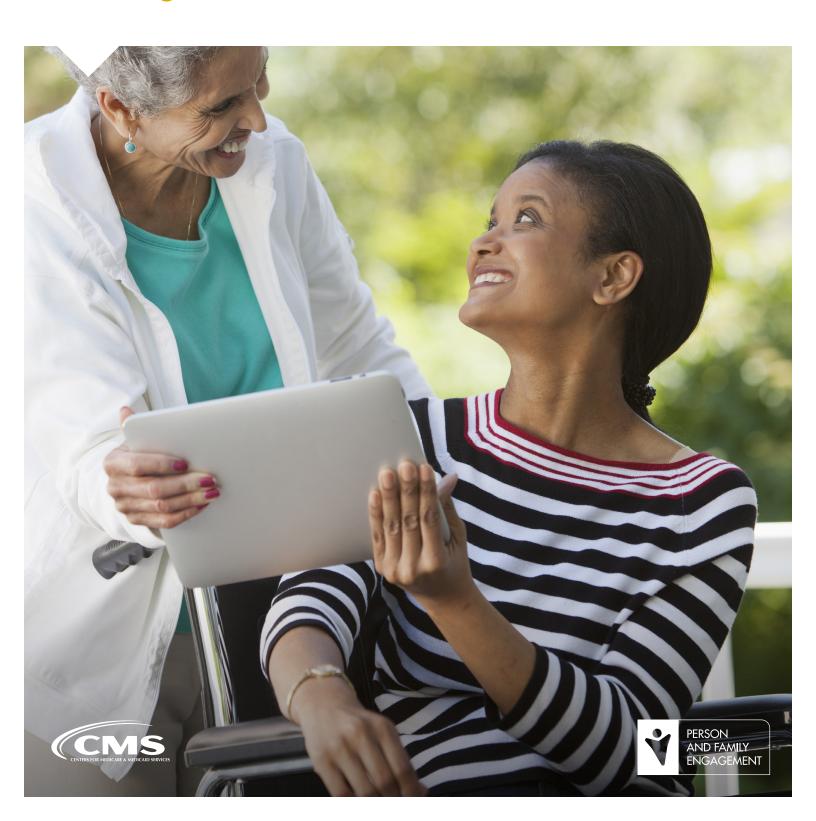
# PERSON & FAMILY ENGAGEMENT STRATEGY

**Sharing With Our Partners** 



#### = INTRODUCTION =

The purpose of this strategy is to...

- ig(1ig) Enhance person and family engagement (PFE).
- Establish definitions and consistency for frequently used terms to help people engage in their healthcare.
- Serve as a guide to support meaningful, intentional application of person and family engagement principles to all policies and programs addressing health, and wellbeing.
- Create a foundation for expanding awareness and enhance person and family engagement.

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.



#### INTRODUCTION

#### Who Is This Strategy For?

Many partners are necessary and essential to successfully engage individuals in their healthcare. CMS hopes that a wide variety of stakeholders will be able to utilize this strategy to expand and spread PFE values, goals, and culture.

#### Partners:

- Federal, state, territorial, tribal, and local governments
- Business
- Industry
- Private sector
- · Professional philanthropic organizations
- · Community and faith-based organizations
- Beneficiaries and other citizens

CMS has 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.

#### **A Call To Action**

This document serves as a guide for individuals and groups looking to incorporate PFE principles into clinical practice, program development, community health initiatives, and other arenas where shared decision making and appreciation of individual values are paramount. This document also provides people with tools and methods to become engaged in their care.

#### Some specific examples of how this document can be used to:

- Broaden and deepen awareness of PFE principles
- · Advance understanding and definitions for common PFE terms
- Identify the values and foundational principles used by CMS to inform and support PFE programs and initiatives
- Understand how PFE is integrated into CMS' overarching goals, through its inclusion in the CMS Quality Strategy and other strategic agency priorities
- Obtain insight into the goals, objectives, and desired outcomes CMS is pursuing in relation to PFE
- · Highlight areas where CMS is driving implementation of PFE principles
- Identify potential areas for collaboration between CMS and other stakeholders
- · Identify what the next steps are in moving forward with PFE work



#### **BACKGROUND** =

#### **Definitions**

#### **CMS Definition of PFE**

"Patients and families are partners in defining, designing, participating in and assessing the care practices and systems that serve them to assure they are respectful of and responsive to individual patient preferences, needs, and values. This collaborative engagement allows patient values to guide all clinical decisions and drives genuine transformation in attitudes, behavior, and practice."



#### Person

The term "person" is used to reflect an individual's identity as more than a patient, to recognize his or her participation in prevention and wellness.



#### **Family**

The term "family" is used broadly to include participants in a person's healthcare including informal caregivers, along with the primary caregivers of persons who are person who are in need of the support of their caregivers to make informed healthcare decisions.



#### Provider

The term "provider" refers to any provider of care and services including both individuals and institutions.





#### **CMS PFE Values**

**Person Centered** – CMS puts the best interest of the public first and actively encourages persons to engage with their providers, and empowers patients and advocates to communicate their personal preferences. CMS applies PFE best practices by meaningfully including patients and advocates in their policy discussions.

Health Literacy – CMS recognizes the importance of health literacy and its role in improved health outcomes. Recognition of low health literacy is essential to ensure every person is able to understand the information presented to them, and able to make informed decisions about their care. Documented information provided to the person and/or family should include definitions of medical terms, diagrams, and pictures of functions and common language in concise single concept sentences for enhanced readability at all levels. Providers, practitioners, and community partners should tailor their guidance and support to accommodate the individual needs of those for who they are providing care and services.

Accountability – CMS has a unique and privileged role in the healthcare of our nation and earns trust by taking responsibility for the outcomes of its actions. CMS continually strives to include the patient's voice, data and evidence in its policy decisions and seeks to make information transparent. CMS provides a structure between the providers of healthcare and the recipients of that care, which encourages persons and providers to co-create their healthcare goals.

**Respect** – CMS recognizes that a successful person-centered approach requires mutual respect between individuals and the providers of their care.

These PFE values will strengthen CMS' ability to reach the three broad aims of **the National Quality Strategy:** 







Healthier People and Communities



Better Care

#### **CMS PFE Foundational Principles**

**Promote Informed Decision Making:** CMS wants individuals to have meaningful tools and information for making decisions about their health and participating in bi-directional decision making with their providers. Through a secure environment that is respectful of privacy, CMS also aims to give individuals electronic access to their health information, and encourages the use of web portals to obtain reliable information about healthcare conditions and related information.



#### **BACKGROUND**

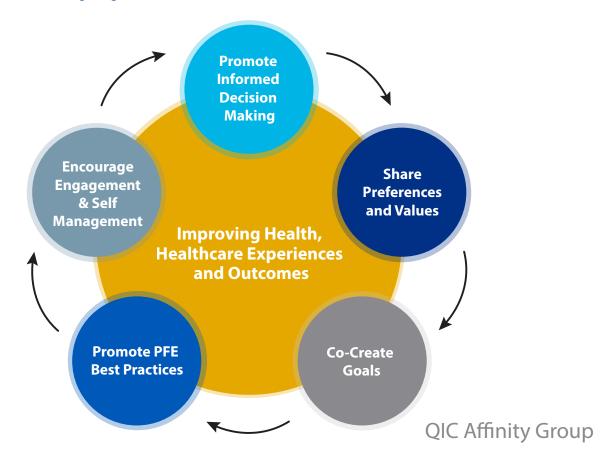
Share Preferences and Values: Persons who are engaged in their care are empowered to communicate their health-related preferences to their healthcare provider. CMS encourages persons to achieve their own optimal results, and providers should engage with persons, families, and caregivers to set realistic goals based on these preferences and values.

**Co-Create Goals:** CMS encourages persons having a clear understanding of their circumstances, diagnosis, prognosis, and healthcare options. Based on this, persons can work together with their healthcare providers to co-create goals to ensure that individual preferences are considered in the healthcare goal setting process.

**Promote PFE Best Practices:** Providers should have access to person and family engagement best practices and techniques that improve experience of care for persons and families.

**Encourage Engagement and Self-Management:** Individuals' accountability and responsibility for their healthcare should be increased. CMS encourages providers to actively engage persons and families in discussions about their healthcare self-management, taking both preventive measures and active steps to improve their health. It is essential to regularly ask individuals about their priorities and experiences to identify any obstacles related to self-management.

Foundational principles guide CMS' actions in achieving its goals for PFE.





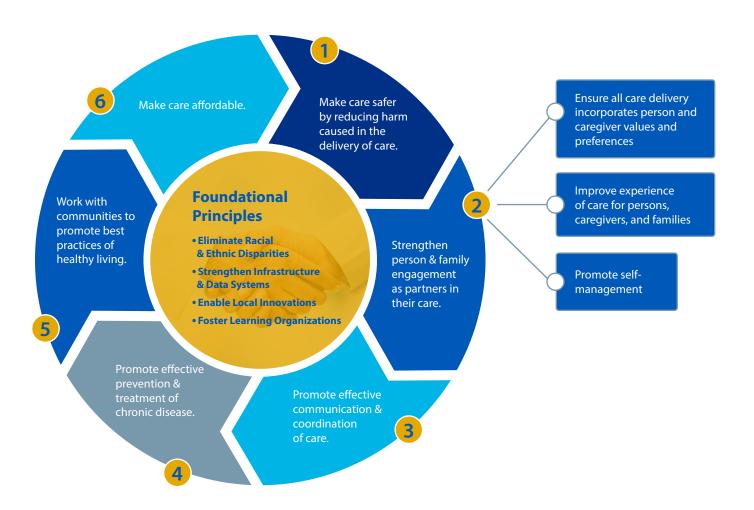
#### **BACKGROUND**

#### **Alignment to the CMS Quality Strategy**

CMS is working to build a healthcare delivery system that is better, smarter, effective, and efficient, – a system that delivers improved care, spends healthcare dollars more wisely, and one that makes our communities healthier. Built on the foundation of the CMS Strategy and the HHS National Quality Strategy, the CMS Quality Strategy identifies 6 priority areas of focus. The PFE Strategy directly aligns with one of these priority focus areas.

### **CMS Quality Strategy Goals**

Better Care. Healthier People. Healthier Communities. Smarter Spending





#### = PFE STRATEGY GOALS =

#### Goal 1:

#### **Partnership with Communities**

Actively encourage person and family engagement along the continuum of care within the broader context of health and well-being, and in the communities in which they live. This will exceed the traditional boundaries of setting-specific care, and will identify opportunities to bridge and forge partnerships among providers, persons, and community resources.

#### Goal 2:

#### Values, Preferences & Self-Managing Care

Promote tools and strategies that reflect person and/or family values and preferences and enable them to actively engage in directing and self-managing their care.

#### Goal 3:

#### **Creating a Culture of Partnership**

Create an environment where persons and their families work in partnership with their healthcare providers to develop their health and wellness goals informed by sound evidence and aligned with their values and preferences.

#### Goal 4:

#### **Experience & Best Practices**

Improve experience and outcomes of care for persons, caregivers, and families by developing criteria for identifying person and family engagement best practices and techniques in the field from CMS programs, measurements, models, and initiatives, that are most ready for widespread scaling and integration across the country.



### **Goal 1 Partnership with Communities**

Actively encourage person and family engagement along the continuum of care within the broader context of health and well-being, and in the communities in which they live. This will exceed the traditional boundaries of setting-specific care, and will identify opportunities to bridge and forge partnerships among providers, persons, and community resources.

### Identify and promote community resources already in place that are culturally and linguistically appropriate.

- Duplication of effort is minimized and we build upon existing resources and best practices.
- · Community partners learn from one another and encourage ongoing improvement.
- Health and well-being is promoted across all settings of care.

### Enhance existing relationship between trusted community partners and patient advocates

(e.g. senior centers, libraries, and faith based organizations).

- Goals/efforts identified by the community are based on needs and preferences of the citizens.
- Community partners use two-way communication with healthcare providers/systems to guide priorities within each community.
- · Community partners support and form alliances with each other.
- · Community partners are relied on for continuing education and efforts.





#### Goal 2 Values, Preferences, & Self-Managing Care

Promote tools and strategies that reflect person and/or family values and preferences and enable persons to actively engage in directing and self-managing their care.

### Promote deployment of self-management and empowerment programs.

- Persons and families believe that engaging in their care and partnering with providers and organizations will help improve the quality and safety of care.
- Persons and families have awareness of and access to promising practices and tools that reflect their personal values and preferences.
- Healthcare navigators, electronic healthcare information, and translation services are used more often.
- New population based payment models include the perspective of persons and families in program design and development.
- The shared decision making process is documented (including all preferences, goals, treatment plans, treatment risks, and benefits) in the medical record or electronic health record.

### Create, expand, and maintain National Person and Family Engagement (PFE) Networks, including National Patient Advisory Councils.

- Individuals have access to advocates who can assist them in navigating the healthcare system and/or aid in developing effective communication strategies for discussing health goals with their providers, practitioners, and community partners.
- Individuals feel they have access to the support they need to make the healthcare decisions that are most likely to improve their health.
- Persons and families experience better quality, improved experiences, and greater satisfaction through improved access to necessary healthcare or community resources such as transportation or language access services.

# Incorporate and integrate person and family centered initiatives into CMS programs addressing healthcare quality, disparities, regulations, and Conditions of Participation.

- Persons and families are active partners in identifying, obtaining, and maintaining their health and wellness needs to enable them to achieve better health, better care, and lower costs.
- Future CMS policies, programs, quality measures, and innovations in payment models are developed with intentional alignment with the PFE strategy goals and desired outcomes.
- Persons receiving care and their advocates are included in the CMS policy and program design and decision making.
- Among persons who rely on others to manage their health, the identity of the person who
  helps them is documented by providers and support this relationship in the decision
  making process.
- CMS consistently uses a person-centered approach to policy and program design and decision making.







### Goal 3 Creating a Culture of Partnership

Create an environment where persons and their families work in partnership with their healthcare providers to develop their health and wellness goals informed by sound evidence and aligned with their values and preferences.

Develop and promote the use of person and family experience surveys and quality outcome measures that evaluate the impact of best practices across the entire healthcare system, promote healthcare quality improvement and align results with CMS' person and family directed goals.

- Experience surveys are designed in a way that makes it easy for recipients of care and their family and caregivers to express concerns and self-manage personal health and wellness goals
- Experience surveys are translated into multiple languages as appropriate, are administered via
  a method that improves response rates for limited English proficiency (LEP) populations and
  include appropriate questions about the availability of language services.
- Experience surveys are used to identify individuals with language or literacy assistance needs and survey results are utilized to improve health literacy and/or health outcomes.
- Quality measures are developed that are of value to persons, families and providers and are informative in decisions about care
- Persons, families, and providers collaborate to identify survey results and quality measures
  to implement the best practices for improving individuals' expression of concerns and selfmanagement of personal health and wellness goals.
- Experience surveys and quality measures incorporate family perspectives, concerns and objectives for persons who rely on a family member to enact their health and wellness goals.

### Encourage a partnership between providers and the patient and families to co-create health and wellness goals.

- Healthcare providers across the continuum of care attend educational programs on improving person and family/caregiver experience, as well as form partnerships to develop and achieve person-directed health and wellness goals.
- Recipients of care and their family/caregivers have information, resources, and education on how
  to partner with providers in co-designing and managing health and wellness goals.
- Providers, persons, and families have the culturally and linguistically appropriate information and resources needed to participate in pertinent health prevention and care management initiatives such as the Million Hearts Campaign, CDC's Prevent Diabetes STAT, Everyone with Diabetes Counts.
- Providers, persons, and families have information and education on resources to complete
  advance directives that align with the person's wishes concerning end-of-life treatment and care.
- Providers receive training on how to initiate and participate in end-of-life treatment and care discussions with persons and their families/caregivers.
- Providers are strongly encouraged to designate specific time to initiate and participate in end-oflife treatment and care discussions with persons and their families/caregivers.



### Goal 4 Experience & Best Practices

Improve experience and outcomes of care for persons, caregivers, and families by developing criteria for identifying person and family engagement best practices and techniques that are ready for widespread scaling and integration across the country.

# Develop criteria, guidelines and/or standards for person and family engagement best practices and techniques that are aligned with CMS' PFE goals.

- · PFE best practices and techniques are identified.
- The voice of the person and family is activity sought in the development of policy, programs, and innovative payment models.
- Increase access to understandable health information based on language and health literacy level.
- Measures of family engagement are identified and incorporated in the evaluation of PFE for persons who rely on a family member to enact their healthcare plan.
- Providers are trained to utilize standardized person and family engagement behaviors.

#### Improve PFE through widespread implementation of best practices

- PFE best practices and techniques are successfully implemented nation wide in healthcare settings and alongside community partners
- Peer-to-peer mentoring and technical assistance is provided with materials and templates that organizations and their healthcare teams can use while communicating with low English proficiency and low health literacy populations.

### Implementation plan and strategies, resource allocations, and evaluation criteria are specifically re-assessed on an ongoing basis.

 PFE best practices and techniques are continuously improved and successful strategy methods for implementation are shared.





#### **Engaging Persons and Families**

CMS Recognizes that PFE is essential to the health and well-being of our communities, and is committed to supporting, implementing, and integrating PFE principles into all of our actions and programs. Examples of CMS initiatives that incorporate PFE principles include:

- CMMI: The Center for Medicare and Medicaid Innovation
- The Partnership for Patients (PfP) Person and Family Engagement Roadmap
- · Coverage to Care Initiative CMMI's Accountable Care Communities
- Medicaid Family Counseling Programs
- · CMS experience of care surveys
- Quality Improvement Networks National Coordinating Center-Trends in PFE call series

#### **CMS Integration of Person and Family Engagement**

Communication	Preferences and Values	Collaboration	Engagement
Accommodate for different person/family literacy levels and disabilities (e.g. vision, dexterity issues, hearing).	Experiences from patient surveys are utilized to improve communication, engagement, and quality of care received.	Increase collaboration and sharing opportunities among coordinators, group leaders, and staff.	Creation of PFE emerging best practices inventory containing over 350 tools and resources.
From Coverage to Care: National initiative to support consumers with low health literacy and limited English proficiency.	Improve access to integrated community prevention efforts.	Provide schools, families, and communities with tools for promoting healthy living.	Identify patient centered measures.
Create and expand the development of a wide variety of resources available in multiple languages.	Treat family members with respect, provide emotional support for values and preferences.	Partner with all providers (e.g. pharmacists) to increase the understanding of medication side effects.	Encourage patient and family use of online resource center (e.g. use a mix of communication techniques, beneficiary liaisons).



#### = NEXT STEPS =

#### **CMS Next Steps**

CMS is committed to furthering PFE work. Some next steps for the agency include:

### Continuing to incorporate and promote PFE principles in our daily work

- Successfully achieve defined goals and objectives by including PFE principles into of all CMS' programs and policies.
- Monitor success indicators for each PFE goal and objective to assess impact and opportunities for improvement.

#### Partnering to create a better outcome

- Continually soliciting feedback from stakeholders to inform and enhance PFE work across the agency.
- Expand existing avenues for two-way communication existing avenues for two-way communication with beneficiaries.

#### Strengthen PFE principles over time

· Continuously strengthen PFE principles.

### What Are Your Next Steps?

CMS challenges you to evaluate your programs and take action in incorporating PFE related concepts to improve how you interact with persons and their families, ultimately improving their experiences and outcomes.

