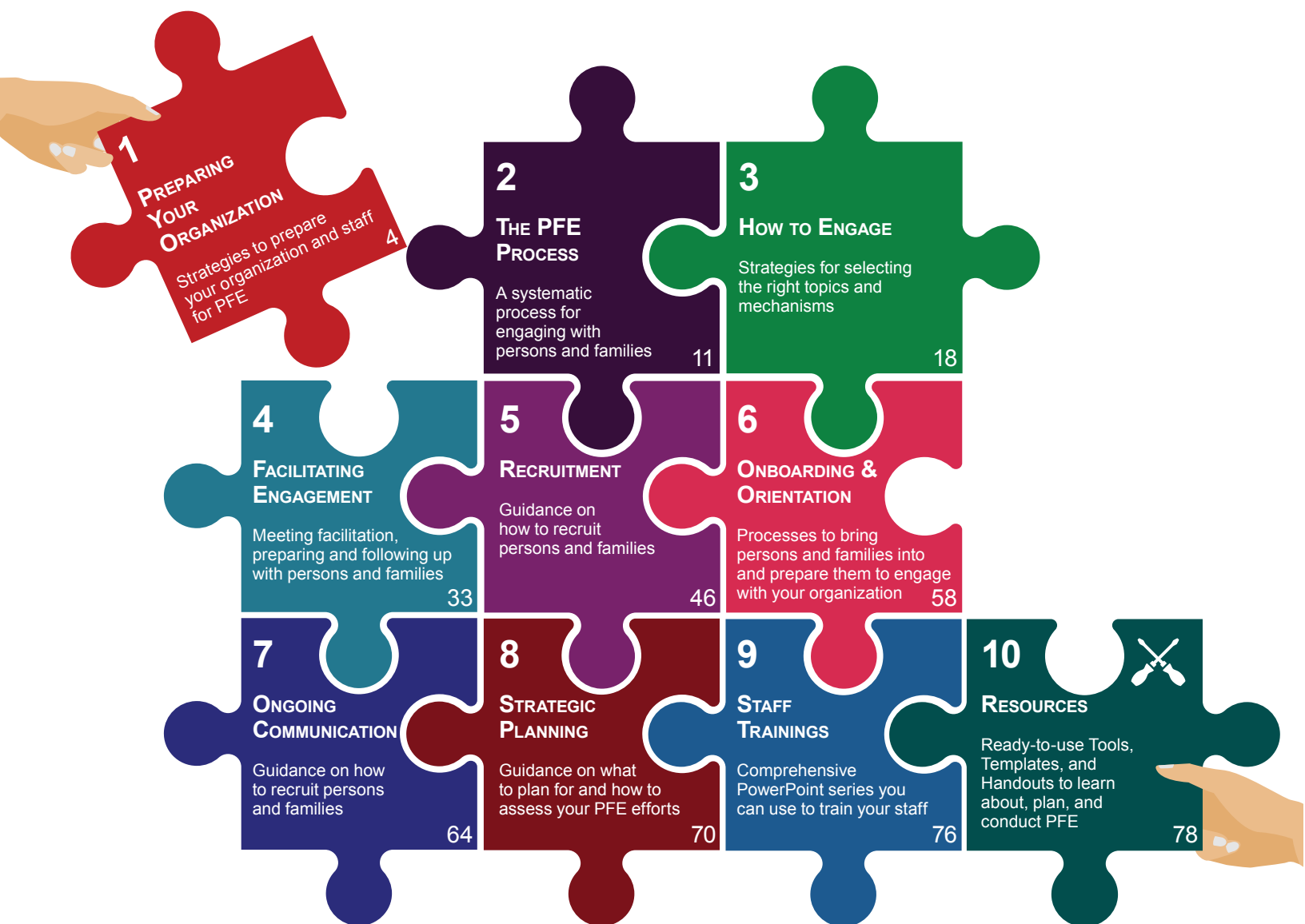
In addition, we provide a preview of each resource at the end of each section. We appreciate the time and effort you put into this important work. Good luck!

## CMS

*Revised by Rainmakers Strategic Solutions LLC under contract to CMS (Contract Number: 75FCMC18D0035, Task Order 75FCMC19F0001), an agency of the U.S. Department of Health and Human Services. The contents presented do not necessarily reflect CMS policy.*



# PFE Toolkit Contents





# Section 1: Preparing Your Organization

## SECTION 1. PREPARING YOUR ORGANIZATION

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

### Topics:

- Organizational Culture
- Budget
- CMS Requirements
- The Paperwork Reduction Act (PRA)
- Confidentiality, Conflict of Interest, and Privacy
- CMS PFE Strategy

### Resources:

At the end of each section, there is a preview of each resource. You can also click the links below to go to the printable versions in [Section 10: Resources](#).

- [Paperwork Reduction Act Decision Tree](#)
- [Personal Health Information and Privacy Agreement](#)



# Section 1: Preparing Your Organization

PFE Partners bring unique perspectives to measure development and implementation. These perspectives are essential to ensuring we deliver measures that are high priority and useful to the public. The input we receive is valuable and purposeful, and sometimes unexpected! It may impact how you approach the work, alter the path you are on, or result in a brand-new course of action. Adding new stakeholders to your work may also bring legal requirements unfamiliar to your organization. Managing unpredictability and tight timelines is challenging, so it is important to ***prepare your organization and staff to work in new and different ways, to expect the unexpected, and to be nimble measure developers***. Preparation is a key tenet of success, so take the time to review this section carefully.

“Give me six hours to chop down a tree and I will spend the first four sharpening the axe.”  
-Abraham Lincoln

## 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, the type of work your organization commits to, and integrating new stakeholders into your workflow.



Yes, bringing PFE Partners to the table may require cultural shifts within your organization! Meaningful engagement with PFE Partners using the systems described in this toolkit will impact your established processes and timelines significantly, require additional time and resources, and may even change the direction or outcome of your projects. This alone may catalyze cultural change within your organization.

Meaningful engagement requires a culture in which:

- The expertise, experiences, values, and perspectives of PFE Partners are central components in the measure development process

- PFE Partners are included and viewed as team members
- PFE Partner input is weighed equally to that of other experts

To successfully navigate integration of 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

Most importantly, successful PFE is only possible with *strong and consistent support from your organization's leadership* who will need to:

- Articulate a unified vision for PFE and link that vision to the organization's goals
- Reinforce the broad, positive impact PFE has on healthcare nationally
- Acknowledge the challenges and support organizational change

# Section 1: Preparing Your Organization

## BUDGET

The budget required to fully integrate PFE Partners into your measure development processes will vary depending on how your organization currently approaches the work. There are a number of factors to consider and plan for, described below.

**Staffing.** Meaningful PFE is relational work and can be time intensive, particularly at the outset when your entire organization has much to do and learn. For example, you will need to develop an organizational PFE strategy, which 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, and how you plan to measure success. You will also need to modify existing structures and processes to fully integrate PFE in measure development, and you will need to spend time developing relationships with PFE Partners. All of this requires effort, planning, development of new skills and expertise, and dedicated staff time. Determining a staffing plan 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 organizations. 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 do the work effectively.

**Training.** You will need to invest in training for your staff and teams to build the skills necessary to ensure effective PFE. For example, your staff may require training on effective meeting facilitation, health literacy considerations, and strategies for incorporating Plain Language into documents shared with PFE Partners. While some training can be done in-house (See the trainings included in [Section 9: Staff Trainings](#)),

much of it will likely require external knowledge and expertise and should therefore be considered in budget planning.

**Recruitment.** Identifying, recruiting, orienting, and onboarding PFE Partners to work collaboratively with your teams takes time, patience, and significant resources. These tasks also require specialized knowledge and experience. Additionally, most organizations don’t have established relationships with a network of advocacy groups to support expedited recruitment. As a result, some organizations may choose to subcontract with external groups that already possess the requisite skills and relationships, identify and draw from patient networks that have already been established by consumer advocacy organizations or other measure developers, or attempt to recruit PFE Partners on their own. Regardless of the approach, it is important to account for these costs in your budget.

**Expanded Timelines.** Incorporating new processes or stakeholders into existing workflow inevitably increases the amount of time and resources needed to complete those processes, particularly at the outset. Effective PFE requires planning to identify meaningful engagement opportunities, extensive coordination and scheduling with external parties, and preparation of tailored materials accessible for PFE

Partners. It is important to reset expectations across all levels of the organization that all measure development timelines will require some modification to accommodate the new PFE work.

**Honoraria.** It is important to acknowledge the time and contributions PFE Partners put into measure development processes with you. They are working with you as volunteers, and most also have full-time jobs, are with you as volunteers, and most also have full-time jobs, are caring for family members, or managing illnesses



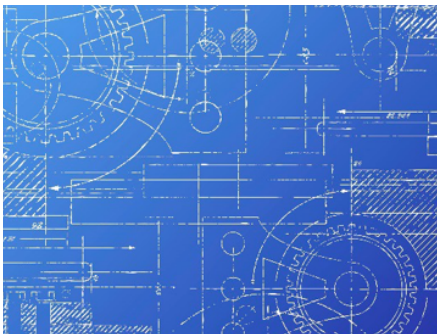
# Section 1: Preparing Your Organization

and chronic conditions themselves. Providing PFE Partners financial remuneration, no matter how large or small, is symbolic of your appreciation and acknowledgement of the time and energy they have contributed. The amount provided to PFE Partners depends on

several factors including the number of projects they work on, the number of meetings they attend, or the length of time they commit to you. It is most appropriate for your organization to establish a uniform amount for each PFE Partner for a similar set of work.

## CMS REQUIREMENTS

**MMS Blueprint.** As you likely already know, CMS developed the Measures Management System (MMS) as a standardized system for measure development and reevaluation. All measure developers are expected



to adhere to MMS processes and guidance. The [MMS Blueprint](#) serves as a developer's roadmap, describing best practices while detailing key steps and

contract deliverables required within each phase of measure development and providing templates and other resources. The MMS Blueprint is updated regularly to meet the evolving needs of measure developers. Version 15.0, released in September 2019, includes a new chapter in section 2 titled 'Tools and Resources

in Measure Development.' Section 3 was significantly updated to reflect current policy and changes in quality measures topics. Additionally, Version 16.0 will be released in 2020.

Be sure to review this section of the MMS Blueprint carefully to ensure your PFE plans align with the processes and requirements described. This may require integrating existing processes with new ones, adapting existing processes, or eliminating processes that do not work in an environment that prioritizes and values collaboration with PFE Partners. Once you determine how PFE may impact your timeline and deliverables production, you will need to acquire approval from your CMS COR for any modifications. Integrating existing processes with new ones, adapting existing processes, or eliminating processes that do not work in an environment that prioritizes and values collaboration with PFE Partners. Once you determine how PFE may impact your timeline and deliverables production, you will need to acquire approval from your CMS COR for any modifications.



## THE PAPERWORK REDUCTION ACT (PRA)

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 you to recruit, interact with, and solicit input from the public. **PRA applies to PFE!**

**When does PRA apply?** Whenever you contact the public to collect data or information if:

- Data/information collection is federally sponsored
- Data/information collection includes standardized questions

**Don't Worry!  
There's an exemption  
for measure  
development and  
reevaluation!**

- Ten or more respondents will participate

What counts as "federally sponsored"? Any work paid for with federal dollars! This includes work you do under contract with federal agencies such as CMS, Agency for Healthcare Research and Quality (AHRQ), and Food and Drug Administration (FDA). This is true whether you are a prime or subcontractor, a consultant, or a vendor. If you are reaching out to the public on behalf of and with funding provided by the federal government, even if the funding comes through another group or organization, it counts!


# Section 1: Preparing Your Organization

**What counts as data/information collection?** Any time you are asking more than one person the same set of questions, PRA applies. Common examples that may be subject to PRA requirements include:

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

**PRA exemption.** The Medicare Access and CHIP Reauthorization Act (MACRA) of 2015 provides PRA exemption for measure development and reevaluation. The exemption does not apply to implementation related activities such as Hospital Compare displays. To determine if PRA applies and whether you are eligible for the exemption, first review your PFE plans

and the Paperwork Reduction Act Decision Tree (see [Section 10: Tools and Templates](#)) with your Contracting Officer Representative (COR) and the Office of Strategic Operations and Regulatory Affairs (OSORA), as necessary, to categorize the work (development, implementation) and assess how PRA and the exemption may apply. Once you establish exemption eligibility, you or your COR may also need to consult with the Office of Management and Budget (OMB) to confirm your exemption. Once you receive approval to collect information from the public, you are free to start recruitment. ***This process takes time so plan ahead!***

Additional PRA FAQs can be found [here](#). 

## CONFIDENTIALITY, CONFLICT OF INTEREST, AND PRIVACY

It is important to establish expectations regarding confidentiality, conflict of interest, and personal health information (PHI) and privacy prior to launching your PFE work. Doing so protects both your organization's interests and the interests of the PFE Partners with whom you collaborate. For example, it is likely that during your collaboration with PFE Partners they will 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 your work, and they will likely want to share their stories with you. It is your job to make sure they feel comfortable and to protect their privacy. One way to do this is to create and walk through a Personal Health Information and Privacy Agreement that both you and the PFE Partner signs (template provided, see [Section 10: Tools and Templates](#)).

**!**  
**Some PFE Partners will be unaccustomed to completing these types of documents.**

**Plan to build in adequate time to explain the documents, why they are so important, and to help them.**

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

## CMS PFE STRATEGY

**CMS Person and Family Engagement Strategy.** In December 2016, CMS released its PFE Strategy. Designed for a wide variety of stakeholders, CMS developed this strategy to share the Agency's person and family engagement vision and encourage the entire healthcare community to consider and take action to incorporate the principles into their work practices.

The PFE Strategy was developed by the CMS intra-agency Person and Family Engagement Affinity Group with input from key stakeholders including patient advocacy groups, associations, providers, and caregivers and describes CMS's PFE values, foundational principles, and goals.

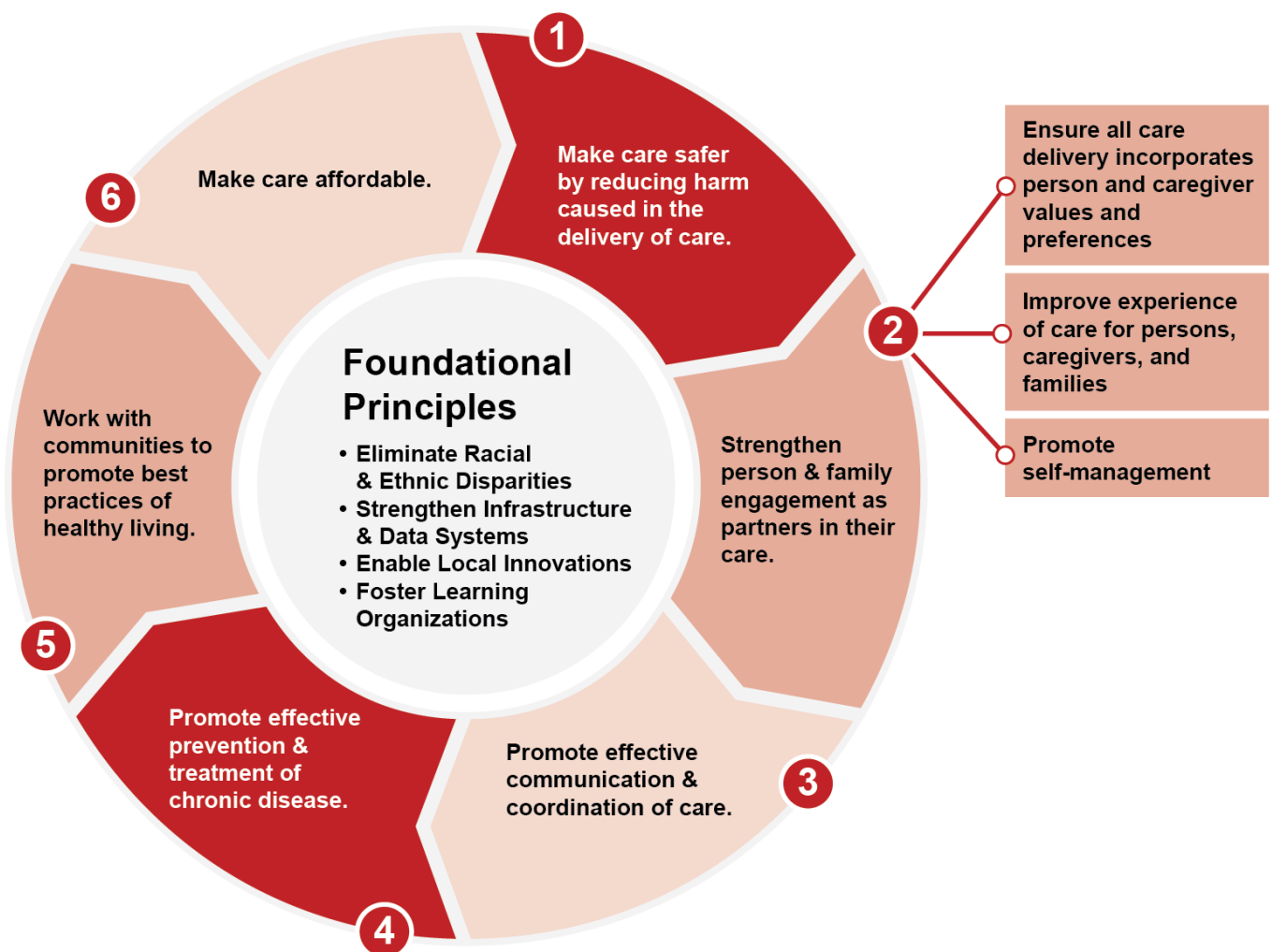


# Section 1: Preparing Your Organization

*"Person and family engagement goes beyond informed consent. It is about proactive communication and partnered decision-making between healthcare providers and patients, families, and caregivers. It is about building a care relationship that is based on trust and inclusion of individual values and beliefs."*

CMS PFE Strategy, 2016

The PFE Strategy directly aligns with one of the priority focus areas of the CMS Quality Strategy – **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, improving their experiences, and enabling them to actively engage in directing and self-managing their care. The Figure below shows the CMS Quality Strategy.



Take the time to familiarize yourself with CMS's PFE Strategy to ensure your PFE efforts are appropriately aligned.

# Preparing Your Organization



See the printable version of this resource in [Section 10](#).



See the printable version of this resource in [Section 10](#).

See the printable version of this resource in [Section 10](#).



## Section 2: The PFE Process

### SECTION 2: THE PFE PROCESS

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This section describes a systematic process for engaging with PFE Partners and how it will benefit your organization.

Topics:

- How It Will Help You
- The Phases

Resources:

- [PFE Process Summary](#)



## Section 2: The PFE Process

Whether or not PFE is new to your organization, one thing is certain – ***meaningful engagement will change how you do things and the outcome of your work.*** PFE Partners bring a unique type of expertise, one rooted in experience and often tied to emotion. While introducing any new stakeholder into a process may alter workflow and present unexpected challenges, bringing an impassioned group with a personal stake in the work requires deliberate, thoughtful consideration to process. It is natural to focus on the outcome of your work (the measure you're developing), but doing so may bias the choices you make along the way and limit the possibilities of the outcome (if you start a task knowing where you want to go, that's where you'll end up). So remember – ***good outcomes follow good processes!*** Taking the time to understand the underlying process of engagement will allow you to identify what you are doing well and what you need to change. ***A systematic, flexible process is critical to successful PFE and developing truly patient-centered measures.***


“When the outcome drives the process, we will only ever go where we've already been. If process drives the outcome we may not know where we're going, but we will know we want to be there.”  
-Bruce Mau, Designer

The process of measure development is complex and varies across organizations. Whatever your current process, incorporating PFE Partners will change how you do things and will ultimately impact the outcome of your work and the measures you develop. Meaningful PFE commands its own process – well-defined, logical steps that systematically guide your organization through the phases of engagement and yield quality measures designed with authentic person and family input. Ideally, the PFE Process will be incorporated into and become an integral part of your current measure development processes.

### HOW IT WILL HELP YOU

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.

**Prepared staff.** Establishing a systematic process will help orient your staff to PFE in a digestible way and provide them a road map to follow. This is particularly important for team members who may be new to PFE. Reviewing the PFE Process with your staff will also



### PFE Process

Logical step by step guide for measure developers to maneuver through planning, recruitment, and engagement with PFE partners to produce quality measures designed with authentic person and family input.

help prepare them for the changes to come while providing you the opportunity to reset expectations related to measure development workflow and timelines. It will also allow you to examine and plan for new challenges staff may experience.

**Shared vision.** You will need broad organizational support to ensure your PFE work is successful. This begins with a shared understanding of what PFE is and a commitment to the PFE Process. The PFE Process itself serves to anchor this shared vision across your

## Section 2: The PFE Process

organization, and when challenges arise or setbacks occur, you can always go back to it to assess goals and determine the appropriate path forward.

**Approachable framework.** A systematic process breaks down PFE 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 step-wise process allows you to establish and share accountability across team members. You can assign certain team members responsibility for specific phases of the process

(recruitment, prep calls with PFE Partners, etc.) which supports each team member's sense of ownership and accountability for the outcome of your PFE work.

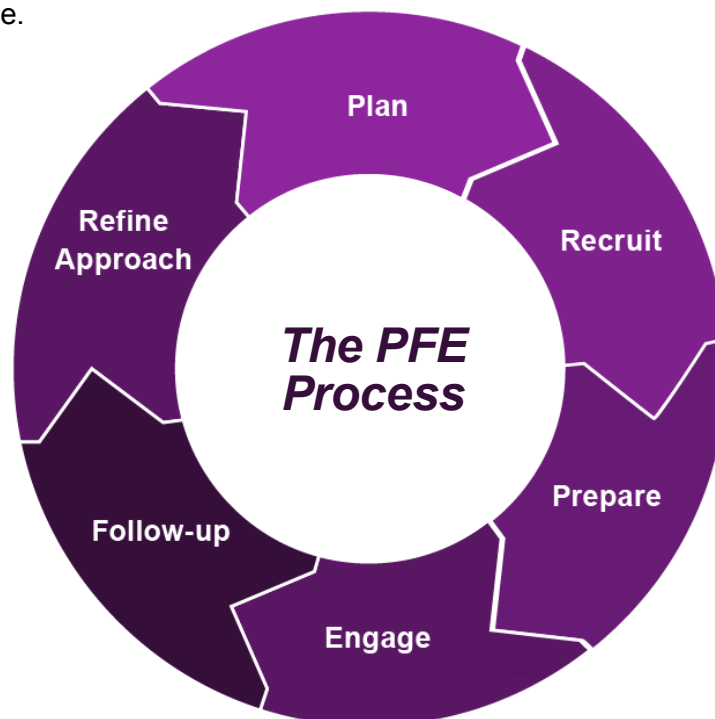
**Future organizational planning.** Using a systematic process inherently organizes all your PFE work into distinct components that you can track for staffing, evaluation, and budgeting purposes.



### THE PHASES

There are six critical phases in the PFE Process: plan, recruit, prepare, engage, 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 step-wise, the overall process must remain adaptable; this allows for modifications or improvements based on your teams' experiences moving through each phase.

A description of each phase is provided on the following page. Specific information and guidance for each phase is provided in the sections that follow. For more information, please also refer to the PFE Process Summary handout (see [Section 10: Resources](#)).



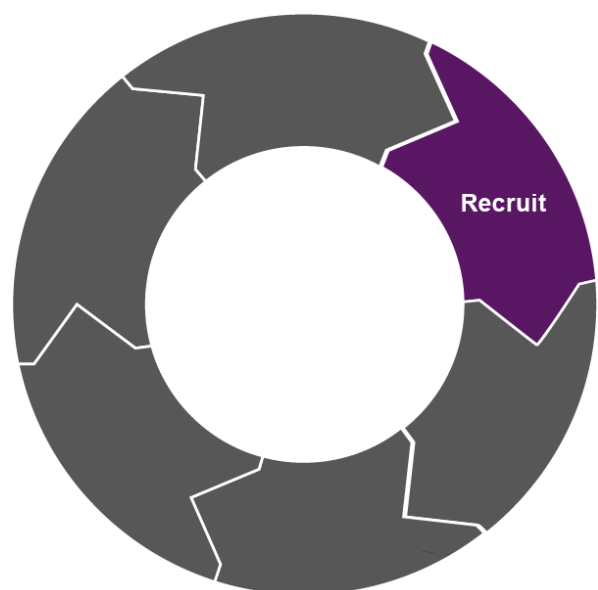
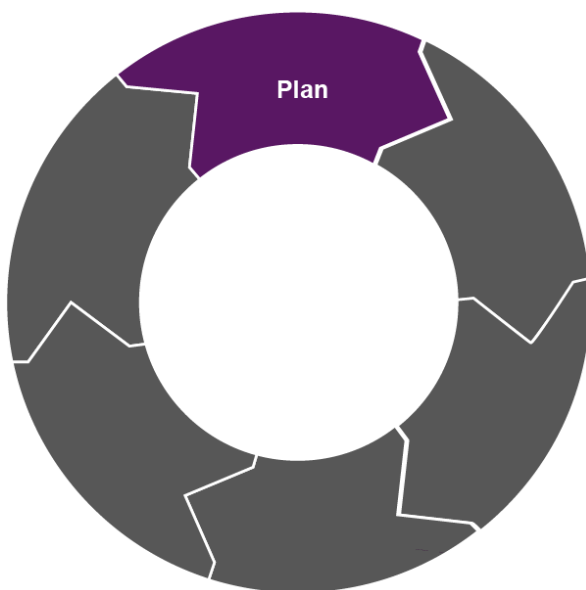
## Section 2: The PFE Process

### Strategic Planning ([Section 3: How to Engage](#) and [Section 8: Strategic Planning](#))

The most critical phase of the PFE Process is strategic planning- working with your teams to determine the why, what, how, who, and when of engagement. You will need to define the goals of the project and specific objectives for engaging PFE Partners in the work (the why). Once you understand why PFE is needed, you can then identify targeted components of measure development for which you would like PFE Partner input (the what). These pieces will all help you select the appropriate mechanism for engaging with PFE Partners (the how). What you are seeking input on will naturally dictate the specific characteristics of PFE Partners that will support the goals of your project and therefore who you will target during recruitment (the who). Lastly, contractual obligations and your overall project timeline will dictate when you can integrate PFE into your projects (the when). For example, are you looking for patients to join a Technical Expert Panel (TEP) for a specific measure, or do you need to find people who can weigh in on varied conceptual components? When adequate time and consideration is allocated to this phase, your teams will be set up to succeed. Also take time before moving to the next phase to allocate staff and resources and conduct staff training on PFE Fundamentals and Process, Strategic Planning, and Recruitment (see [Section 9: Staff Trainings](#)).

### Recruitment ([Section 5: Recruitment](#))

Once strategic planning is complete, you should 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, or patients with Type 2 Diabetes who have experience participating on multi-stakeholder meetings. These characteristics will guide you in identifying suitable recruitment strategies and appropriate organizations who will facilitate recruitment (for organizations planning to seek external recruitment support). Recruiting PFE Partners that are a good match for both the content area (for example, end of life care) and engagement mechanisms (surveys, patient only meetings, TEPs), poses unique challenges and can take quite a long time. Be sure to allot adequate time to this phase! It is recommended that you start at least 45 days in advance of your first activity, to allow for time in the event of a candidate drop-out and to provide time for onboarding and orientation. Additionally, to reduce the likelihood for candidate drop-outs, decisions on the inclusion of candidates should be communicated to potential candidates within ten days of their interview.



## Section 2: The PFE Process

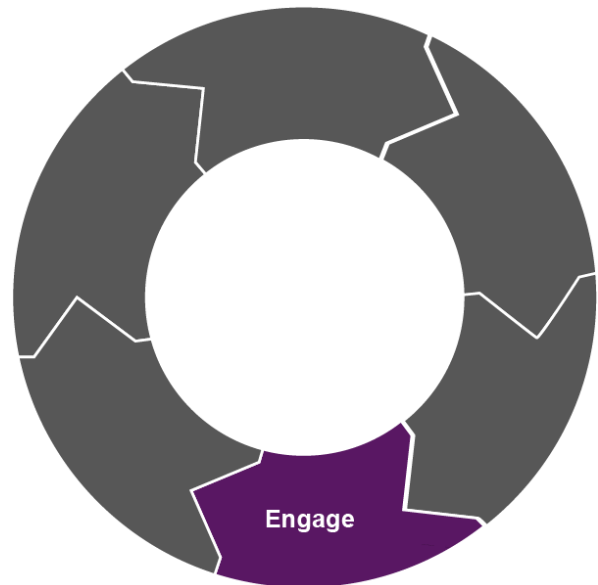
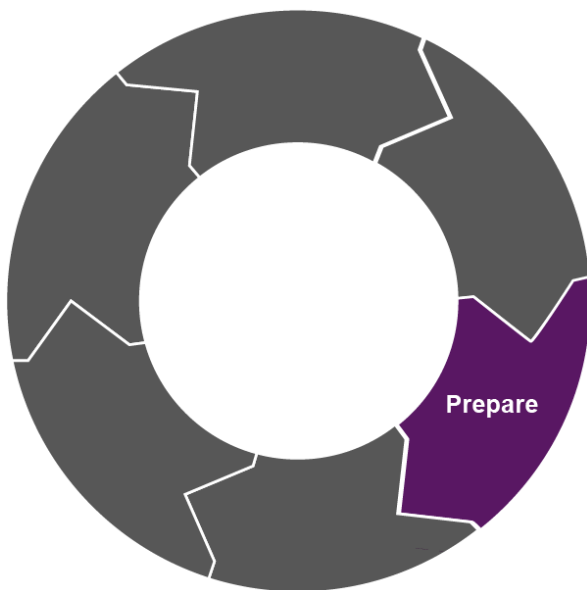
### Prepare PFE Partners and Staff ([Section 6: Onboarding and Orientation](#))

Preparation begins with the basic procedures of orientation and onboarding (see [Section 6: Onboarding and Orientation](#)). The orientation and onboarding processes should be executed in a timely fashion following recruitment efforts; for example, after interviewing potential candidates, decisions regarding the selection of candidates and invitations to join your project team 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, conflict of interest (COI), and privacy documentation. Your teams will also meet with PFE Partners to share your organization's vision for PFE and orient them to the work you are doing and how they will contribute. Once orientation and onboarding are complete, you will then prepare PFE Partners to engage on your specific project (see [Section 6: Onboarding and Orientation](#)). To adequately prepare PFE Partners, you will need to meet with them individually, ideally one to two days prior to the engagement activity. During

these prep calls, you will review the specific objectives of the engagement, discuss the types of questions they may be asked, set clear expectations, and answer any content-related questions. During these calls, you should also explain how the engagement will go and how feedback will be solicited. Most importantly, you need to reiterate during the prep calls that PFE Partners are experts and bring a critical expertise to measure development that you do not have. Prepare staff by providing training in Effective Meeting Facilitation (see [Section 9: Staff Trainings](#)).

### Engagement ([Section 4: Facilitating Engagement](#))

This phase includes planning, facilitating, and following up on the engagement activity itself (e.g., TEP, focus group, working group, interviews) and can 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 utilize best practices and be cognizant of opportunities for improvement in your processes.



## Section 2: The PFE Process

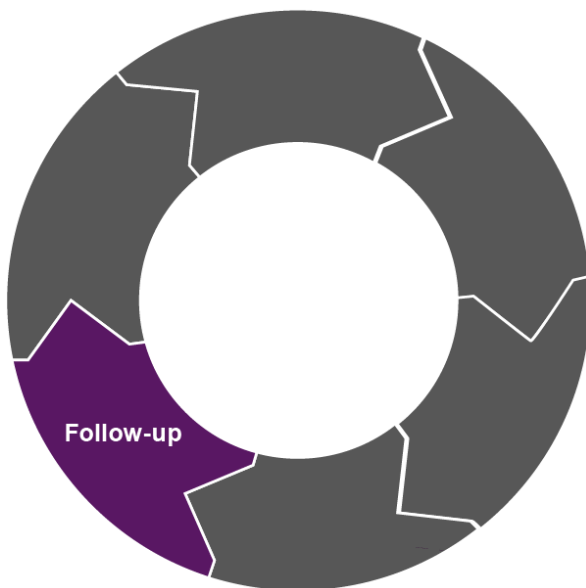
### Follow-Up with PFE Partners ([Section 7: Ongoing Communication](#))

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, you will seek to 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 during the activities or may have developed additional perspectives since the engagement occurred. The 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.

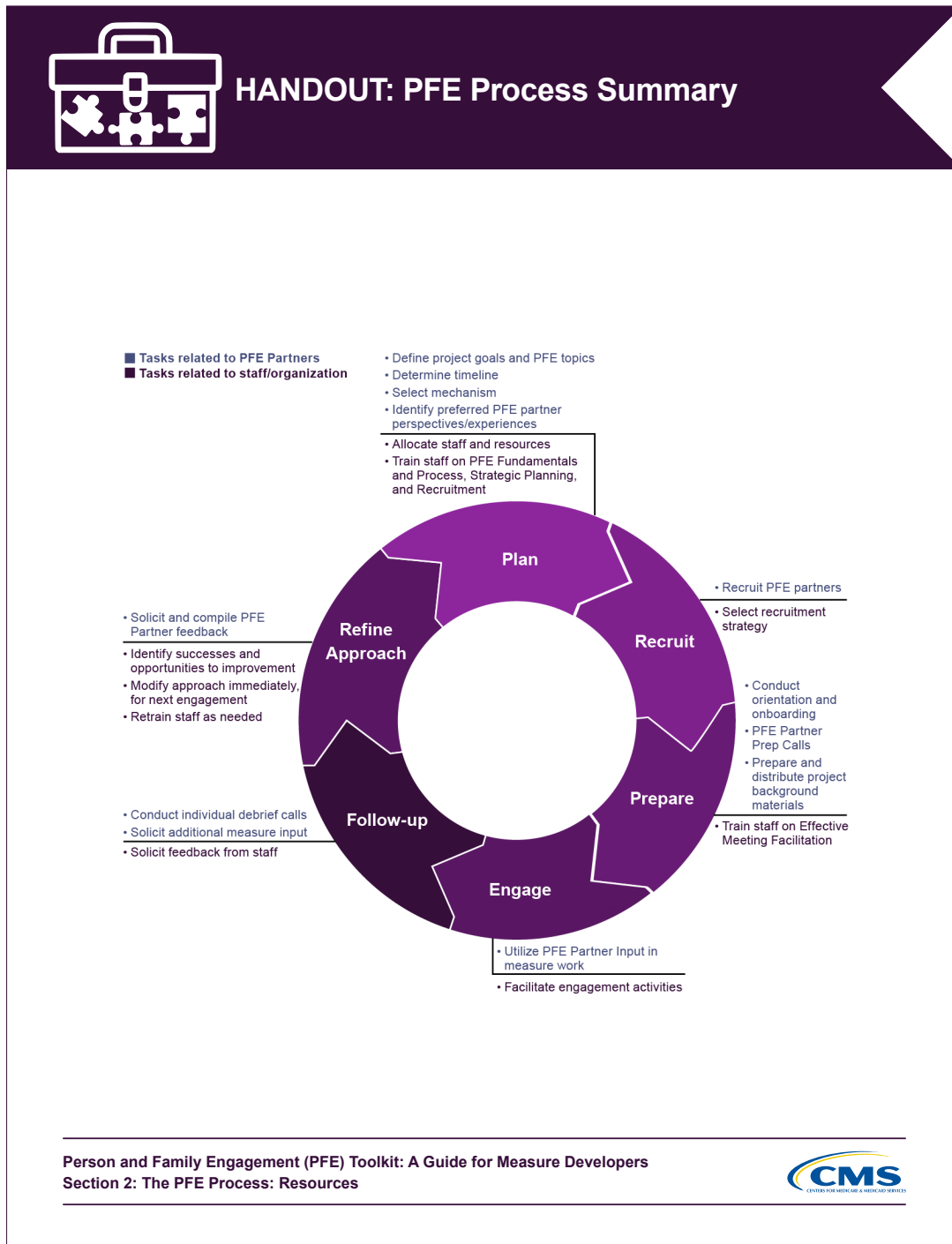
### Refine Approach

Consistently monitoring your approach to PFE and making improvements in real time helps ensure the PFE Partners have positive and meaningful experiences, the input you receive from them is authentic, and your engagements are rich, productive, and impactful. Some organizations may opt to design standardized metrics of success. These measures are used to solicit anonymous feedback from PFE Partners and help you understand where things are going well versus where improvements can be made. 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 you are maintaining high quality standards of practice organizationally.



## Section 2: The PFE Process



Locate the printable version of this resource in [Section 10](#).



## Section 3: How To Engage

### SECTION 3. HOW TO ENGAGE

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This section provides recommendations for selecting topics suitable for engagement, and mechanisms for engaging with PFE Partners on these topics. It also includes strategies and examples for handling highly technical topics.

#### Topics:

- Selecting the Right Topics for Each Meeting
- Selecting an Engagement Mechanism
- Matching PFE Partners to Engagement Mechanisms and Projects
- Strategies for Discussing Quality Measures with PFE Partners
- Success Story

#### Resources:

- [Engagement Topics and Decisions Summary](#)
- [Choosing Your Engagement Mechanism](#)



## Section 3: How To Engage

Measure development is complex and riddled with key decision points and unexpected setbacks. By design, it includes substantial and varied input from experts along the way. Like any other stakeholder you engage with during measure development, PFE Partners bring to the table requisite expertise that others you are working with do not have. **PFE Partners are experts!** They will use their unique perspectives to collaborate with your teams to set goals, prioritize activities, and make decisions (yes, even the technical ones!). With PFE Partners, you will **build high-quality, patient-centered measures** to advance truly patient-centered care!

“When people who attend experience that their presence is truly wanted and valuable, and that their unique gifts is necessary for the best outcome of the gathering, the possibility for authentic engagement, leading to success, is greatly enhanced.”  
-The Art of Convening, Craig and Patricia Neal with Cynthia Wold



### SELECTING THE RIGHT TOPICS FOR EACH MEETING

Deciding which specific topics or questions to bring to your PFE Partners for each engagement can be challenging. Your time with them may be limited or you may not know what will be most helpful to your project. You may also worry that you won't know how to present specific topics, particularly those that are highly technical. Selecting the right topics to engage in with PFE Partners is easier if you approach it systematically. For more details, see the Engagement Topics and Decisions Summary Tool (see [Section 10: Resources](#)).

#### Step 1: Go back to basics.

Remember that meaningful engagement means collaborating in ways that impact the measure you are working on – you are not “checking the box” so you can say you worked with persons and families. You are engaging with PFE Partners because they bring an expertise you don't have and will make your measure better. By the way, it's a good idea to also remind your PFE Partners of this regularly!

#### Step 2: Revisit your goals.

Sometimes we become so focused on what we are doing that we lose sight of why we are doing it. Go back to your Strategic Plan (see [Section 8: Strategic Planning](#)) and review your project goals and specific engagement objectives. Only include topics that will help you achieve these targets. Deprioritize other topics for now. You can always come back to them later.

#### Step 3: Use selection criteria.

Now you've successfully narrowed down the potential topics to those which not only help achieve project and PFE goals, but also capitalize on the expertise of your PFE Partners: What next?



Use the three criteria described below to target the right topics.

#### ENGAGEMENT TOPIC SELECTION CRITERIA

##### 1. Discussion is feasible

Do you have the information, data, or evidence required for 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?

##### 2. Feedback is actionable

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

##### 3. Topic is within scope

Does the work fall within your scope of work and CMS's expectations?

## Section 3: How To Engage

### SELECTING AN ENGAGEMENT MECHANISM

For more details, see the Choosing Your Engagement Mechanism Tool (see [Section 10: Resources](#)).

#### *Technical Expert Panel (TEP)*

A group of multi-stakeholder experts who participate in a set of meetings (typically conference calls) to weigh in on key measure decisions (often required by the MMS Blueprint).

Ideal number of PFE Partners: Three

- Integrating PFE Partners into existing measure development activities
- Multiple meetings
- Discussion-focused

#### *Measure Working Group*

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.

Ideal number of PFE Partners: Four to eight

- Early input
- PFE Partner-only
- Multiple meetings
- Discussion-focused

#### *Concept Advisory Group*

A group of PFE Partners who meet with measure developers to develop, refine, or prioritize conceptual frameworks or measure concepts for one or more measures.

Ideal number of PFE Partners: Four to eight

- Early input
- PFE Partner-only
- Multiple meetings
- Discussion-focused

#### *Communication Workshop*

PFE Partner-only meetings focused on acquiring “knee-jerk” reactions and specific edits to language, displays, or measure framing.

Ideal number of PFE Partners: Four to six

- Rapid input
- One or two meetings
- PFE Partner-only

#### *Interview*

A focused discussion with an individual PFE Partner or small group of PFE Partners.

Ideal number of PFE Partners: One to three per interview

- Specific input on a subject area of PFE

#### *Survey*

Online, email, paper, or phone survey to PFE Partners to elicit “real time” input or feedback on broad concepts, prioritize or rank options, or conduct a rapid vote on a key measure decision.

Ideal number of PFE Partners: Unlimited

- Rapid input
- Structured/quantitative feedback
- Early input
- Large number of PFE Partners

!

**These mechanisms are just a starting point. You are encouraged to be creative and to work with PFE Partners in ongoing 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.**

## Section 3: How To Engage

### Town Hall

A one-time conference call or webinar between the measure developer and a large group of PFE Partners to gain broad insight into a key measure decision.

Ideal number of PFE Partners: 10 to 25

- Large number of PFE Partners
- Rapid input
- Discussion-focused

### Public Opportunities

Include PFE Partners in public comment periods during new measure development or rulemaking to weigh in on aspects of measure development or on use of a measure in CMS programs. This can be a supplement to direct PFE on a measure project.

Ideal number of PFE Partners: Unlimited

- Integrating PFE Partners into existing measure development activities
- Large number of PFE Partners
- Ensure PFE throughout all phases of measure development

### Focus Groups

Are typically defined by facilitated discussions among a group of deliberately selected individuals to identify perceptions about a particular topic. These groups may be held in-person, online via webinar, or 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.

- Integrating PFE Partners into a targeted topic with specific input requests (e.g., priority rankings, experiences with a particular procedure)
- Average around 25 PFE Partners
- Flexible around time commitments (i.e., range from 1 hour to full day)
- Ensure PFE throughout all phases of measure development



**CASE STUDY:** Let's take a deeper dive into the "How" step of the Strategic Plan - selecting the engagement mechanism - using the diabetes measure discussed below.



- We're early in the development process: We have some ideas about the measure concept, but we're still deciding on the specific measure outcome.
- We're too early in the development process for a TEP, and we would prefer a mechanism that is focused on PFE Partners only to make sure we are hearing all their ideas and concerns.
- We're probably too late in the development process for a Concept Advisory Group, since we have a basic concept selected for our measure.
- To select the outcome, we'll need to describe the background of the project, share some options, and give the PFE Partners a chance to ask questions and provide feedback. Therefore, we'll want a mechanism that allows for discussion- a meeting as opposed to a survey.
- We might need to do some research into feasibility of the ideas the PFE Partners share during the first meeting and then come back to the group to discuss again, so we'll want a mechanism that includes multiple meetings.



**A Measure Working Group seems like the best mechanism for this stage of our project!**

## Section 3: How To Engage

### 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 to collaborate with you using that mechanism. Your goals should be 1) to ensure that PFE Partners have a positive experience with your organization and are able to make an impactful contribution to your work, and 2) your organization gets the support it needs to make high-quality, patient-centered measures. To create a good fit, you'll want to consider a PFE Partner's characteristics and role together with the type of mechanism and the individual project topics or content.

#### *PFE Partner Characteristics*

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. A PFE Partner with experience with multiple chronic conditions or frequent hospital stays, for instance, may be able to contribute to any number of measures even if they have not experienced the specific outcome you're measuring. Additionally, some PFE Partners have special causes on which they want to focus their engagement, and others may want to utilize their skills in Plain Language, graphic design, or public speaking.

Many PFE Partners have had a significant (possibly negative) healthcare experience or cared for someone who has, and you'll want to be sensitive to their experiences. Be sure these individuals have had enough time since their hospitalization, other medical event, or loss of a loved one prior to engaging. Also, be sure to ask if they are comfortable discussing sensitive topics such as end-of-life decision making, hospice care, or medical errors if those issues are relevant to your project.

Some potential PFE Partners have worked in healthcare in addition to their experience as a patient, family caregiver, or advocate. These professional backgrounds may affect their experience navigating the healthcare system or their perceptions of their care because they possess a greater understanding of their condition or procedure, as well as their healthcare provider policies and practices. You may choose to limit your recruitment of these individuals or be selective about which projects they join.

#### *PFE Partner Roles*

While you should always consider an individual as opposed to only a category or role, certain roles tend to be better matches for certain engagement mechanisms. For example, mechanisms that involve multi-stakeholder dynamics such as TEPs can sometimes be intimidating for patients or family caregivers inexperienced in these settings, making advocates a better fit. Alternatively, advocates 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](#).

## Section 3: How To Engage

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

PFE Partner Roles	Mechanism Fit	Additional Considerations
<b>Patient</b>  Individuals who interact with the healthcare system on a regular basis and who are living with or managing one or more health conditions	<b>Best Fit:</b> Group, Concept Advisory Group, Communication Workshop, Survey, Interview, Town Hall  <b>Conditional Fit:</b> TEP  Based on specific PFE Partner characteristics: <ul style="list-style-type: none"> <li>• Multi-stakeholder experience</li> <li>• Outgoing</li> <li>• Not intimidated</li> </ul>	End-of-life conditions, adequate time since medical events, healthcare-related employment
<b>Family Caregiver</b>  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		End-of-life conditions, adequate time since medical events, age and relationship of person cared for, healthcare-related employment
<b>Consumer</b>  Individuals who have experience with the healthcare system but may not be currently living with or managing a health condition		Healthcare-related employment
<b>Advocate</b>  Individuals who work at nonprofit, mission-oriented organizations that represent a specific constituency of consumers or patients	<b>Best Fit:</b> TEP, Measure Working Group, Concept Advisory Group, Communication Workshop, Town Hall  <b>Conditional Fit:</b> Survey, Interview	Perspectives of constituent group versus personal experience

## Section 3: How To Engage

### STRATEGIES FOR DISCUSSING QUALITY MEASURES WITH PFE PARTNERS

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

The approach you use will depend on many factors, such as the PFE Partners themselves and your engagement mechanism, as described above, as well as the topic, question, or decision you discuss. For more sample topics, see the Engagement Topics and Decisions Summary Tool (see [Section 10: Resources](#)).

We recommend three broad strategies you can use to plan for highly technical discussions: generating ideas, weighing options, and 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 looking for. Following the overview of the strategies, we'll describe several success stories to provide examples of how you can implement and tailor these techniques for various technical measurement topics.

Enhance all strategies with these best facilitation practices:

- Introduce new vocabulary prior to technical discussions.
- Portray contrasting options or new concepts using concrete examples.
- Honor PFE Partners' diverse learning styles and preferences while maximizing overall comprehension using visual aids.



## Section 3: How To Engage

### 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. You realize you need more PFE Partner input to define the outcome. You decide to use the Generating Ideas strategy with a Concept Advisory Group of six patients and family caregivers to determine the specific outcome you should measure. In your first meeting, 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're considering measuring, typical patients, and what their care looks like.

#### A Typical Surgical Patient:

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

You then 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.

#### Existing Outcome Measures for Surgical Procedures

- Readmission rates
- Mortality rates
- Complication rates
- What other outcomes could we measure?

### Sample Questions

- We are considering developing a measure that looks at X outcome for Y population. How might you use a measure like this? Is there a different type of measure you would be more likely to use?
- How might special populations [provide examples] use this measure?
- Do the measure exclusions affect the usefulness of the measure? How?
- How is the way we've described this healthcare event/treatment/ situation similar or different from what you have experienced?
- What do you think are the most important aspects of care related to this condition/procedure/ process/treatment?
- How do you decide which aspects of your care are most important to you? Do you decide based on your overall experience, if you felt well-cared for, your health outcome, the success of your treatment, or something else?
- Within the scope of X type of condition (for example, digestive disease), which specific conditions (for example, Crohn's disease, acid reflux, etc.) are of most importance to you?
- Within the scope of X type of procedure (for example, orthopedic surgery), which specific procedures (for example, hip replacement, spinal surgery) are of most importance to you?
- What do concepts like "improvement" or "recovery" mean to you following a procedure or treatment?



## Section 3: How To Engage

You then ask a series of open-ended questions about the most important outcomes for patients having the procedure.

- What would tell us that something negative happened to the patient or that they received poor quality care?
- What would tell us that something positive happened to the patient or that 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?

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

You decide to conduct further research on the options recommended by PFE Partners to assess the feasibility of effectively measuring those outcomes.

### 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 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?

## Section 3: How To Engage

### Strategy 2: Weighing Options

**Definition:** PFE Partners 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're still defining the scope of the measure and later, such as when you're developing and testing measure specifications. Before meeting with PFE Partners or conducting a survey, you would typically 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. 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 there are pros and cons to both approaches. You have begun collaborating with a Measure Working Group of seven PFE Partners 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.

### 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 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?

#### OPTION A

#### Exclude Hospice Patients

Patient A was diagnosed with terminal cancer and enrolls in hospice care. The patient is admitted to the hospital and is experiencing multiple organ failure. The patient develops a painful pressure injury. The ulcer may have occurred due to breakdown of the skin related to the multiple organ failure, because the care team did not adhere to the care protocol for prevention of pressure injuries, or both. If the care team did not provide appropriate care, you have missed the opportunity to measure this quality signal because you opted to exclude hospice patients from the measure.

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### OPTION B

#### Include Hospice Patients

Patient B was diagnosed with terminal cancer and enrolls in hospice care. The patient is admitted to the hospital and is experiencing multiple organ failure. The care team reviews the patient's care goals with their family and determines that to maximize the patient's comfort, they will limit turning of the patient (a key part of the standard pressure injury prevention care protocol.) The patient develops a painful pressure injury. Because you opted to include hospice patients in the measure, the pressure injury of this patient is counted in that hospital's score. Do you think the hospital should be measured based on this patient's pressure injury? Is the development of the pressure injury a signal of the quality of care provided to the patient?

You then share other information on pros and cons of the inclusion or exclusion of hospice patients for their consideration.

#### A measure that includes hospice patients:

- More inclusive measure - can measure quality of care for hospice patients
- Cohort 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

### 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 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?

## Section 3: How To Engage

### Strategy 3: Evaluating Preliminary Results or Displays

**Definition:** PFE Partners react to open-ended or closed-ended questions about preliminary results, outputs, or displays. Results may include testing results or provider performance or measure scores. Language and displays may include sample descriptions of the measure specifications or 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. Ask questions about how PFE Partners may use the results and if they can understand them. Ask if language and displays highlight the information most important to them.

#### Example:

Your team recently completed specifications on a surgical readmission outcome measure. The measure 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 that this novel approach provides more detailed quality information to hospitals and to patients, and you try to determine the best way to display the results. You convene a concept advisory group 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.

### 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 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?

## Section 3: How To Engage

**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 three separate 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 that 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.

### 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 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?

## Section 3: How To Engage

### SUCCESS STORY

**Your Objective:** Build conceptual frameworks


**Engagement Strategy:** Generating Ideas

**Mechanism:** Concept Advisory Group




Your team is interested in developing quality measures addressing shared decision-making. You are attempting to develop a conceptual framework for how shared decision-making is conducted in various settings. You want to be sure any future measures in this area are meaningful to patients. You ask for a PFE Partner to help define shared decision-making and develop a conceptual framework for how decisions regarding diagnosis and treatment can be made among individuals on the healthcare team. In this early stage of development, you decide to convene an Concept Advisory Group 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 shared decision-making. You walk through topics such as who to include in decision-making, how to include them, and when to include them in various situations such as emergency settings, acute conditions, and managing chronic conditions. The result is a comprehensive conceptual framework co-designed with PFE Partners that represents PFE Partners' highest priority areas for shared decision-making and numerous areas for future research and measure development work.

# Section 3: How To Engage



**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 e-measures or patient-reported outcome measures; individual condition/procedure measures versus facility-wide measures, 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	If the measure topic (condition, procedure, etc.) has already been selected, determine what outcome you will measure such as readmission rates, complications, or length of stay in the hospital.
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 feasibility of using new data sources; recommend further analysis of different analytic approaches.
Create or improve measure reporting displays	Measure reporting displays 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	Measure descriptive language 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.

Person and Family Engagement (PFE) Toolkit: A Guide for Measure Developers  
 Section 3: How To Engage: Resources




Locate the printable version of this resource in [Section 10](#).


**TOOL: Choosing Your Engagement Mechanism**

	Technical Expert Panel (TEP)	Measure Working Group	Concept Advisory Group	Communication Workshop	Individual Interview	Survey	Town Hall	Public Opportunities
Multiple meetings	✓	✓	✓					
1-2 meetings				✓	✓			
Discussion-focused	✓	✓	✓		✓		✓	
Early input		✓	✓			✓	✓	
PFE Partner-only		✓	✓	✓	✓		✓	
Rapid input				✓	✓	✓	✓	
Individual input on a specific subject area of PFE Partner expertise					✓			
Structured/quantitative feedback				✓		✓		
Large number of PFE Partners						✓	✓	✓
Integrating PFE Partners into existing measure development activities	✓							✓
Engage PFE throughout all phases of measure development	✓	✓	✓	✓	✓	✓	✓	✓

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# Section 4: Facilitating Engagement

## SECTION 4. FACILITATING ENGAGEMENT

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

### Topics:

- Scheduling Meetings with PFE Partners
- Preparing PFE Partners
- Meeting Facilitation
- Meeting Facilitation Troubleshooting
- Following-up with PFE Partners
- Success Story

### Resources:

- [Steps Leading Up to Your Engagement](#)
- [Drafting Meeting Materials](#)
- [Meeting Facilitation Troubleshooting](#)
- [Effective Meeting Facilitation](#)
- [Script for Meeting Introduction and Wrap Up](#)

## Section 4: Facilitating Engagement

Meeting with PFE Partners is often the most exciting and rewarding part of the engagement process. You will form personal connections, make key decisions, and build patient-centered measures- together. The materials you use before and during your meetings can teach PFE Partners critical background information and effectively guide discussions and decision-making- if you take the time to design them with your PFE Partners in mind. Focus on highlighting essential content, use an appropriate level of detail, and choose simple, straight-forward language with plenty of examples and visuals to enhance understanding. Practice the four key elements of effective meeting facilitation: open communication, adequate preparation, customized meeting management, and real-time refinements to ensure your meetings are productive and positive experiences for you and your PFE Partners.



*The facilitator's job is to support everyone to do their best thinking. To do this, the facilitator encourages full participation, promotes mutual understanding, and cultivates shared responsibility.”*  
- Facilitator's Guide to Participatory Decision-Making by Sam Kaner, et al

### SCHEDULING MEETINGS WITH PFE PARTNERS

Most PFE Partners have a variety of important obligations such as full-time or part-time work, caregiving responsibilities, or managing an illness. Busy schedules and competing priorities may make meeting and scheduling difficult, but you can employ

many strategies to ensure it goes as smoothly as possible, for both your organization and the PFE Partners. For more details, see the Steps Leading Up to Your Engagement tool (See [Section 10: Resources](#)).

#### Planning:

- Begin scheduling one month prior to your goal 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 work day (example, meeting start time of 5 PM)

#### Share Meeting Times with PFE Partners:

- Use a poll for easy tracking
- Allow PFE Partners at least 1 week to respond
- Follow up if you do not hear

#### 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
- If no meeting time works well, repeat this process

## Section 4: Facilitating Engagement

### Tips and Tricks

**Meeting Duration.** The duration of each meeting should not exceed 90 minutes. However, keeping the discussion to 1 hour is preferable. Longer meetings can be fatiguing. If you have a full agenda, consider hosting numerous meetings to ensure participants remain energized during the discussion while still getting to all your content.

- **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 National Quality Forum (NQF) 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 meeting see [Section 7: Ongoing Communication](#).
- **In-Person Meetings.** Avoid holding an in-person meeting with only some PFE Partners while others must participate via phone or webinar. Keep the meeting format consistent for all participants to avoid any imbalance in perspectives.

- **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 should attendance be low.
- **Technology.** Some PFE Partners may be unfamiliar with online tools that will help you facilitate scheduling. Plan to offer customized support, as needed.
- **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'll 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.

## Section 4: Facilitating Engagement

### PREPARING PFE PARTNERS

Thoroughly preparing PFE Partners to engage with your teams is critical to ensuring effective engagement. They 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 two main components: backgrounders and prep calls.

**Backgrounders.** Prior to engaging PFE Partners on a project that is new to them, you should prepare background materials that will help them understand the subject matter and the goals of the project. It is good 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.

Make sure your background materials are succinct and incorporate [plain language standards](#).

It is important to avoid jargon, acronyms, and technical terms while your PFE Partners are learning the project background. Once incorporated into the workflow a bit more, PFE Partners will become familiar with the language you use. If you must use jargon, acronyms, or technical terms in the background materials, be sure to define them.

- Vet materials before distributing them to PFE Partners to ensure they are accessible from a health literacy perspective (for example, 6th or 7th grade reading level).
- Distribute background documents approximately two weeks prior to kicking off your collaboration with PFE Partners so that they 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 (described below).

**Preparatory 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. This is best applied to TEPs, Measure Working Groups, and other ongoing, small group engagement activities. Why take the time to conduct prep calls for PFE Partners?

- Helps PFE Partners feel prepared to fully and meaningfully 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.
- Demonstrates that their partnership matters to you and continues building relationships.
- Helps your team effectively run your upcoming engagement activity by explaining confusing 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 terms they do not understand
- How their experience or perspective ties into the content and how they can contribute.
- If there is anything they would like the project team to know or address prior to or during the engagement.

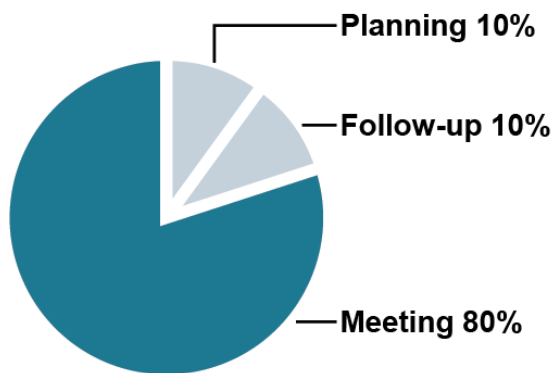
If you do not have the resources to conduct individual phone calls with each PFE Partner prior to each engagement, consider holding group prep calls with multiple PFE Partners. Some PFE Partners may decline to have prep calls with you before each engagement, especially if the group has met several times already. Continue to offer prep calls each time, but let PFE Partners know it is perfectly acceptable for them to choose not to participate.

## Section 4: Facilitating Engagement

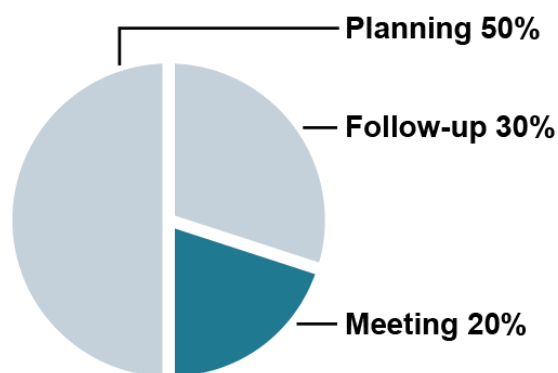
### MEETING FACILITATION

Successfully facilitating meetings with PFE Partners is critical to achieving your PFE goals. The good news is that meeting facilitation is a skill that can be honed with preparation and practice. 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



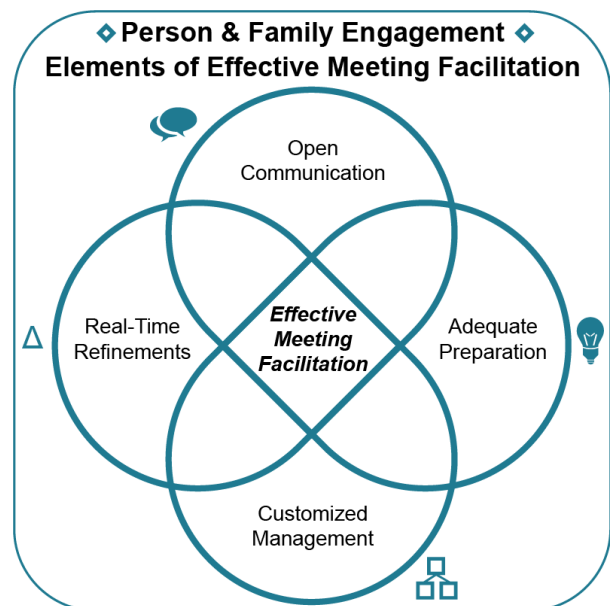
#### PFE Meeting Model



Effective facilitation is uniquely important for meetings with persons and families because many 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
- May not have experience interacting with measure developers

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



## Section 4: Facilitating Engagement

### Element 1. Open Communication

Open communication supports mutual understanding and respect, and fosters true partnership.

Remember, you are building a new team, a new partnership. PFE Partners want to be part of your team! So, treat them as team members when communicating with them. Openness is **bi-directional**. It includes sharing and learning from each other, being open to new ideas, and being courteous and respectful. Communication should be **ongoing** (See [Section 7: Ongoing Communication](#)). **Honesty** is a key component of open communication. Honesty is about defining the boundaries of your project, sharing what you are uncertain about, and explaining why you are making certain decisions, all in a way where PFE Partners still feel comfortable openly sharing their ideas. Finally, communication can be **casual and technical**. To build a partnership and get valuable input, it is on you to take the time to teach PFE Partners what you know. Avoid excessive technical jargon in the beginning, while they are still learning. Instead, teach them the technical terms that will be used so that they can start to grasp the big picture concepts. Start casually with the big picture, and once PFE Partners grasp those concepts, you can drill down into the details of the technical content that you are eager to discuss. Soon you will get to a point where you can communicate technically but still continuously teach and reinforce their understanding of technical terms and concepts. Be sure to routinely communicate with PFE partners in-between meetings to keep the lines of communication open. It is recommended that 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.

Think critically about all **logistics**: when and how to schedule meetings, ensuring you have a meeting space with the technology you need, reserving your meeting space for some time before the call to allow time for setup and after the call for debriefing with your internal project team, and strategizing an approach to obtain feedback from any PFE Partners who are unable to join the meeting. **Tailor** the contents of meeting materials.

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- Prepare all meeting materials using Plain Language based on health literacy guidelines. This includes everything from background handouts to the agenda and slides. CMS's Toolkit for Making Written Material Clear and Effective is a health literacy resource with guidance on how to make written material in printed formats easier for people to read, understand, and use.
- The objectives and discussion items for the meeting should be clearly written on the agenda along with a list of participants and the dial-in and/or webinar information. Be prepared to fix any audio or webinar technology issues that may arise during the meeting and make a backup plan in case a technology issue disrupts the meeting.

Define technical terms. Keep materials short and easy to follow. Avoid repeating content that the PFE Partners have already received. **Distribute** materials early to give PFE Partners time to review. For more details, see the Drafting Meeting Materials tool (see [Section 10: Resources](#)). The standard is one week prior to the meeting. This is one of PFE Partners' most commonly requested actions. 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 within 7-14 days before the first scheduled activity to allow adequate time for candidates to review, ask questions, and complete tasks. Finally, get to **know** your team. Getting to know your PFE partners will help you develop a working relationship. It makes them more comfortable discussing personal experiences. It also helps you, as a facilitator, to better understand the context of their input. You can learn more about them by reading the biographies or resumes they provide, asking them questions, and sending them your team's biographies with headshots. Refer to the Sample "Getting to Know You" Questions and Biographies Tool (see [Section 10: Resources](#)).



## Section 4: Facilitating Engagement

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Whether you are communicating casually 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. There are many ways to facilitate a meeting, and it is important to **select** a format before the meeting.

Recommended formats include, but are not limited to, **Round Robin** (the facilitator calls on participants one at a time for a response), **Modified Round Robin** (a Round Robin that leads into an open group discussion or an open group discussion that ends with a Round Robin), or **Question-Driven** (participants provide input on specific topics, respond, and discuss 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.** There are times when you 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. 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 is expected from PFE Partners and what they 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 Guide (see [Section 10: Resources](#)).

Finally, it is important to **start and end** your meetings well. 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. Do not underestimate the importance of PFE Partner introductions. They need to have the opportunity to share their story and explain why they are interested in your work. It helps establish them as experts to the rest of the group, it allows them to be heard, and it gets them to open up, which makes the discussion that follows easier, 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.

Presentation format is not recommended!



## Section 4: Facilitating Engagement

### Element 4. Real-Time Refinements

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

The key word is **ongoing**. You want to ensure the PFE Partners have a good experience and continue working with you. To **modify** your approach to facilitating productive meetings, use feedback that you gather 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. Reassess your approach after each meeting. How did the meeting go? What could have gone better? What can you change? Doing this not only ensures ongoing success, but demonstrates to your PFE Partners that you value them and their time.

More information about effective meeting facilitation can be found in the Effective Meeting Facilitation Handout (see [Section 10: Resources](#)) and the Effective Meeting Facilitation Training in [Section 9: Staff Trainings](#). In addition, review the Script for Meeting Introduction and Wrap Up Template (see [Section 10: Resources](#)).

## Section 4: Facilitating Engagement

### MEETING FACILITATION TROUBLESHOOTING

Even with effective meeting facilitation, challenges arise. Below are four common challenges and helpful techniques to address them. Refer to the Meeting Facilitation Troubleshooting Guide Handout for an overview of these techniques (see [Section 10: Resources](#)).

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

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

**Scenario 2:** Sometimes a PFE Partner won't 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 perspectives.
- If you identify a PFE Partner who contributes substantially less than others:
  - 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 that they have time to prepare a response ahead of time.
  - Consider using a “Round Robin” meeting format to ensure that everyone has an opportunity to speak.

- Reinforce the PFE Partners' value to the project. This can be done through email or a one-on-one call outside of group meetings. Ensuring they feel their perspectives are important can instill confidence and encourage more active participation.

**Scenario 3:** Sometimes a PFE Partner will dominate 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 their 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 that everyone has an opportunity to speak.
- Set time limits (for example, two minutes) for responses at the start of the meeting or immediately before asking each question.

**Scenario 4:** PFE Partners disagree with one another.

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

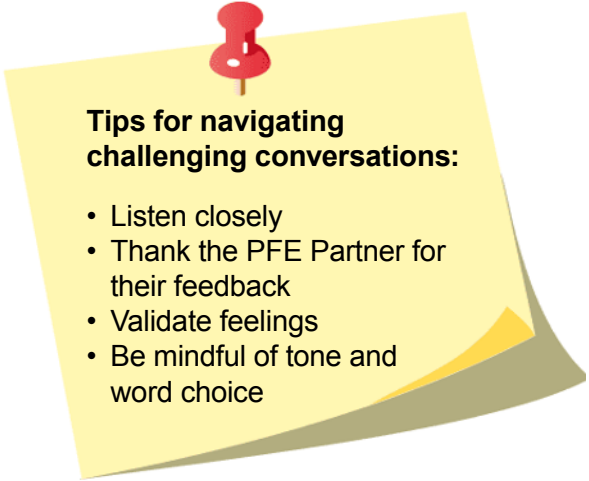
## Section 4: Facilitating Engagement

### 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. The “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 that they may not feel comfortable sharing with the engagement facilitator directly.

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

- Use PFE Partner input to continue doing things that positively impacted PFE Partners' experiences
- Use PFE Partner input to improve areas that negatively impacted their experiences
- Answer lingering questions or address concerns in real time
- Demonstrate that their partnership matters to you, and continue building relationships
- Obtain additional measure or project input
- Troubleshoot meeting facilitation challenges together



#### Tips for navigating challenging conversations:

- Listen closely
- Thank the PFE Partner for their feedback
- Validate feelings
- Be mindful of tone and word choice

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?



#### Debrief Call Logistics

- Thank them 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 template for each call
- Take notes to share questions or concerns with your project team
- Be an active listener, pay close attention, avoid interrupting
- Rephrase and ask questions

Ask PFE Partners open-ended questions such as:

- 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 (e.g., Google Forms, SurveyMonkey), or even using a brief survey for some meetings, and phone calls for others. 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 Partner experiences and offer to support them in their engagement with you.

## Section 4: Facilitating Engagement

### SUCCESS STORY

**Your Objective:** Select data source for a new measure

**Engagement Strategy:** Weighing Options

**Mechanism:** Concept Advisory Group



Your team is planning to develop a new outcome measure. You are considering two options - whether to develop a measure using Medicare claims data or one based on electronic health records, an electronic clinical quality measure (eCQM). You decide to convene a Concept Advisory Group because this mechanism type is often best suited for this early, conceptual decision-making phase. In two meetings, you share a list of pros and cons for each measure type, such as how quickly the measure can be developed, what burden will be placed on providers in collecting and reporting their data. You also describe how and when CMS could use the measure, how current the results and data distributed to providers will be, and the level of detail of clinical information obtainable from a claims-based measure compared to data from an eCQM. 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 ideal measure type for this new measure. You feel confident that 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 4: Facilitating Engagement

**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?

- ☐ **Welcome your newly recruited PFE Partners as soon as recruitment is complete**
  - Send a friendly welcome email, this will set the tone for your communications with your PFE Partners!
  - Make sure PFE Partners know the overall engagement plan: what to expect before, during, and after an engagement
- ☐ **Prepare and share background on your project**
  - Keep the background short (1-5 pages) but include relevant information PFE Partners will need to know
  - Send the background at least 1 week prior to the first engagement, but more time is better
- ☐ **Schedule your engagement**
  - Get scheduling started as soon as possible
  - Schedule at least 3 weeks in advance
  - Offer multiple options, on different days, and at varying times (including evenings)
- ☐ **Prepare and share your meeting materials (duration: ~2 weeks)**
  - Share materials at least 1 week in advance of the engagement, 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
- ☐ **Remind PFE Partners of their engagement**
  - Send an email with link-in information and materials the day of the meeting for easy access
- ☐ **Host the engagement!**

Month, Year	
1	2
3	4
5	6
7	8
9	10
11	12
13	14
15	16
17	18
19	20
21	22
23	24
25	26
27	28
29	30
31	

Person and Family Engagement (PFE) Toolkit: A Guide for Measure Developers  
Section 4: Facilitating Engagement: Resources

Locate the printable version of this resource in [Section 10](#).

**TOOL: Drafting Meeting Materials**

**SUGGESTIONS FOR DRAFTING MEETING MATERIALS**

- Team Introductions
- Introduce Topic and Ask Questions
- Review and Recap Overall Engagement Timeline
- Review Next Steps
- Include Glossary of Key Terms

**Key Considerations when drafting materials**

- How much background information do PFE Partners need in order 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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**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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# Section 4: Facilitating Engagement

**HANDOUT: Effective Meeting Facilitation**

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**Person & Family Engagement (PFE) Tips for Effective Meeting Facilitation**

**BEFORE THE MEETING**

- Distribute tailored materials at least 1 week in advance
- Prepare PFE Partners - provide clear assignments to be completed before meetings
- Take the time to teach the basics - not everyone says "cohort"
- Know your team - read their bios, know their story, no assumptions
- Select a meeting format that drives discussion
- Develop Mitigation plan for common meeting challenges

**DURING THE MEETING**

- Allow for introductions
- Set expectations - describe how decisions will be made, articulate scope of current meeting
- Review where we've been, where we are, 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 - call out those talking over others, stick to time limits
- Optimize participation - provide opportunities for everyone to contribute, prompt those who are 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
- Check in regularly - send updates or new literature, share milestones
- Start planning for next meeting

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**HANDOUT: Effective Meeting Facilitation**

Person & Family Engagement (PFE) Toolkit: A Guide for Measure Developers  
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**Person & Family Engagement (PFE) Elements of Effective Meeting Facilitation**

**REMEMBER!**  
We are ONE team  
PFE Partners are Experts  
PFE Partners want to do a good job

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**TEMPLATE: Script for Meeting Introduction and Wrap Up**

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The script below can be used during meeting introductions and wrap ups with PFE Partners. It's important to orient your 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're not able to join the webinar you can follow along in the PowerPoint slides we 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 is muted and your phone line is also 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**

**If a Technical Expert Panel**

The TEP members on this call span various backgrounds and areas of expertise. We understand that you all are representing yourselves and not the organizations you are a part of. 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 that your feedback will provide us with strong rationale and support to build the best measure possible together.

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**TEMPLATE: Script for Meeting Introduction and Wrap Up**

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**If 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 that 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 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.

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# Section 5: Recruitment

## SECTION 5. RECRUITMENT

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This section offers guidance on how to recruit PFE Partners using three different recruitment options and reviews recruitment timeline considerations.

### Topics:

- PFE Partner Roles
- Options for Identifying and Recruiting PFE Partners
- PFE Recruitment Process and Contacts
- Recruitment Timelines
- Success Story

### Resources:

- [Sample PFE Partner Recruitment Questions](#)

## Section 5: Recruitment

The success of your person and family engagement efforts is directly correlated to your organization's ability to recruit a diverse selection of PFE Partners with whom you can collaborate. Finding patients, family caregivers, consumers, and advocates who are willing to dedicate their time to measure development projects can seem overwhelming. 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.** For example, 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, once you start reaching out, you will find many individuals who are as passionate about improving the quality of healthcare as you and your colleagues are.

“Great vision without great people is irrelevant.”  
– Jim Collins, American Business Consultant

### PFE PARTNER ROLES

When recruiting PFE Partners, it is important to recognize that they typically represent four distinct categories of perspectives. See [Section 3: How to Engage](#) for more information about selecting PFE Partners who represent roles that best fit the engagement mechanism and your PFE goals. For reference, we define each role below:

- **Patients:** Individuals who interact with the healthcare system on a regular basis, and who are living with or managing one or more health conditions.
- **Family 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 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), and faith-based organizations.

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PFE Partners often possess a combination of perspectives and therefore may fit into more than one of these roles. For example, a family caregiver can possess attributes similar to those of an advocate, depending on their experiences. You should discuss with PFE Partners the primary role they intend to represent in their engagement with you.

### OPTIONS FOR IDENTIFYING AND RECRUITING PFE PARTNERS

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

- Approach A. Build organizational capacity to identify and recruit persons and families
- Approach B. Select an organization to identify and recruit persons and families
- 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 requires existing relationships with groups, organizations, and other entities that work closely and have established relationships with persons, family caregivers, consumers, and advocates. Alternatively, you will require the staff and resources to build those relationships.

This approach also necessitates staff who can recruit persons and families with the characteristics and experiences that will be of most value to your upcoming projects, and then onboard and orient those persons and families to ensure their effective engagement (for example, prepare general background documents, conduct an orientation webinar or 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 that you identify and ultimately collaborate with PFE Partners who are best suited for the work.

#### Approach B: Partner with an External Organization

Partnering with an external organization to conduct your recruitment can be an effective way partner with an organization that has existing relationships with persons and families, and/or with organizations

and entities that work closely with persons, family caregivers, consumers, and advocates. It is also advisable to partner with an organization that possesses extensive experience and expertise recruiting, onboarding, and orienting persons and families to engage in research, quality improvement, and/or measure development.

Note that this approach also requires financial resources. You may need to consider building in the costs associated with recruiting, onboarding, and orienting into your contracts with CMS, and then subcontract to an external organization to fulfill those deliverables.

#### Approach C: Draw from an Existing Network

A third recruitment approach involves partnering with an organization that curates an existing network of patients, family caregivers, consumers, and advocates, and then recruiting 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. 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 two options, your organization will still need to train and prepare your staff to work effectively with PFE Partners and begin building your own relationships with the PFE Partners you work with. To get started, see [Section 9: Staff Trainings](#).



**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.**

### PFE RECRUITMENT PROCESS AND CONTACTS

This section will be most helpful to organizations electing to do their own recruitment of PFE Partners. If you decide to partner with an external organization or draw from an existing network, however, those organizations may follow a similar approach to the one described below, and this section will give you an idea of the steps that go into recruiting PFE Partners. The PFE recruitment process includes three main steps:

1. Defining a “good fit”
2. Reaching out (see the following pages for potential organizations to get started)
3. Holding conversations with potential PFE Partners

#### Recruitment Step 1: Defining a “good fit”

When seeking out 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:

##### Highly Recommended

- Familiarity and experience with the healthcare system as a patient or a family caregiver
- Varying healthcare experiences—both positive and negative
- Experience with target conditions or procedures
- Representative of diverse patient populations (for example, age, gender, race, education, geography, etc.)

- Inquisitive and ability 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
- Openness to changing timelines and project goals throughout their participation

##### Recommended Depending on Project Goals and Engagement Mechanism

- Experience participating in multi-stakeholder processes and/or Patient and Family Advisory Council
- Understanding of quality measures or experience with measure development
- Experience with healthcare writing, journalism, graphic design
- Technical skills necessary for virtual activities (e.g., access to a computer, regularly checks e-mail, reliable access to a telephone)

While desired PFE partner characteristics may shift during the project, it is recommended that you identify at least three characteristics to guide your initial recruitment efforts. Characteristics such as demographics, diagnoses, and specific lived experiences may become clearer and more focused closer to the engagement activity and more general personality characteristics (e.g., comfortable speaking in larger groups, openness to shifting timelines, collaborative attitude) should be sought out in the initial stages of recruitment.



**CASE STUDY:** 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. We will use the same example below as we use in **Section 8: Strategic Planning** related to the diabetes measure.

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



- We want to have a mix of Type I and Type II diabetes participants, and we’ll want to have several of them be patients managing the disease
- Since family caregivers can play a key role in managing a chronic condition like diabetes, we’ll recruit several family caregivers
- Since we’re having a PFE Partner-only group, we don’t need to worry about multi-stakeholder experience
- We’ll also think about representation by women and men, people of different ages, and a variety of social and cultural backgrounds



## Section 5: Recruitment

### Recruitment Step 2: Reaching Out

The second step in the recruitment process is to reach 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, as well as 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. And, if you are seeking patients who have specific conditions, you will likely need to be more targeted in your outreach. See the Sample PFE Partner Recruitment Questions tool (see [Section 10: Resources](#)).

#### 1. 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 or not they focus on healthcare issues. However, many of the individuals associated with these organizations have experience serving as volunteers and likely have had experiences with the healthcare system.

**Citizen Action.** More information available here: <http://www.citact.org/>

#### Community Centers

**Kiwanis Club.** More information available here: <http://www.kiwanis.org/>

**League of Women Voters.** More information available here: <https://www.lwv.org/>

**Lion's Club.** More information available here: <http://www.lionsclubs.org/en/>

**National Consumers League.** More information available here: <http://www.nclnet.org/>  
Neighborhood Associations

**Young Men's Christian Association (YMCA).** More information available here: <http://www.ymca.net/>

**YWCA.** More information available here: <http://www.ywca.org/>

#### 2. Population-specific organizations.

These organizations focus on the well-being of older adults and may be able to identify PFE Partners with Medicare coverage and/or staff who can serve in the advocate role.

**AARP.** More information available here: <https://www.aarp.org/>

**Area Agency on Aging.** More information available here: <https://www.n4a.org/>

**National Council on Aging.** More information available here: <https://www.ncoa.org/>

#### Senior Centers Retirement Communities

#### 3. Organizations that focus on the well-being of diverse populations and/or health equity.

They may be able to identify PFE Partners from diverse backgrounds and non-dominant racial or ethnic groups, and/or staff who can serve in an advocate role.

**Asian & Pacific Islander American Health Forum.** More information available here: <http://www.apiahf.org/>

**Black Men's Health Project.** More information available here: <http://blackmenshealthproject.org/>

**Black Women's Health Imperative.** More information available here: <https://www.bwhi.org/>

**National Association for the Advancement of Colored People (NAACP).** More information available here: <http://www.naACP.org/>

**National Alliance for Hispanic Health.** More information available here: <https://www.healthyamericas.org/>



## Section 5: Recruitment

### 4. Condition-specific organizations.

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

**American Heart Association.** More information available here: <http://www.heart.org/>

**American Cancer Society.** More information available here: <http://www.cancer.org>

**American Diabetes Association.** More information available here: <http://www.diabetes.org/>

**National Health Council.** More information available here: <http://www.nationalhealthcouncil.org>

**National Breast Cancer Coalition.** More information available here: <http://www.breastcancerdeadline2020.org>

### 5. Persons and families with experience serving on a Patient and Family Advisory Council or Committee (PFAC).

In recent years, hospitals and ambulatory practices around the country have launched PFACs. The persons and families who participate in PFACs have experience sitting on a healthcare body and may be a good fit for measure development work.

**The Partnership for Patients (PfP) initiative** is a public-private partnership working to improve the quality, safety, and affordability of healthcare for all Americans. CMS awarded contracts to 16 Hospital Improvement Innovation Networks as a part of the PfP. Hospitals within the Innovation Networks are working to achieve a set of patient and family engagement criteria, one of which is to create a PFAC. More information available here: <https://partnershipforpatients.cms.gov/>

**The Comprehensive Primary Care Plus (CPC+) initiative** is a national multi-payer initiative designed to strengthen primary care. CPC includes a focus on patient and caregiver engagement and many CPC practices have launched PFACs. More information available here: <https://innovation.cms.gov/innovation-models/comprehensive-primary-care-plus>

**The Transforming Clinical Practice Initiative (TCPI)** is designed to help clinicians achieve large-scale health transformation. TCPI includes a focus on patient and family engagement and many TCPI practices have launched (or are working to launch) a PFAC. More information available here: <https://innovation.cms.gov/innovation-models/transforming-clinical-practices>

Massachusetts passed a law in 2009 mandating that hospitals create a PFAC to obtain licensure. More information, including **Massachusetts' hospitals PFAC** annual reports, available here: <https://www.hcfama.org/patient-and-family-advisory-councils-pfacs>

### 6. Patients with experience in research.

The following 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.

**Patients Like Me:** <https://www.patientslikeme.com/>

**Patient-Centered Outcomes Research Institute (PCOR).** More information available here: <https://www.pcori.org/>

**WeGo Health Experts.** More information available here: <https://www.wegohealth.com/>

## Section 5: Recruitment

### 7. Organizations that work with patient advisors.

The following organizations work to promote partnerships between persons and families and other healthcare stakeholders and have developed a network of patient advisors with experience collaborating to improve healthcare.

**Institute for Healthcare Improvement.** More information available here: <https://www.ihl.org>

**Institute for Patient- and Family-Centered Care.** More information available here: <http://www.ipfcc.org/about/index.html>

**National Partnership for Women & Families.** More information available here: <http://www.nationalpartnership.org/>

### 8. 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.

**Patient Family Centered Care (PFCC) Partners.** More information available here: <https://pfccpartners.com>

**Planetree:** <https://planetree.org>

More information available here: <https://bphc.hrsa.gov/>

## Section 5: Recruitment

### General Outreach Tips

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

- Contact churches, synagogues, and other faith organizations to engage lay and professional health ministers on staff. These lay and professional health ministers 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.
- Outreach to individual consumer or advocates who can recommend peers.
- Send direct notices through e-mail, patient portals, or regular mail to Medicare beneficiaries.
- 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.
- 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.**

## Section 5: Recruitment

### Recruitment Step 3: Holding Conversations with Potential PFE Partners

Once a potential PFE Partner has been identified, 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.
- Answer any questions the potential PFE Partner may have.

The goal of conducting conversations with potential PFE Partners is to determine whether there is a “fit” between your organization's measure development needs and their interests and experience. It is not recommended to “interview” potential PFE Partners, but to have a discussion to explore whether there is an alignment of goals and interests.

After this conversation, you will be able to determine whether the potential PFE Partner is a good fit for your project. If so, you can invite them to participate and initiate onboarding. If you determine that the potential PFE Partner is not a good fit, you should follow up and explain why. You may also want to ask them 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 10 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 (see [Section 10: Resources](#)).



**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 family 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. It is recommended that communications regarding partner selection or delays in proceeding

with onboarding are provided within 7-10 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).
- 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).



With **Recruitment Options one and two**, 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. **Recruitment Option three** 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 8: Strategic Planning**).



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 well in advance of future engagements or maintain lists of potential contacts you identify along the way.

### SUCCESS STORY

**Your Objective:** Select measure cohort and determine inclusion and exclusion criteria

**Engagement Strategy:** Weighing Options

**Mechanism:** Measure Working Group



Your team is developing a measure of length of hospital stay following a surgical procedure. You're trying to establish your cohort inclusion and exclusion criteria. You decide to use the Weighing Options strategy with a Measure Working Group of eight PFE Partners to determine whether a specific subset of patients should be included in the measure cohort. Your team tests the model with and without those patients included. The model without those patients performs slightly better. Your statisticians are comfortable with either approach. PFE Partners feel strongly that the specific subset of patients should be included in the cohort because they represent a key population, and the measure will be significantly less useful to patients if the specific subset is not included. PFE Partners think that the benefits of including them far outweigh the small improvement in performance when excluding them. Your team decides to align the measure with the PFE Partners' recommendation and include the specific subset of patients in the measure cohort. This deference increases the face validity and enhances overall rationale for this measure decision when presenting to your TEP or the NQF.



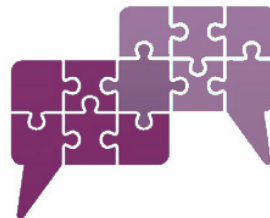
## Section 5: Recruitment



### TOOL: Sample PFE Partner Recruitment Questions

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

- ☐ Please share your experiences—both personal and professional—with the healthcare field.
- ☐ 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 (ex. 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?
- ☐ Ideally, how much time would you like to spend on this work monthly?
- ☐ 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, and 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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Locate the printable version of this resource in [section 10](#).



## Section 6: Onboarding & Orientation

### SECTION 6. ONBOARDING AND ORIENTATION

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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.

#### Topics:

- Onboarding
- Orientation
- Success Story

#### Resources:

- [Sample Email Communication Template](#)
- [Sample “Getting to Know You” Questions and Biographies](#)
- [PFE Charter Template](#)
- [Orientation Checklist](#)

## Section 6: Onboarding & Orientation

Preparing PFE Partners to engage with you requires more than just diving into a discussion on measure development in your first meeting. You are building relationships, and that requires mutual understanding and early preparation. ***Onboarding and orientation are two key steps that make up the welcome process for PFE Partners who are newly collaborating with you.*** In these steps, you will provide background information, review essential processes, complete necessary paperwork, and establish the responsibilities of everyone involved. Once onboarding and orientation are complete, PFE Partners will be ready to engage with the measurement team.



*Coming together is a beginning. Keeping together is progress. Working together is success.”*  
- Henry Ford

### ONBOARDING

**Onboarding** may be your first opportunity to interact with PFE Partners directly if you utilized 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 Templates (see [Section 10: Resources](#)).

Onboarding Topics:

- Greet PFE Partners with a welcoming email. Use the time to describe your appreciation for their collaboration and the importance of their contributions.



**Onboarding often sets the tone for the remainder of your relationship with each PFE Partner. Taking the time to get to know each other will promote better engagement once your measure project begins. Ensure that you are building in adequate time (i.e., no less than 4 business days) for your Partners to complete the necessary onboarding documentation.**

- 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 healthcare for patients.



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

- Describe the type of support you will provide PFE Partners as your collaboration progresses.
- Identify a point of contact, someone who can be reached for a variety of issues and 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 Personal Health Information and Privacy Agreement Tool (see [Section 10: Resources](#)).
- Obtain biographical information from each PFE Partner using the Sample “Getting to Know You” Questions and Biographies Tool (see [Section 10: Resources](#)). Include any necessary conflict of interest information, if applicable to your specific activity. In gathering conflict of interest information,

## Section 6: Onboarding & Orientation

- communicate the purposes of this data collection for participants to ensure they 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.

### Roles and Responsibilities

The **Onboarding** process should also include a discussion of roles and responsibilities, focusing on what PFE Partners should expect and what will be expected of 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 kind of project or engagement mechanism the PFE Partner will engage in 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
- What is expected of PFE Partners (for example, review materials, attend meetings, share their opinions)
- What PFE Partners can expect of the measure developer (for example, create background materials, facilitate meetings, be open to making measure decisions with PFE Partner input)

Review the Sample Email Communication Templates for examples of a welcome email and an email for communicating with PFE Partners (see [Section 10: Resources](#)). In addition, review the PFE Charter Template (see [Section 10: Resources](#)).

### ORIENTATION

Offering PFE Partners **Orientation** is an important opportunity to 'lay the groundwork' prior to your collaboration. At this point, PFE Partners have been welcomed to your team and will 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** 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. 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 team introductions - including your team and the PFE Partners.
- Set the broader context - review the "ins and outs" of measure development and healthcare quality.
- Provide background on your project, what to expect, and next steps.
- Build PFE Partner skills in multi-stakeholder engagement by reviewing engagement best practices and defining various stakeholder groups.

- For more information, review the Orientation Checklist template (see [Section 10: Resources](#)).

### Recommended Orientation Participants

- PFE staff
- Project team members and team leadership
- Organizational leadership, when possible

**!**  
Prepare Orientation materials using plain language, following health literacy guidelines, and via 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.

## Section 6: Onboarding & Orientation

### SUCCESS STORY

**Your Objective:** Design or select tools


**Engagement Strategy:** Weighing Options

**Mechanism:** Concept Advisory 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 one or a combination of several patient surveys to assess the measure outcome. A number of these surveys already exist for the procedure of interest, but they were developed for different purposes than the goal of your measure. You decide to convene a Concept Advisory Group of six PFE Partners to select the appropriate survey tools/questions using the Weighing Options strategy. Your team conducts preliminary research to identify all the available surveys and the questions included in each. You present each survey instrument to your PFE Advisory Group and ask them to discuss their perspectives and opinions on the highest and lowest priority survey questions in a series of meetings. You follow up with a survey asking them to select two from the top four choices determined in your meetings. You take these top two choices back to your team and conduct feasibility analyses on using those surveys in your measure. By co-designing a custom survey with PFE Partners, you can be confident that the measure will be useful to patients and resonate with their values and perspectives.

## Section 6: Onboarding & Orientation

**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 that 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]


**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. The survey will take approximately 10-15 minutes to complete. It 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]

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Locate the printable version of this resource  
in [section 10](#).

**TOOL: Sample “Getting to Know You”  
Questions and Biographies**


**SAMPLE INTERVIEW QUESTIONS**

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

**SAMPLE BIOS**




**Jane Doe\* (Patient):** Jane lives in Anytown, USA. She received her bachelor’s degree in anthropology from a top research university and has focused on using writing and interviewing to promote awareness around race, class, and ability. Jane has multiple chronic conditions and considers herself a self-advocate for access to healthcare. Jane recognizes the particular struggles young people have with navigating the healthcare system, especially with a disability.



**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 services 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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Locate the printable version of this resource  
in [section 10](#).



## Section 6: Onboarding & Orientation

 **TEMPLATE: PFE Charter**

[Insert Month and Year]

### INTRODUCTION

What is the Personal Health Information and Privacy Agreement?

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
- 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.]

### 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
- Making materials friendly for all audiences, including patients

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 **TEMPLATE: PFE Charter**

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
- Completing experience surveys

Our Responsibilities:

- Partner with PFE Partners in their quality measurement work
- Respect all PFE Partners and ensure their voices are valued and appreciated
- Deliver clear materials before activities
- Report on your contributions to quality measurement projects
- Ask 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:

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Person and Family Engagement (PFE) Toolkit: A Guide for Measure Developers  
Section 6: Onboarding & Orientation: Resources




Locate the printable version of this resource  
in [section 10](#).

Locate the printable version of this resource  
in [section 10](#).


 **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.

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



Person and Family Engagement (PFE) Toolkit: A Guide for Measure Developers  
Section 6: Onboarding & Orientation: Resources



Locate the printable version of this resource  
in [section 10](#).



# Section 7: Ongoing Communication

## SECTION 7. ONGOING COMMUNICATION

---

This section provides tips for communicating and managing relationships with PFE Partners before, after, and between their engagements with you.

### Topics:

- Project Communication
- Supporting PFE Partners
- Success Story

### Resources:

- [Project Communication Tool](#)

## Section 7: Ongoing Communication

At heart, engaging with PFE Partners is relationship-based, and it is nearly impossible to develop relationships during complex meetings. Ideally, your relationships with PFE Partners will grow over time, during and between meetings, 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 shows that you value their input and motivates them to continue working with you*** on current and future projects

“Go beyond merely communicating to ‘connecting’ with people.”  
- Jerry Bruckner, Author  
*The Success Formula for Personal Growth*

### PROJECT COMMUNICATION

Throughout the months and/or years of your measurement project and PFE, 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 (see [Section 10: Resources](#)).

#### 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.
- 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> to help PFE Partners readily sort and respond to communications from your team.
- During onboarding, be sure 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

- Be sure automated survey tool messages do not go to PFE Partner spam inboxes.
- Provide clear instructions for completing the survey.

#### Phone

- Between meetings, some PFE Partners may prefer to discuss their concerns or measure feedback 1:1 by phone as opposed to email or in the larger group meetings.
- Calling PFE Partners directly may help you connect with individuals who are not responsive to emails.

#### Mail

- Some PFE Partners will need paper copies of meeting materials, surveys, and other paperwork. Allow extra time for mailing these materials.

## Section 7: Ongoing Communication

### When and What to Communicate

You can, and should, communicate with your PFE Partners frequently throughout all stages of your project, such as:

**!**  
**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 that syncs their calendars.

#### 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 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 a meeting

- 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). 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 measurement milestones as soon as they occur (for example, if the measure is submitted to the NQF for endorsement).

#### During gaps in “active” engagement

- Alert PFE Partners if they should expect a long gap before the next meeting is scheduled.

#### After the “active” engagement/project is complete

- 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 (for example, if measure specifications are complete), of 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.

## Section 7: Ongoing Communication

### SUPPORTING PFE PARTNERS

---

Ongoing communication with PFE Partners about their PFE experience is critical to the success of your work and goes beyond discussion of 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](#)). Are they finding the work meaningful? Do they feel valued? Do they feel that they are having an impact on the project and on improving healthcare? 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.



## Section 7: Ongoing Communication

### SUCCESS STORY

**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 feel strongly that for this chronic health condition, the preliminary risk-adjustment model you developed does not fully account for several key patient factors that go beyond clinical comorbidities. 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 NQF, 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 7: Ongoing Communication



### TOOL: Project Communication

#### How To Communicate?

- Use plain language
- 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 clear and concise in your communications, lay out specific questions or materials

#### 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 meetings

- Send meeting invitation several weeks in advance
- 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 asking PFE Partners about their experience
- Reiterate next steps

#### 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

- You make a decision on the measure
- You obtain results from analyses
- Measure is submitted to NQF
- Measure goes into public comment
- Measure is included in rulemaking (MUC list, Notice of Proposed Rulemaking)

##### Changes to measure timeline

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

Person and Family Engagement (PFE) Toolkit: A Guide for Measure Developers  
Section 7: Ongoing Communication: Resources



Locate the printable version of this resource in [section 10](#).



## Section 8: Strategic Planning

### SECTION 8. STRATEGIC PLANNING

---

This section provides guidance on each step of the planning process that is key to the success of your engagement efforts with PFE Partners. It is important to know before launching a project with PFE Partners what you hope to accomplish, by when, and with whom.

#### Topics:

- Importance of Creating a Strategic Plan
- How to Develop a Strategic Plan
- Completing the Strategic Planning Template
- Success Story

#### Resources:

- [Strategic Planning Template](#)
- [Elements of Strategic Planning](#)

## Section 8: Strategic Planning

As a measure developer, you most likely have an established process for your quality measure work. You know how to plan for each step of the process and are familiar with all the important technical considerations. Now that you've committed to engaging meaningfully with persons and families, you will need **a plan that fully integrates PFE into your workflow**. This section outlines key considerations for incorporating PFE into your processes and provides targeted guidance to help you plan strategically. We'll use a case study to provide examples of how you might answer each of the planning questions to determine **Why, What, How, Who, and When** for your engagement. Refer to other sections of this Toolkit, where indicated, for in-depth guidance on complex steps such as recruitment.

“A goal without a plan is just a wish.”  
- Antoine de Saint-Exupery, Pilot/Writer

### IMPORTANCE OF CREATING A STRATEGIC PLAN

A detailed, comprehensive strategic plan is critical to successful engagement with persons and families for several reasons. First, developing the plan prior to starting the work ensures you are making informed decisions regarding project timelines, staffing, other resource needs, and what product you can deliver. Secondly, the 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. Each project invariably has unique challenges and nuanced considerations and will require tailored planning. 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 Strategic Planning Template we will review here (see [Section 10: Resources](#)), within 10 business days of initial discussions with your COR to guide your project timeline. Ten days is recommended to ensure that 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. It is recommended to continuously update the plan with shifts in project scope or timelines. It is recommended that revisions to strategic plans are made within 3-5 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 (see [Section 10: Resources](#)).

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

## Section 8: Strategic Planning

and prepare these individuals (see [Section 5: Recruitment](#) for recruitment strategies and guidance.) Be sure to begin the planning process early, and allow time for consultation and review within your organization. Also, make sure you have buy-in from everyone in your organization who may be impacted by, or needs to participate in, the elements of your plan.

It is optional but highly recommended that your team

create an internal database or spreadsheet tracker of your recruitment efforts and timelines. Particularly with engagement activities that involve multiple PFE partners, it is essential that you and your team are able to clearly identify any gaps in recruitment needs, potential delays to project timelines, and candidate drop-outs so that you may be able to redirect recruitment efforts accordingly.

### 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

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. Think about why engaging with PFE Partners is critical to the success of this project at this time. Your PFE goals might be wanting to develop a patient-centered new measure or ensure patients can understand the language you use to describe the measure outcome. Or 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. These goals drive everything else. Write them down and reference them regularly.



**CASE STUDY:** “Our overall goal is to develop a new outcome measure related to diabetes care. I want to make sure the specific outcome we’re measuring is something that truly matters to patients; therefore, our PFE goal is to select the measure outcome together with a group of PFE Partners.”

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

You might select topics for PFE based on where you are in the development cycle. Are you ready to select a cohort or develop a risk-adjustment methodology? Or are you earlier in the process where you’re prioritizing what measure to create or selecting an outcome? PFE partners will often surprise you and show you ways they can shape your measurement project that you never imagined. Still, it’s 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 course. A list of measurement topics to get you started is included in the Engagement Topics and Decisions Summary Tool (see [Section 10: Resources](#)). At this stage of the planning process, you don’t 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.



**CASE STUDY:** “I’m going to ask PFE Partners to help my team prioritize and select an outcome for the diabetes 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.”

## Section 8: Strategic Planning

### Step 3: How – The Engagement Mechanism

This PFE Toolkit refers to the way you engage with PFE Partners as the “engagement mechanism,” which could be a Measure Working Group, a concept advisory 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. For more guidance and examples of engagement mechanisms, see [Section 3: How to Engage, Part 2: Selecting an Engagement Mechanism](#).



**CASE STUDY:** *“We’re fairly 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 working 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 each have their own unique experiences. You’ll 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. For example, you may want to find PFE Partners who are similar to the cohort of your measure or who have experience with your outcome, but you’ll also want to think about other characteristics such as comfort participating in group settings and availability to participate in the frequency and level of effort for your project. For more information about PFE Partner characteristics and recruiting PFE Partners to collaborate with you, see [Section 5: Recruitment](#).



**CASE STUDY:** *“We should have some patients who have Type 1 and Type 2 diabetes on the working group. Because diabetes is a chronic condition, family caregivers who help care for someone with diabetes would also have helpful perspectives. We’ll want to hear from people who have other health conditions that impact how they manage their diabetes. We also want to ensure we have a variety of different backgrounds and social characteristics represented.”*

### 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 NQF endorsement. Integrating PFE into measure project timelines can be one of the most challenging aspects of this work. It can be difficult to predict when a critical dataset will be available for testing or when analyses will be completed and ready for review. Incorporate meaningful engagement with PFE Partners into your timeline from the beginning. Be sure to allow enough time before you begin engaging PFE Partners, as well as between your engagement activities. It is recommended to build substantial “cushions” into your timeline to allow for delays without shortchanging your time with PFE Partners.



**CASE STUDY:** *“We’ll need several months to meet with our PFE Partners to select the outcome. Then it takes my team about a year to finish the measure specifications and complete testing, and we may want to bring our PFE Partners in again at a later phase of development. That means we should start meeting with our PFE Partners in about two to three months. We should start recruiting now!”*

### The Final Step: A Completed Plan

Now that you have a plan for your engagement, make sure you have buy-in from other key members of your project team and organization. Continually update the plan for your engagement throughout the process to ensure that your team accounts for any changes in project scope. You can now begin recruiting!

## Section 8: Strategic Planning

### SUCCESS STORY

**Your Objective:** Evaluating Preliminary Results or Displays to Assess Measure Usability

**Engagement Strategy:** Evaluating Preliminary Results or Displays


**Mechanism:** Measure Working Group



For the past six months, you have been collaborating with a Measure Working Group of five PFE Partners on the development of a new outcome measure assessing complication rates following procedures in ambulatory surgical centers. You bring the preliminary measure results to your Working Group 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 point out that the majority 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 that 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 that 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 Measure Working Group’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 Measure Working Group.



# Section 8: Strategic Planning


**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, etc.)

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

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, etc.)

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

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:

\_\_\_\_\_


\_\_\_\_\_

\_\_\_\_\_

Person and Family Engagement (PFE) Toolkit: A Guide for Measure Developers  
Section 8: Strategic Planning: Resources



Locate the printable version of this resource in [section 10](#).


**TEMPLATE: Strategic Planning**

For each engagement, please fill in the following fields:

**Engagement Proposal**

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:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_


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

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

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**HANDOUT: Elements of Strategic Planning**


ELEMENTS OF STRATEGIC PLANNING



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Locate the printable version of this resource in [section 10](#).


**HANDOUT: Elements of Strategic Planning**

ELEMENTS OF STRATEGIC PLANNING (cont'd)

**WHY & WHAT**

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

**HOW**

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


**WHO**

- Number of Participants
- Preferred demographics
- Key experiences, expertise, and characteristics

**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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Locate the printable version of this resource in [section 10](#).



## Section 9: Staff Trainings

### SECTION 9: STAFF TRAININGS

---

This section of the toolkit contains links to three “off-the-shelf” trainings with both presenter (contains speaker notes) and participant slide decks to prepare your staff to engage with persons and families.

#### Topics:

- How to Use These Trainings
- Training Contents

#### Resources:

- [Facilitator Guide for Activities in PFE Training Series](#)

## Section 9: Staff Trainings

Person and family engagement in quality measurement is hard work. It's also probably new to many of the measure development staff at your organization. Effective training yields higher quality engagement and will help your team achieve their engagement goals. This section of the toolkit contains links to three “off-the-shelf” trainings with both presenter (contains speaker notes) and participant slide decks. These trainings can be used to prepare your organization and staff to be successful in any PFE work.

“Practice is the hardest part of learning, and training is the essence of transformation.”  
- Ann Voskamp, *One Thousand Gifts: A Dare to Live Fully Right Where You Are*

### HOW TO USE THESE TRAININGS

The PFE Training Series is comprised of three sessions. The sessions cover the main topics from the toolkit, with references to the relevant sections of the toolkit. Each training session includes a PowerPoint slide deck, short video clips of measure developers further explaining key topics, and one or more activities to apply the skills and concepts presented in the slides.

The training is designed to be given by a member of your organization. We recommend you identify one or more individuals to become PFE leaders within your organization who can train and support other staff. The

toolkit includes two versions of each training session 1) a presenter version that includes speaker notes in the slide deck and information on how to facilitate the activities; and 2) a matching participant version that has a “clean” version of the slide deck without notes that is meant for distribution to staff. Your organization's PFE leader should become familiar with the toolkit contents, as well as the presenter version of the training materials, prior to training other staff. Please see the Facilitator Guide for Activities in PFE Training Series (see [Section 10: Resources](#)).

### TRAINING CONTENTS

The Toolkit PFE Training Series covers the following topics:

#### PFE Training Series Session 1: PFE Fundamentals

- Outline of the goals of PFE
- Description of PFE Partners and PFE perspectives
- Highlight of potential PFE pitfalls and best practices
- Description of leadership and organizational requirements

#### PFE Training Series Session 2: Process, Strategic Planning, and Recruitment

- Review of the systematic PFE Process
- Exploration of key strategic planning



## Section 10: Resources

Tools, templates, and handouts have been provided to you throughout the toolkit. This section organizes these resources so they are easily accessible and ready for use. All materials are in a printable format.

A list of all tools, templates, and handouts is included below.

### TOOLS

---

- [Paperwork Reduction Act Decision Tree](#) Section 1
- [Engagement Topics and Decisions Summary](#) Section 3
- [Choosing Your Engagement Mechanism](#) Section 3
- [Drafting Meeting Materials](#) Section 4
- [Sample PFE Partner Recruitment Questions](#) Section 5
- [Sample “Getting to Know You” Questions and Biographies](#) Section 6
- [Project Communication Tool](#) Section 7
- [Facilitator Guide for Activities in PFE Training Series](#) Section 9

### TEMPLATES

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- [Personal Health Information and Privacy Agreement](#) Section 1
- [Steps Leading up to your Engagement](#) Section 4
- [Script for Meeting Introduction and Wrap Up](#) Section 4
- [Sample Email Communication Templates](#) Section 6
- [PFE Charter Template](#) Section 6
- [Orientation Checklist](#) Section 6
- [Strategic Planning Template](#) Section 8

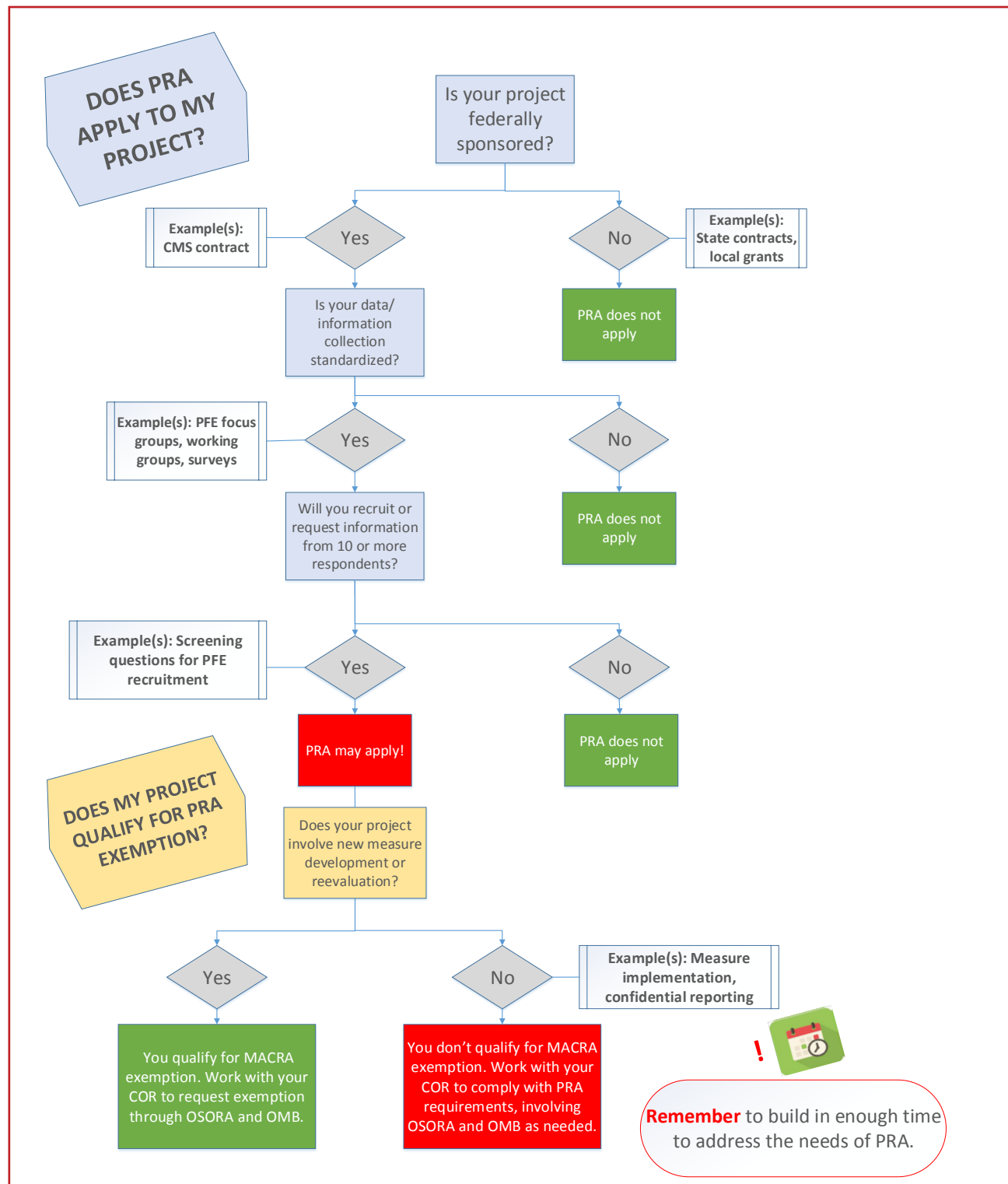
### HANDOUTS

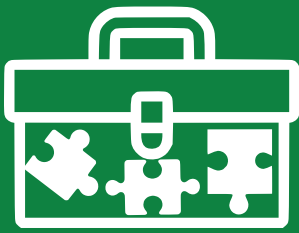
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- [PFE Process Summary](#) Section 2
- [Meeting Facilitation Troubleshooting](#) Section 4
- [Effective Meeting Facilitation](#) Section 4
- [Elements of Strategic Planning](#) Section 8



# TOOL: Paperwork Reduction Act Decision Tree





# 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, e-measures, or patient-reported outcome measures; individual condition/procedure measures versus facility-wide measures, 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	If the measure topic (condition, procedure, etc.) has already been selected, determine what outcome you will measure such as readmission rates, complications, or length of stay in the hospital.
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 feasibility of using new data sources; recommend further analysis of different analytic approaches.
Create or improve measure reporting displays	Measure reporting displays could include how measure results are displayed in public-facing materials such as on <i>Hospital Compare</i> or other reporting sites, or other resources meant to support the use of the measure.
Create or improve measure descriptive language	Measure descriptive language could include measure name, measure information in methodology reports, or how the measure is described in public-facing materials such as on <i>Hospital Compare</i> or other reporting sites.





# TOOL: Choosing Your Engagement Mechanism

	Technical Expert Panel (TEP)	Measure Working Group	Concept Advisory Group	Communication Workshop	Individual Interview	Survey	Town Hall	Public Opportunities
Multiple meetings	✓	✓	✓					
1-2 meetings				✓	✓			
Discussion-focused	✓	✓	✓		✓		✓	
Early input		✓	✓			✓	✓	
PFE Partner-only		✓	✓	✓	✓		✓	
Rapid input				✓	✓	✓	✓	
Individual input on a specific subject area of PFE Partner expertise					✓			
Structured/quantitative feedback				✓		✓		
Large number of PFE Partners						✓	✓	✓
Integrating PFE Partners into existing measure development activities	✓							✓
Ensure PFE throughout all phases of measure development	✓	✓	✓	✓	✓	✓	✓	✓



## TOOL: Drafting Meeting Materials

### SUGGESTIONS FOR DRAFTING MEETING MATERIALS

Team Introductions

Introduce Topic and Ask Questions

Review and Recap Overall Engagement Timeline

Review Next Steps

Include Glossary of Key Terms

#### Key Considerations when drafting materials

- How much background information do PFE Partners need in order 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?



## TOOL: Sample PFE Partner Recruitment Questions

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

- ☐ Please share your experiences—both personal and professional—with the healthcare field.
- ☐ 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 (ex. 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?
- ☐ Ideally, how much time would you like to spend on this work monthly?
- ☐ 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, and 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?





# TOOL: Sample “Getting to Know You” Questions and Biographies

## SAMPLE INTERVIEW QUESTIONS

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

## SAMPLE BIOS

---



Jane Doe\* (Patient): Jane lives in Anytown, USA. She received her bachelor’s degree in anthropology from a top research university and has focused on using writing and interviewing to promote awareness around race, class, and ability. Jane has multiple chronic conditions and considers herself a self-advocate for access to healthcare. Jane recognizes the particular struggles young people have with navigating the healthcare system, especially with a disability.



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 services 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: Project Communication

## How To Communicate?

- Use plain language
- 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 clear and concise in your communications, lay out specific questions or materials

## 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 meetings

- Send meeting invitation several weeks in advance
- 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 asking PFE Partners about their experience
- Reiterate next steps

### 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

- You make a decision on the measure
- You obtain results from analyses
- Measure is submitted to NQF
- Measure goes into public comment
- Measure is included in rulemaking (MUC list, Notice of Proposed Rulemaking)

### Changes to measure timeline

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



# TOOL: Facilitator Guide for Activities in PFE Training Series

## STRATEGIC PLANNING EXERCISE

---

### Part 1

- This activity should take about 10 minutes
  - Materials needed:
    - Strategic Planning Template (explained in Section 8 of the toolkit, printable version provided in Section 10)
    - Writing utensils
1. Break up the participants into groups of 3-5 people
  2. Instruct the groups to:
    - a. Select a project for which they're hoping to engage PFE Partners, and then
    - b. As a group, fill out the Project Background part of the Strategic Planning Template for that project
  3. You can provide an example project:
    - a. You are at the beginning stages of developing a patient-reported outcome
    - b. You decide to convene a Working Group with 8 PFE Partners
  4. After 8 minutes, ask participants to share key takeaways with the larger group

### Part 2

- This activity should take about 10 minutes
  - Materials needed:
    - Strategic Planning Template
    - Writing utensils
1. Instruct participants to:
    - a. Break up into the same groups
    - b. As a group, fill out the **Engagement Proposal** part of the Strategic Planning Template for the same project chosen in Part 1
  2. After 8 minutes, ask participants to share key takeaways with the larger group





# TOOL: Facilitator Guide for Activities in PFE Training Series

## COMMUNICATION ACTIVITY

---

- This activity should take about 5 minutes
- Materials needed:
  - Images, like the examples provided on the next page of this guide – 1 image for every 2 participants
  - Blank half-sheets of paper – 1 for every 2 participants
  - Envelopes
  - Writing utensils
- Purpose of activity: to demonstrate the importance of communication – be specific; start with the big picture before getting into the details; 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 that every 2 participants will have 1 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

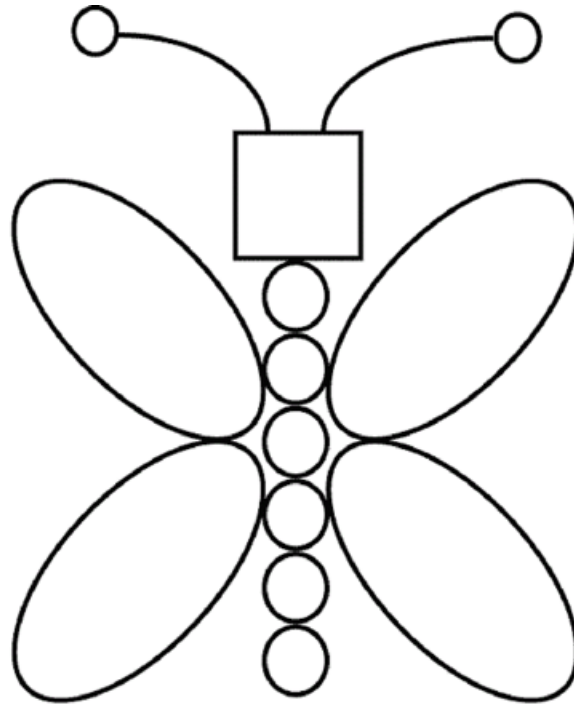
### During the Training

4. Break up the participants into groups of 2
5. 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
6. Instruct the pairs that:
  - a. They will sit back-to-back so that they can't see each other
  - b. One person will open the envelope to find an image, and will describe as best they can what the image is to their partner
  - c. The other person will draw what they are hearing on the blank half-sheet of paper
7. Inform participants that this is a challenge to think critically about the way you are communicating and listening
8. After 2-3 minutes, ask participants to show each other the images and drawings and share key takeaways with the larger group



## TOOL: Facilitator Guide for Activities in PFE Training Series

Example Images for Communication Activity:





# TOOL: Facilitator Guide for Activities in PFE Training Series

## CHALLENGING SCENARIOS AND SCRIPT ACTIVITY

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- This activity should take about 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 guides
    - Writing utensils
  - Purpose of activity: to 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 3-5 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
    - a. For Scenarios A and B, groups should discuss how they would respond to the scenario and answer the question(s) provided
    - b. For the Script Activity, groups should write out scripts according to the prompts and 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



## This image shows a single sheet of white paper with horizontal blue ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.



When convening a multi-stakeholder meeting, your task team likely has some specific goals in mind, whether it's getting sign-off on risk adjustment strategies or 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 B2: There is discord among working group members. In one new measure working group of patient-reported outcomes, 3 members recommended adding an additional survey to capture general health status, while the other 4 members felt that would only create an undue burden for patients and providers.

This image shows a single sheet of white paper with horizontal blue ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.



# Challenging Scenarios Activity

## 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 that you would like to hold a 1:1 with the member prior to the next meeting to get the member on the same page so that they can be more productive during the next call.

In the 1:1 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, open to change and feedback.

Often, a TEP will align perfectly with your expectations heading into the meeting. At other points, however, a TEP will have problems coming to a consensus, or even 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, make sure to ask clarifying questions to make sure the team understands all viewpoints presented.

It's important to explain to group members why a certain decision was made if there was lack of consensus on approach. You should do your best to 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 that 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 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.





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This image shows a single sheet of white paper with horizontal blue ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.



# Script Activity Sample Facilitator Responses

## Opening a working group (welcome, introductions, etc.)

### Key points:

- Introduce yourself
- Thank members for joining
- Only introduce 1 or 2 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’d 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 that we do and we really appreciate that you are willing to share your perspectives and experiences with us. Here in the room with me are names and roles of 1 or 2 other key team members/presenters], along with some other team members who work on this project. Before I ask you all to introduce yourselves, I wanted to give you a sense of how we’ve structured this call. After introductions, [lead presenter name] will explain the project background using presentation slides, and then we’ll 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’d like each person on the call to introduce themselves – it would be great if you could say your name, where you’re 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 aren’t 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’m hearing you say [summarize in your own words what you heard], did I understand you correctly?”

“Thank you for that comment, [member name]; does anyone want to respond to that?”

“I’m hearing several people mention [common theme]; we’ll definitely take note of that.”

“It seems that there’s some disagreement about [issue]; it’s helpful for us to hear these differing views and we’ll take it all into consideration.”



# TEMPLATE: Personal Health Information and Privacy

[Insert Month and Year]

## INTRODUCTION

### What is the Personal 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 Personal Health Information and Privacy Agreement, we will ask you to sign a statement indicating that you agree to the terms outlined in this document.

#### 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.]

## UNDERSTANDING HOW YOUR INFORMATION IS USED

### Information You Share with Us

You may choose to share personal information about yourself or others. Personal information includes an individual's contact information, health experiences, and personal characteristics (such as race, ethnicity, or gender identity). 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 for 3 purposes, to:

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

### How We Store Your Information

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

### How We Share Your Information

Information Shared during all Activities

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.



# TOOL: Paperwork Reduction Act Decision Tree

In addition, we may share that information with CMS, if requested. We may also 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 will not share any identifying information unless written consent is obtained.

## Information Shared on a Technical Expert Panel (TEP)

You may choose to participate in a specific type of activity called a Technical Expert Panel (TEP). Along with CMS, we make certain information about the TEP public. This 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, then that information and your communications are not subject to confidentiality laws.

## How TEP Participants Can Remain Confidential

Your participation in a TEP 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 the Technical Expert Panel Summary Report will be associated with their role and not their name.

## PFE Partner Signs

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

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## Measure Developer Signs

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

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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?

- ☐ **Welcome your newly recruited PFE Partners as soon as recruitment is complete**
  - Send a friendly welcome email, this will set the tone for your communications with your PFE Partners!
  - Make sure PFE Partners know the overall engagement plan: what to expect before, during, and after an engagement
- ☐ **Prepare and share background on your project**
  - Keep the background short (1-5 pages) but include relevant information PFE Partners will need to know
  - Send the background at least 1 week prior to the first engagement, but more time is better
- ☐ **Schedule your engagement**
  - Get scheduling started as soon as possible
  - Schedule at least 3 weeks in advance
  - Offer multiple options, on different days, and at varying times (including evenings)
- ☐ **Prepare and share your meeting materials (duration: ~2 weeks)**
  - Share materials at least 1 week in advance of the engagement, 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
- ☐ **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!**

Month, Year				
1	2	3	4	5
Recruitment Complete	Send welcome email to your PFE Partners	Prepare your background		
		Schedule the engagement		
8	9	10	11	12
Prepare your background				Share background with PFE Partners
Schedule the engagement				
Prepare your meeting materials				
15	16	17	18	19
Prepare your meeting materials				Share your meeting materials with PFE Partners
22	23	24	25	26
Complete preparatory calls				Send reminder email to PFE Partners
				Host 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's important to orient your 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're not able to join the webinar you can follow along in the PowerPoint slides we 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 is muted and your phone line is also 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

#### **If a Technical Expert Panel**

The TEP members on this call span various backgrounds and areas of expertise. We understand that you all are representing yourselves and not the organizations you are a part of. 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 that your feedback will provide us with strong rationale and support to build the best measure possible together.



# TEMPLATE: Script for Meeting Introduction and Wrap Up

## If 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 that 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 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.





# TEMPLATE: Sample Email Communication

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

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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 that 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]

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

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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. The survey will take approximately 10-15 minutes to complete. It 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]



# TEMPLATE: PFE Charter

[Insert Month and Year]

## INTRODUCTION

---

### What is the Personal Health Information and Privacy Agreement?

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
- 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

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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

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PFE Partners will commit to:

- [List any specific terms of the collaboration here.]

## ROLES AND RESPONSIBILITIES

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### 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
- Making materials friendly for all audiences, including patients



# TEMPLATE: PFE Charter

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
- Completing experience surveys

Our Responsibilities:

- Partner with PFE Partners in their quality measurement work
- Respect all PFE Partners and ensure their voices are valued and appreciated
- Deliver clear materials before activities
- Report on your contributions to quality measurement projects
- Ask permission to contact you about additional opportunities

## PFE Partner Signs

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

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## Measure Developer Signs

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

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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.

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





# 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, etc.)

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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, etc.)

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

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

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Main questions or topic areas for PFE collaboration:

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# TEMPLATE: Strategic Planning

For each engagement, please fill in the following fields:

## Engagement Proposal

Engagement mechanism(s):

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

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Estimated number of participants:

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Preferred PFE Partner characteristics/expertise/experiences:

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

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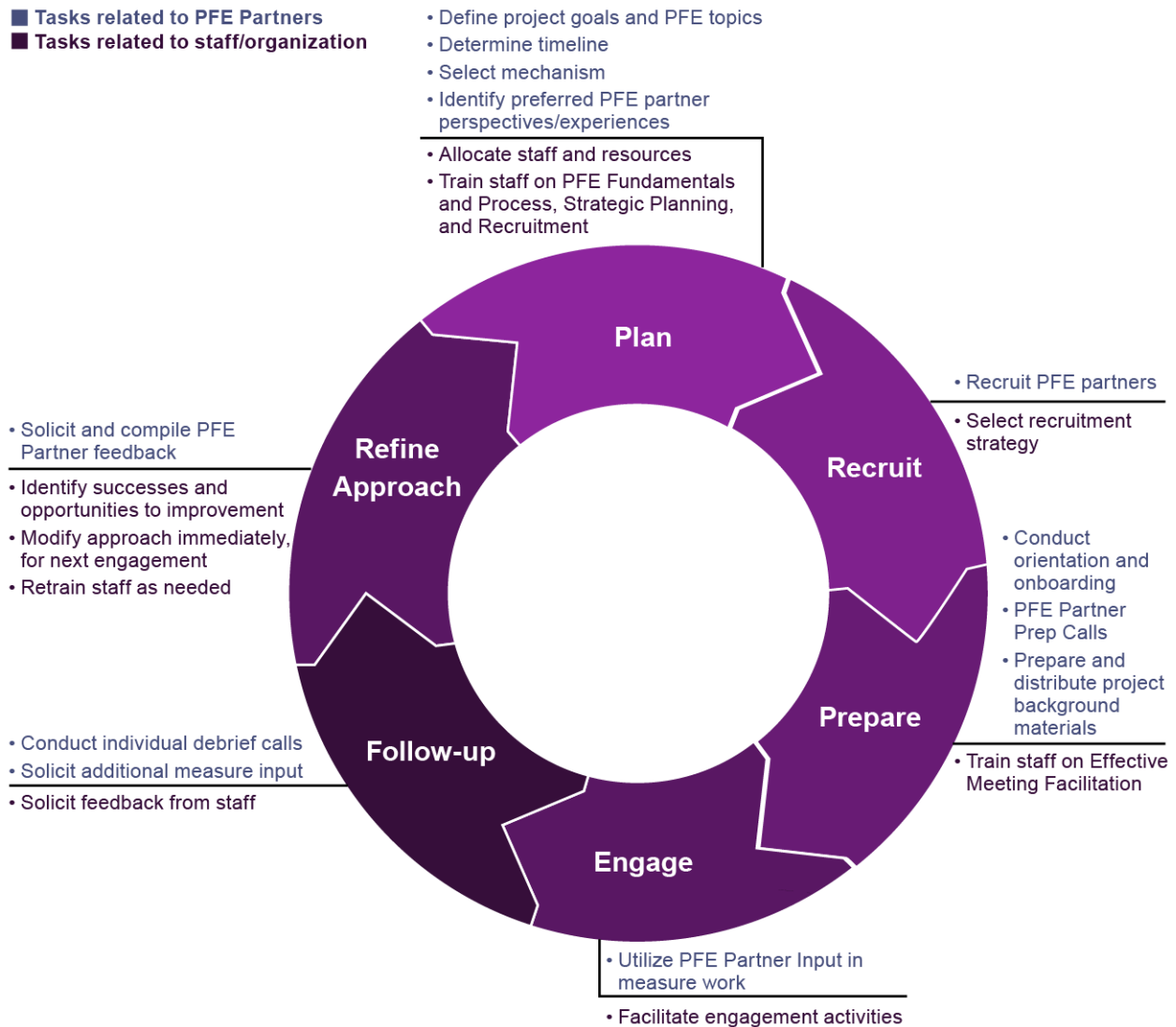
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# HANDOUT: PFE Process Summary

- Tasks related to PFE Partners
- Tasks related to staff/organization







# 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 & Family Engagement (PFE) Tips for Effective Meeting Facilitation

### BEFORE THE MEETING

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- Distribute tailored materials at least 1 week in advance
- Prepare PFE Partners - provide clear assignments to be completed before meetings
- Take the time to teach the basics - not everyone says “cohort”
- Know your team - read their bios, know their story, no assumptions
- Select a meeting format that drives discussion
- Develop Mitigation plan for common meeting challenges

### DURING THE MEETING

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- Allow for introductions
- Set expectations - describe how decisions will be made, articulate scope of current meeting
- Review where we’ve been, where we are, 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 - call out those talking over others, stick to time limits
- Optimize participation - provide opportunities for everyone to contribute, prompt those who are 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

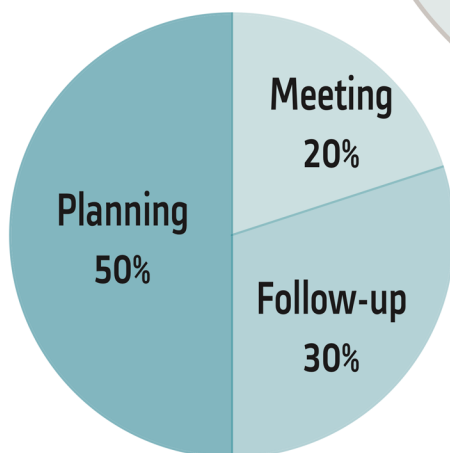
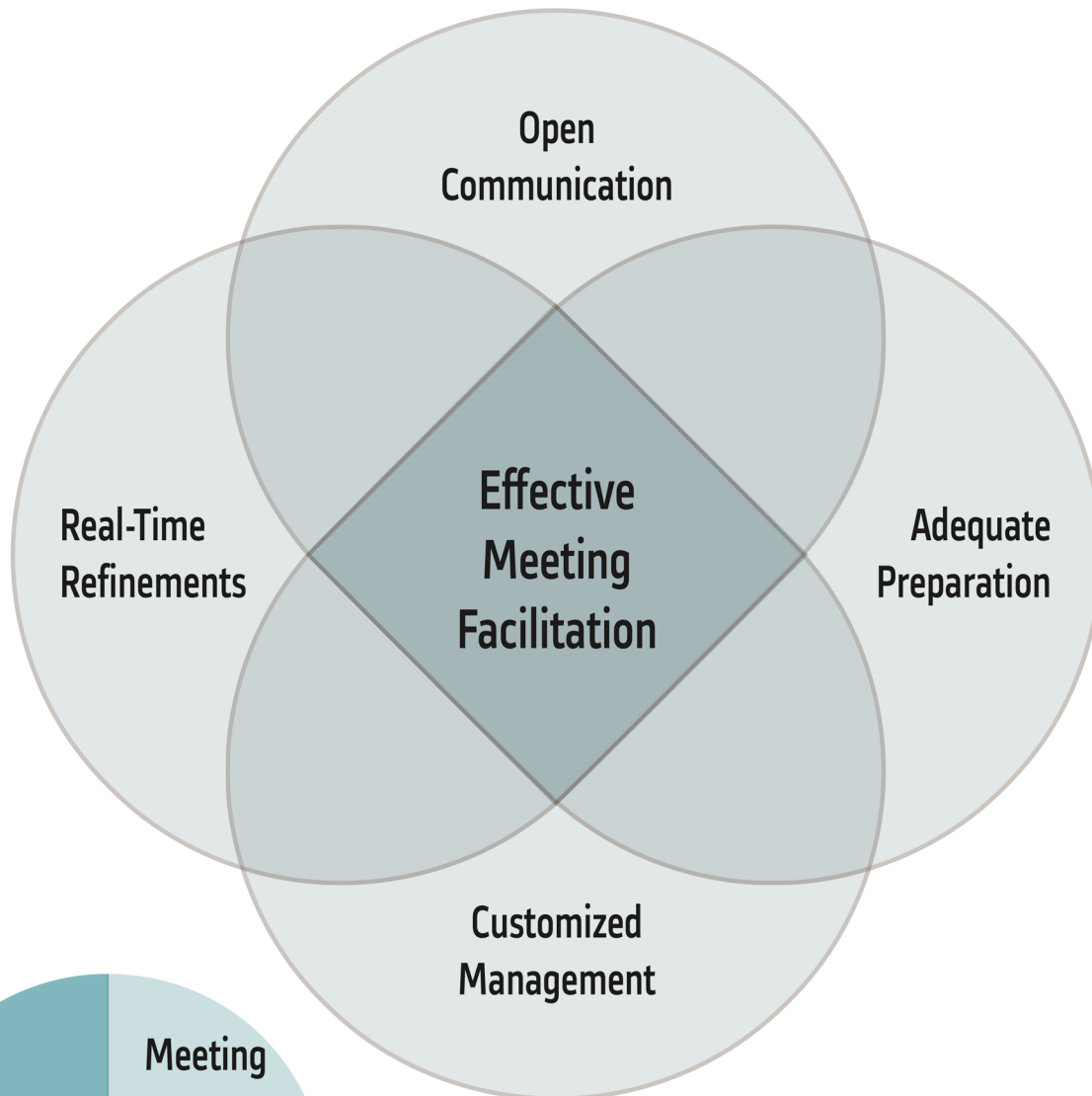
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- Promptly send meeting summaries
- Provide opportunities for folks to contribute between meetings - check in with reserved, seemingly dissatisfied, or absent teammates
- Change what isn’t working - read debrief summaries and strategize solutions
- Check in regularly - send updates or new literature, share milestones
- Start planning for next meeting



# HANDOUT: Effective Meeting Facilitation

## *Person & Family Engagement (PFE) Elements of Effective Meeting Facilitation*



### ***REMEMBER!***

**We are ONE team  
PFE Partners are Experts  
PFE Partners want to do a good job**



# HANDOUT: Elements of Strategic Planning

## ELEMENTS OF STRATEGIC PLANNING





# HANDOUT: Elements of Strategic Planning

## ELEMENTS OF STRATEGIC PLANNING (cont'd)



### WHY & WHAT

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



### HOW

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



### WHO

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- Number of Participants
- Preferred demographics
- Key experiences, expertise, and characteristics



### WHEN

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