Key Steps for Creating Patient and Family Advisory Councils in CPC Practices

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I. Introduction

The overarching goal of the Comprehensive Primary Care Initiative (CPC) is to encourage and facilitate primary care practices in **delivering higher quality, better coordinated, and more patient-centered care.** A central strategy for achieving these important and ambitious goals is through Milestone #4 of the initiative—directly engaging patients and families in their care.

Establishing a **Patient and Family Advisory Council (PFAC)** is one way to meet this milestone as well as a strategy for ensuring that practices improve quality, efficiency, and patients' and families' experiences. Working side-by-side with patients and families is a unique opportunity to not only gain a better understanding of their experiences but also to partner with them to **improve processes, procedures, care delivery and outcomes.**

> **As advisors in a PFAC, patients, families, and providers work together on procedures, processes, and quality improvement strategies to achieve high quality, coordinated, and patient- and family-centered care**

II. Definition

A PFAC is an established council within a health care practice which meets regularly and consists of patients and family members who receive care at the practice. Select providers, clinicians, office staff, and leadership are also integrated members of the PFAC and work with the patient and family advisors to discuss improvements in care, processes, and experiences. Key to the PFAC is that patients and family caregivers are viewed as **respected partners and essential resources to the practice.**

Just as important as understanding what a PFAC **is**, is understanding what it's **not.**

1. **Focus group**: A PFAC is not a group of patients who are convened to answer questions for research purposes. While focus groups meet for a short duration, PFACs come together on an ongoing basis and provide continuing guidance to the overall practice. Also unlike a focus group which is established for discussions around a specific topic, PFAC discussions and topics should be generated from an agenda and workplan established by the group and centered

around improving the practice in ways that meet the needs of patients and families.

2. **A "check the box" activity**: Patient and family advisors will not remain engaged in the PFAC if they feel they are only involved with the practice to fulfill a requirement and are not making a difference. It is critically important for the practice to continually demonstrate that patients' and family caregivers' voices are being heard and taken seriously. Advisors should always know the outcome of their advice, even if their suggestions cannot always be implemented.

III. The Steps

The recommendations described below will help practices take the steps needed to establish a PFAC for the first time or enhance Councils that may already be in place. It is important to keep in mind, however, that developing a PFAC into a productive group that helps affect meaningful change will not be achieved overnight. The preparation and establishment of this type of group will require a deliberate process of planning and follow through and practices should consider assigning resources and staff to coordinate the effort over time.

STEP 1: Establish the PFAC Practice Team

‣ Identify practice staff who view patients and families as untapped resources, recognize that patient and family engagement is a quality improvement strategy, and are interested in creating, managing, and leading a PFAC.

‣ Consider engaging staff from all departments/areas of the office—providers, clinicians, office staff, leadership, etc. to participate in or staff the PFAC.

‣ Assign staff roles and responsibilities. A few examples are described below.

  ‣ **PFAC lead** — An essential role for the success of the PFAC. Manages the work of the PFAC overall, serves as the main point of contact for the patient and family advisors, and coordinates the feedback "loop" from the patient and family advisors to the practice leadership and staff. The lead ensures that the PFAC's ideas and guidance are thoughtfully implemented.

  ‣ **Logistics coordinator** — Coordinates meeting dates/times and locations, transportation needs, meeting materials, and other logistical needs.

  ‣ **Recruitment coordinator** — Oversees recruitment process for patient and family advisors.

  ‣ **Scribe** — Takes minutes and other notes at PFAC meetings.

STEP 2: Define and establish the mission, vision, and goals of the PFAC

‣ As a practice team, draft **mission, vision, and goals statements** for the PFAC to review. A few items to consider during that process are:

  ‣ What would you like to accomplish in 3 months? 6 months? 1 year?

  ‣ Why is this work important to your practice?

‣ How will you measure your success?

‣ How will you continually foster relationships with patient and family advisors?

Best practice*: Although practice staff should have a firm understanding of the purpose of the Council and draft mission, vision, and goal statements, ultimately patients and family caregivers should play a role in shaping the PFAC's structure, agendas, and workplans. Be prepared to discuss these statements at the first meeting, seek feedback, and be open to changes.*

▶ Determine the structure of the PFAC:

‣ Determine **how many** patient and family advisors will participate in the PFAC.

‣ Consider whether or not patient and family advisors' service will be **term limited**. If so, how long will terms be?

‣ Draft a **Compact** or similar document that outlines staff and patient and family advisor roles, responsibilities, and expectations. Plan to discuss the Compact at the first PFAC meeting and incorporate patient and family advisors' feedback. (See **Attachment A** for a template).

Best practice*: Eight to ten patient and family advisors on a PFAC is ideal. Ensure that the advisors are representative of your patient population in terms of age, race, ethnicity, geography, family structure, clinical needs, etc.*

STEP 3: Meeting logistics

▶ Think through the logistics of PFAC meetings: Dates, times, and locations of meetings.

▶ Transportation/parking—Provide directions and instructions to Council members who may be driving or taking public transit.

▶ Have contact information for the PFAC lead ready to share with patient and family advisors.

▶ Reimbursement/stipend—Some practices recognize patient and family advisors' contributions by offering honoraria, such as gift cards or catering at meetings. Additionally, consider that some patient and family advisors may not be able to participate in the PFAC without some form of reimbursement for their time or travel.

▶ Child/elder care—Some patient and family advisory members may not be able to participate in the Council because of child or elder care responsibilities. Consider whether the practice can offer these services during meeting times.

STEP 4: Identifying Patient and Family Advisors

▶ Not every patient or family caregiver in a practice will be a good "fit" for a PFAC. Similar to professional roles and responsibilities, certain skills and qualities are better suited for this work and a practice should dedicate ample time to identifying patients and family caregivers who will be the best match.

▸ When thinking about patients and family caregivers to reach out to, consider seeking those who have:

   ▸ Familiarity and experience with the practice (as a patient or a family caregiver)

   ▸ Representative of the population most impacted by the care changes being sought

   ▸ Willingness to speak up

   ▸ History of providing constructive feedback to the practice

   ▸ Able and interested in devoting time and energy to working with the practice

Best practice: *In addition to ensuring the patient and family caregivers reflect the diversity of the practice's patient population, also look for those who have had varying experiences at the practice—both positive and negative—and seek variety in diagnosis, treatments, and programs utilized.*

STEP 5: Recruitment

▸ Once a practice is familiar with the types of characteristics to look for in patient and family advisors, begin looking for specific individuals to serve on the PFAC. The recruitment process can take place through a variety of ways:

   ▸ Ask providers, clinicians, and office staff for suggestions based on their patient populations.

   ▸ Post and advertise notices in the practice's waiting room and examination rooms.

   ▸ Send notices through e-mail, patient portals, or regular mail. Use the practice's electronic health record to identify patients in targeted populations to ensure diverse representation (e.g., patients with diabetes, patients over age 65, African American patients).

   ▸ Place notices in local publications, including newspapers.

   ▸ Contact local community-based organizations that serve populations that also receive care at the practice for recommendations (e.g., Local AARP chapter, houses of worship, Area Agency on Aging, YMCA).

Best practice*: To ensure the most efficient and effective recruitment process, consider engaging in more than one of the outreach methods above simultaneously.*

▸ After going through the suggested recruitment process above, practices will likely have two separate lists of potential patient and family advisors: 1. Individuals who contacted the practice after receiving the email, seeing the ads, etc. and indicated their interest in participating in the PFAC and 2. Individuals who were recommended by providers, clinicians, office staff, or community-based organizations. The next step—the interview process—will need to be approached slightly differently for each group. (See **Attachment B** for sample discussion questions for use in initial conversations with potential patient and family advisors.)

- **For interested individuals who contacted the practice after receiving the email, seeing the ads, etc**.—Practice should be prepared to ask the sample discussion questions at the time the patients or family members call. Use the conversation as an opportunity to get a sense of their past health care experiences at the practice, availability, and interest in the work.

- **For recommended individuals**—When calling these individuals, practice staff should first be looking to gauge the patient or family member's interest in participating in the PFAC. If the individual responds positively, continue through the discussion questions and, as with the group above, get a sense of their past health care experiences at the practice and availability.

Best practice: *In both scenarios, end the conversations reiterating the value of a PFAC and the importance of embedding patients and family caregivers in the practice as a strategy for enhancing care delivery and quality.*

STEP 6: Invitation and Preparation for First PFAC Meeting

- Decide on the date, time, and location of the first meeting. Ensure this is a firm date and will not change for any reason in the coming weeks.

- Review the information gathered through the interviews and make final decisions on the eight to ten patient and family advisors to include on the PFAC. Call each individual to invite them to participate and let them know when the first meeting will take place.

- Send an invitation to all involved staff and emphasize the importance of their attendance. Follow-up with each staff member a few days later to ensure the meeting is on their calendars.

- Create a "welcome packet" for each patient and family advisor and staff member. Include items such as:

  - Organization chart

  - Mission, vision, goals statements

  - Compact

  - Agenda

  - Background documents (e.g., fact sheets, supporting documents, links to available resources)

  - Health care glossary and acronyms list (For sample lists, see **Attachments C and D**).

  - Contact information for staff member who will be the point person for patient and family advisors

  - Proposed future (three to five) meeting times and topics

- When drafting or compiling the "welcome packet" materials, consider factors such as literacy level and writing in plain language. The materials should be understandable and accessible for the patient population the practice will be recruiting.

▸ Send the welcome packet to all patient and family advisors a week before the meeting date and also make it available online, if possible.

▸ Identify a mechanism for PFAC members to provide staff with ongoing feedback about their involvement in the Council as well as a plan for how staff will use that feedback. This process will be very important to ensure the sustainability of the PFAC. Patients and families will lose interest in the Council if they feel their feedback is not being valued or used.

Best practice: *Consider following up with a phone call to each patient and family advisor to ensure they received their welcome packets and ask if they have any questions. Let them know there will be a point-person to offer them support throughout their time on the PFAC, and how to contact that individual. Demonstrating from the start that patient and family advisors are valuable assets to the PFAC and will be supported sets the tone for the entire Council as a place of collaboration and partnership.*

STEP 7: First Meeting

▸ Ensure all staff arrive at the first meeting prepared and begin on time. Open by welcoming patient and family advisors and strive to make them feel comfortable and valued, and emphasize the important role of the PFAC. Consider structuring the remainder of the meeting around the items below:

   ▸ After welcoming the members, begin with a round of introductions so both staff and patient and family advisors become familiar with one another.

   ▸ Reiterate the purpose of the PFAC and underscore that patient and family advisors will be viewed as key partners and will work side-by-side with staff to enhance the way care is delivered in the practice.

   ▸ Explain how patient and family advisors' feedback and ideas will be collected, used, and implemented. It is critical for patient and family advisors to hear and understand the impact of their feedback and how it will (or will not be) implemented.

   ▸ Walk through Compact, mission, vision, and goals statements and welcome feedback.

   ▸ Review agenda and actively discuss each item.

   ▸ At the end of the meeting, discuss potential topics/agendas for the next three to five meetings.

Best practice: *Patient and family advisors will most likely not have a professional background in health care and, therefore, some of the content being discussed at PFAC meetings may be new and unfamiliar.* **Not** *having this background is one of the best reasons to partner with and engage these individuals—***they bring the important and unique perspectives of patient or family members.** *During the first meeting or two, understand that it will take time for patient and family advisors to get up-to-speed on lingo, practice operations, etc. Be supportive during this onboarding process. Take time to provide and go over background materials and resources and be available to answer any questions or concerns. Use plain language always.*

STEP 8: Sustaining the PFAC

▸ Research and experience have shown that effective PFACs have a very positive impact on care delivery and efficiency. Like any new process or relationship, ongoing support and nurturing will be needed to keep the Council engaged and operating at its highest capacity.

▸ When planning for the long-term sustainability of a PFAC, consider the following best practices:

  ▸ Allocate adequate staff time and resources to regular meetings, meaningful topics, and cultivating personal relationships with advisors.

  ▸ Share how patient and family advisors' feedback has been implemented and how/when changes are made to the practice.

  ▸ Commit to checking in on patient and family advisors and ask if they are feeling valued and supported. If the answer is "no," ask how staff can help.

  ▸ Recognize the contributions and commitments of advisors. Consider, with their approval, acknowledging their service by listing their names in the waiting room area, website, etc.

  ▸ Ensure that members are always representative of patients and families being served by the practice.

  ▸ Always treat patients and families as equal and respected members of the team.

STEP 9: Take advantage of available expertise

The National Partnership for Women & Families is a non-profit consumer organization located in Washington, DC that offers technical assistance to the multi-stakeholder collaboratives and the physician practices in the CPC initiative as they integrate consumer and patient representatives and work together to transform primary care in their regions.

For additional resources from the National Partnership, the Institute for Patient- and Family-Centered Care (IPFCC), and TransforMED on creating PFACs and other opportunities for engaging patients and families, visit the CPC Learning Collaborative website.

Tailored technical assistance is available to meet the unique needs of each CPC market. Contact Jennifer Sweeney, Director of Consumer Engagement and Community Outreach, at jsweeney@nationalpartnership.org or (202) 986-2600 for more information.

Sample Compact: Patient /Family Advisor and Practice Compact

Purpose of Patient and Family Advisor Program:

[PRACTICE NAME] believes that patients and family caregivers are respected and essential partners in the aim to deliver patient- and family-centered care. Clinicians and staff at [PRACTICE NAME] recognize that partnering with patient and family advisors to improve processes, procedures, and care delivery is crucial to ensuring that the care delivered to patients meets their needs and achieves the practice's goals of:

- LIST PRACTICE IMPROVEMENT GOALS HERE. Focus on goals that are meaningful and use language that is understandable to patients and families.
  - For example: Improving support services offered to patients and family caregivers so they can better manage their care or the care of a loved one.

Patient and Family Advisor Roles and Responsibilities:

- Help the practice establish patient- and family-centered care priorities.
- Help the practice identify and implement strategies to support patients and families, improve their experiences with care, and strengthen communication and collaboration between health care providers and patients and families.
- Attend meetings regularly and read materials and agendas prior to meetings.
- Maintain confidentiality of any sensitive information shared during meetings.
- Speak up and share health care/caregiving experiences and perspectives with the practice in constructive ways.
- Balance individual perspectives with the larger goal of improving care for all patients in the practice by recognizing that the experiences of one may not be same as the experiences of many.
- Assist the practice in planning, implementation, and evaluation of quality improvement projects.
- Contribute to staff and clinician understanding of patient- and family-centered care principles.

Practice Roles and Responsibilities:

- Designate a practice leader who will participate in meetings with patient and family advisors and communicate patient perspectives to practice peers.

- Focus efforts on meaningful, collaborative projects, ensuring that there are regular opportunities for patient and family advisors to engage in the work to assess, redesign and evaluate the practice's processes and procedures.

- Distribute agendas and background material and educational resources on practice-related matters in advance of meetings.

- Designate a staff support person whom patient and family advisors may contact to ask questions about agenda items and practice-related areas prior to meetings.

- Establish meeting ground rules in collaboration with patient and family advisors to ensure effective meetings.

- Ask patient and family advisors periodically about their experience as advisors. Find out whether they believe they are making a positive impact and whether they feel supported in their work. If the answer is "no," ask how staff can help.

- Create ways for patient and family advisors to interact periodically with the practice's Board of Directors, if applicable.

- Share how patient and family advisors' feedback has been implemented and how/when changes are being made to the practice.

- Always treat patients and families as equal and respected members of the team.

Sample Discussion **Questions**

The purpose of the conversations with potential patient and family caregivers is to gauge their interest in and availability for participating on a Patient Family Advisory Council (PFAC). Keep in mind that many of the patients and family caregivers will not have heard of a PFAC before, so it will be important to clearly explain the purpose and value of the group and how critical their feedback will be for improving the quality of care at the practice. (When speaking to a patient or family caregiver who was recommended by a physician in the practice, make sure to reference that when explaining the reason for the phone call).

Below are **sample discussion questions** to consider when talking to patients and family caregivers about participating on a PFAC:

▸ Tell me about your general feelings about your care at [PRACTICE NAME]. What have you liked? What could we potentially do better?

▸ Are you comfortable speaking up in a group setting? The group will include doctors, nurses, office staff, and other patients and family cargivers. Would you be willing to share your experiences and speak candidly with all of these individuals present?

▸ Do you have any volunteer experience where you've served on a committee or council before? (Such as for a school, church, community organization, etc?)

▸ In terms of time commitment, we expect to meet [INSERT FREQUENCY OF MEETING TIMES—MONTHLY, ETC—AND LOCATION).Would you be able to volunteer your time to this effort?

▸ Do you see any barriers or challenges in participating in our effort? (i.e. time, transportation, childcare, availability, chronic condition limitations?) How could we help you overcome those challenges?

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Health Care Glossary

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Accountable Care Organization (ACO) is a group of health care providers (e.g. primary care physicians, specialists, hospitals and others) who agree to assume collective responsibility for the cost and quality of care of a group of patients and are paid in a way that incentivizes improved quality and efficiency of health care.

Ambulatory Care is medical care that does not require an overnight stay in a hospital. Ambulatory Care can be provided in physicians' offices, clinics, emergency departments, outpatient surgery centers, as well as hospital settings that do not involve a patient being admitted for an overnight stay.

Benchmark (benchmarking) is a way for hospitals and doctors to compare data on quality of care, both internally and against data from other hospitals and doctors, to identify best practices of care and improve quality.

Best practices are the most up-to-date treatments for patients, which result in the best patient health and minimize patient risk of death or complications.

Centers for Medicare and Medicaid Innovation (CMMI) is a new division within CMS, created by the health reform law, charged with testing new payment and health care service delivery models in Medicare and Medicaid. The Center will rapidly test, evaluate, and then bring to scale new payment and health care delivery strategies that could improve quality and encourage better coordinated, more patient-centered care.

Centers for Medicare and Medicaid Services (CMS) is the agency within the U.S. Department of Health and Human Services that administers Medicare, Medicaid, and the State Children's Health Insurance Program. Marilyn Tavenner is currently the Acting Administrator for the agency.

Chronic care model is a model of care that advocates for more productive interactions between patients and care teams. The model elements include:

▶ systems that provide access to data that helps doctors and patients coordinate their care (such as reminders about needed services);

▶ support for doctors and patients in making decisions about treatment plans that are based on the best available scientific evidence;

▶ support for patients to become empowered and effective in managing their own health and health care (such as working together with doctors to set manageable goals, create treatment plans, and solve any problems along the way);

▶ working with community organizations to help meet the needs of patients (such as

connecting them to nutrition, exercise, or disease management classes that might be offered by local senior centers);

▸ health system leaders that work to create a culture around continually improving the safety, coordination and quality of care (such as processes to ensure patients have regular follow up from their care team, and that the care that is provided fits with patients' needs and preferences.)

Chronic disease/condition is a sickness that is long-lasting or recurrent. Examples include diabetes, asthma, heart disease, kidney disease and chronic lung disease.

Clinical practice guidelines (also called clinical care guidelines) are a set of recommendations based on scientific evidence that help physicians and their patients make decisions about appropriate health care for specific medical conditions. Clinical practice guidelines identify and evaluate the most current information about prevention, diagnosis, prognosis, therapy, risk/benefit and cost effectiveness.

Cognitive Impairments are difficulties with memory, thinking, speech, or another mental function, caused by illness or injury, which may affect daily life.

Comparative effectiveness research compares multiple medications or treatments to determine which is most effective for different types of patients.

Co-morbidity is the presence of one or more diseases in addition to a previously diagnosed illness. For example, a patient may have both diabetes and heart disease.

Consumer/Patient/Beneficiary refers to an individual who has significant personal or family experience with the health care system, either as an individual receiving care (such as someone covered by Medicare – a beneficiary) or as a family caregiver.

Consumer Advocate (also called consumer representative) refers to individuals who work at nonprofit, mission-oriented organizations that represent a specific constituency of consumers or patients. What distinguishes consumer advocates is their primary emphasis on the needs and interests of consumers and patients. Another important characteristic of consumer advocates is they typically do not have a financial stake in the health care system. Examples of consumer advocacy organizations include AARP, YWCA and faith-based organizations.

Consumer Assessment of Healthcare Providers and Systems (CAHPS) or Hospital Consumer Assessment of Healthcare Providers and Systems (H-CAHPS or CAHPS Hospital Survey) are surveys that ask consumers and patients to report on and evaluate their experiences with health care. The H-CAHPS survey focuses specially on hospital care, while CAHPS focuses on care in non-hospital settings (physician offices, nursing homes, etc.). These comprehensive and evolving set of standardized surveys cover topics that are important to consumers, such as the communication skills of providers and the accessibility of services. The results of CAHPS and H-CAHPS surveys are publically reported to allow valid comparisons to be made across all settings.

Collaborative Consumer Engagement is the act of working in partnership with consumers,

consumer advocates, patients and their families/caregivers to improve the health care delivery system.

Coordination of Care ensures that patients and all members of a patient's care team have access to and take into consideration all required information on a patient's conditions and treatments to ensure that the patient receives appropriate health care services.

Cost refers to the actual amount of money paid to a health care provider for a health care service.

Cultural Competency in health care describes the ability of systems to provide care to patients with diverse values, beliefs and behaviors, including tailoring the way care is delivered to meet patients' social, cultural, and linguistic needs.

Delivery System refers to the way medical care is organized and provided to patients. This includes the care, products, and services patients receive from doctors, hospitals, and other professionals.

Department of Health and Human Services (HHS or DHHS) is the U.S. government agency that is responsible for protecting Americans' health and for providing essential human services, particularly for the most vulnerable. Secretary Kathleen Sebelius currently leads the agency.

Effective Care means health care services that are of proven value and have few, if any, significant tradeoffs. The benefits of the services so far outweigh the risks that all patients with specific medical needs should receive them. These services, such as beta-blockers for heart attack patients, are backed by medical theory and strong evidence of value, determined by clinical trials or other studies.

Episodes of Care refers to a series of encounters or visits to health care facilities to treat a health condition. Thinking of care in this holistic way is useful for measuring both the quality of care received and the efficiency of the care provided.

Electronic Health/Medical Record (EHR or EMR) is medical software that contains the electronic history of a patient's medical care. The use of electronic records makes the health care system more efficient, allows for better coordination of care and provides patients the opportunity to view and control their own medical records.

Evidence-based Medicine is the use of the most current, best available scientific research and practices with proven effectiveness in daily medical decision-making, including individual clinical practice decisions by well-trained, experienced clinicians. Evidence is central to developing performance measures for the most common and costly health conditions.

Family Caregiver is a family member or friend who cares for and supports a patient with a chronic health condition or an illness.

Functional Status refers to an individual's ability to do normal daily activities to meet basic needs, fulfill usual roles, and maintain health and well-being. Testing a patient's functional

status is an important part of care for the elderly. Decrease in functional status is measured by a person's loss of independence in activities of daily living (ADLs) over a period of time.

Federally Qualified Health Center (FQHC) is a health organization that offers primary care and preventive health services to all patients regardless of their ability to pay for care. An FQHC may be a public or private nonprofit organization and must meet specific criteria, including 51% consumer representation in governance, to receive government funding.

Fee-For-Service is an approach to payment for care under which patients or a third party (such as a health plan) pay physicians, hospitals or other health care providers for each office visit or health care service a patient receives.

Health Care Acquired Condition/Hospital Acquired Infection (HAC or HAI) is an illness or infection that a patient didn't have when they checked into the hospital – that is passed on to them as a result of contaminated medical equipment or germs from other patients, doctors, or staff.

Health Disparities are differences in the delivery of health care, access to health care services and medical outcomes based on ethnicity, geography, gender, sexual orientation, and other factors that do not include socioeconomic status or insurance coverage. One of the goals of health care quality improvement efforts is stratifying quality data by race/ethnicity/language (R/E/L) in order to better understand where inequities exist and eliminate them.

Health Information Technology (Health IT or HIT) is a term that refers to the use of electronic medical (or health) records, as well as computers, software programs, electronic devices and the Internet to securely store, retrieve, update and transmit information about patients' health.

Health Literacy is the degree to which individuals are able to obtain, process and understand basic health information and services needed to make appropriate health decisions. Health literacy is not simply the ability to read. It requires a complex group of reading, listening, analytical and decision-making skills, and the ability to apply these skills to health situations. For example, health literacy allows people to understand instructions on prescription drug bottles and doctors' forms, as well as talk about health needs and concerns with a doctor or nurse.

Health/Disease Registries are lists of people diagnosed with a specific disease, such as diabetes.

Hospital Discharge is the process by which a patient is released from the hospital by health care professionals.

Hospital Readmission occurs when a patient is readmitted to the same hospital after discharge. Readmissions rates, usually within a certain time period (7-60 days), are viewed as an indicator of the quality of care delivered to patients, with low readmissions rates associated with better care.

Inpatient Care is the delivery of health care services to a person who has been admitted to a

hospital or other health facility for a period of at least 24 hours.

Intervention includes any type of treatment, preventive care or test a person could take or receive to improve his/her health or help with a particular problem. Intervention can also be used to describe a way of improving quality of care.

Meaningful Engagement is a set of practices established to activate stakeholders in all aspects of a project's design, governance, implementation and evaluation. This is a term often used with respect to multi-stakeholder bodies.

Meaningful Use is a federal program that gives health care providers funding for health information technology (HIT) adoption. Providers need to show they are using "certified electronic health record technology" in ways that improve the quality of care, individual access to health information and the health of populations.

Medical Error is a mistake that harms a patient. Adverse drug events, hospital-acquired infections and wrong-site surgeries are examples of preventable medical errors.

Medication Management includes activities to ensure the safe and effective use of prescription and over-the-counter drugs. This includes helping patients keep track of the prescription and over-the-counter drugs they are taking, and when, so that they are taken properly and don't cause a bad reaction or side effect.

Misuse (of care) occurs when an appropriate process of care has been selected, but a preventable complication occurs and the patient does not receive the full potential benefit of the service. Avoidable complications of surgery or medication use are misuse problems. Giving a patient penicillin for strep throat, despite a known allergy to that antibiotic, is an example of misuse.

Outcome refers to a patient's health—whether it improves, declines or stays the same—after an encounter with the health care system.

Outpatient Care is medical or surgical care that does not include an overnight hospital stay.

Overuse (of care) describes unnecessary care or circumstances where the potential for harm exceeds the potential for benefit. Prescribing an antibiotic for a viral infection like a cold, for which antibiotics are ineffective, is overuse. Overuse can also apply to repeated diagnostic tests and surgical procedures.

Patient Activation Measure (PAM) is a series of tools to measure how likely a patient is to be an informed, active participant in his/her own healthcare. Physicians sometimes use PAM to identify a patient's stage of activation, and then work with that patient to individualize their care plans.

Patient- and Family-Centered Care (PFCC) is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients and families. It is based on the core concepts of dignity and respect for patient and family perspectives and choices; sharing complete and unbiased information

with patients and families in ways that are affirming and useful; participation in care and decision-making at the level patients and families choose; and collaboration between patients, families, health care practitioners, and health care leaders in policy and program development, implementation, and evaluation, facility design, professional education, and delivery of care

Patient Centered Medical Home (PCMH) is not an institution, but a way of delivering outpatient care that emphasizes readily accessible, comprehensive, coordinated care, and active involvement of the patient and family in health care decisions. In a medical home, the primary-care doctor operates as a "home base" for patients, overseeing all aspects of patients' health and coordinates care with any specialists involved in the patient's care.

Patient Experience Data (also called Patient Satisfaction Data) is information that reflects quality from the perspective of patients by capturing observations and opinions about what happened during the process of health care delivery. Patient experience data include various indicators of patient-centered care, including access (whether patients obtain appropriate care in a timely manner), communication skills, customer service, and helpfulness of office staff and information resources. The CAHPS survey (see above) is an example of a tool for measuring patient experience.

Patient and Family Advisory Councils (PFAC) are a way to engage patients and families in policy and program decision making in health care settings. These councils help design, implement, and evaluate changes in policies, programs, and practices that affect the care and services individuals and families receive. Councils generally include patients, family members, consumer advocates, and community members, as well as health care clinicians and administrative staff. PFACs may be referred to by many names such as Patient-Provider Councils, Patient Advisory Boards, Consumer Advisory Boards, etc.

Patient Protection and Affordable Care Act (also called the Affordable Care Act or ACA) is the name of health reform legislation signed by President Obama in 2010. In addition to expanding access to health care, the law includes provisions aimed at improving quality of care, reforming the payment system, protecting patients' rights, and reforming health insurance.

Pay-for-Performance (P4P) is a way of paying hospitals and physicians based on whether they meet specific health care quality objectives. The goal is to reward providers for the quality—not the quantity—of care they deliver.

Payers are the entities that pay for medical treatments. Examples include health plans, HMOs, self-insured employers and uninsured patients.

Payment Reform seeks to improve ways of reimbursing providers based on value instead of volume (as opposed to the fee-for-service method of payment).

Preventive Care is health care services that prevent disease or its consequences. It includes primary prevention to keep people from getting sick (such as immunizations), secondary prevention to detect early disease (such as mammograms) and tertiary prevention to keep ill people or those at high risk of disease from getting sicker (such as helping someone with lung disease to quit smoking).

Price Transparency is making the charges of a given health care service at different facilities available to the public.

Primary Care is basic or general health care that helps patients and families to maintain and improve their health. It includes a range of prevention and wellness services, and treatment for common illnesses. Primary care is traditionally provided by doctors trained in: family practice, pediatrics, internal medicine and occasionally gynecology.

Provider refers to a professional who provides health services, including primary care physicians, nurses, specialists (such as podiatrists or cardiologists) and other allied health professionals (such as physical therapists). Hospitals and long-term care facilities are also providers.

Provider Incentives are used to motivate specific provider behavior within the health care system. Examples of incentives include monetary rewards for providers who provide high quality care.

Public Reporting makes information about hospital, physician and physician group performance available for consumers and others. The expectation is that a public report of local hospitals'/physicians' performance will motivate and improve performance and allow consumers to choose providers based on performance.

Purchasers are the entities that not only pay the premium for health care costs, but also control the premium dollar before paying it to the provider. Employers and state governments that provide health insurance to their employees are examples of purchasers.

Quality (of care) is the right care, at the right time, for the right reason, ideally at the right cost.

Quality/Performance Measures are ways to evaluate the care provided by doctors and hospitals based on accepted national guidelines. These measures evaluate access to medical care, the way care is given, patient results after treatment (outcomes), patient experiences with care, and use of medical services.

Resource Use is the amount of health care services used for a patient, including the number, cost and intensity of services provided.

Risk Adjustment in health care refers to the use of factors such as severity of illness or age to estimate the risk involved in a patient undergoing a particular intervention. Adjusting for risk when reporting performance measures allows for comparison of performance and quality across organizations and communities.

Self-Management is the ability of individuals to manage their health problems or conditions on a day-to-day basis. It is a skill that enables individuals and their families to use existing health services, as well as make choices about health care providers, medication, diet, exercise and other lifestyle issues that protect or damage health.

Shared Decision-Making (SDM) is a process in which patients and their doctors make medical decisions together, while taking into account clinical guidelines and the patient's preferences, life situation, needs, and values.

Shared Savings is a way of encouraging hospitals and physicians to reduce health care spending (while maintaining high levels of quality and safety) by offering them a percentage of any net savings they generate as a result of their efforts. The goal is to reward providers for the quality, safety, and cost-effectiveness – not the quantity – of care they deliver.

Stakeholder refers to any person, group or organization that can affect or be affected by the health care system, such as patients, providers, employers and health plans.

Transparency is the process of collecting and reporting health care cost, performance and quality data in a way that can be accessed by the public and is intended to improve the quality of health care and ultimately improve the health care system as a whole.

Transition of Care refers to the movement of a patient from one health care setting to another, such as from a hospital to a nursing facility, or to home.

Underuse (of care) refers to the failure to provide a health care service when it would have produced a good result for a patient. Examples include failure to give preventive services to eligible patients (e.g., mammograms, flu shots for elderly patients, screening for hypertension) and proven medications for chronic illnesses (steroid inhalers for people with asthma; aspirin, beta-blockers for patients who have suffered a heart attack).

Value-based Purchasing refers to the concept of health care purchasers (i.e. employers) holding health care providers accountable for both cost and quality of care. Value-based purchasing brings together information on the quality of health care, including patient outcomes and health status, with information on cost of care. It focuses on managing the use of the health care system to reduce inappropriate care and to identify and reward the best-performing providers.

(Unwarranted) Variation refers to differences in the use of health care services that cannot be explained by differences in patient illness or patient preferences. Variation may occur because of differences in the degree to which providers follow clinical guidelines (meaning that the quality of care provided to patients is better or worse depending on how well a clinician follows these guidelines), as well as differences in the amount of service (such as tests, surgeries, etc.) delivered to different populations. Research on variations has shown that people living in areas where cost of care is higher and where use of services is higher do not have longer life expectancy than those in areas where cost of care is lower. More care is not necessarily better care.

Health Care Acronyms

AUGUST 2012

ACA	Affordable Care Act (Also known as PPACA- Patient Protection and Affordable Care Act)
ACO	Accountable Care Organization
ADA	Americans with Disabilities Act
AHA	American Hospital Association
ALOS	Average Length of Stay
AMA	American Medical Association
AHRQ	Agency for Health Care Research and Quality
ARRA	American Recovery and Reinvestment Act
BCBS	Blue Cross Blue Shield
BP	Blood Pressure
CAHPS	Consumer Assessment of Healthcare Providers and Systems
CDC	Centers for Disease Control and Prevention
CDSMP	Chronic Disease Self-Management Program

CG-CAHPS	Clinical & Group Consumer Assessment of Healthcare Providers and Systems
CE	Consumer Engagement
CHF	Congestive Heart Failure
CMS	Centers for Medicare and Medicaid Services
CMMI	Center for Medicare and Medicaid Innovation
COPD	Chronic Obstructive Pulmonary Disorder
EBM	Evidence-based medicine
ED	Emergency Department (preferred to ER)
EHR	Electronic Health Record
EMR	Electronic Medical Record
FFS	Fee For Service (payment type)
FQHC	Federally Qualified Health Center
HAC/HAI	Health Care Acquired Condition/Health Care Acquired Infection

HCAHPS	Hospital Consumer Assessment of Healthcare Providers and Systems	**NCQA**	National Committee for Quality Assurance
HF	Heart Failure	**NPWF**	National Partnership for Women & Families
HHS	U.S. Department of Health and Human Services	**NQF**	National Quality Forum
HIPAA	Health Insurance Portability and Accountability Act	**ONC**	Office of the National Coordinator for Health Information Technology (HIT)
HIT	Health Information Technology	**P4P**	Pay for Performance
HITECH	Health Information Technology for Economic and Clinical Health Act (part of the ARRA legislation)	**PAM**	Patient Activation Measure
		PBPM	Per Beneficiary Per Month
HMO	Health Maintenance Organization	**PCMH**	Patient Centered Medical Home
HRSA	Health Resources and Services Administration	**PCP**	Primary Care Physician/Provider
HQA	Hospital Quality Alliance	**PCORI**	Patient-Centered Outcomes Research Institute
IHI	Institute for Healthcare Improvement	**PDSA**	Plan, Do, Study, Act (method used in quality improvement activities)
IOM	Institute of Medicine		
IPA	Independent Practice Association	**PFAC**	Patient & Family Advisory Council
IPFCC	Institute for Patient- and Family-Centered Care	**PM/PM**	Per Member Per Month
		PO	Physicians Organization
LDL	Low-density Lipoprotein (Cholesterol)	**PPACA**	Patient Protection and Affordable Care Act (also known as ACA – Affordable Care Act)
MU	Meaningful Use		

PPO	Preferred Provider Organization	**SSA**	Social Security Administration
QI	Quality Improvement	**TA**	Technical Assistance
R/E/L/G	Race, Ethnicity, Language, Gender	**TCAB**	Transforming Care at the Bedside
ROI	Return on Investment	**USPSTF**	U.S. Preventive Services Task Force
SDM	Shared Decision Making	**VBID**	Value Based Insurance Design
		VBP	Value Based Purchasing