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.

The National Partnership for Women & Families is a nonprofit, nonpartisan advocacy group dedicated to promoting fairness in the workplace, access to quality health care and policies that help women and men meet the dual demands of work and family. More information is available at www.NationalPartnership.org.

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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 caregivers. 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?

Health Care Glossary

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Accountable Care Organization (ACO)

- Is a group of health care providers (e.g. primary care doctors, specialists, hospitals, and others) who:
  - Agree to work together and take responsibility as a team for deciding how to provide the best care for patients at the lowest cost;
  - Are paid in ways that make them want to work even harder to provide excellent care while keeping costs down.

Ambulatory Care

- Is medical care that does not require an overnight stay in a hospital.
- This kind of care can be provided in the following places:
  - Doctors' offices,
  - Clinics,
  - Emergency departments,
  - Outpatient surgery centers; as well as
  - Hospital, but that does not involve a patient being staying overnight.
- Of interest: "Ambulatory" comes from the word "ambulate" which means to "walk" or "move about."

Benchmark (benchmarking)

- Is a way for hospitals and doctors to keep track of, and measure, how well they are doing at providing excellent care while keeping costs down.
- To do this, they gather information (data) over different periods of time. Then, they use this information to:
  - Measure how well they are doing from one period to the next.
  - Measure how well they are doing compared to other hospitals and doctors.
  - Find out what treatments work best and use that information to provide even better care. Treatments that work the best are often called "best practices."

Best practices

- Are the most up-to-date treatments for patients.
- These are also practices which result in the best patient health and lower patient risk of death or complications.

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 (SCHIP or CHIP).

Center for Medicare and Medicaid Innovation (CMMI)

- Is a new division within the Centers for Medicare and Medicaid Services (CMS), created by the health reform law, passed in 2010.
- It tests new ways of providing health care, and paying for health care, through the Medicare and Medicaid programs.
- The Center will test these new ways of providing and paying for health care to see which ones work best. The goal will be to improve the quality of care and to encourage care that is better coordinated and more patient-centered.
- Then the Center will test, or try out, new methods in a few places. If they work well, the Center will expand these methods to many more places.

Chronic care model

Is a way of providing care that encourages better and more helpful interactions between patients and their health care providers. This includes the following:

- **Improved coordination of patient care:** Uses systems and tools to give health care providers access to all the information they need to provide good care for a patient. For example, doctors might organize their practice to improve communication with other doctors' offices and use electronic medical records to get easy access to patients' health information. Using these systems and tools helps coordinate the different care that patients get and prevent medical errors. The goal is to provide the best care with the least confusion.
- **Better decision-making by doctors and patients:** Provides support for doctors and patients in making decisions together about treatment plans that are based on the best scientific research;
- **Patients to be involved in their own care:** Helps patients to become more empowered and effective in managing their own health and health care;
  - For example: Working together with doctors to 1) set manageable goals, 2) create treatment plans, and 3) solve any problems along the way.
- **Additional outside support to help patients manage their health:** Involves working with community organizations to help meet patients' needs;
  - For example: Connecting patients to nutrition, exercise, or disease management

programs that might be offered by local senior centers.

- **Leadership committed to continued improvements:** Health system leaders work to create a culture around continually improving the safety, coordination, and quality of care;
  - For example: Creating ways to be sure that 1) patients have regular follow up from their care team, and that 2) the care that is provided fits with patients' needs and preferences.

Chronic disease/condition

- Is a sickness that is long-lasting or that comes back or flares up, from time to time.
- 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 research, that are used to identify and evaluate the most current information about the best way to care for patients. There are guidelines about how to do the following kinds of things:
  - prevent illness
  - identify illness
  - predict the course of an illness
  - treat illness
  - figure out risks and benefits
  - keep costs down
- These guidelines help doctors and their patients make decisions about appropriate health care for specific medical conditions.

Cognitive Impairments

- Are types of problems with the mind, which may affect daily life.
- They include having problems with the following:
  - Memory,
  - Thinking,
  - Speech, or
  - Another mental function.

Collaborative Consumer Engagement

- Is when health care providers work in partnership with consumers, consumer advocates, patients, and their families/caregivers.
- This is done to improve the health care delivery system and make sure it meets the needs of patients and their families/caregivers.

Comparative Effectiveness Research (CER)

- Is research that compares different medicines or treatments.
- It is done to figure out which medicines or treatments work the best for different types

of patients.

Co-morbidity

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

Consumer/Patient/Beneficiary

- Refers to a person who has significant personal or family experience with the health care system.
  - It can refer to a person receiving care (such as someone covered by Medicare – a beneficiary).
  - It can also refer to a family caregiver.

Consumer Advocate (also called Consumer Representative)

- People who work for non-profit organizations and represent the needs and interests of certain groups of consumers or patients. For example, American Cancer Society consumer advocates represent the concerns of cancer patients. These advocates help make sure that consumers and patients have a voice in the health care system.
- Examples of consumer advocacy organizations include: AARP, American Cancer Society, March of Dimes, and faith-based organizations.

Consumer Assessment of Healthcare Providers and Systems (CAHPS)

- Is a survey that asks consumers and patients to report on and evaluate their experiences with health care.
- It focuses on care in *non-hospital settings* (physician offices, nursing homes, etc.).
- It asks the same questions and is scored in the same way, wherever it is used. It continues to be improved, as needed.
- It asks questions about how care is given. For example, it asks questions about how well health care providers talk with their patients and how easily patients can get the health services they need.
- The CAHPS survey is done every year. The results are sometimes reported to the public.

Consumer Assessment of Healthcare Providers and Systems (H-CAHPS or CAHPS Hospital Survey)

- Is a survey that asks consumers and patients to report on and evaluate their experiences with health care.

- Unlike the CAHPS survey, this survey focuses on *hospital care*.
- It asks the same questions and is scored in the same way, wherever it is used. It continues to be improved, as needed.
- It asks questions about how care is given. For example, it asks questions about how well health care providers talk with their patients and how easily patients can get the health services they need.
- The H-CAHPS survey is done every year. The results are sometimes reported to the public.

Coordination of Care

- Ensures that patients and all members of a patient's care team have, and consider, all required information on a patient's conditions and treatments.
  - For example, a primary care doctor knows what medicines a patient has been prescribed by other doctors. He can look at the complete list of the patient's medicines to find and prevent dangerous drug interactions.
  - Or, a hospital lets a patient's primary care doctor know when the patient is leaving the hospital to go home. This helps make sure the primary care doctor can give the patient the best follow-up care needed.

Cost

- Refers to the amount of money paid to a health care provider for a health care service.

Cultural Competency (in health care)

- Describes the ability of health care systems to provide good care to patients with diverse values, beliefs, and behaviors.
- It includes the ability to customize the way care is delivered to meet patients' social, cultural, and language-related needs. This means taking the following kinds of things into consideration when making suggestions for treatment or preventive care:
  - Income
  - Living conditions
  - Daily lifestyle/schedule
  - Food preferences and diet
  - Education
  - Reading skills
  - Health beliefs
  - Main language spoken

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 a U.S. government agency responsible for protecting Americans' health, in many

ways, and for providing essential human services, particularly for people who need the most help. This includes financial assistance for people with low incomes.

Effective Care

- Means providing treatments that research has shown work well. The benefits of using the treatment are much greater than any problems or risks that might come up from using the treatment.
  - For example, research shows that taking medicines known as beta-blockers can lower a patient's risk of heart attack. While some patients may experience side effects from taking beta-blockers, such as being tired and getting headaches, many patients decide that the benefits outweigh the risks. In other words, patients are often willing to put up with being tired and sometimes having headaches if it means they will be less likely to have a heart attack.
- These are services that are backed by medical theory and have strong evidence of value, determined by clinical trials or other research studies. They have been well-researched.

Episodes of Care

- Refers to a series of encounters or visits to health care facilities to treat a specific health condition, within a specific period of time.
- Thinking of care in this way is useful for measuring both the quality of care received and the efficiency of care provided.

Electronic Health/Medical Record (EHR or EMR)

- Generally, it is a medical record kept on a computer, instead of in a paper chart.
- Specifically, it is medical software with the electronic history of a patient's medical care.
- Using electronic records has a number of advantages:
  - It makes the health care system more efficient.
  - It allows for better coordination of care. Each provider can now see what another provider has done, so they can work better together to care for each patient.
  - It also gives patients the chance to look at and control their own medical records.

Evidence-based Medicine

- Involves making medical decisions based on information and practices that have been carefully researched, written about, and proven to work.
- Is the use of the most up-to-date, best available scientific research and practices with proven effectiveness in daily medical decision-making.
- It includes individual clinical practice decisions by well-trained, experienced health care clinicians.
- Evidence, or proof, is central to developing performance measures (deciding how to best treat for the most common and expensive 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.

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.
- It must also meet specific criteria to receive government funding. This includes having a Community Governing Board, with more than half of the Board members (at least 51%) being made up of people who use the health center's services.

Fee-For-Service

- Is a way of paying for care provided by doctors , hospitals, or other health care providers.
- With this approach, patients or a third party (such as a health plan) pay for:
  - Each office visit or health care service a patient receives; or
  - Each health care service a patient receives.

Functional Status

- Refers to a person's ability to do normal activities of daily living (ADLs).
- These are activities that people engage in to meet basic needs, fulfill usual roles, and maintain health and well-being.
  - For example, getting dressed, bathing, and using the bathroom are ADLs.
- A decrease in functional status is measured by a person's inability to do ADLs over a period of time.

Health Care Acquired Condition/Hospital Acquired Infection (HAC or HAI)

- Is an illness or infection that a patient didn't have when he/she checked into the hospital.
- Instead, it 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 how health care is delivered and how easy it is for patients to get

based on factors such as:

- Race,
- Ethnicity, (people's national or cultural background),
- Language,
- Geography, (where people live)
- Gender, (whether they are male or female)
- Sexual orientation, (whether they are lesbian, gay, bisexual, or transgender)
- Education, and/or
- Income

- One of the goals of health care quality improvement efforts is to find where unfair and unjust health care practices exist and get rid of them. One method used to identify these unfair practices is stratifying quality data. This means separating the data by R/E/L/G, which means:
  - Race,
  - Ethnicity,
  - Language, and
  - Gender

Health Information Technology (Health IT or HIT)

- Is a term that refers to the use of electronic medical (or health) records, instead of paper records.
- It uses computers, software programs, electronic devices, and the Internet to securely manage information about patients' health in a secure way. This includes:
  - Storing information,
  - Retrieving information,
  - Updating information, and
  - Transmitting information

Health Literacy

- Is the degree to which individuals are able to get, 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 medicine 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.
    - For example: A diabetes registry lists people with diabetes.
- Health/disease registries are used for purposes such as research, public health, or quality improvement.

Hospital Discharge

- Is the way that a patient is released from the hospital by health care professionals.
- After a hospital discharge, a patient may be going home or to another health care setting, such as a rehabilitation center or nursing home.

Hospital Readmission

- Happens when a patient is readmitted to a hospital after being released.
- Readmissions rates, usually within a certain time period (7 to 60 days), are viewed as one way of telling how well patients are being cared for.
- Low readmissions rates tend to mean that patients are getting better care and do not need to return to the hospital because of more health problems.

Inpatient Care

- Is giving health care services to a person who has been admitted to a hospital or other health facility for at least 24 hours.

Intervention

- Something that is done to improve a patient's health or help with a particular problem.
- This includes any type of treatment, preventive care, or test a person could take or receive.

Meaningful Engagement

- Is a way to actively involve different groups of people in all aspects of a project's design, governance, implementation, and evaluation.
- This is a term often used when describing groups that include patients, providers, and employers.

Meaningful Use

- Is a federal program that gives health care providers money to help them start using health information technology (HIT).
- Providers need to show they are using "certified electronic health record technology" in ways that:
    - Improve the quality of care,
    - Improve patients' access to health information, and

- Improve the health of populations.

Medical Error

- Is a mistake that harms a patient.
- Examples of preventable medical errors include: Adverse drug events, hospital-acquired infections, and surgeries on the wrong part of the body.

Medication Management

- Includes activities to ensure the safe and effective use of prescription and over-the-counter medicines.
- This includes helping patients keep track of:
  - Which prescription and over-the-counter medicines they are taking, and
  - When they are taking them.
- This is done so that people take medicines in the right ways and don't have a bad reaction or side effects.

Misuse (of care)

- Occurs when these things take place:
  - An appropriate process of care has been selected,
  - But a preventable complication occurs, and
  - The patient does not receive the full benefit of the health care service.
- Avoidable complications of surgery or medicine use are misuse problems.
  - For example: Giving a patient penicillin for strep throat, despite a known allergy to that antibiotic.

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 either of these things:
  - Unnecessary care; or
  - Times when care is given and the chance of causing harm is greater than the possibility of benefit.
- For example: Prescribing an antibiotic for a viral infection like a cold, when antibiotics

do not work.

- Overuse can also happen when medical tests and surgical procedures are unnecessarily run more than once.

Patient Activation Measure (PAM)

- Is a way to measure how likely a patient is to be an informed, active participant in his/her own healthcare.
- Doctors sometimes use PAM to figure out how ready a patient is to change his or her behavior.
- Doctors then work with that patient on his or her care plan.

Patient- and Family-Centered Care (PFCC)

- Is a way of going about the planning, delivery, and evaluation of health care.
- It is based on partnerships among health care providers, patients, and families that are good for everyone involved.
- It is based on the following core concepts:
  - **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** among patients, families, health care practitioners, and health care leaders in: 1) policy and program development, implementation, and evaluation, 2) facility design, 3) professional education, and 4) delivery of care.

Patient Centered Medical Home (PCMH)

- Is not an institution or a place.
- Instead, it is a way of delivering outpatient care that emphasizes:
  - Care that is easy to access, is comprehensive and well-coordinated; and
  - Active involvement of the patient and family in health care decisions.
- In a medical home, the primary-care doctor acts as a "home base" for patients.
  - That doctor is chosen by the patient and becomes the patient's personal physician.
  - The doctor (along with nurses, medical assistants, and others in the office who are part of the "care team") oversees all aspects of patients' health and coordinates care with any specialists or other providers involved in the patient's care.
  - Patients do not need a referral from their primary care doctor to see other doctors. This is because the primary care doctor serves more as a manager than a "gatekeeper" of each patient's care.

Patient Experience Data (also called Patient Satisfaction Data)

- These are measures of how patients evaluate their health care experiences.
- It does this by capturing the patient's observations and opinions about what happened during the process of health care delivery.
- Patient experience data is information on how well the patients' needs are met. It looks at the following parts of the patient experience:
  - **Access**. Can patients get care when they need it?
  - **Communication skills**. Is information provided to patients in a way they can understand?
  - **Respect**. Are patients treated with courtesy and respect?
  - **Support**. Do patients get the information and support they need to take care of their health conditions?
- 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 involve 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 and family members,
  - Community members,
  - Consumer advocates,
  - Doctors, nurses, and other health care providers, 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 the quality of care,
  - Improving the payment system (the way health care is paid for),
  - Protecting patients' rights;
  - Changing health insurance.

Pay-for-Performance (P4P)

- Is a way of paying hospitals and doctors based on whether they meet specific health care quality goals.
- The goal is to reward providers for the quality—not the quantity—of care they deliver.

Payers

- Are the organizations or the people that pay for medical treatments.
- Examples include: Health plans, HMOs, self-insured employers, and uninsured patients.

Payment Reform

- Seeks to improve ways of reimbursing (paying) providers based on value instead of volume of the care they have provided.
- This is different from the fee-for-service method of payment. With that method, providers get paid regardless of the quality of the care that is given.

Premium

- Set amount of money that is paid to cover a patient's health insurance benefits.
- Premiums can be paid by employers, unions, employees, or shared by both the insured individual and their employer, for example.

Preventive Care

- Are health care services that prevent disease or its consequences.
- This includes:
    1. **Primary prevention:** to keep people from getting sick (such as immunizations),
    2. **Secondary prevention**: to detect early disease (such as mammograms) and,
    3. **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, or preventing complications from diabetes like foot or eye problems).

Price Transparency

- Is making the charges of a given health care service (such as an x-ray or MRI) at different facilities available to the public, so that those prices are "transparent" or easy to see.

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.
- This includes:
  - Primary care doctors and 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 steps taken to motivate specific provider behavior within the health care system.
- For example: Bonuses for providers who provide high quality care.

Public Reporting

- Makes information about hospital, physician, and physician group performance available to the public.
- The expectation is that a public report of local hospitals' or doctors' performance will:
  - Motivate and improve performance, and
  - Allow the public to choose providers based on performance.

Purchasers

- Are the organizations and people (often employers, unions, etc.) that do both of the following:
  - Decide on what benefits the insured person gets, including the amount of money given to him or her to cover health care expenses.
  - Work with groups that provide health insurance coverage to debate the cost of premiums (the portion of money the patient pays for his or her health care) and the overall cost of care.
- For example: Employers and state governments that provide health insurance to their employees are purchasers.

Quality (of care)

- Is the right care, at the right time, for the right reason.
- Ideally, it is also 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.
- This includes:
  - How many services were provided,
  - How much of each service was provided, and
  - How much those services cost.

Risk Adjustment

- In health care, this means taking certain factors into consideration in order to estimate the risk involved in a patient getting a particular intervention.
- For example:
  - **Age** can play a role in estimating the risk of getting some treatments. A younger person may recover more easily than an older person.
  - **Severity of disease** can play a role, as well. Someone with early stage cancer may recover more easily than someone in a later stage of the same cancer.
- If these factors are not taken into consideration, it is hard to make fair comparisons. Organizations adjust for risk when reporting their performance measures - meaning how well they are providing care for patients.
- Reporting on performance measures allows them to see how they are doing in comparison with other organizations and communities.

Self-Management

- Is the ability of individuals to take care of health problems or conditions on a day-to-day basis.
- It is a skill that allows individuals and their families to use existing health services.
- It also helps patients make choices about:
  - Health care providers,
  - Medicines, and
  - Diet, exercise, and other lifestyle choices that protect or damage health.

Shared Decision-Making (SDM)

- Is a process in which patients and their doctors make medical decisions together.
- This is done while taking into account:
  - Medical recommendations, and
  - The patient's preferences, life situation, needs, and values.

Shared Savings

- Is a way of encouraging hospitals and doctors to lower health care spending, while keeping high levels of quality and safety.
- This is done by giving hospitals and doctors a percentage of any net savings they generate as a result of their efforts.
- The goal is to reward health care 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.
- It includes:
  - Patients,
  - Providers,
  - Employers, and
  - Health plans.

Transparency

- Is the process of gathering and reporting data about health care in a way that can be accessed by the public. Making data "transparent" means making it easier for people to see.
- This includes data on:
  - Cost,
  - Performance, and
  - Quality.
- It 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.
- For example: The movement of a patient from a hospital to a nursing facility, or from a nursing facility to home.

Underuse (of care)

- Happens when a health care service is *not* provided to a patient, but could have led to a good result.
- For example:
  - **Failure to give preventive services to eligible patients** (such as mammograms, flu shots for elderly patients, screening for hypertension), and
  - **Failure to give trusted medicines for chronic illnesses** (such as steroid inhalers for people with asthma or aspirin and beta-blockers for patients who have suffered a heart attack).

Value-based Purchasing

- Refers to the concept of health care purchasers (i.e. employers or government programs like Medicare) holding health care providers accountable for both cost and quality of care.
- Value-based purchasing brings together two types of information that purchasers use to decide whom to pay to provide care for their employees. This includes:
  1. Information on the quality of health care, including patient outcomes and health status, and
  2. 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.

Variation

- Refers to differences in the use of health care services that c*annot* be explained by:
  - Differences in patient illness, or
  - Differences in patient preferences.
- Instead, this variation *may* be explained by:
  - Differences in the ways providers follow medical recommendations (meaning that the quality of care provided to patients is better or worse depending on how well a clinician follows these recommendations),
  - Differences in the amount of service delivered to different populations (such as tests, surgeries, etc.).
- Research on variations has shown that people living in areas where the cost of care is higher, and where use of services is higher, do *not* have longer life expectancy than those in areas where the cost of care is lower. In other words, more care is *not* necessarily better care.

Health Care Acronyms

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

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