



Centers for Medicare & Medicaid Services

# Person and Family Engagement Strategy

FINAL

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# 1. Overview

The purpose of the Centers for Medicare & Medicaid Services (CMS) Person and Family Engagement (PFE) Strategic Plan is to guide the meaningful and intentional implementation of person and family engagement throughout CMS policies and programs. This plan lays the foundation for expanding awareness and guidance on person and family engagement by providing goals and objectives that are effective, sustainable and scalable.

While this plan supports the implementation of the CMS Quality Strategy Goal 2: Strengthen persons and families as partners in their care, it is also a foundational component to achieving the overarching CMS strategy.

This strategic plan takes into consideration work in person-centered care being done across the Department of Health and Human Services (HHS) operating divisions including the Agency for Community Living (ACL), the Substance Abuse and Mental Health Services Administration (SAMHSA), the Health Resources and Services Administration (HRSA), Assistant Secretary for Planning and Evaluation (ASPE), the Agency for Healthcare Research and Quality (AHRQ), the Office of the National Coordinator (ONC) and the Department of Veterans Affairs.

An example of person and family engagement being incorporated into the Agency's work includes, but is not limited to, the Partnership for Patients (PfP) Person and Family Engagement Roadmap. This roadmap "recognize[s] that partnering with persons and families is a critical factor in achieving improvements in the quality and safety of care" and also highlights person and family engagement "strategies that are generalizable, effective, [and] help achieve sustainability." Measurement and metrics are also emphasized to demonstrate the importance of being able to measure success and conduct ongoing monitoring, feedback and coaching. These steps serve as a building block to "creating a culture shift...where the patient is truly [included in the care team]<sup>1</sup>."

A second example of how CMS has incorporated person and family engagement into its work is shown in the From Coverage to Care initiative launched by the CMS Office of Minority Health. This initiative outlines multiple approaches and tools to engage the person and family in his or her care. These tools include methods to understand benefits and connect to primary care and preventive services to help patients live a long and healthy life. This approach also addresses the need for culturally and linguistically appropriate materials to help the patient and family understand the information needed to make health care decisions.

CMS is at the forefront of the nationwide effort to transform health care delivery to meet the person-centered goals of each individual in creating a health care system that fully engages persons and families in the design, delivery and evaluation of care. It is hoped that this strategy elevates the level of current dialogue about person and family engagement, while also establishing definitions and consistency for frequently used terms related to engaging persons in their health care.

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<sup>1</sup> Hospital Engagement Network (HEN) staff interview.

## 2. Introduction

Beginning as early as the 1900s, there has been the recognition of a patient’s right to protect the integrity of one’s own body and the need for patient consent or knowledge regarding what shall be done<sup>2</sup>. The basic elements of informed consent, as outlined in this groundbreaking case, served as the cornerstone of patient participation to the extent that it initiated the practice of disclosing information to patients about their care and medical services rendered. Over the past few decades, this one-way street of informing the patient has evolved into a two-way street of communicating with patients. As the concept of patient engagement has evolved, so too has the expectation of many persons to be educated about their diagnosis, treatment options, care and outcome.

### **Impact on Health Care Policy**

Person and family engagement is an essential part of developing national health care policy, quality measurement, reporting and improvement initiatives and new payment models. In many cases, when the health, safety, values and goals of the individual are considered, health care delivery improves. Individuals who feel responsible for their health and are engaged with their health care providers can help to improve the American health care system. Empowered persons who are truly partners with their providers in setting health care goals and making health care decisions are better able to actively participate in moving toward achieving those goals. It is essential for health care providers to create meaningful partnerships with persons, families and caregivers to bring their preferences into the care discussion<sup>3</sup>.

In addition to improving the individual’s experience, advancement of person-centered care models could improve quality of care and health outcomes, engage people more actively in their health care and reduce costs and disparities in care<sup>4</sup>.

This plan uses “family” broadly to include participants in a person’s health care including informal caregivers, along with the primary care givers of persons who are in need of the support of their care givers to make informed health care decisions. For purposes of this plan, the term “provider” refers to any provider of care and services including both individuals and institutions. For clinical purposes, the Institute of Medicine defines patient-centered care as “respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions.” The National Quality Forum defines person and family centered care as “an approach to the planning and delivery of care across settings and time that is centered on collaborative partnerships among individuals, their defined family and providers of care. It supports health and well-being by being consistent with, respectful of and responsive to a person’s priorities, goals, needs and values.” Using these key definitions as a foundation, CMS defines person and family engagement as follows: “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

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<sup>2</sup> Schloendorff v. Society of N.Y. Hosp., 105 N.E. 92, 129–30 (1914).

<sup>3</sup> Epstein RM, Street RL, Jr. Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. National Cancer Institute, NIH Publication No. 07-6225. Bethesda, MD, 2007.

<sup>4</sup> Hibbard, J., Greene, J., & Overton, V. Patients with Lower Activation Associated with Higher Costs; Delivery Systems Should Know their Patients’ ‘Scores’. Health Affairs. February 2013, 32(2), 216-222.

transformation in attitudes, behavior and practice.” This strategy recognizes each individual as a person, because individuals are not always patients; however, the terms person and patients may both be utilized depending on the setting and situation being referenced.

For purposes of this strategy, self-management refers to the act of supporting persons and family to be educated, engaged and active participants in the decision making process of their care. The AHRQ defines self-management support as “the help given to people with chronic conditions that enables them to manage their health on a day-to-day basis. Self-management support can help and inspire people to learn more about their conditions and to take an active role in their health.”

A person-centered approach considers the individual as multifaceted, not merely as the carrier of a particular symptom or illness, or “receiver” of services. For example, the Affordable Care Act requires that states receiving federal funds develop systems that are responsive to the needs and choices of beneficiaries receiving Home and Community-Based Services (HCBS), maximize independence and self-determination and provide coordination to assist with achieving a community-supported life. This approach demands that providers and individuals share power and responsibility in goal setting, decision-making and care management. It also requires giving people access to understandable information and decision support tools to equip them and their families with the information to manage their health and wellness, navigate the full span of the health care delivery system and make their own informed choices about care.

### **Health Literacy**

Persons are often expected or required to navigate many tasks associated with their health care needs. These tasks include identifying and accessing services needed, understanding risks and benefits of options, determining reliability of information received, processing and referencing test and lab results, communication with one or more providers or practitioners, locating information relevant to health services needed and compliance with treatment plans. One common thread in the quest for improved and active person engagement and participation is the need for providers, practitioners and community partners to be able to identify their patients’ level of health literacy in order to then address the needs of their patients. According to AHRQ, reduced health literacy is associated with an increased risk of emergency department visits, hospitalizations and death<sup>5</sup>. Under the ACA, health literacy is defined as the extent to which a person poses the “...capacity to obtain, communicate, process and understand health information and services in order to make appropriate health decisions<sup>6</sup>.”

People identified as having low health literacy experience communication challenges and report both a decrease in well-being and less understanding about their medical conditions and treatment plans<sup>7</sup>. Person centered health care must be individualized to accommodate the complexity of the person’s medical needs, socio-economic status, other social determinants and cultural preferences, which affect the person’s health and ability to participate in and manage their care.

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<sup>5</sup> National Network of Libraries of Medicine, Health Literacy, <https://nnlm.gov/outreach/consumer/hlthlit.html>.

<sup>6</sup> Centers for Disease Control and Prevention, Health Literacy, <http://www.cdc.gov/healthliteracy/learn/>.

<sup>7</sup> Committee on Health Literacy for the Council on Scientific Affairs, Health Literacy Report of the Council on Scientific Affairs, *Journal of the American Medical Association*, February 10, 2999, <http://jama.jamanetwork.com/article.aspx?articleid=188749>.

## Caregiver and Family Support

While the majority of adults prefer to manage their own care, some decide to make health care decisions through co-management or delegation of health care decisions to family members or close friends. Societal factors such as age, socio-economic factors, education level, cultural beliefs and traditions and health characteristics all impact the way that a person may choose to manage their health care. Due to the subtle nuances of how these unique factors impact the way that individuals make health care decisions, it is imperative that discussions about health care include an open dialogue of the parties who should be included in health care conversations. The co-creation of health care goals should provide the opportunity for family members, close friends or caregivers to participate in these important conversations about health.

## 3. Organizational Tenets

The following are the organizational tenets of this strategy:

### 3.1 Vision

A transformed health care system that proactively engages persons and caregivers in the definition, design and delivery of their care.

### 3.2 Mission

To create an inclusive, collaborative and aligned national person and family engagement framework that is guided by person-centered values and drives genuine transformation in attitudes, behavior and practice.

### 3.3 Values

These PFE values will strengthen CMS's ability to reach the three broad aims of the National Quality Strategy (Better Care, Healthier People and Communities, Affordable Care) and goals of the CMS Quality Strategy:

**Person Centered** – CMS puts the best interest of its beneficiaries first, actively encouraging persons to engage with their providers and empowering patients and advocates to communicate their personal preferences. CMS continues to meaningfully include 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 appropriately 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 health care 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 health care and the recipients of that care, which encourages persons and providers to co-create their health care goals.

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

## 4. The Person and Family Engagement Strategy

### 4.1 Foundational Principles

Foundational principles guide CMS's action toward each of the PFE goals. To ensure that these principles are actively addressed, how these principles are embedded in each goal will be continuously evaluated.

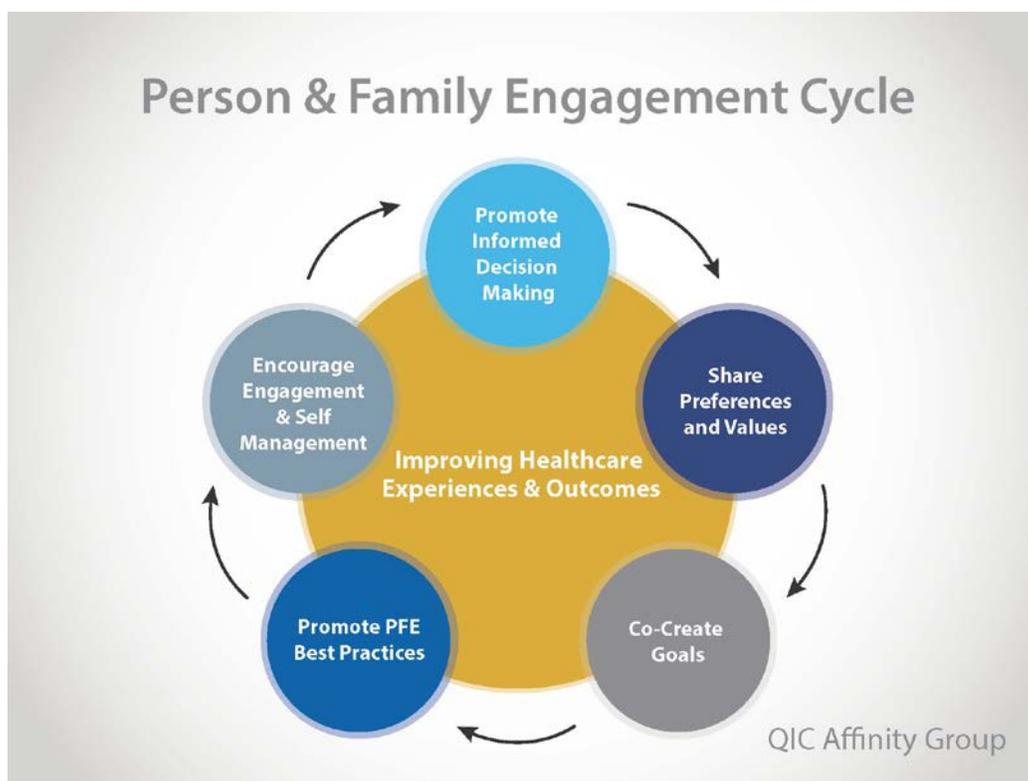


Figure 1. The PFE Engagement Cycle

#### **Promote Informed Decision Making**

CMS wants individuals to have evidence-based tools and information from an array of modalities that are meaningful when making decisions about their health. Armed with information about health conditions, health care status, how best to manage a particular condition and understanding how best to meet their needs based on the relevant diagnosis, individuals are

better able to participate in bi-directional decision making with their health care provider, practitioner, or community partner. 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 health care conditions and related information.

### **Share Preferences**

The engaged person is empowered to communicate his or her health-related preferences to their health care provider. CMS encourages persons to achieve optimal results given their circumstances and providers should engage with persons, families, and caregivers to set realistic goals.

### **Co-Create Goals**

CMS encourages persons to have a clear understanding of their circumstances, diagnosis, prognosis and health care options. Based on this, persons can work together with their health care provider, practitioner, or community partner to co-create goals to ensure that individual preferences are considered in the health care 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. Various organizations, such as the National Partnership for Women and Families, have already recommended best practices for person and family engagement<sup>8</sup>. Criteria to identify which best practices are ready for wide scale adoption and integration in applicable settings will help providers determine which best practices are most appropriate.

### **Encourage Engagement and Self-Management**

Individuals' accountability and responsibility for their health care should be increased by encouraging providers, practitioners and community partners to actively engage individuals in health care discussions including the person's self-management of their health, taking both preventive measures and active steps to improve their health outside of the inpatient or outpatient provider settings. It is essential to regularly ask individuals about their priorities and experiences to identify any obstacles related to self-management.

## **4.2 Drivers and Policy Levers**

CMS is actively engaged in activities to further involve persons and families and considers every lever available to ensure engagement. CMS finds that change happens when there is alignment across quality measurement, quality improvement, payment policies and oversight activities. Persons and family engagement is no different in that regard. Four areas of activity are considered for ensuring a broad based approach to engagement including:

- Policies, Programs and Quality Improvement
- Benefit Design, Value and Incentives

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<sup>8</sup> National Partnership for Women & Families. National Strategy for Quality Improvement in Health Care' Reflects and Unprecedented Commitment to More Patient-Centered Care and to Improving Communication, Coordination of Care. 2011, March 22. <http://www.nationalpartnership.org/news-room/press-releases/national-strategy-for-improvement-in-health-care.html>.

- Engagement in Decision Making, Care Coordination, Prevention and Treatment
- Family and Caregiver Support and Engagement

*This graphic illustrates the different ways that CMS works to engage people and their families.*

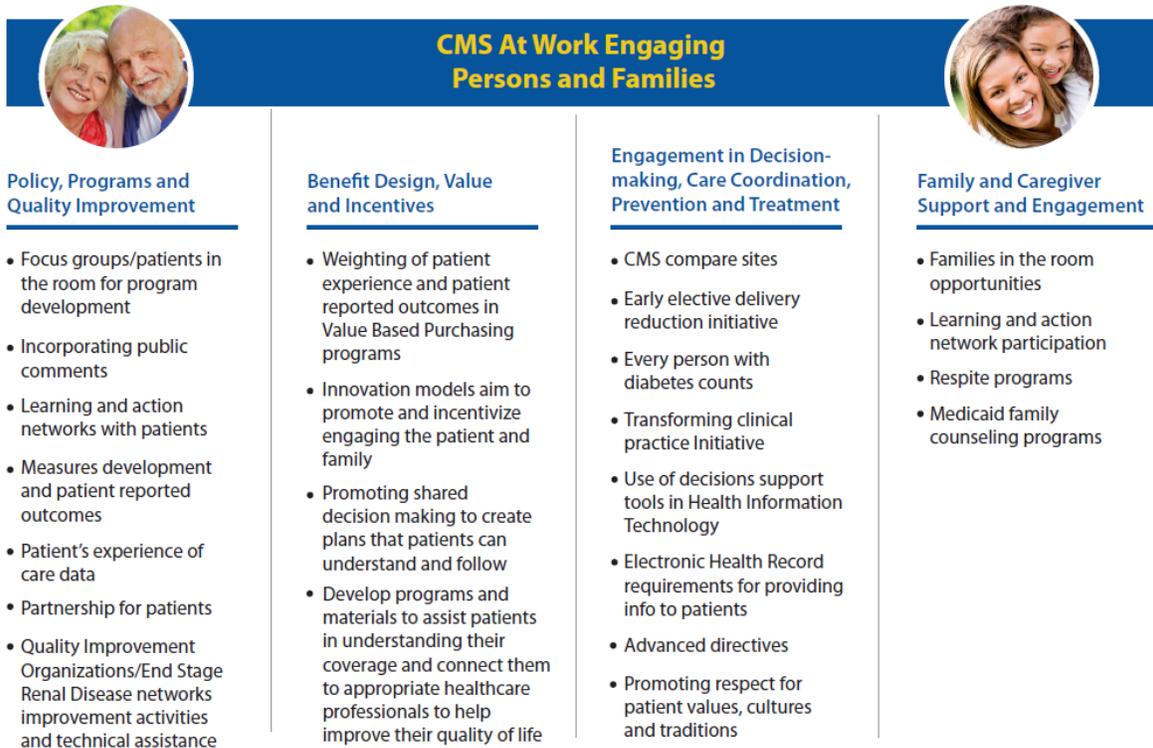


Figure 2. CMS at Work Engaging Persons and Families

### 4.3 Partners and Roles

Many partners are essential to successfully engage individuals in their health care. CMS is a convener of these partners and a foundation-setter for the health care community. CMS will establish a basis from which these partners can expand and spread PFE values, goals and culture. This strategy will be shared with these partners to help inform their work.

#### CMS

As a lead partner, CMS has the capacity to directly drive or implement changes to payments, regulations, quality measurement and practice transformation and to improve transparency in service of the goals and objectives outlined in this strategy. CMS has developed this strategy to share the Agency's person and family engagement vision and encourage the entire health care community to consider and take action to incorporate the principles into their work practices.

#### Partners

To achieve its goals, CMS forges partnerships among federal, state, territorial, tribal and local governments; business, industry and other private sector partners; professional philanthropic organizations; community and faith-based organizations; beneficiaries and citizens to improve

health. CMS also works closely with State Medicaid and Children's Health Insurance Program Agencies that partner in financing and implementing health care programs. Private sector insurers are key partners, who often model their approaches to payment and delivery on CMS's approaches.

Internally, CMS components also participate in Affinity Groups, including the Person and Family Engagement Affinity Group, through which groups of individuals interested in and working on particular topics to come together and develop an aligned approach to incorporate person and family engagement concepts throughout CMS's work.

## 5. The Person and Family Engagement Strategy Goals

### 5.1 Alignment to CMS Quality Strategy Goals

The PFE strategy is aligned with the CMS Quality Strategy Goal 2: *Strengthen persons and families as partners in their care*. The objectives of that goal are:

1. Ensure all care delivery incorporates person and caregiver preferences
2. Improve experience of care for persons, caregivers and families
3. Promote person self-management

The PFE Strategy includes four goals:

1. 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.
2. 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.
3. Create an environment where persons and their families work in partnership with their health care providers to develop their health and wellness goals informed by sound evidence and aligned with their values and preferences.
4. 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.

### 5.2 Goal 1

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

## 5.2.1 Goal 1 – Objectives and Desired Outcomes

Objectives	Desired Outcomes
Identify and promote community resources already in place that are culturally and linguistically appropriate.	<ul style="list-style-type: none"> <li>• Duplication of effort is minimized and we build upon existing resources and best practices</li> <li>• Health and well-being is promoted beyond the health care setting to include community partners</li> <li>• Community partners learn from one another and encourage ongoing improvement</li> <li>• </li> </ul>
Enhance existing relationships between trusted community partners and patient advocates (e.g., senior centers, libraries and faith based organizations).	<ul style="list-style-type: none"> <li>• Goals/efforts identified by the community are based on needs and preferences of the population</li> <li>• Community partners use two-way communication with health care providers/systems to guide priorities within each community</li> <li>• Health care providers have knowledge of community resources and referral sources that can be incorporated into health care treatment planning with the patient and their families</li> <li>• Community partners support and form alliances with each other</li> <li>• Community partners are relied on for continuing education and efforts</li> </ul>

## 5.3 Goal 2

*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.*

### 5.3.1 Goal 2 – Objectives and Desired Outcomes

Objectives	Desired Outcomes
Promote deployment of self-management and empowerment programs.	<ul style="list-style-type: none"> <li>• Persons and families believe that engaging in their care and partnering with providers and organizations will help improve the quality and safety of care</li> </ul>

	<ul style="list-style-type: none"> <li>• Persons and families have awareness of and access to promising practices and tools that reflect their personal values and preferences</li> <li>• Health care navigators, electronic health care information and translation services are more highly utilized</li> <li>• New population based payment models include the perspective of persons and families in program design and development</li> <li>• 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</li> </ul>
<p>Create, expand and maintain National Person and Family Engagement (PFE) Networks, including National Patient Advisory Councils.</p>	<ul style="list-style-type: none"> <li>• Individuals have access to advocates who can assist them in navigating the health care system and/or aid in developing effective communication strategies for discussing health goals with their providers, practitioners and community partners</li> <li>• Individuals feel they have access to the support they need to make the health care decisions that are most likely to improve their health</li> <li>• Persons and families experience better quality, improved experiences and greater satisfaction through improved access to necessary health care or community resources such as transportation or language access services</li> </ul>
<p>Incorporate and integrate person and family centered initiatives into CMS programs addressing health care quality, disparities, regulations and Conditions of Participation.</p>	<ul style="list-style-type: none"> <li>• Persons and families are active partners in identifying, obtaining and maintaining their health and wellness to enable them to achieve better health, better care and lower costs</li> <li>• Future CMS policies, programs, quality measures and innovations in payment models are developed with intentional alignment with the PFE strategy goals and desired outcomes</li> </ul>

	<ul style="list-style-type: none"> <li>• Persons receiving care and their advocates are included in CMS policy and program design and decision making</li> <li>• 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</li> <li>• CMS consistently uses a person-centered approach to policy and program design and decision making</li> </ul>
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## 5.4 Goal 3

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

### 5.4.1 Goal 3 – Objectives and Desired Outcomes

Objectives	Desired Outcomes
<p>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 health care system, promote health care quality improvement and align results with CMS's person and family directed goals.</p>	<ul style="list-style-type: none"> <li>• Experience surveys are designed in a way that makes it easy for recipients of care and their family/caregivers to express concerns and self-manage personal health and wellness goals</li> <li>• 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</li> <li>• 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</li> <li>• Quality measures are developed that are of value to persons, families and providers and are informative in decisions about care</li> </ul>

	<ul style="list-style-type: none"><li>• Persons, families and providers collaborate to identify survey results and quality measures to implement the best practices for improving individuals' expression of concerns and self-management of personal health and wellness goals</li><li>• 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</li></ul>
<p>Encourage a partnership between providers and the patient and families to co-create health and wellness goals.</p>	<ul style="list-style-type: none"><li>• Health care 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</li><li>• 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</li><li>• 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</li><li>• Providers, persons and families have information and education on resources to complete advance directives if desired that align with the person's wishes concerning end-of-life treatment and care</li><li>• Providers receive training on how to set aside time for, initiate, and participate in end-of-life treatment and care discussions with persons and their families/caregivers</li></ul>

## 5.5 Goal 4

*Develop meaningful measures and tools aimed at improving the experience and outcomes of care for persons, caregivers and families. Also, identify person and family engagement best practices and techniques in the field that are ready for widespread scaling and national integration.*

### 5.5.1 Goal 4 – Objectives and Desired Outcomes

Objectives	Desired Outcomes
<p>Develop meaningful measures and tools, guidelines and/or standards for person and family engagement best practices and techniques that are aligned with CMS’s PFE goals.</p>	<ul style="list-style-type: none"> <li>• PFE best practices and techniques are identified</li> <li>• The voice of the person and family is actively sought in the development of policy, programs and innovative payment models</li> <li>• Increase access to understandable health information based on language and health literacy level</li> <li>• Measures of family engagement are identified and incorporated in the evaluation of PFE for persons who rely on a family member to enact their health care plan</li> <li>• Providers are trained to utilize standardized person and family engagement behaviors</li> </ul>
<p>Improve PFE through widespread implementation of best practices (as determined under objective #1).</p>	<ul style="list-style-type: none"> <li>• PFE best practices and techniques are successfully implemented nationwide in health care settings and alongside community partners</li> <li>• Peer-to-peer mentoring and Technical Assistance is provided with materials and templates that organizations and their health care teams can use while communicating with LEP and low health literacy populations</li> </ul>
<p>Implementation plan and strategies, resource allocations and evaluation criteria are specifically re-assessed on an ongoing basis.</p>	<ul style="list-style-type: none"> <li>• PFE best practices and techniques are continuously improved and successful strategy methods for implementation are shared</li> </ul>

Note that the provided objectives are examples of how CMS will accomplish the stated strategy goals and are not exclusive.

## Attachment A – The CMS Integration of PFE

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

Communication	Preferences and Values	Collaboration	Engagement
Help people with new health care coverage understand their benefits and connect to primary care and preventative services that are right for them.	Develop a Hospice CAPHS survey to capture patient/caregiver experience of care.	Creation and expansion of the PFE Network (patient advocates, patient advisors, PFP partner organizations).	Creation of PFE emerging best practices inventory containing over 350 tools and resources.
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.	Development and execution of 15 well-attended PFE Affinity Group Master Classes.
From Coverage to Care: National initiative to support consumers with low health literacy and limited English proficiency.	Improve access to integrated community prevention efforts.	Improve health through evidence-based community interventions.	Inclusion of patients and family members in technical expert panels (TEP) such as the Star Rating TEP to identify patient centered measures.
Shift change huddles and bedside reporting.	Efforts to prevent disease before it develops. Expanded adoption of healthy life style behaviors across the person's life span.	Provide schools, families, and communities with tools for promoting healthy living.	Access CMS Managed Care and Quality Improvement Contractors against patient experience and quality of care measures.
Establish an integrated communication program to raise awareness about healthcare disparities.	Improve care and quality of life for all Americans through the elimination of disparities.	Recruitment through partnering with different state agencies and executive leadership participation in discussions and meetings.	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).